



At risk of exclusion from CRPD and SDGs implementation:

Inequality and Persons with Deafblindness



Initial global report on situation and rights of persons with deafblindness
September 2018

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AT RISK OF EXCLUSION FROM CRPD AND SDGS IMPLEMENTATION: INEQUALITY AND PERSONS WITH DEAFBLINDNESS

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 initial global report on the situation of persons with deafblindness 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) combining the largest population-based analysis of persons with deafblindness conducted to date (disaggregation of 22 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.

Women and men with deafblindness from across the world took part in the Helen Keller World Conference in June 2018, and were consulted to confirm the findings and elaborate on the recommendations for this report.



PARTICIPANTS OF THE 2018 WORLD CONFERENCE HELEN KELLER

June 2018, Benidorm, Spain



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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 [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 22 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 were presented at the 2018 Helen Keller World Conference. Women and men with deafblindness from across the world shared their experiences and elaborated on the recommendations for the report.

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 interpreter-guides, 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.

A DIVERSITY OF SUPPORT SERVICES (NON-EXHAUSTIVE LIST)	
MOBILITY AND COMMUNICATION	
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.
COMMUNICATION	
Tactile Communication	<p>Tactile sign language: a common means of communication used by persons with deafblindness. Signs are primarily indicated in the palm of the hand.</p>
	<p>Tactile fingerspelling: a variation of tactile sign language using finger-based signs that follow a specific pattern.</p> 
	<p>Tactile alphabet: communication based on spelling words, letter by letter, and indicating block letters in the palm of the hand of the individual.</p> 
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	Braille is a system that uses a series of raised dots (six in two columns of three) to represent letters or groups of letters.
	Moon is similar to braille but uses raised, adapted capital letters that are simpler to feel.
ASSISTIVE DEVICES	
Hearing	Hearing aid: a small electronic device that is placed behind or inside the ear to amplify sound and speech. Essential in combination with clear speech interpretation.
	Cochlear implant (CI): a surgically implanted electronic device that provides a sense of sound, bypassing the hearing process that has been impaired.
	Loop: 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	Braille reader/display: a device enabling one and/or two-way communication through computers, smartphones and similar devices using braille.
Mobility	Red and white striped cane: 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.

KEY PRECONDITIONS FOR INCLUSION

RECOGNITION OF DEAFBLINDNESS & THE PROVISION OF SPECIFIC SUPPORT SERVICES

To participate and be included in community, work, education or political life, persons with deafblindness require both the removal of environmental barriers as well as those that prevent access to quality support services. Accessibility features for persons with deafblindness include a wide range of passive accessibility elements related to the built, informational and communicational environment. These features are also common to other persons with disabilities, such as documents being accessible in braille, captioning, tactile patterns on floors, contrasted colours in facilities, loop systems and accessible websites.

However, due to the specific functional restrictions caused by deafblindness, such accessibility features are often insufficient and individual support is required. Through the survey and exchanges at the 2018 Helen Keller World Conference, WFDB members highlighted the lack of awareness and recognition of deafblindness. Indeed, many governments mistakenly assume that services for deaf or blind people are sufficient for persons with deafblindness. Due to the fact that accessibility issues are widely known, this report focuses on two key asks from WFDB members: official recognition of deafblindness and the provision of specific support 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.

	High-income countries (N=19)	Upper-middle income countries (N=13)	Lower-middle and low-income countries (N=18)	ALL (N=50)
0-24%; 25-49% 50-74%; 75-100%				
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%

THE VICIOUS CIRCLE: A LACK OF AWARENESS AND A LACK OF RECOGNITION

The majority of WFDB members consulted highlighted the need for greater visibility of deafblindness. Members also suggested the need to raise societal awareness of persons with deafblindness and their communication requirements so that steps can be taken to make society more inclusive.

A vicious circle was identified in relation to the non-recognition of deafblindness whereby a lack of understanding about the diversity and issues faced by persons with deafblindness contributes to a lack

of recognition of deafblindness as a unique disability. This, in turn, reinforces their invisibility, lack of awareness and access to support.

“People always think that persons with deafblindness are ‘totally deaf and totally blind’ and we always have to explain! People don't accept that a person cannot have ‘only’ a combination of both hearing and vision impairment, which creates a unique situation.” (participant at 2018 HKWC consultation)

It was also reported that health and rehabilitation professionals lack an understanding of the situation of persons with deafblindness. For example, professionals often consider people that are not fully deaf and blind as either a deaf person with a visual impairment or a blind person with a hearing impairment. This leads to persons with deafblindness being underestimated and limits the development of adequate support services that are truly responsive to each individual's specific needs.

In many countries, deafblindness is not considered a standalone disability, and as a result persons with deafblindness are qualified as having multiple disabilities. Some countries, including India through its recent disability rights legislation, acknowledge deafblindness but include it within a multiple disabilities category, thus potentially limiting the positive effect of legal recognition on the development of support services and resource allocation.

Several WFDB members mentioned that, because deafblindness is not recognised in their country, individuals have to select either deaf or blind on official forms and documents, which leads to invisibility in statistical or administrative data. In the EU, as of 2014, only three of the 27 states were collecting official census data regarding the number of persons with deafblindness .

In disability and eligibility determination, a lack of recognition leads to people receiving two separate disability and/or medical certificates. This creates an additional administrative burden and cost for persons with deafblindness and their families.

Where data is available, governments consider persons with deafblindness as a small group that require only the minimum allocation of resources. Again, a lack of understanding about the diversity and extent of communication and support required leads to a significant underestimation of the resources needed to provide appropriate levels of support.

“The government does not support activities or projects for persons with deafblindness because, as it is a small number of people, it cannot show a huge social impact and achieve a significant political return.” (participant at 2018 HKWC consultation)

One recurrent issue is the non-recognition of persons with deafblindness within the disability movement. Whilst there has been progress in recent years, it is still a challenge for organisations of persons with deafblindness to secure adequate resources in many countries, both rich and poor. Once again, a lack of official recognition deprives organisations of persons with deafblindness the necessary resources to carry out much-needed awareness raising and advocacy work.

RECOMMENDATIONS

For national governments:

- *Recognise deafblindness as a unique disability in law and practice.*
- *Raise awareness about the specific situation and requirements of persons with deafblindness.*
- *Collect and analyse data about the experiences, barriers and support requirements of persons with deafblindness.*
- *Recognise the specificity of communication systems used by persons with deafblindness.*
- *Include deafblindness as a specific disability group and facilitate eligibility determination procedures.*
- *Support organisations of persons with deafblindness to carry out outreach, awareness raising and advocacy.*

For DPOs:

- Recognise and include organisations of persons with deafblindness as distinct and integral members of the disability movement.
- Support the official recognition of deafblindness as a unique disability in law and practice.
- Raise the awareness of member states regarding their obligations towards persons with deafblindness under the CRPD.

For the UN and Development Agencies:

- Universal recognition of deafblindness as a unique and distinct disability, including in international classifications.
- Collect and analyse data about the experiences, barriers and support requirements of persons with deafblindness.
- Raise the awareness of member states regarding their obligations towards persons with deafblindness under the CRPD.
- Support the official recognition by member states of deafblindness as a unique disability in law and practice.
- Support organisations of persons with deafblindness to carry out outreach, awareness raising and advocacy work.

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 interpreter-guides 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.

	High-income countries (N=19)	Upper-middle income countries (N=13)	Lower-middle and low-income countries (N=18)	ALL (N=50)
0-24%; 25-49% 50-74%; 75-100%				
Availability of professional interpreter-guides	63%	15%	6%	30%
Does the government pay for interpreter-guide services?	42%	8%	6%	20%
Availability of professional mobility support	74%	15%	22%	40%
Availability of professional support for accessing information	63%	31%	33%	44%

ONGOING EFFORTS

From laws to enforceable regulation, the long advocacy road towards recognition and the development of interpreter-guide service.

Sense International, Peru

In 2010, the Peruvian authorities passed two key laws. Law 29524 recognised deafblindness as a unique disability and Law 29535 recognised Peruvian sign language. The laws had different fortunes: while Law 29524 was regulated the following year with the Supreme Decree 006-2011-MIMDES, the second piece of legislation was only regulated recently, as part of Supreme Decree 006-2017-MIMP.



Both laws and their regulations mandate the Ministry of Education to approve complementary provisions on the requirements and profile of interpreter-guides and sign language interpreters.

However, the Ministry of Education failed to take immediate action, and so Sense International Peru designed and implemented a training programme for interpreter-guides in 2011. The programme sought to create good practice and tangible evidence that would help the Peruvian authorities to regulate, adopt and scale the service.

Subsequently, in 2012, coordinated efforts were undertaken between the Directorate of Special Education of the Ministry of Education to prepare the profile and requirements of the interpreter-guide; however, the proposals developed were never approved.

In parallel, Sense International Peru worked with CONADIS to create a register of interpreters and interpreter-guides. This was achieved through the approval of the Resolution of the Presidency 020-2017-CONADIS/PRE. This registers interpreters and interpreter-guides accredited by the Ministry of Education.

At the beginning of 2017, the Ministry of Education had still not approved the complementary provisions for interpreter-guides mandated by law. Sense International Peru once again recalled the Ministry's legal obligation to approve these requirements and suggested the creation of a working group to develop a proposal. In October 2017, the Direction of Special Education of the Ministry of Education convened the Civil Society Organisations (CSO) to two round table working groups to develop the requirements and profiles of interpreters and interpreter-guides. By the end of December, both groups had developed concrete proposals for approval.

However, continuous changes of Ministers of Education and Directors of Special Education have delayed the process. For this reason, in early 2018, Sense International Peru supported the creation of a formal Sectoral Commission, which included all of the Directorates of the Ministry of Education, with the purpose of creating a formative proposal for interpreters and interpreter-guides.

On April 2018, the Ministerial Resolution 144-2018-MINEDU was approved, making the Sectoral Commission responsible for formulating a training proposal for interpreters and interpreter-guides. The Commission was given a deadline of 180 days to submit a proposal to the Minister of Education, who must approve it.

Such difficult and slow translation of legislative gains and achievements is all too common across countries. It highlights the importance of the strong and continuous mobilisation of persons with deafblindness and their allies in order to successfully develop practice, conduct legal advocacy and engage with authorities.



Ministry of Education Sectoral Commission members with SIP Director

An exchange between WFDB members at the 2018 Helen Keller World Conference confirmed the scarcity of interpreter-guide and interpretation services for persons with deafblindness. A lack of awareness and recognition of the specific requirements of persons with deafblindness leads to confusion and an overreliance on specific services for blind and deaf people, which are also limited.

“Sign language is not a communication system, it is a language used by persons that are deaf. For many persons with deafblindness it is part of the communication system that includes other elements, different receptions and emission channels (not only visual but also tactile), creating a system that is tailored to the individual.” (participant at 2018 HKWC consultation)

Good practice does exist, however. In Spain, for instance, Law 27/2007 recognises the specific communication systems used by persons with deafblindness.

In most low and middle-income countries, the few existing services that do exist are concentrated in major cities and there is little to no provision in rural and remote areas. A combined lack of awareness and the relatively small number of persons with deafblindness results in significant underinvestment.

“(...) the government does not realise that some deafblind people need interpreters all day. The government only look at the numbers. They discriminate, and they need to look at us like people and understand our full requirements.” (participant at 2018 HKWC consultation)

The scarcity of resources can lead to competitive behaviour between groups, with service providers for deaf people occasionally monopolising interpretation services to secure funding. In countries such as Croatia, however, effective collaboration takes place between organisations of deaf and deafblind people.

The lack of services severely restricts the social and economic participation of persons with deafblindness, as well as increasing their dependency.

“There are few interpreters and the government does not pay for those services. We have to pay or use family and friends as interpreters. Everyone has to find the guide interpreter to get and keep a job but we have to pay for their services and that takes 50% of a person’s salary.”

Whilst the situation is better in higher-income countries, major issues still exist. Few countries fully recognise and acknowledge the specific requirements of persons with deafblindness, and therefore there remains a lack of adequate services. Where services do exist, the financial support provided by government is often limited and does not adequately cover the work, family and community participation needs of persons with disabilities.

Comments and feedback from WFDB members suggest that the awareness of government decision-makers, proactive DPOs and service providers may be more important than a country’s wealth in terms of the development of appropriate services.

Some countries, including Japan, Australia and a number of Scandinavian nations, have been cited as the most developed in terms of service provision. These countries provide trained interpreter services funded by local, regional and central governments, reflecting the required diversity of services (braille, whisper, sign interpretation and haptic signals, amongst others), as well as offering support in the workplace. However, in many high-income countries, the specificities of deafblindness remain unacknowledged, and as a result support services are either non-existent or insufficient.

Another issue is unequal access to services within countries that have high level of decentralisation, as well as limited access to services. For example, in some areas of certain countries, where the number of hours of interpretation granted to persons with deafblindness have been cut.

Whilst the current situation is unsatisfactory, some progress is being made, and there may be a growing trend towards broader recognition of deafblindness in a number of countries. For example, in situations where national recognition is lacking, some sub-national authorities are taking action. In

India, for example, some states have issued certificates specifying deafblindness as a distinct disability, despite the national government categorising the term as a multiple disability.

RECOMMENDATIONS

For countries:

- *In line with CRPD, ensure access to support services that facilitate inclusion and independent living, and enable access to information, communication and mobility. This could be achieved by:

 - *Officially recognising the specificity of accessibility and support service requirements for persons with deafblindness.*
 - *Developing partnerships with DPOs, NGOs and the private sector to ensure the development of support services across sectors.*
 - *Ensuring adequate and sustainable funding for existing and newly created services.*
 - *Ensuring access to affordable and high quality assistive devices.**
- *Refrain from decreasing the level of support currently provided to persons with deafblindness.*
- *Increase international cooperation between countries that have developed adequate support systems and those that are willing to engage.*
- *Include accessibility and non-discrimination requirements in all public procurements, including goods and services, as well as in accreditation and licensing for telecommunication services, amongst others.*

For the UN and development agencies:

- *Support governments to develop support services, including technical and financial assistance, and facilitate international technological exchange.*
- *Include accessibility and non-discrimination requirements in public procurement regulations.*

Making telecommunications accessible

The critical role of public and private sector collaboration

At the 2018 Helen Keller World Conference, Ryan Bondroff, Consumer Relationship Manager for Sprint, presented a range of accessibility services provided in the United States, and outlined the company's partnership with federal and state governments to provide barrier free telecommunication to persons with deafblindness.

Sprint Accessibility offers communication products and services that eliminate communication barriers for customers who are deaf, deafblind, have a hearing or vision loss, and cognitive, speech or mobility disabilities. Those services include the Sprint IP Relay which is fully accessible to persons with deafblindness, supporting them to make and receive relay calls independently via large print or braille formats on mobile devices and computers.

Aside from network connectivity, three pre-conditions are required to create an environment that allows the development of such services:

- Governments need to understand and acknowledge the specific communication requirements of persons with deafblindness to effectively support full access.
- A relay service provider (RSP) needs to be established.
- A dialogue and agreement should be put in place between the government, the RSP and telecommunications operators.

Sprint wants to help create the right environment and partnerships by facilitating a dialogue between stakeholders to set up a RSP. For instance, Sprint has been contracted to introduce a relay service in New Zealand following the government's decision to establish a service for the deaf, deafblind and hard of hearing communities.

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.

At the 2018 Helen Keller World Conference, the findings from this research were presented to WFDB members. Women and men with deafblindness enriched this information with their personal experiences and elaborated on the recommendations.

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

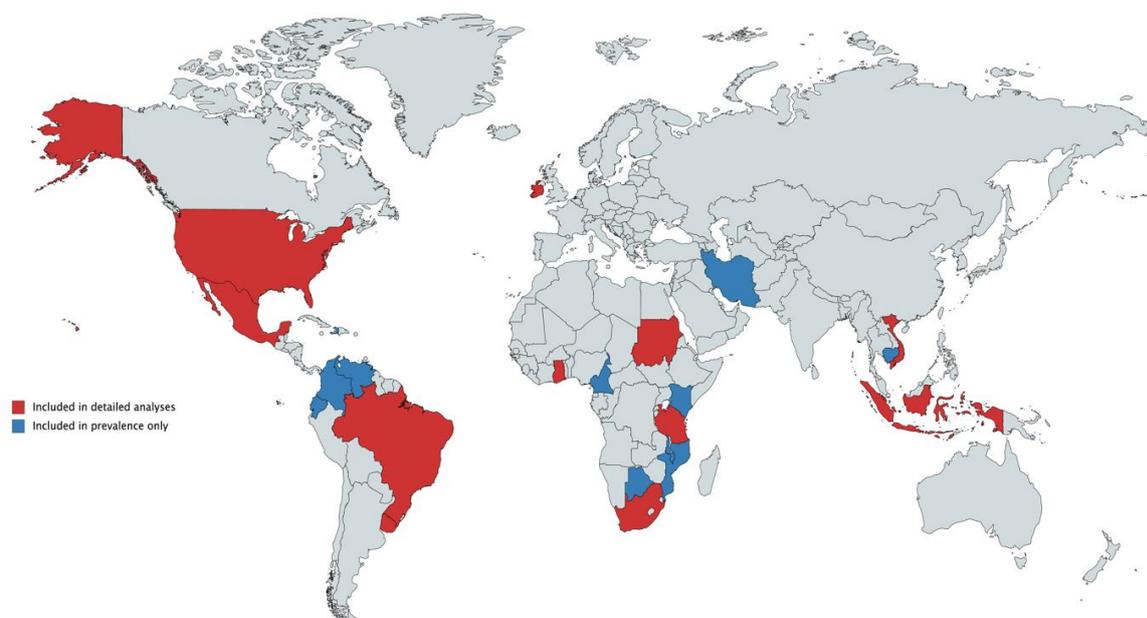


Figure 1. Countries included in the data analysis

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.***

Statistical Appendix 1 provides an in-depth look at the data analysis methods employed, including an explanation of key statistical terms, such as ‘95% confidence’ and ‘odds ratios’.

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 DbI (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. Extended analyses are focused on the sub-set of censuses.

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

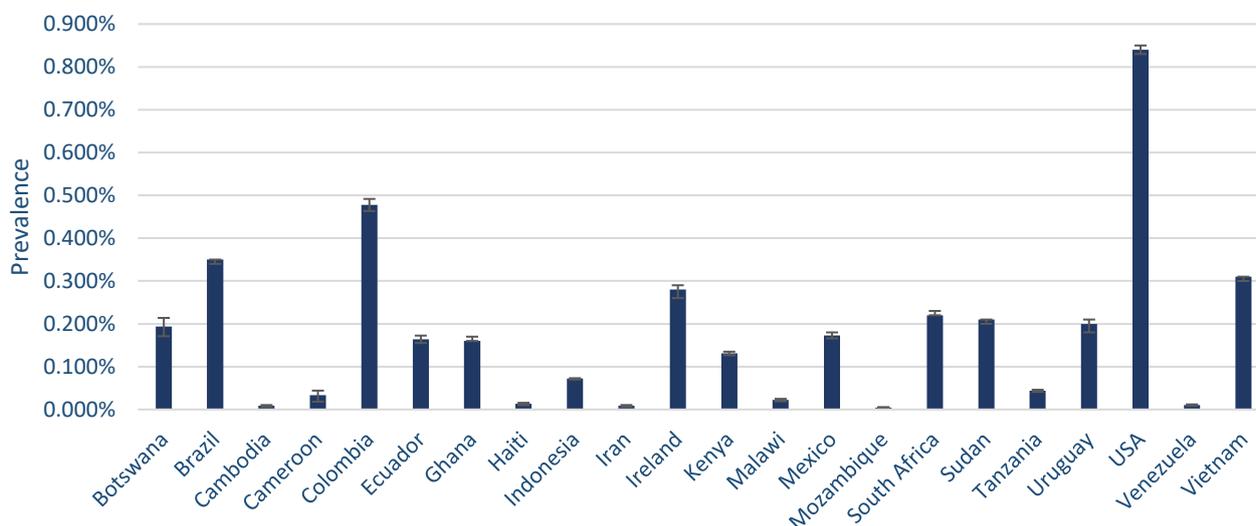


Figure 2. Prevalence of deafblindness among people aged 5 years and over across 22 countries

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

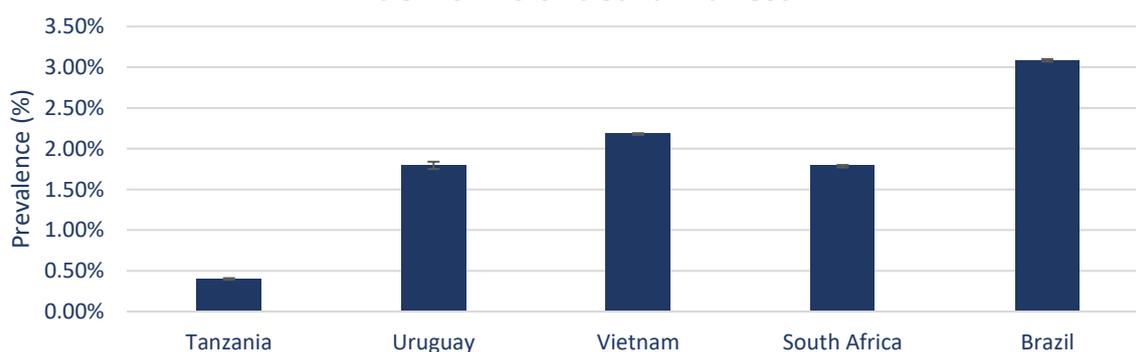


Figure 3. All-age prevalence of moderate deafblindness using the WG Questions

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.

Deafblindness becomes more common as people age

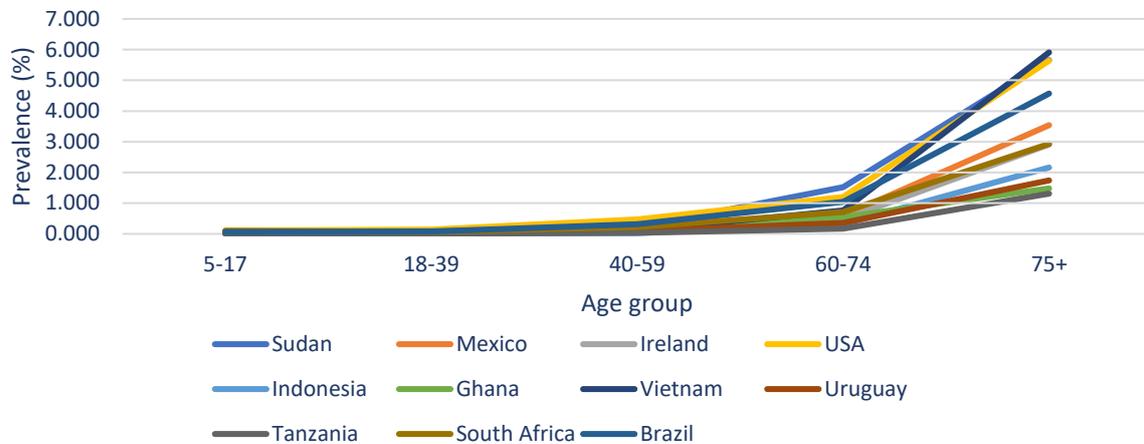


Figure 4. Prevalence of deafblindness by age

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.

Deafblindness is higher in women than men in most countries

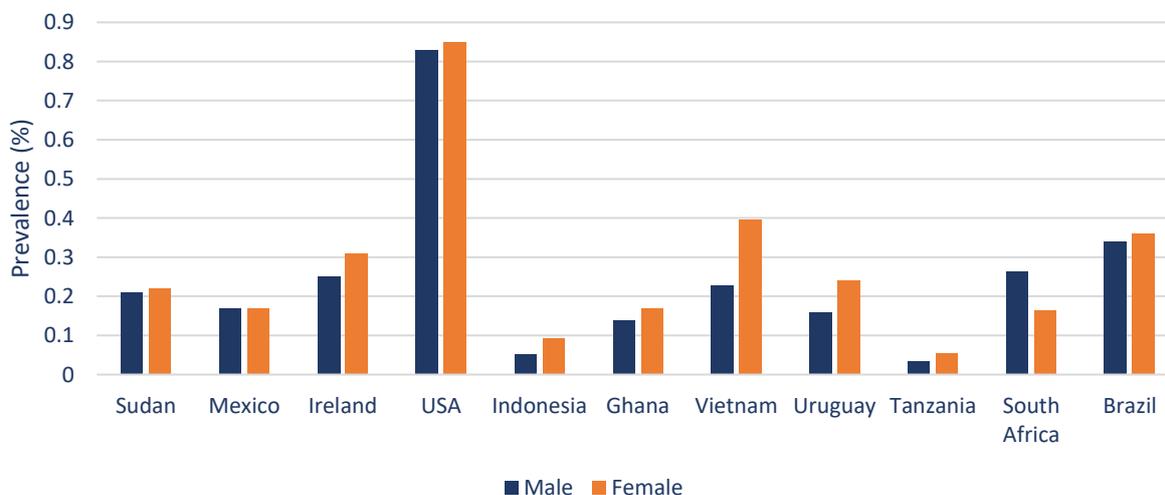


Figure 5. Prevalence of severe deafblindness by sex

RECOMMENDATIONS

- Adopt, in consultation with persons with deafblindness and their organisations, a consistent definition and measurement of deafblindness, and collect, disaggregate and analyse data, to assess and monitor situation of persons with deafblindness, including through relevant analyses of national datasets using the Washington Group Short Set questions or other methods.
- Conduct additional research on the issues facing persons with deafblindness, including health status and access to healthcare, social participation and wellbeing, quality of work and education, causes, and age of onset. Undertake impact evaluations of interventions designed to improve inclusion.

PERSONS WITH DEAFBLINDNESS AND POVERTY

WHAT DOES THE DATA SAY?

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 disabilities¹** (Figure 6). The 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. In Vietnam, households that included members with other disabilities were marginally more likely to be poor in comparison to households that included family members with deafblindness.

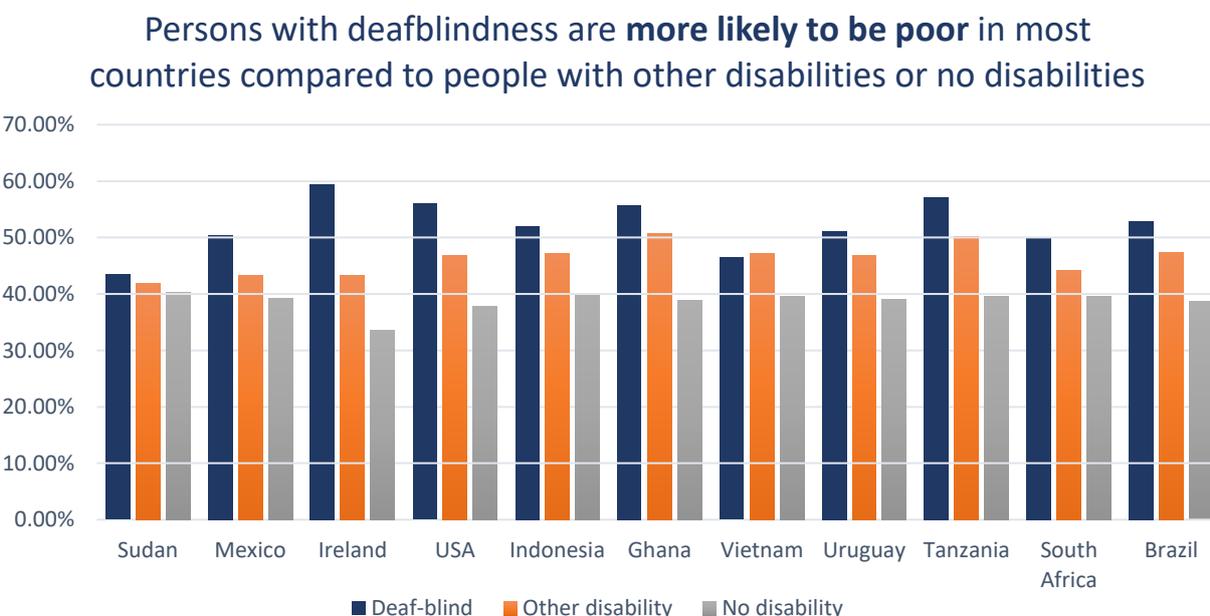


Figure 6. Proportion of households with persons with deafblindness that are in the bottom 40% in terms of socio-economic status compared to households with people who have other disabilities and households with no members who have disabilities

In disaggregating poverty by the age of the household member with deafblindness (<50 years or 50+ years), households including younger adults with deafblindness (under 50 years) were statistically more likely to be living in poverty in five countries (Brazil, South Africa, Vietnam, the United States and Indonesia) (Figure 7). This suggests that younger persons with deafblindness may have a greater impact on the situation of the household.

¹ Derived from a principal component analysis of household assets and dwelling characteristics.

Poverty was more common in households with younger members with deafblindness

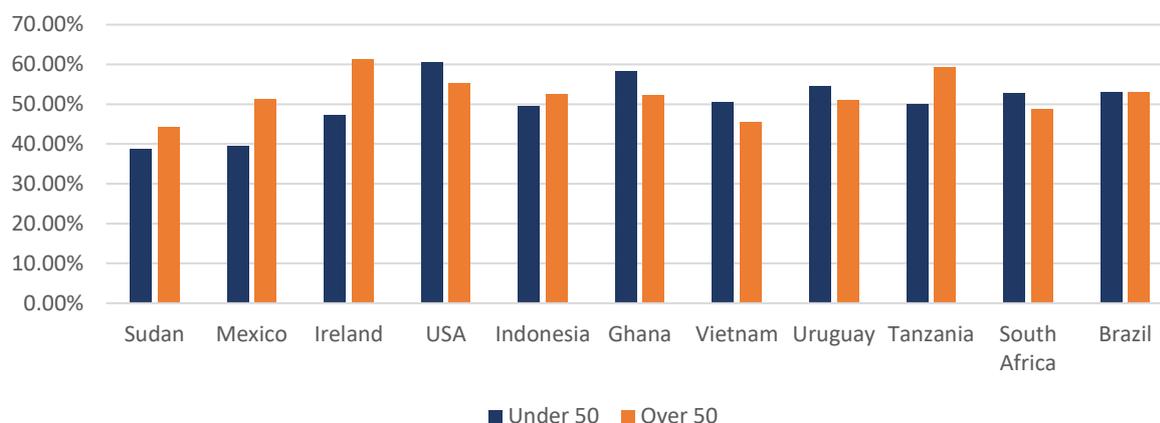


Figure 7. Proportion of households with members with deafblindness living in the bottom 40%, by age of person with deafblindness (<50 years and 50+ years)

OUR VOICE

Unsurprisingly, the survey revealed that high-income countries offer better social protection support in comparison to low and middle-income nations. WFDB members reported that, when programmes are in place to support persons with disabilities, they benefit from them. Whilst issues exist with regards to disability assessment and determination processes, such as the need for two different certificates related to sight and hearing impairments, as outlined in section 1, this does not impede access to benefits.

Social protection	High-income countries	Low and middle-income countries
Are the needs of persons with deafblindness adequately covered in national social protection and/or welfare laws and policies?	66%	27%
Are there any social protection or poverty reduction services for persons with deafblindness in your country?	66%	45%

In low and middle-income countries, as well as some high-income nations, social protection benefit schemes tend to focus on basic poverty-related issues and do not cover the extra costs related to interpretation or mobility challenges. As a result of limited service provision and low social benefits, persons with deafblindness cannot afford the support they need. One of the key issues is that policymakers do not view support services and assistive technology as a ‘fundamental need’, and consider them luxuries in comparison to shelter and food. However, these services are essential for daily living, especially for persons with deafblindness who have high support needs.

In addition, the majority of disability and/or welfare benefits are conditioned on the basis of either being labelled incapable to work or on an income threshold. As such, a person with deafblindness seeking to work would not receive support to pay for transport or the extra cost of accommodation, factors that are rarely, if ever, covered by employers.

Poverty Trap: The Impact of Disability-Related Costs on Persons with Deafblindness And Their Families

An innovative South African study on the extra costs of disability (DSD, 2014) illustrated the significant cost impact of disability for persons with deafblindness and their families. The cost of assistive devices to enable communication, for example, was highest for persons with deafblindness. Personal assistance costs were also among the highest.

Considering that, in 2014, the monthly disability grant was R1,340 per month, the majority of persons with deafblindness would not be able to afford such assistance. Consequently, a family member would have to stay at home to support the person, incurring an opportunity cost, which was amongst the highest for all groups of persons with disabilities. The table below outlines the range of costs identified by the study (this list is not exhaustive).

Type of cost	Costs	Comments
Human assistance		
Paid assistance	R6,000-R14,000 per month	Full-time, depending on skill level
Family member	R0	Opportunity cost due to income loss
Professional interpreter	R2,200 per day	
Travel		
Public transport	Double fare	For the person and his or her assistant or interpreter
Driver	R7,000 per month	
Assistive technology		
Computer	R8,000-R32,000	Dependent on the type of equipment, e.g. a braille or APICS blind reader
Software	R0-R6,000	NVDA available free of charge; costs incurred for alternative software
Internet/mobile phone	R600	

Source: Hanass-Hancock Jill (2015). Elements of the Financial and Economic Costs of Disability to Households in South Africa. A Pilot Study. National Department of Social Development, Republic of South Africa, Pretoria.

RECOMMENDATIONS

- *Disability determination and eligibility processes should consider persons with deafblindness as a distinct disability group.*
- *Disability schemes should take into consideration the significant extra cost of deafblindness, including assistive technology, personal assistance and interpreter-guide services.*

PERSONS WITH DEAFBLINDNESS AND WORK

WHAT DOES THE DATA SAY?

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 8 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.

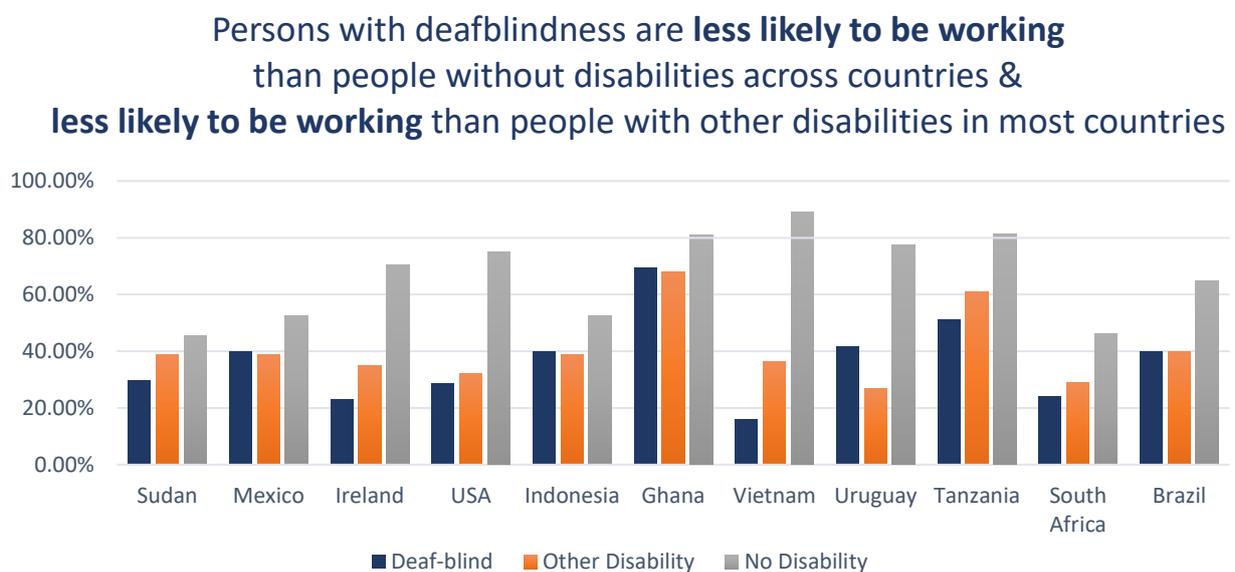


Figure 8. Working status of adults (18 years and over) with deafblindness, other disabilities and no disabilities (has worked in the last 12 months, excluding people currently studying)

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%²) and Ghana (11%) were lower. This trend was inconsistent, however, as high gaps in participation were also evident in Indonesia (55%) and Vietnam (73%).

Excluding Uruguay, where the sample size was too low for age-stratified analysis, people with deafblindness across all age groups were statistically less likely to be working than people without disabilities in all datasets except Sudan, where there was no statistical difference in the 15 to 29 age group (see Figure 9 overleaf). In comparison to people without disabilities, the gap in participation appears to increase with age, and is most pronounced amongst older adults in high-income settings.

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. However, younger people with deafblindness were statistically more likely to be working than younger people with other disabilities

² Gap in crude percentage points, not a proportion.

in the United States and Brazil, with no statistical differences evident for this age group in other countries. People with deafblindness aged 30 to 49 were statistically less likely to be working than people with other disabilities in Ireland, Tanzania and South Africa, and more likely to be working in Ghana and Brazil. In the oldest group of working age adults (50 to 64), people with deafblindness were less likely to be working than people with other disabilities in Ireland, the United States and South Africa.

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), after controlling for age and gender.

People with deafblindness who are not working are much less likely to be seeking work than people without disabilities who are not working



Figure 9.

Amongst people of working age who were not working, people with deafblindness were much less likely to be looking for work than people without disabilities, and this was statistically significant in eight of the eleven datasets. People with deafblindness were also statistically less likely to be working than people with other disabilities in three datasets (the United States, Indonesia and Vietnam), and more likely to be looking for work than people with other disabilities in 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].

OUR VOICE

Employment	High-income countries	Upper-middle income countries	Low-income countries
Are the needs of persons with deafblindness adequately covered in national employment policy?			
Are persons with deafblindness receiving support to access employment services?			

The majority of WFDB members had a negative perspective of the efforts made by governments to ensure equal opportunities to work and employment for persons with deafblindness. Whilst half of all respondents from high-income countries stated that employment policy adequately covers the needs of persons with disabilities, only 17% felt that appropriate employment support measures were in place. Members highlighted discrepancies between policies and implementation.

WFDB members from low and middle-income countries stated that employment policies do not really consider persons with deafblindness. However, services do exist to support those in work, especially in relation to livelihood and self-employment. The differences between higher and lower-income countries can be attributed to the fact that employment in lower income countries is typically informal with little social protection support. In high-income countries, however, significant barriers to work exist in a mostly formal labour market. As a result, many persons with deafblindness may receive disability benefits, which are often determined by resource threshold or incapacity to work criteria.

ONGOING EFFORTS

Vocational training, self-employment and social participation in India

The recently enacted Rights of Persons with Disabilities Act 2016 includes the provision of a 1% job reservation for persons with multiple disabilities, including persons with deafblindness. Prior to the implementation of the Act, there was no provision for persons with deafblindness; however, it is still too early to measure the impact of these changes.

In India, the majority of adults with deafblindness are in self-employment. As such, Sense India and its partner organisations in 22 states across the country have implemented a vocational training programme for young adults with deafblindness. The programme follows multiple avenues.

An advocacy and awareness-raising programme for officials has resulted in the Industrial Training Institute (ITI) enrolling young adults with deafblindness on vocational training schemes. At the same time, 90 adults with deafblindness have received training support, coaching and seed money to set up their own income generation activities. Thanks to a network of partner organisations, more than 450 young adults with deafblindness have benefitted from vocational training in either centre or community-based programmes. Vocational training and self-employment contribute also to tackle social isolation. To strengthen this aspect, there is engagement to enhance social participation, with the support of family members and local communities.



WFDB members from different countries highlighted several common issues:

- There is a critical link between education and employment: Scandinavian countries provide a good example of governments investing in high quality education for children with deafblindness. This empowers children, gives them confidence and provides them with the necessary employability skills. In the majority of countries, however, a lack of adequate education, orientation and mobility training, daily living skills for children and young people with pre-lingual and post-lingual deafblindness, severely limits employment opportunities. In addition, few countries offer effective career guidance, internship and job placement services that could build a bridge between education and employment.
- Prejudices of employers. Attitudes constitute a major barrier for many persons with disabilities, but are magnified as a result of a lack of awareness about the communication requirements of persons with deafblindness. This is compounded by a lack of government support for interpreter-guide services, which may significantly increase the cost faced by employers who hire persons with deafblindness. It is clear that, in countries where governments pay for interpreter-guide services, persons with deafblindness find it easier to gain employment. Quota and tax incentive policies could theoretically help; however, the issues outlined above significantly reduce the potential positive impact. Examples were shared of companies employing persons with deafblindness to achieve tax breaks and subsequently not offering them meaningful work or telling them to stay at home.
- A lack of recognition of deafblindness as unique disability. This leads to people being excluded from legislation in many countries, such as in Bolivia, where employment law does not mention persons with deafblindness. Often persons with deafblindness are not included in vocational training and employment programmes for other persons with disabilities.
- Few countries reported that their respective governments were financially supporting interpreter-guide services in the workplace. This significantly reduces the inclusion of persons with deafblindness in the labour market.
- In a number of countries, persons with deafblindness face restrictions in terms of legal capacity. For example, a bank may require a person with deafblindness to have someone present to sign a contract in order to open a bank account. This limits individuals' ability to manage their finances and engage in economic activities.

A study carried out by Sense International in Peru in 2018 concluded that the main barrier to the employment of persons with disabilities, and persons with deafblindness in particular, is the prejudice of employers and co-workers. The study recommended that work placement measures should not focus on a 'typical' job that persons with disabilities could do, but that people are provided with support to find work that matches their profile and aspirations. It also highlighted the importance of the use of 'internal mentors' as an effective approach to ensure the sustainability of inclusion. The implementation of Law No. 29524, which recognises deafblindness as a unique disability and mandates the state to promote the training and accreditation of interpreter-guides to support people with deafblindness, was identified by the study as a vital development. The study also recommended the introduction of incentives to encourage companies to do more to include persons with disabilities, in particular persons with deafblindness, since current tax benefits are insufficient and have not made an impact.

WFDB members also described a range of interesting practice, such as persons with deafblindness who are in employment offering peer support and mentoring to those looking for work.

RECOMMENDATIONS

- *Ensure that persons with deafblindness are adequately included in employment-related laws, policies and programmes.*
- *Ensure the adequate provision of interpreter-guides for work and employment.*

ONGOING EFFORTS

Peer counselling to support the transition from school to work for young persons with deafblindness in Germany

For many young people, the transition from school to working life is impeded by two essential challenges. Firstly, there is a lack of deafblind adult role models. As the majority of young persons with deafblindness grow up in hearing families, they typically struggle to overcome barriers in a hearing and visually-orientated environment. Secondly, young persons with deafblindness may have to cope with emotional challenges and identity issues, which are often inadequately tackled by the formal support programmes offered by organisations.

This project (funded by the German Federal Ministry of Labour and Social Affairs and undertaken by the Universities of Cologne and RWTH-Aachen) promotes the integration and reintegration of young persons with deafblindness into the labour market via the support of peer counselling. Successfully included adults with deafblindness are selected as mentors and receive training to become peer counsellors. The mentors are then 'matched' with young persons with deafblindness (mentees). During the peer counselling sessions, the mentor helps his or her mentee to acknowledge their personal situation and empower them to follow identified career pathways. A key element of the programme is developing people's self-confidence and independence. The process is supported and monitored by professional coaches. The mentors also signpost young people to relevant opportunities and support, and share their own experiences to inspire and motivate.

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

WHAT DOES THE DATA SAY?

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 (33% gap), Indonesia (62%) and Vietnam (75%).**

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.

Of those children aged 5 to 17 who were not enrolled in school, children with deafblindness were less likely to have ever previously been enrolled than children without disabilities in seven of the nine datasets. They were also less likely to have ever been enrolled in school than children with other disabilities in four of the datasets. However, due to the small sample size, some findings have wide confidence intervals and should be interpreted with caution.



Children with deafblindness are up to **23 times less likely to be in school** than children without disabilities, and less likely to be in school than children with other disabilities

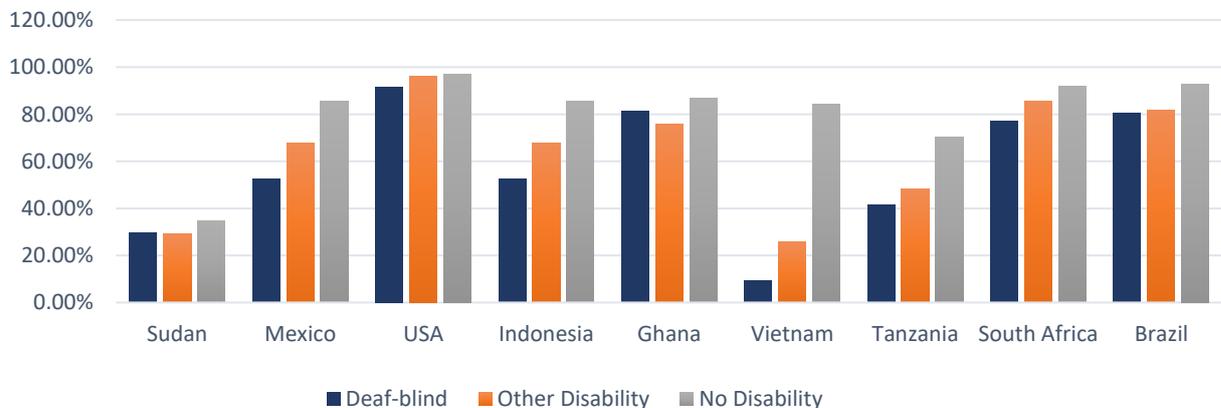


Figure 10. Educational status of children (aged 5 to 17 years of age) with deafblindness, children with other disabilities, and children without disabilities

Children with deafblindness who are not in school are less likely to have ever been enrolled than children without disabilities

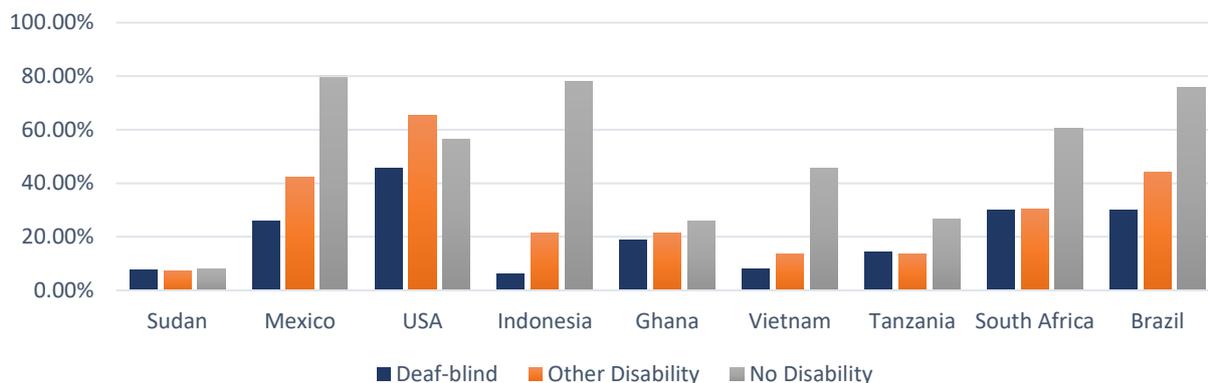


Figure 11

Adults with deafblindness were less likely to have attended school as children than adults with other disabilities and adults without disabilities in each dataset. After accounting for age and gender (given that adults with deafblindness are likely to be older than adults without disabilities), this finding was still statistically significant in all datasets, with the exception of Mexico and Uruguay, where there was no significant difference between adults with deafblindness and those with other disabilities. Considering that age of onset is likely to have been after the completion of education for many adults with deafblindness, this may be due to adults with lower socio-economic status being less likely to attend school or seek healthcare for functional limitations related to ageing.

Adults with deafblindness are less likely to have ever been to school than adults with other disabilities and adults with no disabilities in most countries

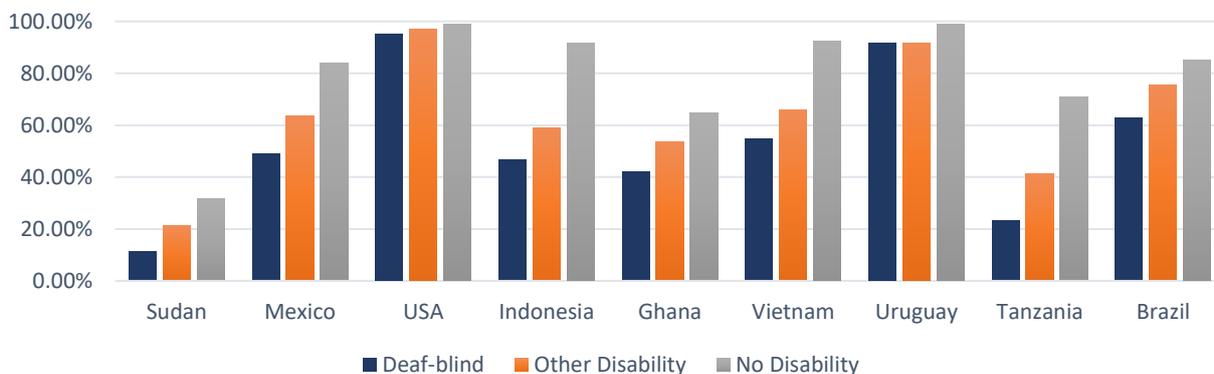


Figure 12.

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.

OUR VOICE

Education	High-income countries	Low and middle-income countries
Are the needs of persons with deafblindness adequately covered in national education laws and policies?	44%	18%
co-existence of inclusive and special education	55%	55%
Access to special education only	33%	45%

Education is a key issue for WFDB members. They identified strong links between employability, social participation and the educational opportunities accessible to children and young persons with deafblindness. Whilst the situation is more pronounced in low-income countries, less than half of the respondents from high-income countries consider education policies to adequately cover the needs of children with deafblindness. In more than half of the countries included within this study, governments provide a mix of special and inclusive education. A third of high-income countries, and nearly half of lower income countries, however, only provide special education.

FOCUS ON INDIA

Significant steps towards inclusion but children with deafblindness are missing out

India is often considered a good example of a country seeking to develop public policies aimed at including children with disabilities in primary and secondary schools. The country’s education policy covers the inclusion of ‘all’ children, including those with deafblindness (6 to 18-years-old), and there are approximately 55,000 children with deafblindness enrolled under the government’s inclusive education programme. The government-provided school system is free to all, and a specific programme covers aids and appliances, nutrition and occasional access to personalised assistance.

The issue however is that as in many other countries such as Colombia, inclusive approach has yet not foster adequate training for education staff and curricula are yet to be truly inclusive. To tackle this issue, Sense India has worked in partnership with the Ministry of Human Resource Development and the World Bank to develop guidelines on curriculum adaptation to support mainstream teachers to adapt existing curricula to benefit children with deafblindness.

In addition to public schools, a number of privately run mainstream schools with resource centres to support the needs of children with disabilities, including deafblindness, exist across India. These centres also enable adults with deafblindness to access higher education and vocational training programmes.

Despite these developments, children with deafblindness are still primarily supported by NGOs through day care and community-based programmes.



Discussions that took place during the 2018 Helen Keller World Conference highlighted several issues:

- In many countries, a lack of awareness about deafblindness results in both families and institutions failing to recognise the right of children with deafblindness to go to school, and that education obligations apply to all children, regardless of disability.
- A lack of early identification and intervention programmes means that parents do not learn to communicate with their children. This makes it more difficult for parents to understand and accept their child's disability, as well as to access support. This, in turn, impacts on a child's development.
- In the majority of countries, there is limited data on the numbers of children with deafblindness in or out of school.
- In many countries, there are no specific educational support programmes for children and young people with deafblindness. Indeed, the majority of support initiatives are either only for deaf or blind children. Teachers are not adequately trained and there is no adaptation of curricula. Members referenced numerous education policies that did not consider children with deafblindness. Existing schools for blind or deaf children may or may not support children with deafblindness; however, there is no systematic approach.
- While specific support services might be available in some high-income countries, these opportunities are unlikely to be available in the majority of low and middle-income countries. There are also discrepancies within countries, with services predominantly concentrated in the capital or major cities, but not in rural areas or smaller towns.
- The importance of developing formal and non-formal education services for young people and adults with deafblindness who did not have access to educational opportunities as children.

Whilst the vast majority of WFDB members support and are in favour of inclusive education, many also call for the further development of resource centres for children with deafblindness, which provide communication, mobility and daily living skills, and prepare children for school. In some countries, resource centres collaborate with mainstream schools and support teachers who have pupils with deafblindness, training them in communication and pedagogy adaptation.

Community-based programmes also provide initial support to children in their homes to prepare them for school and to raise awareness and confidence amongst parents. WFDB members insisted on the importance of developing links between schools, families and communities to ensure the inclusion of children with deafblindness.

It was also suggested that, in some countries, it might be easier to obtain adequate support in private schools rather than public sector institutions, which increases the inequalities faced by poorer families.

RECOMMENDATIONS

- *Ensure that the requirements of persons with deafblindness are taken into account in inclusive education laws, policies and programmes, and efforts are made to adapt curricula, train teachers and provide support to students.*
- *Ensure the availability of resource centres that support mainstream schools, children with deafblindness and their families.*
- *Ensure the adequate provision of interpreter-guides.*

IN OUR OWN WORDS

GERMAN GUERRERO, COLOMBIA

“I started to lose my vision around 10 years old and, by the time I was 14, I had lost all my sight. My family tried various solutions until a doctor told me the best ‘medicine’ was education! So then our focus shifted to integration into daily life.

“I tried to go to a regular school close to home, but as my sight deteriorated, I found I couldn’t see the chalk board. The doctor advised me to go to the Institute for the Blind to continue with my education. After primary school, I went to a secondary school where I encountered many obstacles. As I had relatives in the United States, my family decided to send me there for better education opportunities. I got a secondary education through an open programme with exams every six months and I started studying music – but then I realised I was losing my hearing. It was a difficult time. However, I then got to meet the Association of People with Deafblindness.

“In 2009, the CRPD came into force in Colombia. The National Council for People with Disabilities started to contribute to the implementation of the CRPD. Article 24 references deafblindness and the provision of inclusive high quality education for everyone.

“In Colombia, when I was young and growing up it was very difficult. Now there are more laws and regulations to enable inclusive education. Deafblindness is recognised as a unique disability. Around 350 schools now have a model of inclusive education. We have guidelines about enabling children with deafblindness to attend regular schools and be part of regular classes.

“However, there’s still more work to do. The education system is not yet providing inclusive, high quality education for all. Most schools are not yet accessible, curricula are not adapted, teachers do not receive training to support people with deafblindness, and there is a lack of interpreter-guides. Decision-makers don’t really understand what people with deafblindness want and need, and don’t commit resources to support them. There is a National Council for People with Disabilities and a liaison group through which we, as deafblind leaders, work to tell the government what is required to fully implement the law.

“No-one should suffer what I suffered in the past. Everyone should have access to an inclusive education and, as deafblind leaders, we have to keep working to make the right to an education a reality in our countries. This is because education is the key to independence and to fighting for other rights. The CRPD must be well implemented, which means: adapting the school curricula; making schools accessible; increasing teacher training on working with people with deafblindness; and increasing access to interpreter-guides.

ONGOING EFFORTS

Early identification and intervention in Romania

By the time children with deafblindness reach school age, it is often too late for them to make significant progress in their development and rehabilitation, which can dramatically affect their learning, communication and socialisation.

In 2007, teachers in Romania raised this issue, and Sense International Romania developed a programme to adequately identify deafblindness in babies. These children would then be referred to early intervention services as early as possible so that they could benefit from sensory stimulation therapies, which ultimately improve development, learning and independence.

Partnerships were developed with local child welfare authorities, schools and hospitals in four locations across the country. Nationally, and in partnership with the Ministry of Education, an early intervention curriculum was developed and approved, describing the pathway from the hearing screening and visual testing of babies to specific sensory stimulation therapies.

Multidisciplinary teams were formed and trained, consisting of special education teachers, psychologists, social workers, physiotherapists, ophthalmologists, neonatologists and audiologists. Parents were also key members of the team, delivering early intervention to their children.

Babies at risk of deafblindness underwent hearing screening and visual testing. Children referred to early intervention support centres would benefit from multisensory stimulation, functional visual training, perceptive hearing education, speech therapy and physiotherapy, while parents benefited from information, support and counselling. The children were at the centre of the programme and an individualised intervention plan was tailored to the requirements of each child.

A national legal framework was developed for early identification and intervention to be fully embedded in the Romanian education system so that this pilot can be scaled up. It is currently in the process of being approved by the government.

Providing early intervention services for infants with sensory impairments in Kenya

Sense International launched an early intervention programme in 2017 in partnership with one hospital and three health centres. The three-year programme is piloting the first ever sensory screening and early intervention programme for children aged 0 to 3 years in Kenya. The programme aims to screen 75,000 infants for congenital impairments, provide referrals for children with single sensory impairments, and enrol children with deafblindness in early intervention services, including sensory stimulation and other therapies.

Early intervention units were established within a Ministry of Health hospital and three health centres. Health workers and community health volunteers have been trained to administer the first step risk-factor questionnaire. Any child found to be at risk is sent for screening using visual and auditory testing equipment. Trained occupational therapists then test children's vision and hearing. Children receive further referrals and therapy based on their individual needs.



Christina Moraa's son, Simon (pictured), was one of the first children to be tested. Christina said: "I never suspected that my son had a problem with his hearing. Thankfully, the screening was provided for free, and they have promised support for my child's assessment and treatment."

PERSONS WITH DEAFBLINDNESS AND HEALTH

WHAT DOES THE DATA SAY?

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].

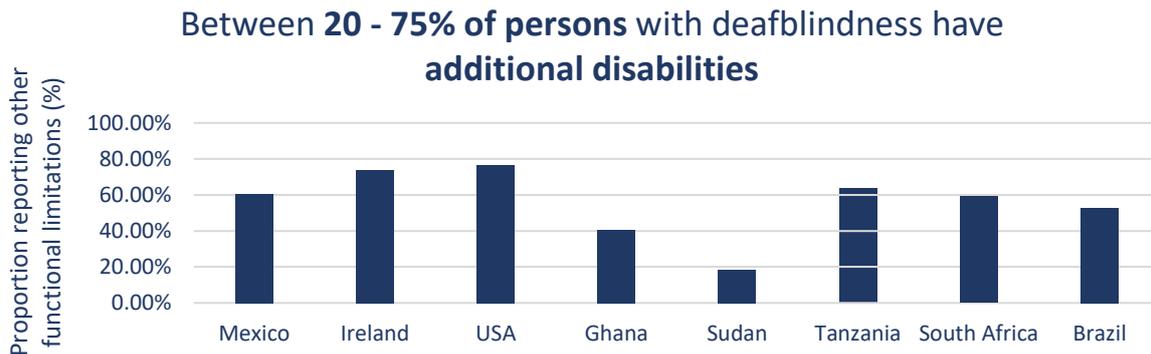


Figure 9. Proportion of persons with deafblindness reporting other functional limitations

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].

OUR VOICE

Health	High-income countries	Low and middle-income countries
Are the needs of persons with deafblindness adequately covered by the national health system?	55%	36%
Access to health-specific services	66%	27%
Particular attention to the sexual and reproductive health and rights of women and men with deafblindness	11%	9%

The survey indicates that health seems to be more accessible for persons with deafblindness than education, especially in high-income countries. Two-thirds of respondents from high-income countries reported having access to specific health services compared to only 27% in lower-income countries. However, both high and low-income countries are reported to be failing persons with deafblindness in terms of sexual and reproductive health services.

The consultation undertaken at the 2018 Helen Keller World Conference provided a more detailed picture of healthcare for persons with deafblindness, highlighting several key issues:

- Medical professionals lack knowledge about the causes and specificity of deafblindness, particularly in children, which leads to poor early identification and intervention.
- Healthcare staff also lack knowledge about the specific communication requirements of persons with deafblindness, which often leads to professionals talking to interpreter-guides or family members rather than the person themselves. This can have a serious impact, including misdiagnosis, as the person is unable to explain his or her symptoms. Furthermore, persons with deafblindness are unable to access information about proposed treatment, leading to a limited understanding of their own medical history.
- In emergency situations, health providers often have no idea how to communicate with a person with deafblindness. This means that the experience can be extremely frightening and/or violating for the person, who does not know what is happening.
- Health promotion and prevention campaigns, for example on immunisation, non-communicable diseases and HIV/Aids, are often inaccessible.
- The profound isolation and lack of socialisation experienced by persons with deafblindness can result in severe distress. A lack of adequate mental health support and services exacerbates this issue.

WFDB members shared good practice that tackle issues linked to access to health in different countries. Several interesting initiatives emerged, including:

- In Denmark, the Association for the Deafblind provides its members with personalised cards stipulating their communication requirements and needs. These can then be placed on a hospital

bed in case of emergency, alerting providers to their needs. Information kits on deafblindness have also been distributed to health providers.

- In Sweden, the government has organised a deafblindness ‘team’ to provide support on health, rehabilitation and social inclusion, with a specific focus on mental health.
- Australia has a national booking service that enables persons with deafblindness to book interpreter-guides when using health facilities. Whilst effective, this system works better in private than public practice.
- In Mexico, a training course has been developed to support interactions between nurses and persons with deafblindness. A training workshop on basic communications systems has also been offered to student nurses at the university. Due to its success, the approach will be replicated in the future.
- In Tanzania, Romania, Kenya, Uganda, and India, Sense international has developed early detection and intervention programs (see page 33).
- In Malawi, VIHEMA Deafblind has led a pilot project on access to sexual and reproductive health (see below).

RECOMMENDATIONS

- *Provide adequate training to healthcare staff both on the causes of deafblindness and the specific communication requirements of persons with deafblindness.*
- *Ensure access to adequate sexual and reproductive health services, with an emphasis on women and girls with deafblindness.*
- *Ensure the provision of adequate early detection and intervention services, in partnership with education providers.*
- *Ensure the adequate provision of interpreter-guides.*

ONGOING EFFORTS

Persons with deafblindness and sexual reproductive health in Malawi

Malawi ratified the CRPD and has endorsed the SDGs. However, not all beneficiaries of the charters are being reached accordingly. Amongst the most vulnerable are persons with deafblindness and in particular women and girls. They experience a lack of access to health services and facilities, health information and communication support, and experience negative attitudes from health workers. This often means that women and girls do not visit health services. They are also exposed to gender-based violence and unwanted pregnancy.

This is why VIHEMA Deafblind Malawi has started advocating for Sexual Reproductive Health Services (SRH) and family planning to be more accessible for women and girls with deafblindness.

VIHEMA carried out a pilot programme that provides training for women with deafblindness and their families, as well for health professionals, including midwives, clinicians and environmental health assistants. Health workers were trained to more effectively communicate about sexual and reproductive health, and given relevant information on supporting women and girls with deafblindness.

Before the training, women and girls with deafblindness did not go to health centres due to staff not being able to communicate and the negative attitude of some workers. The twin track approach embedded helped to break down some of the barriers and facilitate access. A number of women with deafblindness have also proactively engaged in discussions with women without disabilities about family planning. The project also tackled the incorrect belief that forced sterilisation protects women with disabilities from sexual violence.

Whilst the project has achieved positive results, our advocacy work continues, as further changes are needed in both the policies and protocols of the healthcare system in Malawi. Progress will ensure the inclusion of persons with disabilities, especially persons with deafblindness.

PERSONS WITH DEAFBLINDNESS AND PARTICIPATION IN POLITICAL AND PUBLIC LIFE

OUR VOICE

Political participation	High-income countries	Upper-middle income countries	Lower-income countries
Laws restricting the right to vote or to be elected	17%	0%	20%
Active support to engage in political participation	17%	17%	25%

The survey found that, whilst few countries legally restrict the right to vote of persons with deafblindness, few actually provide support to enable political participation.

At the 2018 Helen Keller World Conference, WFDB members were keen to share their experiences about political participation and engagement in public life. There is an acute perception that this is the only way to ensure that persons with deafblindness are recognised and get the attention they deserve and the services they require. Discussions were focused on the key issues in three domains: voting rights and accessibility, personal engagement in consultative mechanisms and beyond, and the development of DPOs.

- Voting rights and accessibility:
 - Accessibility is a key issue in terms of political participation, both with regards to access to information about parties and their programmes, and the day of an election itself.
 - In the majority of countries, no interpretation is provided on televised news or during political debates, preventing persons with deafblindness from making informed decisions. As a consequence, persons with deafblindness have access to limited political information. Many often do not even know the names of political parties or what they stand for. In turn, this reinforces existing prejudices among some families that persons with deafblindness are unable to vote.
 - Voting ballots are often inaccessible. Where they are accessible, persons with deafblindness do not always have access to the right support to be able to vote.
- Political representation of persons with deafblindness:
 - Persons with deafblindness are not adequately represented in politics at all levels. There is a lack of persons with deafblindness elected or appointed within the political arena.
 - People face prejudices from people without disabilities and persons with other disabilities.
- Development of DPOs of persons with deafblindness:
 - Many WFDB members expressed their frustration with the lack of recognition of organisations of persons with deafblindness, both by governments and disability movements.
 - Whilst some countries have made progress, there is not yet true and full recognition of persons with deafblindness. As a result, there is little support and funding to enable people to participate in the political process.

IN OUR OWN WORDS

The importance of participation of deafblind persons in the advancement of public policies at local level

São Paulo, Brazil. Eulália Alves Cordeiro

“My name is Eulália Alves Cordeiro. I am a person with deafblindness. I’m a counsellor at the Municipal Counsel of the Persons with Disabilities in the capital of São Paulo.

“Since 2002, persons with deafblindness from the Brazilian Association of Persons with Deafblindness (named ABRASC) started to participate directly in the Municipal Counsel of the Persons with Disabilities. This engagement increased the visibility of deafblindness, giving participants the chance to express themselves, fight for their rights, and to use their voice to show that they were able to actively take part in public politics in the same way that other persons with disabilities are able to. However, deafblindness still doesn’t have a specific seat at the table. Indeed, deafblind persons usually take over alternatively the chair of the deaf persons, the blind persons or the group of persons with multiple disability.

“As of December 2017, seven deafblind persons work as counsellors or participate in working groups across three Brazilian cities. They work in different sectors related not only to discussions on disability policies, but also on policies for women and health, among other issues.

“Across many states in Brazil, persons with deafblindness are unable to rely on the provision of interpreter-guide services at schools and universities. As a result of our advocacy work.” São Paulo, however, is the only city that provides interpreter-guide services for persons with deafblindness, guaranteed by a municipal ordinance.

Beyond the many challenges identified, WFDB members shared several encouraging developments and initiatives:

- In Croatia, the country’s deafblind association asked for and received financing from the government to provide deafblind interpreters on the day of an election. Voting lists were made accessible, in large print and braille formats. Persons with deafblindness were also given information on the different parties and programmes. In addition, a person with deafblindness has been elected to the country’s parliament.
- In the upcoming election in Sweden, persons with deafblindness who communicate using braille will automatically receive information about the election, as well as their voting card, in braille.
- In India, significant advocacy work has taken place with the Electoral Commission, notably inviting them to train persons with deafblindness on election procedures and the use of the voting machine. Such interaction has raised awareness among officials, who have since taken steps to increase the accessibility of elections. On Helen Keller Day 2018, Sense International India received news from the Election Commission that people with deafblindness will be included within the electoral process for the first time. Accessibility will be improved so that adults with deafblindness can participate in forthcoming general elections.
- In Malawi, the Electoral Commission introduced a tactile ballot. However, there is still room for improvement and the introduction of more features for persons with deafblindness.
- In São Paulo, Brazil, persons with deafblindness have been actively involved in the municipal council (see above).
- In Denmark, the country’s organisation of persons with deafblindness disseminates a twice-yearly magazine to inform policymakers and politicians about the key issues faced by persons with deafblindness, as well as their key needs and demands.

RECOMMENDATIONS

- Ensure that the right to vote is granted to all persons with deafblindness.
- Take into consideration the accessibility requirements of persons with deafblindness with regards to election campaigns, voting materials and polling stations.
- Support the engagement of persons with deafblindness in political and public life.
- Support organisations of persons with deafblindness and involve them as a distinct disability group in all consultations with disability movements.

FOCUS ON KENYA PARTICIPATION IN POLITICAL AND PUBLIC LIFE

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.

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-ea.org

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



Image 1. Emma Mbugua



PERSONS WITH DEAFBLINDNESS AND SOCIAL LIFE

WHAT DOES THE DATA SAY?

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.

People with deafblindness are less likely to be married than people without disabilities in all datasets except Sudan and Uruguay.

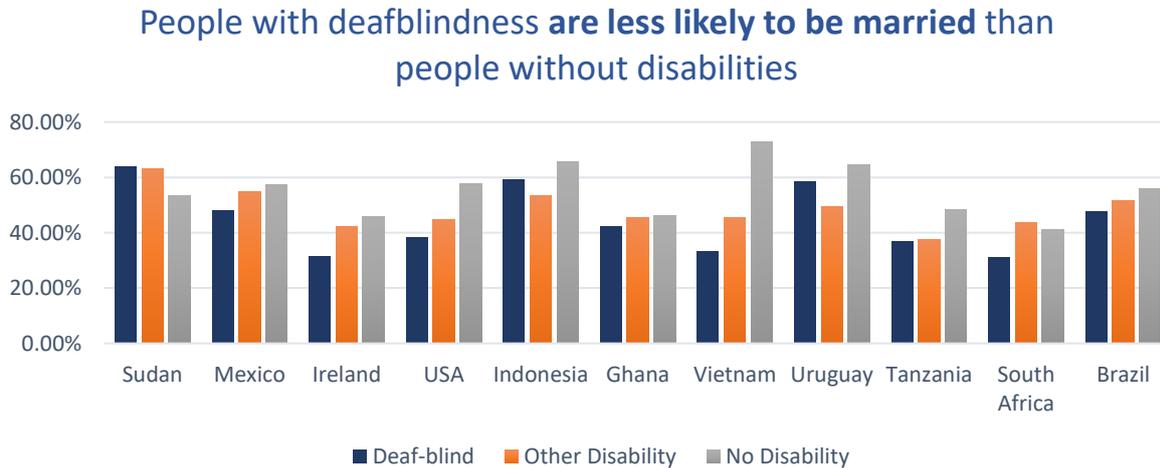


Figure 14

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.**

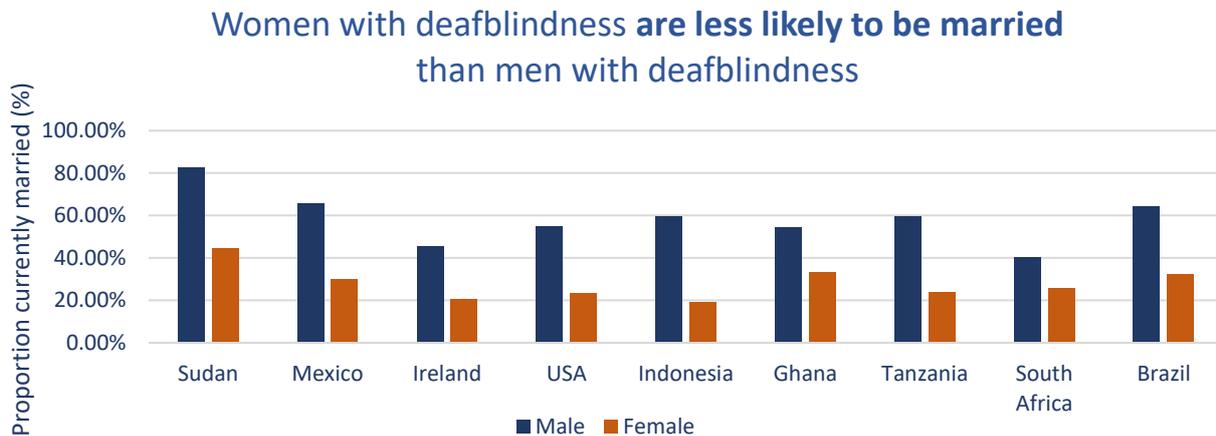


Figure 10. Marital status among women and men with deafblindness

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.

Children with deafblindness are more likely to have an absent parent than children without disabilities in five out of nine countries

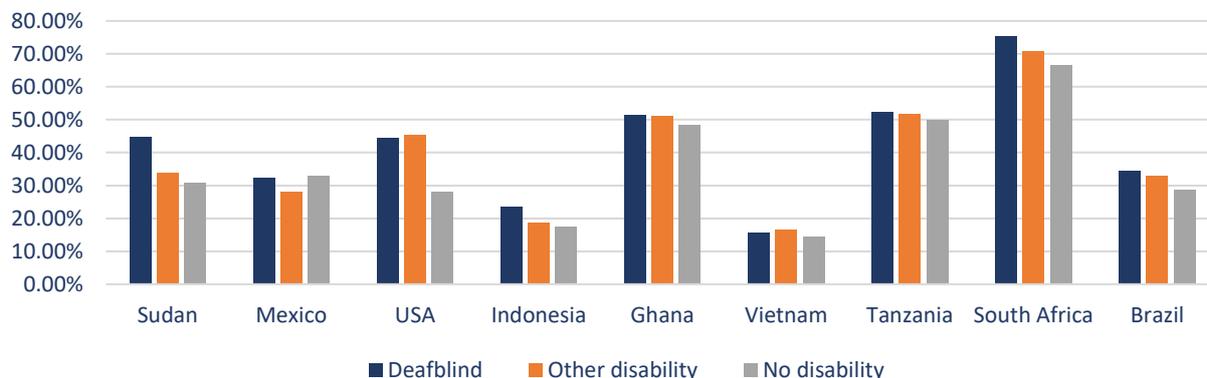


Figure 11. Proportion of children aged 5 to 17 years with one or both biological parents absent from the household

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].

OUR VOICE

Community inclusion	High-income countries	Upper-middle income countries	Low-income countries
Access to regular community services	50%	50%	40%
Community support services provided	83%	33%	20%

Unsurprisingly considering the issues highlighted with regards to the inaccessibility of interpreter-guides, only half of all respondents from high and middle-income countries (and 40% of those from low-income countries) stated that they had access to regular community services. Discussions with WFDB members showed that accessing such services was only possible with the support of family members and that autonomous use was a serious problem. With regards to specific community support services aside from interpreter-guides, 85% of respondents from high-income countries stated that they had access to such services, compared to 33% of respondents from middle-income and 20% from low-income countries. It is clear that very few disability support services exist beyond those provided through NGO-organised community-based programmes.

Confirming the findings from the literature, WFDB members highlighted the severe isolation that most persons with deafblindness experience. A lack of accessibility, limited employment opportunities and an accumulation of barriers severely restrict the participation of persons with deafblindness.

Each individual follows a different pathway, and this is often dependent of whether deafblindness is pre- or post-lingual, and whether it is acquired at a younger or older age. In all cases, however, a lack of adequate support for a person and his or her family, the cost of assistive devices, the lack of interpreter-guide services, and the lack of rehabilitation services significantly restricts social participation and increases isolation.

WFDB members also highlighted the issues of stereotyping and a lack of knowledge amongst family members and friends, which caused isolation within family and friendship groups. Poor communication and family support can lead to issues such as violence, neglect and abuse, and, in extreme cases, persons with deafblindness may be locked away in their homes or medicated so that they sleep all day. Families may also be over protective and prevent individuals from taking risks and participating in the community. Isolation and a lack of independent living skills can result in severe anxiety amongst family members, particularly older parents who fear what will happen to their adult children after they pass away.

Due to gender-based discrimination, each of these elements is magnified for women with deafblindness, who are more exposed to abuse and sexual violence.

The very few people who master communication techniques in the environment of a person with deafblindness imply that connections are usually formed through an intermediary, such as an interpreter-guide. Awareness needs to be raised so that people, particularly community service providers, are aware of even the basic communication requirements. Typically, when persons with deafblindness retain some residual hearing and sight, people do not communicate effectively.

A lack of support for interpreter-guide services is a critical barrier across a range of countries and situations. As outlined in this report, few countries provide adequate, high quality services so that persons with deafblindness can gain a meaningful education, work and social participation. People often have to choose when to use their allocated hours of granted support and sacrifice entire aspects of their life.

More positively, WFDB members highlighted the fact that the growth of social media and accessible technology have created a raft of new opportunities through which they can interact with the world and other persons with deafblindness. This should be a major motivation for governments to ensure the accessibility of information communication technology.

Organisations of persons with deafblindness play a critical role in reaching out, stimulating and catalysing social activities that include families and communities. Unfortunately, as previously discussed, many people and their families do not benefit from the necessary support from authorities.

RECOMMENDATIONS

- *Provide early intervention and counselling services for families of children with deafblindness.*
- *Implement community-based intervention programmes to facilitate the social participation and inclusion of persons with deafblindness.*
- *Ensure the adequate provision of interpreter-guides.*

IN OUR OWN WORDS

CARLOS & 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.”



THE LONG READ: BEING A WOMAN AND A MOTHER WITH DEAFBLINDNESS

Camila Indalecio, Brazil

INTRODUCTION

The history of women is marked by struggle and challenges, as we fight for equality and for opportunities within society. Women are often excluded and discriminated against simply because of our gender, and we often have to fight to overcome assumptions and guarantee gender equality. Even today, women across the world face many obstacles to equality, including racial discrimination, violence, poverty and – for those women with disabilities – additional discrimination because we are different. The history of women, however, is defined by the history of women without disabilities. Women with disabilities are, therefore, a minority within a minority. Our stories of struggle and overcoming barriers are either forgotten or unrecognised.

Women with deafblindness also suffer specific discrimination within the disability movement. People with other disabilities perceive us as being incapable of participating in public policymaking, having a family, or gaining employment. Because of the different ways in which we communicate, we are rarely given any opportunities, and few people with deafblindness are able to fight for recognition or the right to equity.

*Many women do not have access to information about healthcare or education.
To these women, **the universe is a silent, dark world.***

We, women with deafblindness, face many obstacles simply because we are women. We are submitted and exposed to various difficulties and challenges. Domestic and sexual violence are often hidden, even by the family. Many women with deafblindness suffer silently, day after day, without anyone to defend or protect them. Many women do not have access to information about healthcare or education. To these women, the universe is a silent, dark world.

However, a number of women with deafblindness do lead productive lives within society. They fight both as women and as mothers, actively advocating for public policies to guarantee their rights, as well as ensuring family protection. This struggle to achieve recognition in society is experienced by each and every person with deafblindness.

BEING A WOMAN WITH DEAFBLINDNESS

I am a woman with acquired deafblindness and Usher syndrome. I found out that I was becoming deafblind when I was 13 years old. When I was 11 I started to lose my hearing and, when I was 23, I lost my sight. Knowing that I would become deafblind when I was 13 did not affect me that much. I was a teenager who was worried about enjoying life to the fullest. My mother, whom I greatly admire, never hid the fact that I would lose both my sight and my hearing. My older sister was already living with deafblindness.

During my time at school, however, I was ashamed to accept my deafness, to use hearing aids, and feared that my peers would not accept me. To interact and follow the classes, I learned to lipread. In the second year of high school, I faced the first situation of discrimination in the classroom. The teacher read a text aloud for us to write down. I couldn't lipread what she said because her head was down while walking around the room. I asked her to speak in front of me, so that I could lipread what she was saying. She replied, "It's none of my business. If you're deaf, it's not my problem. This is not a school for the deaf." The whole room laughed and made jokes about me. I cried and felt full of shame and begged my mother to move me to another school. I finished high school at an inclusive school where many people with physical disabilities were studying. Unfortunately, I was unable to attend college because I could not get a job to pay for my studies. That's when I became my sister's interpreter-guide.

I used to take her to work, to events and leisure activities, and I interpreted newspapers, books, TV and conversations with other family members at home. I began my preparation to live, in the future, as a person with deafblindness. Having seen the routine and barriers faced by my sister in terms of accessibility, I began to imagine what my life as a person with deafblindness would be like. However, wearing their shoes was something totally different.

Despite being part of my sister's experience, I was not prepared psychologically, particularly as I had a much greater challenge ahead of me: the challenge of being a 'deafblind mother'.

Interpreter-guides strive to convey as much information as possible to the person with deafblindness, to help him or her to interact. Sometimes, however, they may become impatient. This happens a lot with some interpreter-guides, as situations arise where they get frustrated, or think that certain information doesn't need to be passed on to the person with deafblindness. To have worked as an interpreter-guide was of great value to me; it prepared me to understand that not everything can be transmitted, even if the interpreter-guide is trying their best. Today, I realise how much I failed my sister.

When I became deafblind, I thought that I was prepared to accept the difficulties and challenges that came with it, due to my experiences and interactions with my sister, other persons with deafblindness and my work and learning as an interpreter-guide. Despite being part of my sister's experience, I was not prepared psychologically, particularly as I had a much greater challenge ahead of me: the challenge of being a 'deafblind mother'. The despair and sense of incapacity took over me and everything I had learned from persons with deafblindness and the professionals vanished from my mind, leaving everything in the dark.

Although my family always supported me, it took me a while to come to terms with it all. It was difficult to accept. I started thinking, 'What now? How am I going to help my deafblind sister and other persons with deafblindness the way I used to do? How will I raise my child and help him with his school work, his daily activities?' This was my worst fear and nightmare: how to fully participate in my son's life and whether he would accept me as a mother with deafblindness. Those were just some of the questions I asked myself during this acceptance process. Many mothers with deafblindness face these challenges, but many of them fear sharing the difficulties they are coping with, afraid of showing themselves as weak. As a result, they keep the pain, the frustration and the despair to themselves.

BEING A MOTHER WITH DEAFBLINDNESS

One of the challenges of being a mother with deafblindness is overprotection from your family. Many people believe that a mother with deafblindness is unable to perform or participate in certain tasks with her children, making her feel incapable or guilty about a situation that is, in truth, socially invented. The mother may end up angry with herself for being deafblind, and she may start to believe that she isn't able to fully participate in the life of her child like other parents. A family's attitude can greatly affect the bond between mother and child, and the child may relate to and respect the other family members more than the mother herself. After undergoing a process of acceptance, my family helped me to interact with my son, encouraging him to be close to me, making him aware of my disability and trying to ensure we had a life like any other family.

My son was three years old when I became deafblind. I could see very little at that time. There were still many discoveries, such as preparing for him to go to school. I worried a lot. That's when we started adapting games so that I could play soccer with him, I could follow his drawings. How did we do that?

While he was drawing, he would tell me what he was doing. We started playing soccer with our hands, sitting on the ground. We used to look for toys that I could feel to play with him. I also wanted to teach my son how to explain different activities to me. For example, while watching children's music videos, he taught me the dance steps and the lyrics of the song.

My other sister, Andreia, who later became both my sister and my interpreter-guide, helped me to come up with ideas and taught my son to guide me, or to let me know when he needed something. This phase was a bit easier. The difficulties came later: school and the times when he got ill.

To enrol my son in school, I had to go with my mother. The school principals did not allow me to enrol because I was deafblind. They thought I was incapable of making decisions about my son. It upset me a lot and my mother felt that she should protect me from situations where I might feel embarrassed or angry. I have always had a strong temperament, and have always confronted my mother when she tries to protect me from situations involving my son.



At pre-school, my child had learning difficulties, and struggled to focus on activities. The teacher and the principal called in my mother to discuss my son. I went along, even though my mother told me not to. The teacher said that my son had not developed because I was deafblind. That, to me, was a huge shock. A slap in the face. I was furious. I pointed my finger at the teacher's face and said, "My son doesn't have problems with his activities just because I'm deafblind. Children of parents without disabilities go through the same situation and I will prove to you that it is not because of my disability, and that I am fully capable of helping my child to thrive at school!"

My mother was initially ashamed, but eventually she realised that I was right to speak up. Because I was taking part in rehabilitation at Grupo Brasil and at the ABRASC, I was able to seek guidance from teachers who work with children with deafblindness. One teacher, Dalva, helped me a lot, and taught me how to use modeling clay so that my son could improve his hand-eye coordination.

Writing was more intuitive. As I have a tattoo, my son liked to pretend that he was tattooing my foot. He then began to draw on my feet and legs, where I have more sensitivity. This gave me an idea and I began to help him write in this way: he drew and wrote, and I corrected. Using this method, he started to develop in his school activities.

Other difficult situations at school included the presentations and parties. My son's first performance is the last image I have of him. It was a dance performance. I've never felt so much pain when looking forward to seeing something in all my life. The desire to watch my son dance was immense. Although my family was interpreting everything – the clothing, the lyrics of the song, how he was dancing – I could only see the flashes of the cameras. I cried so much and I had to try to calm myself down. When the dance ended, the teacher encouraged the children to meet their parents. Arthur, my son, saw me crying and asked why. I lied. I said that I was thrilled to see him dance. I was surprised by his response. Despite being only three years old, he said, "Mom, I know you do not see anymore, but look, I danced very well. I fell, but I stood up quickly!" At this point, I realised that he was becoming aware of my deafblindness. It was clear that the education my family and I had provided him was starting to show results. He understood me and he was close to me.

At another school, my son was bullied for being overweight and for being the son of a woman with disabilities. Once again, the teachers and principals tried to keep me away. They did not want me to participate in his activities and I was again told that he was not developing because I was deafblind. This time, however, I was prepared.

People aren't used to seeing a person with deafblindness playing an active role in their children's lives. This role is usually assumed by another family member. There are still few people who understand the different forms of communication, such as the use of tadoma. When I took my son to school with my sister, and she talked to me, other mothers and fathers would look at me, frightened, suspicious, thinking that I was a lesbian. They started separating their children from mine. My son's classmates made sick jokes and isolated him, because of their parents.

(...) reconciling the fact that I am a woman with deafblindness, a mother and a militant, is difficult. A lot of my time is spent on mobility and communicating. I also need time for translation and interpretation, and require the support of professionals, such as interpreter-guides.

Again, I faced up to the school principals, the teachers, and even the other parents. My mother wanted to protect me from what was happening to my son at school, and tried to solve the issues herself. But I confronted her, explaining that I had the right to know what was going on, whether good or bad.

One day, a group of mothers were whispering about me, and about the fact that I was touching my sister's face. She passed me this information and so I asked her to take me to the group. I explained how I communicate and ended up saying that, if I were a lesbian, they should respect me. In doing so, I gained respect, and they started to see me in a different way. To those who called me a 'pity person' or who said I was sick, I replied that I have no illness, that I am a person with a disability. When you take away the 'Dis' the word that remains is 'ability'.

The role played by the family of a mother with deafblindness is very important. However, the mother herself has to have the courage and desire to face the challenges, and to prevent her family from becoming overprotective. If the family does not support the mother with deafblindness to interact with her own child, enabling them to feel close to each other, how can that bond be strengthened? And what will happen in the future? Sometimes my son rides his bicycle on the street. I sit while other parents accompany their children. My mind is not quiet and every car noise or child's scream terrifies me. I can still communicate and ask for help from someone, though. What about the mothers with deafblindness who can only communicate with tactile Libras or other forms of communication that nobody knows? When I have the opportunity to meet other mothers with deafblindness, I try to share my experiences, teaching them how to participate in their children's school activities.

Family support is critical, as is participation in the development of policies, which will ultimately help to break down the barriers. However, reconciling the fact that I am a woman with deafblindness, a mother and a militant, is difficult. A lot of my time is spent on mobility and communicating. I also need time for translation and interpretation, and require the support of professionals, such as interpreter-guides. As a result, in Brazil today, few women with deafblindness have the opportunity to play an active role in the development of public policies.

I would like to finish by saying how grateful I am to my mother. Although she sometimes tries to protect me from difficult situations – and this is motherly, I know how it is – she has always given me the support I need. She gives me strength to not give up fighting and has never made me feel incapable. She has always encouraged my sister and I to prove that we are capable. My whole family, my brothers, nephews, nieces and brothers-in-law, are the same. I am grateful to all of those who give persons with deafblindness their full support and encouragement.

CONCLUSION AND RECOMMENDATIONS

Combining the largest population-based analysis of persons with deafblindness conducted to date (disaggregation of 22 population-based surveys from low, middle and high-income countries), an academic literature review, surveys conducted amongst members and partners of WFDB and Sense International, and consultation with more than 75 women and men with deafblindness who took part in the Helen Keller World Conference in June 2018, this initial global report examines whether the needs of persons with deafblindness, as recognised in the Convention on the Rights of Persons with Disabilities (CRPD), are being met by governments across the world.

This report will be followed by several reports up to 2030 to monitor the progress being made to realise the rights of persons with deafblindness according to both the CRPD and Sustainable Development Goals (SDGs).

Despite a number of impressive achievements and the tireless advocacy work undertaken by organisations of persons with disabilities and their allies, the report finds that, overall, the issues faced by persons with deafblindness have largely been ignored. As a result, people with deafblindness are being 'left behind', contrary to the fundamental principle that underpins the SDGs.

Globally, a vicious circle exists, whereby a lack of awareness and a lack of recognition of persons with deafblindness as a distinct disability group have led to invisibility and consequently a failure of governments to recognise inclusion requirements. Due to the specific implications of their disability, persons with deafblindness face additional barriers and require specific support, in particular interpreter-guide services and tailored rehabilitation services, among others.

As these services are only available in a few countries, persons with deafblindness benefit little from development efforts, including those aimed at implementing the CRPD.

KEY FINDINGS

Previous estimates suggest that around 0.2% of the world's population are living with deafblindness. Analysis of prevalence data in the report found that this figure ignores a vast number of people with milder forms of deafblindness who experience barriers to participation and discrimination. As such, 2% is a more accurate figure, reflecting the diversity of persons with deafblindness. Within the population of persons with deafblindness:

- While deafblindness is more common among older age groups, deafblindness among children and young adults has a more pronounced impact on daily living, for example in terms of barriers to education, employment and social participation, and a higher risk of poverty.
- They are ten times less likely to be employed than non-disabled people, and 30% less likely to be employed than persons with other types of disabilities.
- Children with deafblindness are 17 times less likely to be in school than non-disabled children, and twice less likely to be in school compared to children with other types of disabilities.
- Families and households that include persons with deafblindness are more likely to be in the bottom 40% in terms of socio-economic status compared to households that include no members with disabilities and households with people who have other disabilities.
- Women with deafblindness experience increased restrictions in terms of participating in a wide range of activities.

In addition:

Between 20% and 75% of persons with deafblindness have additional impairments.

- There is a high prevalence of depression among persons with deafblindness, but low access to mental health services.
- Children with deafblindness are less likely to live with both parents.
- Persons with deafblindness are less likely to be married.

- Persons with deafblindness reported a low quality of life and restrictions in participating across a wide-range of activities.
- Persons with deafblindness aged over 50 are twice as likely to be socially isolated compared to those without a combined sight and hearing impairment.

Information provided by WFDB members and Sense International teams and partners suggest an inadequate policy response from governments:

- There is an overall lack of awareness and recognition of persons with deafblindness as a distinct disability group. It is often wrongly assumed that people only require at best a combination of the services that exist either for blind or deaf people. This, however, ignores the specific barriers and communication requirements of each person with deafblindness.
- While the situation is exacerbated in lower-income countries, few countries have developed effective publicly funded support services for persons with deafblindness, especially interpreter-guide services. A lack of support has a negative impact on a person's social and economic situation, their political participation, and contributes to a high incidence of isolation.
- Employment policies and services do not adequately support persons with deafblindness.
- Education provision is generally inadequate, with an overreliance on special education settings and little attention to children with deafblindness specific requirements in inclusive education policies and processes as well.
- Whilst access to health is better for adults with deafblindness, with the distinct exception of sexual and reproductive health services, it was noted that communication barriers and the negative attitudes of healthcare staff affect the care that people receive. In many countries, healthcare staff do not have the requisite knowledge or training on the causes of deafblindness or the specific communication requirements of individuals.
- Few countries have developed adequate early detection and intervention services for children with deafblindness, which impacts on their development and family relationships.
- There are large discrepancies between high and low-income countries in terms of access to social protection. In most countries, existing support does not cover the extra cost of disability (this cost was estimated to be the highest among persons with disabilities in South Africa).

Case studies provide insights into innovative practices in health, education, employment and personal experiences, and demonstrate the pathways required to ensure the full and effective participation of persons with deafblindness.

RECOMMENDATIONS

The evidence contained in the report confirms that persons with deafblindness are left behind in terms of disability inclusion and development efforts. In addition to the common demands of the disability movement with regards to accessibility, non-discrimination, participation and inclusion, WFDB members have identified the following recommendations to ensure that persons with deafblindness are able to contribute to and benefit from ongoing and future efforts to achieve the SDGs and implement the CRPD:

Pre-conditions for inclusion

- Universal and national recognition of deafblindness as a distinct disability in law and practice.
- Development, in consultation with persons with deafblindness and their organisations, of required support and deafblind interpretation services, in particular interpreter-guides, and adequate public funding to ensure support in education, work and community life.
- Ensure that organisations of persons with deafblindness are considered as a distinct disability group and are included as such in all consultation with persons with disabilities.
- Involve persons with deafblindness and their organisations in awareness raising and inclusion-related programmes, serving as role models, mentors and peer support.

- Adopt, in consultation with persons with deafblindness and their organisations, a consistent definition and measurement of deafblindness, and collect, disaggregate and analyse data, to assess and monitor situation of persons with deafblindness, including through relevant analyses of national datasets using the Washington Group Short Set questions or other methods.
- Conduct additional research on the issues facing persons with deafblindness, including health status and access to healthcare, social participation and wellbeing, quality of work and education, causes, and age of onset. Undertake impact evaluations of interventions designed to improve inclusion.

Social protection

- Disability determination and eligibility processes should consider persons with deafblindness as a distinct disability group.
- Disability schemes should take into consideration the significant extra cost of deafblindness, including assistive technology, personal assistance and interpreter-guide services.

Education

- Ensure that the requirements of persons with deafblindness are taken into account in inclusive education laws, policies and programmes, and efforts are made to adapt curricula, train teachers and provide support to students.
- Ensure the availability of resource centres that support mainstream schools, children with deafblindness and their families.
- Ensure the adequate provision of interpreter-guides.

Health

- Provide adequate training to healthcare staff both on the causes of deafblindness and the specific communication requirements of persons with deafblindness.
- Ensure access to adequate sexual and reproductive health services, with an emphasis on women and girls with deafblindness.
- Ensure the provision of adequate early detection and intervention services, in partnership with education providers.
- Ensure the adequate provision of interpreter-guides.

Work and employment

- Ensure that persons with deafblindness are adequately included in employment-related laws, policies and programmes.
- Ensure the adequate provision of interpreter-guides for work and employment.

Political participation

- Ensure that the right to vote is granted to all persons with deafblindness.
- Take into consideration the accessibility requirements of persons with deafblindness with regards to election campaigns, voting materials and polling stations.
- Support the engagement of persons with deafblindness in political and public life.
- Support organisations of persons with deafblindness and involve them as a distinct disability group in all consultations with disability movements.

Social participation

- Provide early intervention and counselling services for families of children with deafblindness.
- Implement community-based intervention programmes to facilitate the social participation and inclusion of persons with deafblindness.
- Ensure the adequate provision of interpreter-guides.

As this report concludes, persons with deafblindness are still left behind in all countries of the world. The initial steps to amend this and bridge the gaps, as this report shows, are:

50 AT RISK OF EXCLUSION FROM CRPD AND SDGS IMPLEMENTATION

CONCLUSION AND RECOMMENDATIONS

- To establish a universal acknowledgement and recognition of deafblindness as a unique and distinct disability, with its own specific challenges, barriers, support and inclusion requirements.
- Establish publicly funded deafblind interpretation services, in particular interpreter-guides.
- Provide the necessary funding for further research and strengthening of the advocacy work, including funding of the tools and technical support needed.

Fulfilling these steps will contribute to lifting Women and men, girls and boys with deafblindness to a position where they may be able to engage, advocate and contribute on more equal terms paving the way towards full and effective participation and inclusion.

For more information on the global report on deafblindness please contact: globalreport@wfdb.eu

For more information on the World Federation of the Deafblind please visit: www.wfdb.eu

For more information on Sense International please visit: <https://senseinternational.org.uk>

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ANNEX 1 - METHODOLOGICAL NOTE ON THE DATA

Challenges in using census data

A strong preference for surveys using the Washington Group Short Set was included when assessing which datasets to include in the quantitative data analysis. The Washington Group Short Set (see the box below) was designed by the Washington Group on Disability Statistics, and has been endorsed by the United Nations Statistical Division for the 2020 round of censuses as a minimum for monitoring inclusion under the UNCRPD and the SDA [42-44].

Washington Group Short Set of questions for the census

Preamble: "The next questions ask about difficulties you may have in doing certain activities because of a health condition."

1. Do you have difficulty seeing even if wearing glasses?
2. Do you have difficulty hearing even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care, such as) washing all over or dressing?
6. Do you have difficulty communicating (for example, understanding or being understood)?

Response categories:

1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all
(Source: <http://www.cdc.gov/nchs/citygroup.htm>)

The questions were designed for ease of use and comparable interpretation across countries and over time. They are useful in identifying persons with deafblindness from population datasets, allowing analyses to be separated by the severity of functional limitation (e.g. the differences in terms of access to work between those reporting 'a lot' of difficulty or 'cannot do' in both domains, compared to those reporting 'some' difficulty).

However, it proved difficult to identify sufficiently large datasets that had used the Washington Group Short Set, and so some datasets had to be included that did not use this measure. It is important that this method continues to be integrated into population data collection, and for it to be integrated in its entirety. For example, a number of datasets included questions 1 to 4 of the short set, but excluded the questions on self-care and communication that would have been useful to analyse people with deafblindness. By excluding specific questions and using non-comparable alternatives, the population identified in analyses as having 'other disabilities' is also different across datasets, again limiting direct comparability.

An additional concern in terms of the use of census data for deafblindness-related analyses is the frequent exclusion of institutional or homeless populations from either sampling or disability-specific modules. As people with disabilities, including people with deafblindness, are likely overrepresented in these groups, approximations of deafblindness may be underestimated. Furthermore, as people with deafblindness often have multiple impairments, visual and hearing loss may not always be reported, particularly when impairments are captured in a 'check all that apply' approach, rather than through impairment and/or functional limitation-specific questions. Moreover, questions about individual household members are typically answered by the household head, rather than through self-reporting. Proxy reporting has been linked to the underestimation of disability, which likely applies to deafblindness. Furthermore, census data collection is rarely adapted to alternative communication styles, which means that people with deafblindness are often unable to share their experiences directly.

Finally, due to the prevalence of deafblindness being relatively low amongst younger age groups, even some large census datasets do not include sufficient numbers to be able to conduct robust analyses. Indicators in domains such as health and social participation were also lacking. Furthermore, whilst data can provide information on school enrolment and/or attainment and work status, indicators are lacking on the quality of work and education.

Going forward, it is important to achieve consensus and the consistent use of a definition and measurement of deafblindness so that future data is comparable over time and location. In addition, focused studies on deafblindness using alternative data collection methods, such as qualitative methods or in-depth deafblindness-specific surveys, can provide complementary information about the lived experience of deafblindness, which is not always captured in large-scale surveys. In combination, these approaches can help to ensure that deafblindness is captured in monitoring and evaluation of both the CRPD and the SDGs.

STATISTICAL APPENDIX 1: DATA ANALYSIS METHODOLOGY

Data acquisition

The data used in the quantitative analyses was acquired via the IPUMS-International website (<https://international.ipums.org/international/index.shtml>) between 2017 and 2018. IPUMS-International is a collaborative project between the University of Minnesota, National Statistical Offices, international data archives, and other international organisations [45]. The project aims to provide an inventory of global census data for secondary data analyses by qualified researchers.

Datasets were selected for inclusion based on:

Geographic and income level spread.

Sufficient sample size to allow analyses disaggregated by deafblindness.

An appropriate and broadly comparable measurement of deafblindness, with a strong preference for those using the Washington Group Short Set.

Data processing

All of the data was analysed in Stata SE version 15.0.

Data analysis

People with and without deafblindness

Survey respondents under five years of age were excluded from analyses based on the lack of a validated survey tool for measuring deafblindness in that age group. Survey respondents aged five years and older were categorised into one of three mutually exclusive groups:

Persons with deafblindness ('a lot' or greater difficulty seeing and hearing; or a binary 'yes' response to difficulty seeing or hearing; or a binary 'yes' response to being deaf and blind, depending on the survey methodology).

Persons with other disabilities ('a lot' or greater difficulty in any other functional domain; or a binary 'yes' response to having another impairment, depending on the survey methodology).

Persons without disabilities (not included within either of the aforementioned categories).

Prevalence estimates

Prevalence estimates were calculated using the 'SVY' command to account for clustering and to provide a 95% confidence interval. Estimates were also adjusted using IPUMS-International Sample

Explaining confidence intervals and odds ratios

An odds ratio (OR) is a measure of the association between an exposure and an outcome. In this example, OR measures between household poverty (exposure) and whether the person has deafblindness (outcome). The OR represents the odds that an outcome will occur given a particular exposure, compared to the odds of the outcome occurring in the absence of that exposure. An OR of 1 suggests no association between the exposure and outcome. An OR >1 suggests the exposure is associated with a higher chance of the outcome occurring. An OR <1 suggests the exposure is associated with lower odds of the outcome occurring.

The 95% confidence interval shows the range of odds ratios that are likely, with 95% probability. If the confidence interval does not include 1, then the odds ratio is statistically significant (as in the example given above). Confidence intervals are also shown around estimates of prevalence, indicating the range within which we can be 95% sure that the true population estimate exists.

For example:

- Odds of deafblindness for a person living in the poorest household group = $250/262 = 0.95$.
- Odds of deafblindness for a person living in the wealthiest household group = $46/26 = 1.77$.
- Odds ratio = $1.77/0.95 = 1.9$ – 95% confidence interval 1.1 – 3.1.

This means that people living in the poorest households are almost twice as likely to have deafblindness compared to those living in the wealthiest households, and that this result is statistically significant at the 95% confidence interval.

Weights for individuals. Prevalence estimates were stratified by age group and by gender.

Poverty estimates

To compare the socioeconomic status of participants, a principal component analysis of durable household asset ownership (e.g. cars, internet and mobile phones) and housing characteristics (e.g. flooring material, walls and type of sanitation facilities) were computed for each country. Principal component scores were then divided into quintiles. Poverty was defined as being in the lowest two quintiles (bottom 40%). ORs were calculated comparing households including people with deafblindness to households including people with other disabilities and households with no disabilities, adjusted for urban and/or rural region, household size and dependency proportion (number of children <15 years and adults 65+ years over the total household size).

Poverty estimates were also disaggregated based on whether the person with deafblindness was above or below 50 years of age. In households that included multiple members with deafblindness of differing ages, a household was classified as being under 50 if there was at least one member with deafblindness aged below 50. ORs were calculated by comparing households that included members with deafblindness under 50 to households with members with deafblindness over 50, adjusting for household size and dependency proportion.

Demographics

Amongst adults (18+), estimates of several demographic indicators were calculated.

Current marital status was assessed in two ways. First, individuals were categorised as: never married, currently married, widowed or divorced/separated. Second, a binary variable was added: currently married/not currently married. ORs were calculated by comparing people with deafblindness to

people with other disabilities and people with no disabilities. This was adjusted by age group, gender, urban and/or rural region, and stratified by age group and gender.

Presence of biological parents in the household was calculated based on the listed relationships between household members. A child (<18 years) was deemed not to have at least one biological parent present in the household if the household roster did not indicate the presence of that child's biological mother or father. ORs were calculated comparing children with deafblindness to children with other disabilities and children with no disabilities. These were adjusted by age group, gender and urban and/or rural region.

Education

Literacy was calculated as a binary can/cannot read at any level variable with ORs determined as above. Previous schooling was calculated in the same way (any level of schooling versus no schooling).

Livelihoods

Livelihood analyses were restricted to the working age population (aged 15 to 64) and those not currently enrolled in education. A binary variable was created across the datasets on having worked in the past 12 months versus not having worked at all, with stratified and adjusted ORs calculated as above.

Activity status amongst participants who reported that they had not undertaken any work in the last 12 months was assessed as 'unemployed and looking for work' or 'inactive. Inactive includes all those who are not considered to be a part of the labour force, for example due to child care, retirement or a perceived inability to work.

Detailed data tables

Prevalence of deafblindness by age group (%)					
	5-17	18-39	40-59	60-74	75+
<i>Sudan</i>	0.012	0.028	0.210	1.520	5.660
<i>Mexico</i>	0.012	0.013	0.075	0.590	3.540
<i>Ireland</i>	0.036	0.047	0.150	0.470	2.910
<i>USA</i>	0.110	0.140	0.470	1.200	5.640
<i>Indonesia</i>	0.012	0.010	0.025	0.310	2.160
<i>Ghana</i>	0.071	0.088	0.180	0.540	1.480
<i>Vietnam</i>	0.064	0.063	0.105	0.764	5.910
<i>Uruguay</i>	0.018	0.017	0.083	0.360	1.740
<i>Tanzania</i>	0.009	0.008	0.036	0.170	1.310
<i>South Africa</i>	0.100	0.066	0.220	0.710	2.930
<i>Brazil</i>	0.060	0.080	0.310	1.040	4.570

Poverty (in bottom 40%) of households with deafblindness, other disabilities and no disabilities (%)					
	Deafblind	Other disability	No disability	Adj. OR¹	Adj. OR²
<i>Sudan</i>	43.45%	41.93%	40.35%	1.01 (0.94-1.08)	1.19 (1.11-1.28)*
<i>Mexico</i>	50.42%	43.27%	39.22%	1.16 (1.13-1.20)*	1.13 (1.10-1.17)*
<i>Ireland</i>	59.40%	43.20%	33.50%	1.65 (1.44-1.90)*	2.41 (2.11-2.77)*
<i>USA</i>	56.02%	46.85%	37.76%	1.38 (1.34-1.43)*	2.16 (2.09-2.24)*
<i>Indonesia</i>	52.07%	47.25%	39.80%	1.11 (1.06-1.16)*	1.27 (1.22-1.33)*
<i>Ghana</i>	55.79%	50.70%	38.91%	1.14 (1.03-1.26)*	1.39 (1.25-1.55)*
<i>Vietnam</i>	46.48%	47.21%	39.59%	0.91 (0.89-0.94)*	1.01 (0.99-1.04)
<i>Uruguay</i>	51.23%	46.88%	39.10%	1.19 (1.01-1.40)*	1.57 (1.33-1.84)*
<i>Tanzania</i>	57.14%	50.22%	39.50%	1.09 (0.97-1.24)	1.38 (1.22-1.57)*
<i>South Africa</i>	49.96%	44.10%	39.49%	1.18 (1.12-1.26)*	1.48 (1.40-1.55)*
<i>Brazil</i>	52.93%	47.38%	38.66%	1.21 (1.17-1.25)*	1.67 (1.62-1.72)*

¹ Compares deafblindness versus other disabilities
² Compares deafblindness to no disabilities
*Denotes statistically significant difference at 95% confidence level

Working status of adults (18+) with deafblindness, other disabilities and no disabilities (%)					
	Deafblind	Other disability	No disability	Adj. OR¹	Adj. OR²
<i>Sudan</i>	29.65%	38.84%	45.58%	1.32 (1.16-1.5)*	2.08 (1.82-2.37)*
<i>Mexico</i>	39.92%	38.85%	52.38%	0.95 (0.81-1.12)	2.48 (2.12-2.91)*
<i>Ireland</i>	22.90%	34.99%	70.38%	1.75 (1.33-2.32)*	7.3 (5.52-9.63)*
<i>USA</i>	28.73%	32.05%	75.00%	1.14 (1.06-1.22)*	7.27 (6.79-7.79)*
<i>Indonesia</i>	39.92%	38.85%	52.38%	1.95 (1.7-2.24)*	23.29 (20.30-26.71)*
<i>Ghana</i>	69.50%	67.82%	80.82%	0.92 (0.81-1.04)	2.16 (1.9-2.45)*
<i>Vietnam</i>	15.86%	36.20%	88.94%	3.31 (3.05-3.60)*	61.05 (56.27-66.25)*
<i>Uruguay</i>	41.67%	26.96%	77.37%	0.44 (0.25-0.76)*	4.81 (2.79-8.27)*
<i>Tanzania</i>	51.05%	60.86%	81.44%	1.69 (1.31-2.19)*	5.34 (4.14-6.90)*
<i>South Africa</i>	24.10%	28.77%	46.28%	1.20 (1.09-1.32)*	2.47 (2.25-2.71)*
<i>Brazil</i>	39.84%	39.86%	64.72%	0.96 (0.91-1.00)	2.50 (2.37-2.63)*

¹ Compares deafblindness versus other disabilities
² Compares deafblindness to no disabilities
*Denotes statistically significant difference at 95% confidence level

Working status of adults (15-29) with deafblindness, other disabilities and no disabilities (%)					
	Deafblind	Other disability	No disability	Adj. OR¹	Adj. OR²
<i>Sudan</i>	32.56%	33.51%	38.03%	0.93 (0.6-1.46)	1.2 (0.77-1.87)
<i>Mexico</i>	20.06%	28.65%	43.32%	1.12 (0.75-1.66)	3.87 (2.61-5.73)*
<i>Ireland</i>	31.03%	30.71%	50.18%	1.00 (0.45-2.24)	2.29 (1.03-5.1)*
<i>USA</i>	34.39%	33.53%	64.47%	0.79 (0.64-0.98)*	2.73 (2.21-3.38)*
<i>Indonesia</i>	8.67%	19.19%	57.98%	2.70 (1.82-4.01)*	20.90 (14.12-30.92)*
<i>Ghana</i>	63.37%	60.04%	70.27%	0.88 (0.71-1.09)	1.43 (1.16-1.77)*
<i>Vietnam</i>	12.05%	33.73%	90.25%	4.15 (3.46-4.97)*	102.32 (85.72-122.13)*
<i>Tanzania</i>	47.22%	56.49%	77.42%	1.97 (0.99-3.90)	6.19 (3.13-12.24)*
<i>South Africa</i>	23.57%	25.96%	38.05%	1.05 (0.81-1.35)	1.83 (1.42-2.35)*
<i>Brazil</i>	42.26%	37.48%	62.16%	0.77 (0.66-0.90)*	2.19 (1.87-2.57)*
Working status of adults (30-49) with deafblindness, other disabilities and no disabilities (%)					
<i>Sudan</i>	37.86%	47.53%	54.40%	1.32 (0.99-1.77)	2.24 (1.68-2.98)*
<i>Mexico</i>	44.81%	45.63%	61.98%	1.12 (0.75-1.66)	3.87 (2.61-5.73)*
<i>Ireland</i>	27.00%	40.56%	73.30%	1.86 (1.17-2.97)*	7.51 (4.74-11.93)*
<i>USA</i>	34.40%	35.47%	78.88%	0.99 (0.88-1.12)	7.04 (6.24-7.94)
<i>Indonesia</i>	17.58%	32.26%	75.17%	2.59 (1.97-3.39)*	60.49 (46.29-79.03)*
<i>Ghana</i>	79.08%	74.93%	89.13%	0.78 (0.64-0.97)*	2.34 (1.91-2.88)*
<i>Vietnam</i>	14.74%	39.73%	92.57%	-	-
<i>Tanzania</i>	48.86%	62.36%	84.45%	1.94 (1.34-2.79)*	6.41 (4.47-9.20)*
<i>South Africa</i>	30.42%	35.30%	54.33%	1.19 (1.03-1.38)*	2.52 (2.19-2.91)*
<i>Brazil</i>	48.82%	46.22%	71.59%	0.89 (0.82-0.97)*	2.67 (2.46-2.91)*
Working status of adults (50-64) with deafblindness, other disabilities and no disabilities (%)					
<i>Sudan</i>	26.34%	34.24%	52.39%	1.07 (0.9-1.29)	2.28 (1.91-2.72)*
<i>Mexico</i>	40.88%	38.03%	53.52%	0.89 (0.73-1.09)	2.01 (1.65-2.45)*
<i>Ireland</i>	18.92%	26.22%	62.25%	1.60 (1.09-2.36)*	7.57 (4.73-11.93)*
<i>USA</i>	25.85%	30.44%	71.27%	1.34 (1.23-1.46)*	7.92 (7.27-8.63)*
<i>Indonesia</i>	18.25%	29.46%	72.44%	1.74 (1.43-2.11)*	18.66 (15.44-22.55)*
<i>Ghana</i>	62.58%	64.50%	84.06%	1.07 (0.87-1.33)	3.26 (2.65-4.02)*
<i>Vietnam</i>	19.24%	35.00%	76.79%	2.39 (2.12-2.70)*	19.84 (17.67-22.28)*
<i>Tanzania</i>	55.97%	62.34%	84.27%	1.24 (0.81-1.89)	3.77 (2.48-5.73)*
<i>South Africa</i>	20.18%	24.02%	41.52%	1.21 (1.06-1.39)*	2.55 (2.24-2.90)*
<i>Brazil</i>	34.32%	34.76%	53.33%	1.06 (0.99-1.13)	2.22 (2.08-2.37)*
¹ Compares deafblindness versus other disabilities ² Compares deafblindness to no disabilities *Denotes statistically significant difference at 95% confidence level					

ANNEX 2 - INCLUDED DATASETS

Country	Income group ^a	Region ^a	Year	Sample size	Survey title	Agency	Measurement of deafblindness
<i>Datasets included in prevalence estimates only</i>							
Botswana	Upper middle	Sub-Saharan Africa	2011	201,752	2011 Population and Housing Census	Botswana Central Statistics Office	Does any listed persons (from section A or B) have any of the following disabilities: partially sighted, total blindness, partial hearing or deafness
Cambodia	Lower middle	East Asia and the Pacific	2008	1,340,121	General Population Census of Cambodia, 2008	Cambodia National Institute of Statistics, Ministry of Planning	If the person is physically and/or mentally disabled, give the appropriate code number from the list below. Codes: In seeing, In hearing
Cameroon	Lower middle	Sub-Saharan Africa	2005	1,772,359	Third General Census of Population and Housing	Bureau Central des Recensements et des Études de Population, Cameroon	Does [the respondent] have any serious disability that limits his/her full participation in life activities (such as mobility, work, social life, etc.? a. sight (Yes/No) b. hearing (Yes/No)
Colombia	Upper middle	Latin America and the Caribbean	2005	4,117,607	General Census 2005 (XVII of Population and Dwelling and VI of Housing).	Departamento Administrativo Nacional de Estadística (DANE)	Does [the respondent] have permanent limitations for: sight, despite using contact lenses or glasses? (Yes/No); hearing, even with hearing aids? (Yes/No)
Ecuador	Upper middle	Latin America and the Caribbean	2010	1,448,233	VII Censo de Población y VI de Vivienda, 2010	Instituto Nacional de Estadística y Censos, Ecuador	[For all persons who reported having a permanent disability that has lasted for more than one year]. The disability of the respondent is (more than one answer is allowed): Visual (blindness)? Auditory (deafness)?
Haiti	Low	Latin America and the Caribbean	2003	838,045	Recensement General de la Population et de l'Habitat	République d'Haïti Ministère de l'Economie et des Finances, Institute Haïtien de Statistique et d'Informatique	Does this person have a disability? (Check as many boxes as apply): a. Blind; b. deaf

Country	Income group ^a	Region ^a	Year	Sample size	Survey title	Agency	Measurement of deafblindness
Iran	Upper middle	Middle East and North Africa	2011	1,481,586	2011 National Population and Housing Census	Statistical Center of Iran	Does any member of the household have at least one of the following? (up to three per member) a. blindness; b. deafness
Kenya	Lower middle	Sub-Saharan Africa	2009	3,841,935	2009 Kenya Population and Housing Census	Kenya National Bureau of Statistics	What type of disability does [person] have? (List not more than three) a. visual; b. hearing
Malawi	Low	Sub-Saharan Africa	2008	1,343,078	2008 Population and Housing Census	Malawi National Statistical Office	Does [the respondent] have difficulty or problems in the following? Type of disability: a. Sight b. hearing
Mozambique	Low	Sub-Saharan Africa	2007	2,047,048	III Recenseamento Geral da População e Habitação, 2007	Mozambique Instituto Nacional de Estatística	Does [the person] have any disability? If yes (select): a. blind; b. deaf
Venezuela	Upper middle	Latin America and the Caribbean	2001	2,306,489	XIII Censo General de Población y Vivienda	Venezuela Instituto Nacional de Estadística (INE), Unidad Técnica censal (UTC)	Does [the person] have any disability? If yes (select): a. blind; b. deaf
Datasets included in full analyses							
Brazil	Upper middle	Latin America and the Caribbean	2010	9,693,058	XII Recenseamento Geral do Brasil. Censo Demográfico 2010	Instituto Brasileiro de Geografia e Estatística	Washington Group questions for sight and hearing. Deafblindness considered 'a lot' of difficulty in both domains
Ghana	Lower middle	Sub-Saharan Africa	2010	2,466,289	2010 Population and Housing Census	Ghana Statistical Service	Does [the respondent] have any serious disability that limits his or her full participation in life activities (such as mobility, work, social life, etc.)? Sight (Yes/No); hearing (Yes/No)
Indonesia	Lower middle	East Asia and the Pacific	2010	22,928,795	2010 Population Census	Central Bureau of Statistics	Washington Group questions for sight and hearing (response options: none, some, total). Deafblindness considered 'total' difficulty in both domains

Country	Income group ^a	Region ^a	Year	Sample size	Survey title	Agency	Measurement of deafblindness
Ireland	High	Europe and Central Asia	2011	474,353	Census of Population of Ireland, 2011	Central Statistics Office	Do you have any of the following long-lasting conditions or difficulties? Deafness or a serious hearing impairment (Yes/No); Blindness or a serious visual impairment (Yes/No)
Mexico	Upper middle	Latin America and the Caribbean	2015	11,344,365	Intercensal Survey 2015	Instituto Nacional de Estadística, Geografía e Informática (INEGI)	Does [the respondent] have difficulty doing the following activities in his or her daily life: a. Seeing, even when using glasses (Yes/No); b. Hearing, even when using a hearing aid (Yes/No)
South Africa	Upper middle	Sub-Saharan Africa	2011	4,337,697	Census 2011	Statistics South Africa	Washington Group questions for sight and hearing. Deafblindness considered 'a lot' of difficulty in both domains
Sudan	Low	Sub-Saharan Africa	2008	542,765	5th Sudan Population and Housing Census	Southern Sudan Centre for Census, Evaluation and Statistics	Does [the respondent] have any difficulty in moving, seeing, hearing, speaking or learning? (Mark all that apply) a. difficulty hearing; b. deaf; c. difficulty seeing; d. blind
Tanzania	Low	Sub-Saharan Africa	2012	4,498,022	2012 Population and Housing Census	National Bureau of Statistics, Tanzania	Washington Group questions for sight and hearing. Deafblindness considered 'a lot' of difficulty in both domains
USA	High	North America	2010	3,061,692	National Census	US Census Bureau, USA	Is this person deaf or does he or she have serious difficulty hearing? (Yes/No) Is this person blind or does he or she have serious difficulty seeing even when wearing glasses? (Yes/No)
Uruguay	High	Latin America and the Caribbean	2011	328,425	General Population Census VIII, Homes IV and Housing VI	National Institute of Statistics, Uruguay	Washington Group questions for sight and hearing. Deafblindness considered 'much' difficulty in both domains
Vietnam	Lower middle	East Asia and the Pacific	2009	14,177,590	2009 Population and Housing Census	General Statistics Office, Vietnam	Washington Group questions for sight and hearing. Deafblindness considered 'very difficult' in both domains



AT RISK OF EXCLUSION FROM CRPD AND SDGS IMPLEMENTATION: INEQUALITY AND PERSONS WITH DEAFBLINDNESS INITIAL GLOBAL REPORT 2018

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 initial global report on the situation of persons with deafblindness 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) combining the largest population-based analysis of persons with deafblindness conducted to date (disaggregation of 22 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.

Women and men with deafblindness from across the world took part in the Helen Keller World Conference in June 2018, and were consulted to confirm the findings and elaborate on the recommendations for this report.

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