



March 2023

# SECOND GLOBAL REPORT ON THE SITUATION OF PERSONS WITH DEAFBLINDNESS

Good Practices and  
Recommendations for the  
Inclusion of Persons with  
Deafblindness



*The cover pictures are  
courtesy of Sense  
International.*

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*The information and views set out in this background document are those of the World Federation of the Deafblind (WFDB) and do not necessarily reflect the official opinion of the International Disability Alliance (IDA), the Norwegian Association of the Deafblind (FNDB), the International Centre for Evidence in Disability (ICED) at the London School of Hygiene and Tropical Medicine (LSHTM).*

## ABBREVIATIONS

<b>APR</b>	Adjusted Prevalence Ratio
<b>CBR</b>	Community-based rehabilitation
<b>CDD</b>	Centre for Disability in Development in Bangladesh
<b>CI</b>	Confidence interval
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>DAN</b>	Deafblind Association Nepal
<b>DBI</b>	Deafblind International
<b>EU</b>	European Union
<b>FCDO</b>	UK Foreign, Commonwealth, and Development Office
<b>FDDB</b>	Danish Association of the Deafblind
<b>FNDB</b>	Norwegian Deafblind Association
<b>FSDB</b>	Association of Swedish Deafblind
<b>GDS</b>	Global Disability Summit
<b>GLAD</b>	Global Action on Disability Network
<b>ICED</b>	International Centre for Evidence and Disability at the London School for Hygiene and Tropical Medicine
<b>IDA</b>	International Disability Alliance
<b>IDDC</b>	International Disability and Development Consortium
<b>LSHTM</b>	London School of Hygiene and Tropical Medicine

<b>MICS</b>	Multiple Cluster Indicator Surveys
<b>MSI</b>	Multi-sensory impairment
<b>N</b>	Number
<b>NGO</b>	Non-governmental organisation
<b>NMFA</b>	Norwegian Ministry of Foreign Affairs
<b>OPD</b>	Organisation of persons with disabilities
<b>POP</b>	Population
<b>PPE</b>	Personal protection equipment
<b>SDBP</b>	Society of Deafblind Parents in Nepal
<b>SDG</b>	Sustainable Development Goal
<b>SHAPES</b>	Smart and Healthy Ageing through People Engaging in Supportive Systems
<b>SI</b>	Sense International
<b>SRH</b>	Sexual and reproductive health
<b>TVET</b>	Technical and vocational education and training
<b>UN</b>	United Nations
<b>UNICEF</b>	United Nations Children's Fund
<b>UNPRPD</b>	United Nations Partnership on the Rights of Persons with Disabilities
<b>WFDB</b>	World Federation of the Deafblind
<b>WHO</b>	World Health Organisation

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# CASE STUDY MAP



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**BRAZIL**

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# INTRODUCTION

In 2018, the World Federation of the Deafblind (WFDB) launched the first global report on the situation of persons with deafblindness, *At Risk of Exclusion from CRPD and SDG Implementation: Inequality of Persons with Deafblindness*. This report sought to open a dialogue between national and international disability rights and development stakeholders and drew attention to one of the most marginalised and underrepresented groups in the world. **Representing 0.2% to 2% of the population, persons with deafblindness are very diverse yet hidden group, and are more likely to be poor, unemployed, and have low education outcomes<sup>1</sup>.**

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<sup>1</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, September 2018, <https://wfdb.eu/wfdb-report-2018/>.

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<sup>2</sup>.

- World Federation of the Deafblind, *At Risk of Exclusion from CRPD and SDG Implementation: Inequality and Persons with Deafblindness*

The Convention on the Rights of Persons with Disabilities (CRPD) and Agenda 2030 and the Sustainable Development Goals (SDGs) have triggered greater attention of persons with disabilities. Underscoring the importance of ‘leave no one behind’, there is growing momentum for greater disability inclusion. However, the first global report highlighted that persons with deafblindness are often not legally recognised as a distinct disability group, resulting in persistent statistical invisibility, even where disability data is collected. The lack of reputable data contributes to significant gaps in services to support persons with deafblindness. This “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

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<sup>2</sup> *Ibid.*

issues, as well as their specific inclusion requirements”<sup>3</sup>.

The first global report outlined findings and recommendations across a broad range of policy areas and flagged three initial steps to bridge the gaps:

**1** Establish a universal acknowledgement and recognition of deafblindness as a unique and distinct disability, with its own specific challenges, barriers, support, and inclusion requirements

**2** Establish publicly funded deafblind interpretation services, in particular interpreter-guides/Deafblind interpreters

**3** Provide the necessary funding for further research and strengthening of the advocacy work, including funding of the tools and technical support needed.

Since the first global report was launched in 2018, disability inclusion has gained visibility through global events, such as the Global Disability Summit (GDS) of 2018 in the United Kingdom and

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<sup>3</sup> *Ibid.*

the subsequent GDS in 2022 hosted remotely, as well as networks and mechanisms, such as the Global Action on Disability (GLAD) Network and AT2030<sup>4</sup>. These events and mechanisms have provided valuable space to raise awareness of disability inclusion and serve to advance the global dialogue on the practical ways to implement the CRPD and SDGs. However, economic cuts to bilateral funding, the COVID-19 pandemic lockdowns and restrictions, and increased insecurity in certain regions have affected this progress.

This second global report seeks to build on the findings and recommendations of the first global report and consolidate evidence from different regions and diverse groups, including persons with deafblindness and professionals. This report builds on the quantitative analysis of the first report, providing data on children with deafblindness. The qualitative analysis identifies good practices, essential elements, measures that increase and improve the inclusion of persons with deafblindness, case studies to illustrate and inspire good practices and programmatic approaches, and recommendations across

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<sup>4</sup> GLAD is a coordination body of bilateral and multilateral donors and agencies, the private sector, and foundations working to enhance the inclusion of persons with disabilities in international development and humanitarian action, <https://www.internationaldisabilityalliance.org/content/global-action-disability-glad-network>, May 2022. AT2030 is a network led by the Global Disability Innovation Hub and that tests what works to improve access to assistive technology, <https://at2030.org/>, May 2022.

thematic areas. The aim of this report is to serve as an advocacy tool for WFDB members and their allies to stimulate collaboration and partnerships to advance the rights of persons with deafblindness and to inform stakeholders on how to foster the inclusion of persons with deafblindness. Key audiences for this report include national and local government officials and statutory bodies, donors, non-governmental organisations (NGOs), organisations of persons with disabilities (OPDs), service providers and frontline staff, intergovernmental organisations (such as United Nations entities and country teams), and others.

## Methodology

### Qualitative Research

Building on the main topics of the first global report, the qualitative research for the second report aimed to identify the main factors of good practices, that are in line with the CRPD, to ensure the participation and inclusion of persons with deafblindness in society. The qualitative research explored key findings on best practices by looking at basic factors based on existing knowledge from the first global report and avoided developing detailed technical models for each topic.

Research methods included:



A literature review of over 100 secondary sources, including articles, reports, guides, case studies, briefings, and press releases on best practices for persons with deafblindness supplied by WFDB members and partners



A survey of practitioners and persons with deafblindness on best practices, focusing on key gaps emerging from the literature review



Key informant interviews to develop case studies and short features on core topics.

Sources were included in the review if they were written in English or if they could be reasonably reviewed using online translation technology. Good practices were assessed and defined using human rights standards and principles in the CRPD. Practices and approaches that did not comply with the CRPD were excluded from this report. In some cases, practices that were in the pilot stages were included to demonstrate innovative approaches to advance the rights of persons with deafblindness. WFDB recognises that pilot approaches included in this report will likely require further adjustments to refine the practice.

Most of the literature for the qualitative research consisted of NGO and OPD programmatic reports, articles, and documents, rather than scientific studies. Many of the academic papers were unpublished, and scientific studies often provided data on small numbers of persons with deafblindness. These challenges are due largely to the lack of research conducted on interventions and good practices for persons with deafblindness – a group that is often overlooked in research. A caselaw review was also conducted, which explored international human rights mechanisms. However, there were no significant cases of persons with deafblindness within the UN human rights complaints system.

The survey was circulated to WFDB members and partners, including Deafblind International (DBI) members, Sense International, International Disability Alliance's (IDA) email list, and members of the International Disability and Development Consortium (IDDC) in early 2022. This resulted in 165 responses from 42 countries<sup>5</sup> with a breakdown of 91 responses from upper-income countries, 35 responses from upper middle-income countries, 33 responses from lower middle-income

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<sup>5</sup> The countries include Argentina, Australia, Bangladesh, Benin, Bolivia, Brazil, Bulgaria, Burkina Faso, Cambodia, Canada, Colombia, Denmark, Ecuador, Fiji, France, Germany, Guatemala, Honduras, India, Italy, Kenya, Laos, Lesotho, Malawi, Mexico, Nepal, Netherlands, Nigeria, Norway, Peru, Rwanda, Slovenia, Spain, Sweden, Tanzania, Turkey, Uganda, United Kingdom, Uruguay, USA, Venezuela and Zambia.

countries, and 6 responses from lower-income countries. The data from each country was insufficient to determine the situation in individual countries or regions and came largely from upper and upper middle-income countries. However, the survey data provided information on broad trends across personal experiences, particularly on key gaps in services, and provided insight into the main challenges that persons with deafblindness face.

## Quantitative Research

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The quantitative research explored the situation of children ages 2-17 years old across 36 countries and sought to answer the following questions:

- **How common is deafblindness in children?**
- Across countries, **what are the educational outcomes for children with deafblindness**, and how do they compare to children with other disabilities and children without disabilities?
- Across countries, **what are the health outcomes for children with deafblindness**, and how do they compare to children with other disabilities and children without disabilities?
- Across countries, **what are the wellbeing outcomes for children with deafblindness** and

how do they compare to children with other disabilities and children without disabilities?

The research analysed data from UNICEF's Multiple Cluster Indicator Surveys (MICS), which have been conducted since the 1990s in 118 countries. The MICs have increasingly used the Washington Group-UNICEF Modules for Child Functioning for measuring disability in children who are 2-17 years. For the Washington Group-UNICEF Child Functioning Modules, the child's caregiver is asked about the level of difficulty that their child faces in doing daily activities, including seeing, hearing, walking, remembering/concentrating, communicating, and completing self-care activities. For most questions, there are four responses: no difficulty, some difficulty, a lot of difficulty, and cannot do. In total, 36 country surveys have used the Washington Group-UNICEF Child Functioning Modules, and this report uses data from these 36 countries to explore the situation of children with deafblindness. Combined, the surveys contained information on over 442,000 children, and the indicators aligned to track some Sustainable Development Goals.

Annex 1 describes the prevalence or how common deafblindness is in each country. It is important to note that the sample size of each MICs dataset was often too small to explore the lived experience

of children with deafblindness (e.g., education and health outcomes ) at the national or regional level. Consequently, the quantitative analysis used pooled samples across countries to achieve a sufficient sample size. Although this data provides valuable insight into the experiences of children with deafblindness across 36 countries, it is not suitable for analysis between countries.

Some of the indicators used in MICS may not fully capture the experiences of children with deafblindness. For example, violent discipline was captured through caregivers' responses rather than children's responses, which likely results in underreporting. Furthermore, literacy and numeracy were determined through children performing tasks based on written materials, which are usually not accessible for children with deafblindness. Finally, the Washington Group-UNICEF modules on child functioning are only suitable for children aged two years or more, and indicators for younger children, such as breastfeeding or immunisations, were not possible to calculate, as the data is not available. It is also not known how common deafblindness is in children younger than two years.

## **WFDB Workshop in Kenya 2022**

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On 27-28 October 2022, WFDB held a workshop on the 2<sup>nd</sup> Global Report in Kenya to bring over 35

WFDB members and persons with deafblindness together from across the globe to discuss the draft report, including good practices and lived experiences of persons with deafblindness in line with the CRPD. The technical workshop served as a validation and consultation process, as well as provided an opportunity for WFDB members to build connections between regional and national OPDs of persons with deafblindness. Finally, it increased the understanding of good practices showcased in the report and exemplified how the report could be used as an advocacy tool.

## Report Layout

This report provides an executive summary of key messages and findings. The introduction builds on the work of the first global report, identifies major environmental shifts, explains the methodology of the research conducted, provides an explanation of the diversity of persons with deafblindness, and captures WFDB's findings on the prevalence of deafblindness.

The main findings of the research are organised into two sections:

### **Preconditions for Inclusion**

Preconditions are the essential building blocks or “foundational aspects that are indispensable in addressing the requirements and views of

persons with disabilities and should be considered in public policy-making and programming across all sectors”<sup>6</sup>. More specifically, this section considers the preconditions necessary for inclusion for persons with deafblindness, as a distinct group of persons with disabilities, to support their access to services across all sectors.

## Disability Mainstreaming of Laws, Policies, and Services

Disability mainstreaming is a comprehensive and holistic approach to removing barriers and improving access and opportunities for persons with disabilities on an equal basis with persons without disabilities<sup>7</sup>. This section considers the measures required by persons with deafblindness, as a distinct group of persons with disabilities, across mainstream services and policies aimed to reach the public.

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<sup>6</sup> UNPRPD, *The preconditions necessary to ensure disability inclusion across policies, services, and other interventions*, <https://unprpd.org/sites/default/files/library/2020-08/Annex%202%20UNPRPD%204th%20Funding%20Call%20Preconditions%20to%20disability%20inclusion%20ACC.pdf>, accessed May 2022.

<sup>7</sup> United Nations, Department of Economic and Social Affairs, Disability, *Mainstreaming disability in the development agenda*, <https://www.un.org/Development/Desa/Disabilities/issues/mainstreaming-disability-in-the-development-agenda-2.html>, accessed May 2022.

In each of the chapters presenting the main findings, the problem or situation of persons with deafblindness is briefly outlined, and where applicable, quantitative data analysis is provided. The findings focus on the solutions or key measures to address the situation, link to relevant CRPD provisions, and highlight good practices from literature reviews and case studies, in order to provide links to relevant preconditions for inclusion, and practical recommendations. The voice of persons with deafblindness is included where data has been collected from the survey or key informant interviews. The report concludes with a summary of recommendations.

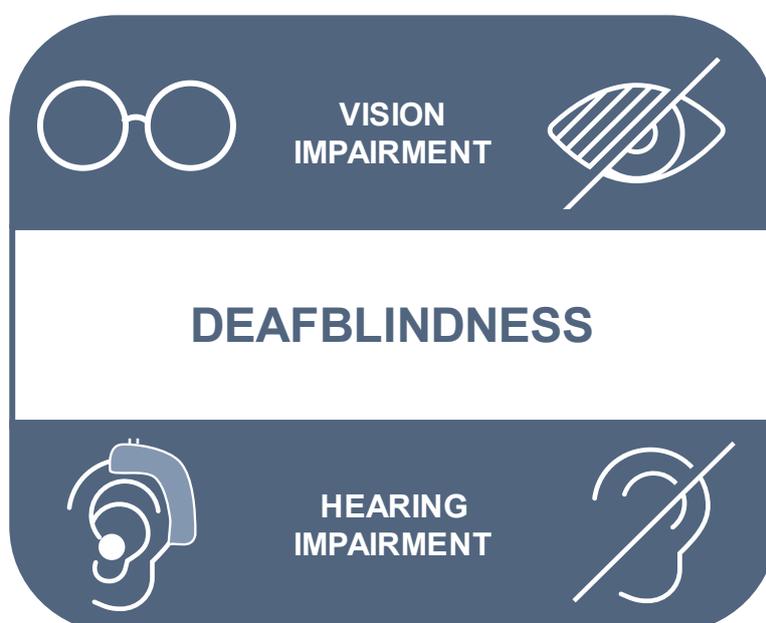
The report is aimed at providing practical advice on formulating legislation, policy, programmes, administrative procedures, and services for persons with deafblindness. However, many of the barriers as well as the solutions reflect the experiences of persons with disabilities in general and the wider approaches to ensure disability inclusion as a whole, in addition to recommendations specific to persons with deafblindness. Therefore, the report provides insight into how disability inclusive approaches can be more inclusive of persons with deafblindness and promotes a broader message about disability inclusion across all groups.

## The Diversity of Persons with Deafblindness

WFDB defines deafblindness based on the Nordic definition 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/Deafblind interpreters, among others<sup>8</sup>.”

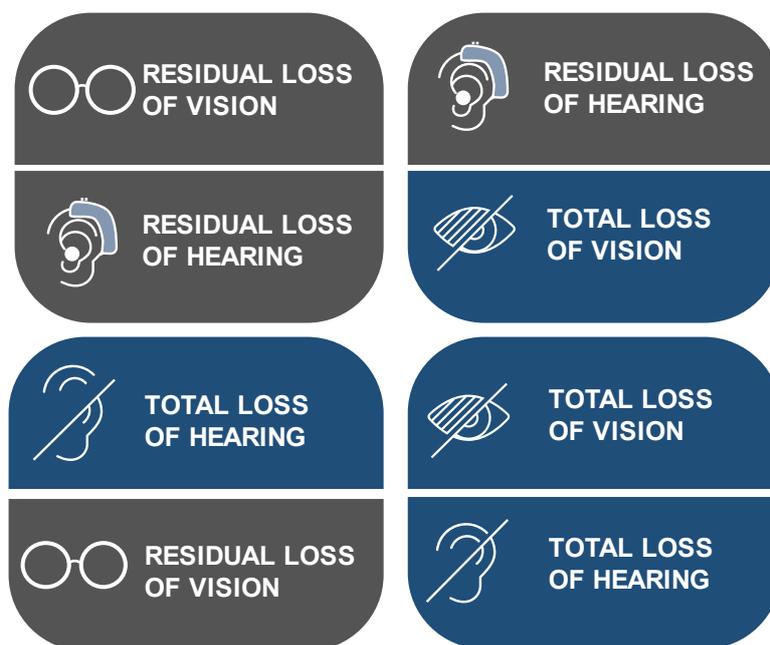
### WHAT IS DEAFBLINDNESS?



<sup>8</sup> The Deafblind Nordic Cooperation Committee, *The Nordic definition of deafblindness*, <http://www.fsdb.org/Filer/DBNSK%20English.pdf>, accessed May 2022; and World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018.

Misunderstandings about deafblindness often contribute to the barriers faced by persons with deafblindness. For example, some persons with deafblindness are completely deaf and blind, but many have some residual vision and/or hearing, of varying degrees.

## THE DIVERSITY OF DEAFBLINDNESS



The age of onset has a significant effect on the consequences of deafblindness, especially in relation to communication and language acquisition. Therefore, a distinction is often made between two groups:

## PRE-LINGUAL

hello!

**Pre-lingual deafblindness**, which is often referred to as congenital deafblindness, is when the vision and hearing impairment is acquired at birth or in the early years before the child develops a language. Causes vary and may include infections during pregnancy, premature birth, birth trauma, cerebral palsy, foetal alcohol syndrome, and some genetic conditions, such as Down's syndrome and CHARGE syndrome<sup>9</sup>

hello!

## POST-LINGUAL

**Post-lingual deafblindness**, which is often referred to as acquired deafblindness, is when the vision and hearing loss is acquired after the development of a language, including spoken or sign languages. Again, causes vary and may include illness, accident, age-related conditions leading to hearing and vision loss, and genetic conditions<sup>10</sup>, such as Usher syndrome, a genetic condition resulting in hearing loss at birth or in childhood and subsequent vision

<sup>9</sup> Sense, *Deafblindness*, <https://www.sense.org.uk/information-and-advice/conditions/Deafblindness/#types>, accessed May 2022.

<sup>10</sup> *Ibid.*

loss after language has been acquired in childhood, adolescence, or adulthood.<sup>11</sup>

Deafblindness is more prevalent among older persons. Though less common in children and young people, deafblindness significantly impacts child development, including language acquisition, learning, and basic life skills. These barriers affect many into adulthood, impacting life skills, social networks, and access to employment<sup>12</sup>. Persons with deafblindness are a diverse group due to the age of onset, variations in residual hearing and/or vision, the cause of deafblindness or associated medical conditions, and the prevalence of other disabilities in addition to deafblindness. This diversity means that the supports, as well as inclusion and accessibility requirements, differ for each individual<sup>13</sup>.

The social exclusion, restrictions to participation, and reduced independence and autonomy that persons with deafblindness experience are a direct result of the barriers in their environments. This means that **accessibility requirements for persons with deafblindness as a broad and diverse group, reasonable accommodations for**

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<sup>11</sup> Sense, *Usher syndrome: causes and diagnosis*, <https://www.sense.org.uk/information-and-advice/conditions/usher-syndrome/usher-syndrome-causes-diagnosis/>, accessed May 2022.

<sup>12</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018.

<sup>13</sup> *Ibid.*

**individuals with deafblindness, and tailored services designed for persons with deafblindness are the key factors for ensuring social inclusion, participation, independence, and autonomy.**

Moreover, “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”<sup>14</sup>. In other words, the unique requirements of persons with deafblindness should not be limited to the requirements of the blind or deaf because of the dual aspect of the impairment.

Persons with deafblindness may also have other additional disabilities (e.g., physical disabilities, long-term medical conditions, neuro-developmental disabilities, psychosocial disabilities, and others) resulting in multiple disabilities. Having deafblindness and additional disabilities can compound the effects of deafblindness as well as the other disabilities. It is, therefore, essential that the supports are holistic and tailored to the requirements of each individual.

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<sup>14</sup> *Ibid.*



*Gertrude, on the left, is a woman with deafblindness and communicates with her interpreter-guide/Deafblind interpreter during a meeting held by WFDB in Nairobi, Kenya, using block alphabet and hand-under-hand signing.*

**Photo taken by  
WFDB**

## Communication

Communication is a central barrier for persons with deafblindness, and it is important to note that each person communicates and interacts with their environment in different ways. In other words, there is no standard way for persons with deafblindness to communicate. The communication approaches depend on the individual's residual hearing and/or vision, age of onset, and whether they have pre-lingual or post-lingual deafblindness. For example, a person with Usher syndrome who is deaf at birth and learns sign language but experiences vision loss in adolescence may be able to communicate with sign language but may require some adaptations, such as visual frame signing<sup>002E</sup>

Some common approaches for communicating include:

### **SPEECH**



This includes clear speech (i.e., speaking clearly and simply) and lip reading (i.e., recognising what is being said by watching the way they speak)

## TOUCH OR TACTILE COMMUNICATION



This includes Braille (i.e., using raised dots to read) or Moon (i.e., using raised lines, curves, and dots), deafblind manual (i.e., spelling words onto the hand), block alphabet (i.e., spelling each letter onto the hand), Tadoma method (i.e., using lipreading by touch), and hand-under-hand signing (i.e., two people signing together using touch)

## SIGNS OR SIGN LANGUAGE



This includes sign language, Makaton (i.e., a simpler version of sign language), visual frame signing (i.e., keeping within a visual frame for people with reduced vision), and objects of reference (i.e., touching objects to represent or identify a person, object, place, activity, idea, etc.)

## NON-FORMAL COMMUNICATION



This is a way to express feelings, wants, and choices without speaking, writing, or signing and may include body language, changes in breathing, facial expressions, eye pointing, gestures, vocalisations, pointing, etc.

## ASSISTIVE DEVICES OR ACCESSIBLE TECHNOLOGY



This involves using assistive devices or accessible technology, such as glasses, magnifiers, hearing aids and loops, speech-to-text interpreting to a screen, smartphones / tablets or laptops, hearing aids with smartphones, talking technology (e.g., Siri, Google Assistant, Alexa), smart TVs or streaming services, alerting devices, modifications to phones (e.g., amplification, visual indicators, relay service, etc.), Braille display technology, and more<sup>15</sup>.

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<sup>15</sup> Sense, *Ways of communicating*, <https://www.sense.org.uk/information-and-advice/communication/>, accessed May 2022.



*Two brothers communicate in tactile signing at the first Dbl (Deafblind International) Africa Conference in May 2022.*

**Courtesy of Dbl**

Sometimes, multiple approaches are used, depending on the situation and the individual's requirements, and approaches may evolve over time. Because most people do not understand these forms of communication, persons with deafblindness often rely on interpreter-guides/Deafblind interpreters or family members to provide interpreter-guide/Deafblind interpreting services.

*A group of persons with deafblindness and interpreter- guides/Deafblind interpreters waiting for the bus in Geneva, Switzerland. In this case, both the services of interpreter-guides/Deafblind interpreters and the use of assistive devices, such as a cane, are essential for orientation and mobility.*

***Photo taken by WFDB***



## Orientation and Mobility

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Orientation and mobility include the ability to navigate the environment and to move around safely using the senses. Combined vision and hearing loss significantly affects the ability of persons with deafblindness to move freely and safely in both familiar and unfamiliar environments. Measures can be taken to make familiar places easier to navigate, such as keeping a consistent layout, using a guide dog or cane, or adapting the environment, such as signage with high contrast or tactile flooring to transition between rooms. Rehabilitation programmes can provide strategies and build confidence in persons with deafblindness to increase their independence. However, many persons with deafblindness require guiding support through an interpreter-guide/Deafblind interpreter.

Some persons with deafblindness may have other disabilities that affect their ability to move or developmental delays that may affect mobility, and therefore, may require other assistive devices, such as wheelchairs.

## Description

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An integral aspect of communication, orientation, and mobility is a description of the environment. This description involves the physical surroundings and objects as well as what is happening in their

environment. These descriptions are necessary when navigating a crowd, entering a building, or going shopping. Without adequate description, persons with deafblindness are unable to understand their environment, how the environment changes, and make decisions about how to react or respond to their environment, including the reactions and emotions of other individuals. Interpreter-guides/Deafblind interpreters help persons with deafblindness to understand their environments (i.e., ‘read the room’) so that they can respond accordingly. Description is a fundamental part of interpreter-guide/Deafblind interpreting services and should be provided in conjunction with communication, orientation, and mobility support.

## Prevalence

WFDB, in partnership with International Centre for Evidence and Disability (ICED) at the London School for Hygiene and Tropical Medicine, undertook quantitative research for the first global report in 2018 on the prevalence of deafblindness, using nationally representative population-based surveys from 22 countries. This research concluded that on average, 0.2% of the population (all ages) has severe deafblindness<sup>16</sup>, and 2.1% of

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<sup>16</sup> Severe deafblindness is defined by Washington Group Question responses of ‘a lot of difficulty’ or ‘cannot do’ to both vision and hearing questions. Moderate deafblindness is defined by Washington

the population may experience milder forms of deafblindness<sup>17</sup>. This research further revealed that there is a strong association between the prevalence of deafblindness and age, with the prevalence of deafblindness in less than 0.1% of the population aged 40 years and under rising to 6% of the population aged 75 and over<sup>18</sup>. The report also noted that the prevalence of deafblindness was slightly higher in women than in men.<sup>19</sup>

The first global report acknowledged that “while deafblindness is more common among older age groups, deafblindness among children and young adults presents additional implications, for example in... education and employment”<sup>20</sup>. For this report, WFDB explored prevalence among children by conducting quantitative analysis using UNICEF’s Multiple Cluster Indicator Surveys (MICS), which have recently incorporated the Washington Group-UNICEF Modules for Child Functioning for children aged 2-17 years<sup>21</sup>. The

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Group Question responses of ‘a lot of difficulty’ or ‘cannot do’ in **either** vision **or** hearing questions and at least ‘some difficulty’ in the other domains. Mild deafblindness is defined by Washington Group Question responses of ‘some difficulty’ in both vision and hearing questions.

<sup>17</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018.

<sup>18</sup> *Ibid.*

<sup>19</sup> *Ibid.*

<sup>20</sup> *Ibid.*

<sup>21</sup> There are two Child Functioning Modules, one for children aged 2-4 and one for children aged 5-17. For both, the child’s caregiver is asked about the level of difficulty that their child faces in doing

Washington Group Questions, including the Washington Group-UNICEF Modules for Child Functioning, are recommended by the United Nations and many others for producing estimates on the prevalence of disability that are robust and internationally comparable. These question sets can also be used to measure the prevalence of deafblindness. WFDB established three prevalence thresholds to define deafblindness in the first global report, which have been replicated for the quantitative analysis of the MICS in this report<sup>22</sup>:

	<b>Severe</b>	Response of ‘a lot of difficulty’ or ‘cannot do’ to both vision and hearing questions
	<b>Moderate</b>	Response of ‘a lot of difficulty’ or ‘cannot do’ in either vision or hearing questions and at least ‘some difficulty’ in the other domain
	<b>Mild</b>	Response of at least ‘some difficulty’ in both vision and hearing questions.

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daily activities, including seeing, hearing, walking, remembering / concentrating, communicating, and with self-care. For most questions, there are four response options: no difficulty, some difficulty, a lot of difficulty, and cannot do.

<sup>22</sup> The response options in the Washington Group Questions are no difficulty, some difficulty, a lot of difficulty, and cannot do.

The severe threshold was used for all other quantitative analyses throughout this report in line with the first global report and the Nordic definition of deafblindness, which states deafblindness as ‘a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other’<sup>23</sup>.

SEVERITY	PREVALENCE	PER 10,000	TOTAL
Severe deafblindness	0.05%	5 children per 10,000	<b>114,000</b> children
Moderate deafblindness	0.14%	14 children per 10,000	<b>297,789</b> children
Mild deafblindness	0.7%	70 children per 10,000	<b>1,430,356</b> children
<b><i>Deafblindness in total</i></b>	<b>0.89%</b>	<b>89 children per 10,000</b>	<b>1,842,145</b> children

<sup>23</sup> Nordic Welfare, Nordic Definition of Deafblindness, <https://nordicwelfare.org/wp-content/uploads/2018/03/nordic-definition-of-deafblindness.pdf>, accessed May 2022.

Across the 36 countries represented in the datasets, the prevalence of severe deafblindness in children aged 2-17 years was 0.05% - i.e., approximately 1 out of 2,000 children have severe deafblindness.<sup>24</sup> The pooled prevalence increased to 0.14% for moderate deafblindness - i.e., approximately 1 out of 700 children, and 0.7% for mild deafblindness - i.e., approximately 1 out of 140 children. While these percentages may appear small, they should not be disregarded. Across the 36 countries, these figures translate to 114,000 children with severe deafblindness, 297,789 children with at least moderate deafblindness, and 1,430,356 children with at least mild deafblindness.

Among the 36 countries, severe deafblindness was most common in the Central African Republic and Sao Tome and Principe, with 0.11% and 0.12% of children with deafblindness. The Democratic Republic of Congo had the highest number of children with severe deafblindness (30,635 or 0.08%). At the moderate and mild thresholds, deafblindness was the most common in Chad (0.34%) and Cuba (2.5%). Prevalence was similar across regions and country income

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<sup>24</sup> For comparison, in the first global report, the unweighted average prevalence in children 5-17 years across 11 countries was 0.046%)

levels. A full list of country-specific prevalence estimates can be found in Table 1, Annex 1.

Prevalence estimates are used to show how many persons with deafblindness are in a population. Having robust, accurate estimates of deafblindness – such as those produced using the Washington Group Questions – are essential for policy and planning. For example, these estimates can help governments to better plan for the supports and services, including the budgets to enable these supports and services, for persons with deafblindness.

# PRECONDITIONS FOR DISABILITY INCLUSION

The twin-track approach for disability inclusion requires disability-specific measures (e.g., disability-specific programming, policies, procedures, etc.) to meet the requirements of persons with disabilities, as well as consistent and systematic mainstreaming of disability across all programmes, policies, and processes. To better illustrate the twin-track approach, features or measures that are commonly required by persons with disabilities are often identified as preconditions for disability inclusion - i.e., a prerequisite to their inclusion<sup>25</sup>.

For example, for education to be inclusive for persons with disabilities, certain steps or preconditions are required, such as identification and assessment of the disabilities of children, rehabilitation services to make them school-ready, access to assistive devices or technologies, and access to live assistance required during school,

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<sup>25</sup> Pacific Disability Forum, *Guideline to Pre-Condition to Inclusion: Persons with Disabilities – COVID-19 Response*, Ref. No. COVI-19\_PDF\_08, <https://www.google.com/search?q=preconditions+for+disability+inclusion&oq=preconditions+for+disability+inclusion&aqs=chrome..69i57j33i160l2j33i22i29i30l7.5476j1j15&sourceid=chrome&ie=UTF-8#:~:text=pre%2Dcondition%20for,uploads%20%E2%80%BA%202021/03,9%20April%202020>, 9 April 2020.

awareness raising of those in education to prevent discrimination, measures to make schools more accessible, etc. These steps or preconditions also apply to other services (e.g., employment, social protection, recreation, and more).

Preconditions for inclusion are the essential building blocks or “foundational aspects that are indispensable in addressing the requirements and views of persons with disabilities and should be considered in public policy-making and programming across all sectors”<sup>26</sup>. This section considers the preconditions or disability-specific measures necessary for persons with deafblindness to support access to services across all sectors looking broadly at disability-specific measures that benefit persons with deafblindness as well as deafblindness-specific measures. These preconditions include:

- Deafblindness as a distinct disability
- Tackling stigma and discrimination
- Accessibility
- Disability-specific services, including
  - deafblind-specific services
    - Identification, assessment, and referral

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<sup>26</sup> UNPRPD, *The preconditions necessary to ensure disability inclusion across policies, services, and other interventions*, <https://unprpd.org/sites/default/files/library/2020-08/Annex%20%20UNPRPD%204th%20Funding%20Call%20Preconditions%20to%20disability%20inclusion%20ACC.pdf>, accessed May 2022.

- > Rehabilitation and communication
- > Assistive devices and technologies and accessible technologies
- > Interpreter-guides//Deafblind interpreters and other forms of live assistance
- > Participation of persons with deafblindness
- > Data collection and research.

## Deafblindness as a Distinct Disability

To ensure that persons with deafblindness have the appropriate supports and services, deafblindness needs to be officially recognised, in law, as a distinct disability of combined dual sensory impairment. In the first global report, WFDB identified the lack of official or legal recognition of deafblindness as a key barrier to the availability of support, and where countries “do officially recognise deafblindness as a distinct disability..., (countries who recognise this distinct disability) are more likely to provide specific support services”<sup>27</sup> for persons with deafblindness. Legal recognition not only increases the likelihood of tailored services, but it is also a practical

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<sup>27</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 8.

necessity within most national legislative systems. It is not known how many countries lack official recognition of deafblindness or definitions that are partially adequate, and systematic legislative and policy research is needed to assess the gaps.

This direct link between legal recognition and the availability of deafblindness-specific supports and services is a key first step to addressing the exclusion of persons with deafblindness in many countries. Often, deafblindness is mistakenly considered to be a combination of two disabilities – deafness and blindness – resulting in a determination of ‘multiple disabilities’ instead of a distinct, standalone disability of deafblindness. Even the words ‘deafblindness’ and ‘deafblind’ are often not recognised by spell check features in digital tools, such as computer operating systems, software, mobile phones, etc., forcing the spelling to either be hyphenated as ‘deaf-blind’ or as two words ‘deaf and blind’. This results in official documents portraying deafblindness as two impairments rather than a single impairment, which adds to the confusion about deafblindness. Misperceptions about deafblindness as multiple disabilities limit the potential of legal recognition of deafblindness as a unique disability, which would in effect filter deafblindness-specific considerations across all services. For example, if a child has been diagnosed with deafblindness, their parents

could request that the school teach deafblind communication methods to their child. If the child is considered to have ‘multiple disabilities’, it may be harder to request deafblindness-specific supports, thus services are less responsive to the requirements of persons with deafblindness<sup>28</sup>.

A respondent to WFDB’s survey noted that general disability categories, such as physical, mental, sensory, and multiple disabilities, may also be problematic for persons with deafblindness. This is because deafness and blindness are more commonly understood to be sensory disabilities, whereas deafblindness may be misplaced as multiple disabilities rather than as a distinct sensory disability.

Another common misperception is that deafblindness is a condition where the person is completely deaf and blind. This misperception, combined with a gap in the legal recognition of deafblindness, often forces persons with deafblindness to choose between blindness **or** deafness based on which of the two senses is more significantly affected. However, accessibility measures and services for the blind or the deaf do not usually meet the requirements of persons with deafblindness because of the combined dual sensory impairment and the inability of persons

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<sup>28</sup> *Ibid.*, p. 9.

with deafblindness to compensate for hearing loss with their sight and vice versa<sup>29</sup>. For example, sign language interpretation services for the deaf are usually insufficient for many persons with deafblindness because these sign language interpreters have not been trained in deafblind communication, orientation, description, and mobility support. Similarly, guiding services for the blind are insufficient in providing deafblind communication. Though persons with deafblindness may access these services for the blind or the deaf, it is often because they have no other options, and the prospect of no services would render them completely isolated.

The best way to ensure that deafblindness is officially recognised is to ensure that it is listed among other types of disabilities recognised in national disability legislation. This national legislation may not be reviewed often and may involve a lengthy process to amend. In lieu of national legal recognition, local legal recognition may be considered as an alternative. For example, a respondent to WFDB's survey highlighted that there was local recognition of deafblindness in Mexico's Jalisco State, but not at the national level. In countries where national legislative changes are delayed, this may be a viable stop-

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<sup>29</sup> *Ibid.*

gap measure. However, national recognition is preferable, as local legislation is likely to result in inconsistencies across national regions and inequalities within the country, including inequalities in service provision.

The underlying cause of the lack of legal recognition of deafblindness is an insufficient understanding and awareness of deafblindness. This lack of understanding is caused by insufficient representation of diversity of persons with deafblindness and their communication requirements, by policymakers, health and rehabilitation professionals, and disability advocates.<sup>30</sup> Because health and rehabilitation professionals are responsible for diagnosing and determining the disability status of individuals, they are gatekeepers of official recognition, and therefore, play a key role. OPDs also play a role in advocating for revised national legislation and in negotiating the revised provisions, including the types of disability and how they are defined. If OPDs of persons with deafblindness are not included in these negotiations, it is unlikely that deafblindness will be fully and correctly recognised.

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<sup>30</sup> *Ibid.*

## Good Practices

WFDB identifies the acceptance of the Nordic definition of deafblindness as a good practice. The Nordic definition provides a lengthy but thorough explanation of deafblindness that may be referred to in legislation and policy and with the full text supplied as a resource to relevant parties. National legislation is written in the official legal language of a country, and therefore, it is essential that WFDB members and allies formulate an official definition of deafblindness in the working languages of each country that lacks this.



*This picture was taken during WFDB's 6th General Assembly in October 2022 in Nairobi, Kenya when the red and white cane was officially recognised as WFDB's universal symbol for deafblindness. Pradip and Christopher, two males with deafblindness pictured above (WFDB elected Board representatives), communicate through tactile signing. They are both users of the red and white cane.*

**Photo taken by WFDB**

## NORDIC DEFINITION OF DEAFBLINDNESS



**Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability.**



### MAIN IMPLICATIONS

To varying degrees, deafblindness limits activities and restricts full participation in society. It affects social life, communication, access to information, orientation, and the ability to move around freely and safely.

To help compensate for the combined vision and hearing impairment, especially the tactile sense becomes important.

#### Comments:

#### **On the combined vision and hearing impairment**

The severity of the combined vision and hearing impairment depends on:

- › The time of on-set, especially in relation to communication development and language acquisition
- › The degree and nature of the vision and hearing impairments

- › Whether it is congenital or acquired
- › Whether it is combined with other impairments
- › Whether it is stable or progressive

### **On the distinct disability**

The fact that it is hard for the impaired senses to compensate for each other means that:

- › Attempting to use one impaired sense to compensate for the other one is time consuming, energy draining, and most often fragmented
- › A decrease in the function of vision and hearing increases the need for making use of other sensory stimuli (i.e., tactile, kinaesthetic, haptic, smell, and taste)
  - › It limits the access to distance information
  - › It creates a need to rely on information within the near surroundings
  - › To create meaning, it becomes necessary to rely on memory and to draw conclusions from fragmented information.

### **On activities and participation**

Deafblindness limits activities and restricts full participation in society. In order to enable the individual to use their potential capacity and

resources, society is required to facilitate specialised services

- The individual and their environment should be equally involved, but the responsibility for granting access to activities lies on society. An accessible society should at least include:
  - Available competent communication partners
  - Available specialised deafblind interpreting, including interpreting of speech, environmental description, and guiding
  - Available information for everyone
  - Human support to ease everyday life
  - Adapted physical environment
  - Accessible technology and technological aids
- A person with deafblindness may be more disabled in one activity and less disabled in another activity. Variation in functioning might be the consequence of both environmental and personal factor
- Specialised competence related to deafblindness, including an interdisciplinary approach, is vital for proper service provision”<sup>31</sup>.

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<sup>31</sup> Nordic Welfare, Nordic Definition of Deafblindness, <https://nordicwelfare.org/wp-content/uploads/2018/03/nordic-definition-of-deafblindness.pdf>, accessed May 2022.

National disability legislation does not need to utilise the full Nordic definition due to its length, but it should list deafblindness as a distinct disability. Furthermore, an official definition of deafblindness should include the following key elements:

- 1 Deafblindness is a distinct and unique disability in law and practice

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- 2 Understanding that it is hard for the impaired senses to compensate for each other

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- 3 Understanding that deafblindness affects communication, access to information, socialisation, development, mobility, orientation, etc.

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- 4 Understanding of the need for tactile communication, assistive devices or technology, and live assistance (e.g., interpreter-guides/Deafblind interpreters)

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- 5 The importance of raising awareness about deafblindness and the requirements of persons with deafblindness

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- 6 Official recognition should be based on the social model of disability with functional assessment and not mere medical evaluation of vision and hearing<sup>32</sup>.

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<sup>32</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p.8-13.

## Recommendations

### Governments

- Adopt a comprehensive official definition of deafblindness, for example, the Nordic definition, and list deafblindness as a distinct disability in national disability legislation
- Actively raise awareness of policymakers and health and rehabilitation professionals on the definition of deafblindness

### OPDs and NGOs

- OPDs advocating for national disability legislation should consult with OPDs of persons with deafblindness, or WFDB in lieu
- of a national deafblind association, to ensure the voices of persons with deafblindness are not excluded

- Raise awareness within the disability movement on the definition of deafblindness
- to facilitate greater understanding and to avoid misrepresenting persons with deafblindness

- Advocate for the inclusion of ‘deafblind’ and ‘deafblindness’ in spell check features of, for example, Microsoft Word, iPhone, and other digital tools, to gain acknowledgement of
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deafblindness as a unique disability and not multiple disabilities

## Donors and Research Institutes

Conduct research to analyse which countries have official recognition of

- › deafblindness, whether it meets the above standards, and how this legal recognition is applied

## Tackling Stigma and Discrimination

Persons with deafblindness are often excluded from services, support, and social life because of their disability. “Discrimination on the basis of disability means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural civil, or any other field”<sup>33</sup>. Therefore, the exclusion of persons with deafblindness is largely due to discrimination and stigma - i.e., the stereotypes, misperceptions, and assumptions about persons with disabilities which often derive

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<sup>33</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 2.

from a lack of understanding about persons with deafblindness.

A common misperception is that persons with deafblindness cannot be helped, supported, or reached because they will not understand the situation or because there is a presumption of inability. These misperceptions only lead to further exclusion and marginalisation. The table below sets out some common misperceptions and facts about persons with deafblindness:

<b>COMMON MISPERCEPTIONS</b>	<b>FACTS</b>
<b>Cannot communicate</b>	Can communicate in a variety of ways.
<b>Cannot learn</b>	There is no single profile of a learner with deafblindness. Persons with deafblindness can learn in a variety of ways with the appropriate supports and accommodations.
<b>Incapable of understanding</b>	There is no reason to assume reduced cognitive functioning unless this has been identified in an individual assessment.
<b>Cannot be independent or autonomous</b>	Levels of support depend on the individual, their environment, and how effectively they have been rehabilitated. Many live independently.

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**Cannot work**

While there are some persons with deafblindness with very high support needs who may not work, most can work. There is no single profile of a worker with deafblindness.

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**Cannot participate**

With reasonable adjustments and access to interpreter-guides/Deafblind interpreters and/or assistive devices and technology, persons with deafblindness can participate.

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**Deafblindness is a curse**

Deafblindness is caused by a range of factors, such as illness, genetic factors, and accidents. Persons with deafblindness and their family members should not be blamed for this. Persons with deafblindness are valuable members of society that deserve respect and dignity<sup>34</sup>.

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<sup>34</sup> Enabled.in, *Deafblindness – Facts, Myths, and Truth*, <https://enabled.in/wp/deafblindness-facts-myths-and-truth/>, 24 June 2014.

## Persons with deafblindness are patients

When discussing the inclusion and rights of persons with deafblindness, the social and human rights models should be adopted, instead of the medical model. The focus should be put on the barriers posed by society, not the impairment or medical condition. Persons with deafblindness should only be perceived as patients when they are seeking medical care.

In addition to misperceptions about deafblindness, some forms of stigma apply the medical model, viewing deafblindness as a problem that belongs to the individual, rather than recognising the systemic attitudinal and environmental barriers that impede the participation of persons with deafblindness. This often leads to unresponsive or inappropriate responses due to the bias of focusing on the condition of deafblindness rather than the barriers faced by the individual, particularly among frontline professionals<sup>35</sup>.

Persons with deafblindness experience vertical discrimination - i.e., discrimination between

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<sup>35</sup> National Centre on Combined Vision and Hearing Impairment / Deafblindness, *Eikholt Annual Report*, October 2021, p. 6.

impairment groups of persons with disabilities. Persons with deafblindness are often referred to as one of the most marginalised and underrepresented groups of persons with disabilities. This is largely due to the communication barriers that persons with deafblindness face (e.g., lack of access to interpreter-guides/Deafblind interpreters, information, and support to keep abreast of developments). Moreover, persons with deafblindness are often excluded because of the diverse needs and requirements, resulting in a lack of recognition or support by the other groups of persons with disabilities. Although there is some recognition of persons with deafblindness as an underrepresented group within the wider disability movement, persons with deafblindness are often not represented in OPDs, and thus, are forgotten or excluded because they are perceived to be too difficult to include. This impacts programmes and policies because persons with deafblindness are excluded from the outset.

Among persons with deafblindness, those with higher support needs, such as persons with pre-lingual deafblindness, are likely to experience even greater marginalisation and exclusion. It is, therefore, essential to consider the requirements of the most marginalised and hardest-to-reach persons with deafblindness and to recognise the diversity of requirements. For example, a young

person with pre-lingual deafblindness may require an interpreter-guide/Deafblind interpreter and some additional rehabilitation to transition into a new job, whereas a young person with post-lingual deafblindness may require access to magnifiers, a special computer monitor, and access to captioning services during meetings. The costs between these two examples can be significant, and it should not be assumed that persons with high support needs are incapable of working simply because their support needs cost more or may take more time to implement.

Governments often do not invest in the supports and services for persons with deafblindness because the prevalence is lower than other disabilities. It is, therefore perceived as being too insignificant of a number of people to warrant the development of specialised or tailored supports or services. This is another form of vertical discrimination that places too much value on prevalence as a justification for allocating funding.

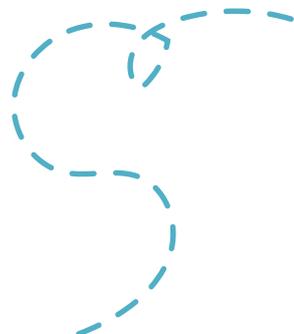
Persons with deafblindness also experience horizontal discrimination - i.e., discrimination between groups with clearly defined identities or characteristics (e.g., race, sex, language, religion, political or other opinion, nationality, ethnicity, indigenous or social origin, property, birth, age, or other status). This leads to multiple and intersecting forms of discrimination - i.e., where a

person experiences discrimination on two or more identities or characteristics, leading to discrimination that is compounded or aggravated<sup>36</sup>. There is very little research on intersectional or multiple discrimination of persons with deafblindness. Because persons with deafblindness experience high levels of social exclusion, it may be difficult to recognise the intersecting nature of multiple discrimination.

Stigma and discrimination can come from all levels of society, including families, local communities, elected officials, civil servants, schools, health centres, pharmacies, shops, employers, etc. Persons with deafblindness often rely on family members for support, and families can sometimes act as a filter or barrier to social inclusion. In addition, persons with deafblindness often do not have the communication support to coordinate and deliver awareness-raising activities to combat stigma and discrimination among these groups.

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<sup>36</sup> Committee on the Rights of Persons with Disabilities, General Comment No. 3 on women and girls with disabilities, CRPD/C/GC/3, 25 November 2016, para. 4c.



*Puspa, a man with deafblindness, is enjoying a conversation outdoors with colleagues on their way to a meeting in Geneva, Switzerland.*

***Photo taken by WFDB***



## Good Practices

According to the CRPD, reasonable accommodation is one of the most effective tools for ensuring equality and non-discrimination. Reasonable accommodations are the “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”<sup>37</sup>. Reasonable accommodation requirements for persons with deafblindness vary for each individual, but common adjustments include:

- Access to interpreter-guides/Deafblind interpreters or other live assistance
- Access to information in accessible formats (e.g., Braille, large print, captioning, audio description, etc.)
- Assistive devices or technology (e.g., magnifiers, Braille display, etc.)
- Adjustments to procedures (e.g., adapted emergency procedures, changes to schedules, changes to standard communication methods, advance access to

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<sup>37</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 2.

information, extra time to enable interpretation, etc.)

Respondents of WFDB's survey indicated that awareness-raising activities are a good practice for addressing stigma and discrimination. The CRPD requires governments to undertake awareness-raising to foster respect for persons with disabilities, combat stigma and discrimination, and promote the capabilities and contributions of persons with disabilities<sup>38</sup>. Awareness-raising is a necessary tool for tackling stigma and discrimination because it attempts to inform, provide facts, correct misperceptions, and compensate for the fact that most persons with deafblindness have been socially excluded, thus leading to misperceptions in the community.

Awareness-raising should be tailored to the target group, using a variety of methods (e.g., awareness campaigns; media, such as radio, TV, social media, news, articles, etc.; training and courses; research; and forums, such as peer support groups for family members). Target groups should include family members, teachers, and school staff, health and rehabilitation workers, government officials and civil servants at national

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<sup>38</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 8.

and local levels, journalists, and employers. Moreover, persons with deafblindness should be provided with practical support, such as interpreter-guide/Deafblind interpreting services, support with coordination, and funding to enable them to drive awareness-raising activities.

These awareness-raising initiatives should consider:

- › Who is leading the awareness-raising and whether the voices of persons with deafblindness are meaningfully included. It is important to distinguish between organisations **for** persons with deafblindness (i.e., parents' groups and NGOs) and organisations **of** persons with deafblindness (i.e., OPDs of persons with deafblindness)
- › Whether a human rights-based approach and the CRPD have formed the basis of the awareness-raising
- › Whether positive images and role models of persons with deafblindness have been used
- › How awareness will be raised across all regions of the country
- › How to reach the whole targeted group
- › How to continuously raise awareness among professional groups that constantly change

(e.g., government officials, frontline staff of service providers, civil servants, etc.). For example, Sense International includes awareness raising in most of its programmes but notes that it is difficult to secure lasting awareness in transient environments (e.g., with civil servants who change jobs and departments frequently).

- › How these initiatives can advance towards sustainable, systemic institutional learning.

It can be very empowering for persons with deafblindness to share their individual stories as part of awareness-raising activities. This encourages the target audience to listen to persons with deafblindness directly, and it exposes them to the experience of engaging with deafblind communication.

## Recommendations

### All

- Incorporate awareness-raising on persons with deafblindness into initiatives aimed at raising awareness on disability more broadly
- › and ensure that these initiatives seek to address common misperceptions and promote positive portrayals of persons with deafblindness

## Governments

- > Legally recognise deafblindness as a distinct disability
 

Ensure laws and policies to address discrimination and promote equality include persons with disabilities as a protected group, and ensure laws and policies to
- > protect persons with disabilities recognise deafblindness and draw attention to the particular needs of persons with deafblindness
 

Ensure reasonable accommodation is
- > protected in law for persons with deafblindness
 

Adopt an awareness- raising strategy that includes raising awareness specifically about persons with deafblindness and map
- > the strategic targets that are most likely to support persons with deafblindness in accessing services and in the community
 

Stop using low prevalence levels as a way to devalue and deprioritise the needs of
- > persons with deafblindness and prioritise funding for tailored services and supports based on need

## OPDs and NGOs

- Tackle horizontal discrimination (i.e., marginalisation of persons with deafblindness among persons with disabilities) and take steps to ensure persons with deafblindness are represented and ensure their voices are heard

- Raise awareness within the disability movement on the definition of deafblindness to facilitate greater understanding and to avoid misrepresenting persons with deafblindness

- Provide more practical support to OPDs of persons with deafblindness, including funding and interpreter-guide/Deafblind interpreting services, to drive and coordinate awareness raising- initiatives of persons with deafblindness

## Donors and Research Institutes

- Include persons with deafblindness in all programmes and research aimed at persons with disabilities

- Conduct research on the nature and impact of intersectional and multiple forms of discrimination experienced by persons with deafblindness and explore interventions that adequately address multiple discrimination.

## Accessibility

Accessibility is a right that enables independence and participation of persons with disabilities on an equal basis with others and often refers to products, systems, services, environments, and facilities that are used by people with diverse requirements<sup>39</sup>. Without access to the physical environment, transportation, information and communication, and other facilities and services provided to the public, persons with disabilities would not have equal opportunities<sup>40</sup>.

Because persons with deafblindness experience barriers to communication and information, accessibility considerations for them are often limited in these areas. However, persons with deafblindness also experience many barriers to orientation and mobility in public spaces<sup>41</sup>. Some of the accessibility measures for persons who are blind, such as providing information in Braille or large print, or for persons who are deaf, such as providing captioning, may help some persons with

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<sup>39</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 9; UNPRPD, *The preconditions necessary to ensure disability inclusion across policies, services, and other interventions*, <https://unprpd.org/sites/default/files/library/2020-08/Annex%20%20UNPRPD%204th%20Funding%20Call%20Preconditions%20to%20disability%20inclusion%20ACC.pdf>, accessed May 2022, p. 4-5.

<sup>40</sup> Committee on the Rights of Persons with Disabilities, *General Comment No. 2 Article 9: Accessibility*, CRPD/C/GC/2, 22 May 2014, para. 1.

<sup>41</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 7.

deafblindness. However, as a group, the accessibility measures for the deaf and/or the blind do not sufficiently meet the requirements of persons with deafblindness.

When accessibility measures are not considered or in place for persons with deafblindness, they are less likely to participate or engage in society. Accessibility applies to groups, whereas reasonable accommodation applies to individuals. There is a duty to provide accessibility for all groups of persons with disabilities, including persons with deafblindness, and to set accessibility standards, which must be adopted in consultation with OPDs. These accessibility standards need to be specified for and communicated to service providers and other relevant stakeholders<sup>42</sup>. Because deafblindness is a low-incidence disability, the accessibility requirements of persons with deafblindness are often not considered and may only be acknowledged as a reasonable accommodation request of individuals. This approach undermines the right to accessibility and the recognition of persons with deafblindness as a distinct group, as accessibility is unconditional<sup>43</sup>.

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<sup>42</sup> Committee on the Rights of Persons with Disabilities, *General Comment No. 2 Article 9: Accessibility*, CRPD/C/GC/2, 22 May 2014, para. 25.

<sup>43</sup> *Ibid.*

## Good Practices

It is crucial that minimum standards for the accessibility of goods and services provided by public and private entities for persons with disabilities must consider persons with deafblindness as a group and consult with their representative organisations. Stakeholders, such as builders, planners, and service providers, may require training to sensitise them and to develop their technical knowledge<sup>44</sup>. Accessibility standards for persons with deafblindness should be considered and applied to the following areas:

- › Transportation
- › Public buildings and pathways
- › Schools
- › Hospitals, clinics, and health centres
- › Libraries, parks, and recreational facilities
- › Television, radio, and other forms of media, such as websites
- › Housing

Accessibility standards for person with deafblindness should consider information and communication as well as orientation and mobility. Wherever possible, universal design principles should be applied. Some key elements for the built environment include:

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<sup>44</sup> *Ibid.*, para. 19.

- › Adequate lighting
  - Contrasting colours through paint, tape,
- › stickers, or choice of colour of furniture or objects
- › Colour coding, visual cues, and/or textural cues
- › Glare reduction
- › Large font and/or Braille signage
- › Loop induction systems
- › Vibration devices to help orient persons with deafblindness (e.g., at street crossings)
- › Use of sound in a space or room (e.g., the ambient noise levels, using spaces that reflect or echo sound to help with echolocation, reducing noise from outside, etc.)
- › Material finish
  - Physical accessibility supports, such as
- › handrails, door handles, level surfaces, etc.<sup>45</sup>

Having a barrier-free environment in cities and towns can help, such as not blocking the pathways, and providing accessibility features, such as spinning tactile devices installed into the control box at a pedestrian crossing and tactile paving to mark the edges of the pathway near

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<sup>45</sup> Deafblind Ontario Services, *Accessibility Guidelines for Sensory Loss*, 3<sup>rd</sup> Edition, 2020, 13-97.

roads or on train platforms. Accessibility tips should be provided to persons with deafblindness and their families to facilitate the adjustment of the home and financial supports should be provided if adaptations are too costly for individuals.

Information and communication should be available in a variety of formats, as the needs of persons with deafblindness vary from person to person. Many of these formats are relevant to other groups of persons with disabilities.

Some examples include:

- Braille / Moon, high contrast large print, audio description or describing images,
- audio versions, summary versions, and Easy Read versions
- Captioning with speaker identification,
- subtitling, textphone, SMS, sign language interpretation
- Augmentative and alternative modes and
- methods.

For virtual and live events accessibility considerations include:

- Speaking one person at a time
- Allowing time for translation and regular
- breaks
- Providing a name before speaking,
- captioning, or type chatting

- › Making the face visible for lip reading
- › Explaining visual aids
- › Using high contrast and large print in presentations
- › Providing captioning with speaker identification and/or sign language interpretation
- › Sending documents or information in advance of meetings as a standard practice
- › Taking notes to share afterward or recording the meeting, if all parties consent<sup>46</sup>.

In addition to these accessibility standards, persons with deafblindness may also require reasonable accommodations, such as access to interpreter-guide/Deafblind interpreting services. However, adopting them will reduce the need for reasonable accommodation requests.

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<sup>46</sup> Deaf Scotland, *Making Zoom Accessible for People Who Are Deafblind*, [deafscotland.org](https://deafscotland.org), accessed May 2022.

## CASE STUDY

### Improving Accessibility in Recreational and Cultural Venues: Lessons from Eulalia Cordeiro in Brazil

Eulalia Cordeiro, a woman with deafblindness from Brazil, was never able to enjoy a visit to her local museums because they were not accessible and had many environmental barriers. In 2019, Eulália joined a working group, 'Grupo Sentido Brasil/Perkins Group' that focused on making museums more accessible. This group comprised of people from different sectors in society, including other persons with disabilities, families, and professionals, such as engineers, architects, teachers, occupational therapists, and mobility and orientation experts. This initiative was funded by museums and the local municipality and covered the costs for Eulália to use an interpreter-guide/Deafblind interpreter.

Eulália represents the perspective of persons with deafblindness in the group and has provided feedback and advice through a range of activities, such as workshops, classes, and site visits, with the aim of improving the accessibility of museums in Brazil and the participation of persons with deafblindness in cultural and recreational activities.

The group worked with four museums:

- › Earth Sciences Museum in Rio de Janeiro
- › Museum of Pathology in Rio de Janeiro
- › Carmo Planetarium in São Paulo
- › Ipiranga Museum in São Paulo.

Starting with the Earth Sciences Museum in Rio de Janeiro, Eulália provided advice on how to improve the accessibility and inclusion of persons with deafblindness, adding valuable feedback to the museum. Due to the success of the group with the Earth Sciences Museum, other museums and cultural sites have joined the initiative.

Examples of some of the accessibility measures adopted by the museums include

- › Audio description of exhibitions and displays
- › Audio guides to help visitors to navigate the museum independently
- › Maintaining a list of interpreter-guides/Deafblind interpreters to share with visitors with deafblindness so that they can arrange interpreter-guide/Deafblind interpreting services.

Eulália has demonstrated that persons with deafblindness can provide valuable advice and technical support to improve the accessibility of public spaces (e.g., by serving on a committee). Eulália hopes to keep working with these venues



PARA TOCAR: reprodução de detalhe da pintura *Independência ou morte!* com destaque para a Guarda de Honra e casa.

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*Pieces of art can be made accessible to visitors with deafblindness, as shown in the image above, in which an A4 relief version of the painting is available for visitors to touch and feel. It also includes an audio description of the painting and an explanation in Braille.*

***Courtesy of Eulália Cordeiro from her visit at the Ipiranga Museum in***

## Recommendations

### Governments

- Develop accessibility standards for persons with deafblindness in consultation with their representative organisations across the
- › physical environment, transportation, information and communications, housing, and other facilities and services provided to the public
  - › Adopt universal design principles for all new building work.

### OPDs and NGOs

- Include persons with deafblindness in accessibility considerations for persons with disabilities and amend policies and practices
- › to avoid automatic or de facto exclusion of persons with deafblindness as an unreachable group.

## Disability-Specific Services

Disability-specific services and disability mainstreaming are necessary components of a twin-track approach. Disability-specific services are specially designed community-based services to meet the requirements of persons with disabilities, including persons with deafblindness.

These services may be arranged in a variety of ways and focus on the following elements:

- Identification and assessment** of disabilities in individuals. In addition, this often involves **referral services** to ensure

➤ that persons with disabilities receive information, advice, and further community supports
- Rehabilitation services** that enable

➤ persons with disabilities to attain maximum independence and participation in all aspects of society
- **Disability support services** that provide direct help or assistance to persons with disabilities so that they can perform daily activities (e.g., access to assistive devices, interpreter-guides/Deafblind interpreters or other live assistance, sign language interpretation, accessibility modifications in the home, etc.)<sup>47</sup>.

These services may be organised and arranged in different ways and may be embedded within mainstream services, depending on the national

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<sup>47</sup> UNPRPD, *The preconditions necessary to ensure disability inclusion across policies, services, and other interventions*, <https://unprpd.org/sites/default/files/library/2020-08/Annex%20%20UNPRPD%204th%20Funding%20Call%20Preconditions%20to%20disability%20i%20nclusion%20ACC.pdf>, accessed May 2022, p.2-4; and Deafblind UK, *Our services: Supporting people with sight and hearing loss and our services for professionals: Supporting people with sight and hearing loss* pamphlets, [www.deafblind.org.uk](http://www.deafblind.org.uk), accessed May 2022.

and local situation. A robust system of disability-specific services enables persons with disabilities to be independent and to participate in the community. It also strengthens their access to mainstream services, such as education, health care, emergency, social protection, employment programmes, etc.

Disability-specific services, whether run by the state, civil society, or private sector, require sustained funding. However, there is a strong economic argument for investing in disability-specific services, which enhances the inclusion and independence of persons with disabilities, thus making them less reliant on others. Because persons with deafblindness are a small group, it is often assumed that they require only the minimum allocation of the resources earmarked to support disability services. This is an underestimation of the support needs and diversity of the group. Deciding resource allocation based on assumptions about overall social impact as a group is a political choice and a major barrier to ensuring supports<sup>48</sup>.

Importantly, many countries lack disability-specific services, including deafblind-specific services, to support for persons with deafblindness altogether.

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<sup>48</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 9.

This is often due to a lack of knowledge and skills of professionals working with persons with disabilities and persons with deafblindness. More specifically, there is often no information resource centre or hub on deafblindness available in the country that provides information materials or training courses on deafblindness in local languages, which perpetuates the gap in developing services and supports for persons with deafblindness<sup>49</sup>.

A disability resource centre or hub is an independent organisation or network of organisations with the primary focus of gathering and providing information and technical resources to persons with disabilities, families, and professionals working with persons with disabilities across a range of services. These resources may include a resource library, an online repository of information and technical guidance, training courses and other learning events, and links with technical experts, ensuring that information resources reflect the latest research on impairments and technical support on good practices, including clinical practices, educational approaches, home-based supports, etc. A resource centre or hub on deafblindness may be

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<sup>49</sup> Boswell, Emma. "Trip to Indonesia", *DBI Review*, Issue 63, April 2020, p. 59 and Exxat, Amal. "Advocating for the Right to Education for Learnings with Deafblindness and Multiple Disabilities in Egypt", *DBI Review*, Issue 61, p. 5; Ezzat, Amal, "Advocating for the Right to Education for Learners with Deafblindness and Multiple Disabilities in Egypt", *DBI Review*, Number 61, July 2018, p. 5-8.

run by OPDs of persons with deafblindness, other OPDs, parents' groups, practitioner groups, NGOs, or a combination of partners, and some may provide disability-specific services for persons with deafblindness in addition to serving as a centre for information and technical resources.

The literature review revealed that several middle-income countries lacked resource centres on deafblindness, which led to costly alternatives or the exclusion of persons with deafblindness from disability-specific services. For example, a rehabilitation professional from the United Kingdom was flown into Indonesia to provide vital rehabilitation training to adults with deafblindness who were setting up an emerging OPD. They could not communicate with each other or function as an OPD without this vital rehabilitation support. This is because Indonesia lacks a central resource centre on deafblindness to train existing rehabilitation professionals or to provide basic information to persons with deafblindness<sup>50</sup>. In other words, disability-specific services for persons with deafblindness cannot exist without the technical knowledge and resources.

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<sup>50</sup> Boswell, Emma. "Trip to Indonesia", *DBI Review*, Issue 63, April 2020, p. 59 and Exxat, Amal. "Advocating for the Right to Education for Learnings with Deafblindness and Multiple Disabilities in Egypt", *DBI Review*, Issue 61, p. 5; Interview with Dwi Ariyani from Disability Rights Fund on support to OPDs of persons with deafblindness in Indonesia, 11 March 2022.

## Good Practices

A ‘standout organisation’ (i.e., a leading national organisation, OPD, parents’ group, research centre, or service provider) is often a driving force in establishing a resource centre or hub on deafblindness, which enables disability professionals and service providers to develop a community of practice and a pool of technical experts, who play a key role in providing disability-specific services for persons with deafblindness. Persons with deafblindness and family members have historically been at the forefront of driving the establishment of such hubs. If there is no obvious organisation to lead an initiative to establish a resource centre, an umbrella group comprised of equal partners can be established to coordinate and share learning, helping to generate a ‘whole country’ response to support persons with deafblindness<sup>51</sup>. However, this type of initiative requires funding as well as coordination and capacity supports.

For some countries, especially smaller low-income countries, a cross-border approach of working with persons with deafblindness, families, and professionals from neighbouring countries or countries with historical or linguistic ties could help

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<sup>51</sup> DeafReach, what would be the next step? Action Research on Discovering Deafblindness within the wider Rwanda Disability Context, October- November 2019, p. 36.

to facilitate information sharing, training expertise, and practical support to establish a resource centre.<sup>52</sup> This could be established through a formal or informal partnership with resource centres that have technical knowledge on methods to support persons with deafblindness, noting that multiple, simultaneous partners could provide a range of technical support. In addition, it is a good practice to include the national deaf association and national sign language users, since sign language is often used by some persons with deafblindness and because sign languages vary across countries and regions. For example, in Rwanda, an umbrella group of NGOs, OPDs, and other stakeholders worked with the Association of Swedish Deafblind (FSDB) to develop a Rwandan Tactile Sign Language<sup>53</sup>.

Another good practice is to recognise disability-specific services for persons with deafblindness in legislative and policy frameworks and to adopt guidelines and criteria to regulate the delivery of assistance and support services with the consultation of persons with deafblindness<sup>54</sup>. For example, in Peru, the law that recognises

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<sup>52</sup> *Ibid.*

<sup>53</sup> *Ibid.*

<sup>54</sup> United Nations Special Rapporteur of the Human Rights Council on the Rights of Persons with Disabilities, report on disability inclusive policies, A/71/314, 9 August 2016, para. 49.

deafblindness as a distinct disability includes a provision on the care of persons with deafblindness, including the requirement of public and private entities to provide interpreter-guide/Deafblind interpreting services free of charge<sup>55</sup>. While this service is still being developed in Peru, this demonstrates a good practice in securing essential disability-specific services for persons with deafblindness. It is unlikely that this service would have been developed without this legislation. It is, therefore, important to identify groups, like persons with deafblindness, who are the most marginalised and to expressly name them and their requirements repeatedly in public policies and programmes to ensure that they are not excluded altogether<sup>56</sup>.

Disability-specific services for persons with deafblindness will vary for each individual. For example, one person may require interpreter-guide/Deafblind interpreting services and several assistive devices, whereas another person may only require assistive devices and training on how to use them. Therefore, it is important to provide a range of disability-based services, which in practice should be tailored to each individual.

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<sup>55</sup> Sense International Peru, Peru Promotes Training of Interpreter Guides for Persons with Deafblindness, Article for DBI Ibero-Latin American Network, 3 August 2021.

<sup>56</sup> United Nations Special Rapporteur of the Human Rights Council on the Rights of Persons with Disabilities, report on disability inclusive policies, A/71/314, 9 August 2016, para 30.

## Recommendations

### Governments

- Establish a comprehensive system for disability-specific services that includes identification, assessment, referral,
  - rehabilitation, and disability support services and incorporates the requirements of persons with deafblindness
- Ensure that persons with deafblindness and their OPDs are actively involved in
  - processes to develop disability-specific services
- Ensure budgets to support services for
  - persons with deafblindness reflect their diversity and needs
- Work alongside civil society, service providers, and donors to support the establishment of a central information sharing and resource centre or hub on deafblindness with resources in local languages
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- Enable cross-border collaboration and information sharing on supports for persons
  - with deafblindness, especially to help establish a national resource centre or hub on deafblindness
- Recognise persons with deafblindness as a hard-to-reach group and outline the
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disability-specific services that they require in legislative, policy, and programmatic frameworks

## **OPDs and NGOs**

Support persons with deafblindness and family members to establish a central information sharing and resource centre or hub on deafblindness with resources in local

- languages for professionals and in accessible formats (e.g., easy-to-read, braille, large print, etc.) for persons with deafblindness

Consider umbrella groups or cross border approaches to enable technical supports

- and information sharing and to establish a resource centre or hub on deafblindness

Advocate for the recognition of persons with deafblindness as a hard-to-reach group and

- advocate for disability-specific services for persons with deafblindness in legislative, policy, and programmatic frameworks

Where disability-specific services for persons with deafblindness exist, identify

- the gaps, and develop advocacy plans to address them

## Donors and Research Institutes

- Consider creative funding approaches to enable the establishment of a central information sharing and resource centre or
  - hub on deafblindness with information resources in local languages, especially in countries that are commonly overlooked by donors and the deafblind community
- Work with civil society actors in a longer-term phased approach to establish a central information sharing and resource centre or
  - hub on deafblindness, which may go beyond the timeframe of donor-established funding cycles of one, three, or five years
- Conduct research on the technical
  - knowledge gaps in countries where disability-specific services do not exist
- Fund initiatives to support the development of disability-specific services for persons
  - with deafblindness based on the priorities of OPDs of persons with deafblindness

## Identification, Assessment, and Referral

The first step for persons with deafblindness in accessing services includes:

- **Identification of their disability**, usually through screening, a risk factor questionnaire, or health checks

- **Assessment of the condition and individual functioning** through tests and comprehensive evaluations to get a full picture

- **Referrals** for additional testing, health and rehabilitation specialists, information on deafblindness, advice on how to make adjustments, and support services<sup>57</sup>.

Deafblindness is not necessarily easy to detect in many cases. For example, infants and young children with deafblindness need to be screened to detect vision and hearing loss<sup>58</sup>, which may not be detected until the child shows signs of developmental delays because deafblindness in children affects their access to information, and thus their learning. In adults, and particularly older persons, the onset of deafblindness can be gradual and therefore easily overlooked. It is often identified by family members if noticed at all. Health care professionals often miss the signs of

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<sup>57</sup> UNPRPD, *The preconditions necessary to ensure disability inclusion across policies, services, and other interventions*, <https://unprpd.org/sites/default/files/library/2020-08/Annex%202%20UNPRPD%204th%20Funding%20Call%20Preconditions%20to%20disability%20inclusion%20ACC.pdf>, accessed May 2022, p. 3.

<sup>58</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 32.

deafblindness because they lack the training on how to identify the risk factors. This can lead to misidentification, for example, the person appears to withdraw, be confused, and does not appear to remember what was said. These signs may be perceived as dementia but may in fact be deafblindness<sup>59</sup>. Misidentification and/or poorly conducted assessments can significantly affect the interventions to treat underlying health conditions, rehabilitate, plan for tailored supports, identify communication needs and approaches, and ensure independence and full participation in society of persons with deafblindness<sup>60</sup>.

Even when deafblindness has been identified, many individuals do not know how to adjust, and families often do not know how to support them. The process for identification, assessment, and referral can be a long, drawn-out process with poor communication for persons with risk factors and their families. Because deafblindness is a low-incidence disability, families often feel isolated because information, advice, and specialist interventions are needed for both the person with deafblindness and their support network.

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<sup>59</sup> Mortensen, Ole E., *When vision and hearing fail*, [www.sufo.dk](http://www.sufo.dk), February 2021.

<sup>60</sup> Nordic Welfare Centre, *Revealing hidden potentials: Assessing cognition in individuals with congenital deafblindness*, <https://nordicwelfare.org/publikationer/hidden-potentials/>, August 2020.

According to respondents of WFDB's survey, many countries do not have a comprehensive system for identification, assessment, and referral for persons with deafblindness across all age groups and geographic regions. Whether this is due to a lack of awareness, technical expertise, or investment, the results lead to social isolation and higher dependence of persons with deafblindness on others. In addition, where deafblindness is not legally recognised, persons with deafblindness may be misidentified and may not obtain the right supports. For example, individuals may be required to obtain two medical certificates - one for vision loss and one for hearing loss – which is expensive and does not adequately describe their disability<sup>61</sup>. Where identification, assessment, and referral services do exist, they are often centrally located (e.g., in the capitol or large cities, making it inaccessible to people who live far away or in rural areas). For example, Sense International noted that they had to pay to move the team that conducted these services, Educational Support, Resource, and Assessment Services (ESRAC) based in Dar Es Salaam, to other parts of Tanzania to support these services that formed a critical element in a recent education programme that they delivered.

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<sup>61</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 9.

## Good Practices

Identification, assessment, and referral services should include early identification and intervention for infants and young children, as it is often difficult for them to make significant progress in their development if deafblindness is not addressed until school age. This process involves:

- **Screening for vision and hearing**, which may involve a risk-factor questionnaire

- **Testing of infants and children that are flagged for risks during screening**

**Referrals to intervention services and specialists as early as possible** to

- improve their development and independence, working in partnership with schools or child welfare systems with a multidisciplinary team, and developing an individualised plan for each child<sup>62</sup>. These referrals may include additional testing and rehabilitation services with for example, audiologists, optometrists, and other specialists. This should also include referrals to information on benefits, social protection, and information and advice offered to families.

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<sup>62</sup> *Ibid.*, p. 32

These services for infants and young children may be more cost-effective if provided within existing health and rehabilitation services and alongside interventions for other disabilities, such as single sensory impairments.

Identification, assessment, and referral services in older adults are similar. Health checks and questionnaires are a good starting point for identifying deafblindness in adults. Health centres, families, caregivers, and targeted recreational facilities, such as libraries, provide opportunities to raise awareness and disseminate risk factor tools. Risk factor tools, such as a question guide or simple screening tool for caregivers and health care staff, can help to identify those at risk of deafblindness or single sensory loss that requires further assessment and referrals<sup>63</sup>. Whether for children or adults, these services may also require:

- **Screening for vision and hearing**, which
- may involve a risk-factor questionnaire
- Identification and assessment protocols
- Training and sensitisation of health care staff to better recognise the risk factors
- Sensitisation training, information resources, and advice for family members

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<sup>63</sup> Mortensen, Ole E., *When vision and hearing fail*, [www.sufo.dk](http://www.sufo.dk), February 2021.

- Good communication for people at risk and families throughout the process for identification, assessment, and referral
- Awareness- raising in the community on deafblindness screening
- Referral pathways for further assessments for at-risk individuals
- Procurement of medical equipment used in assessments and essential medicines
- Access to specialists (e.g., occupational therapists, audiologists, ophthalmologists, etc.)
- A system for collecting data
  - Centralised, tailored, and accessible information resources on deafblindness for practitioners, families, government officials, and other key stakeholders
- Coordination between government ministries and departments (e.g., health, education, etc.)
- Coordination on other disabilities (e.g., single sensory impairments)
- Coordination with rehabilitation services
- Continuity of funding<sup>64</sup>.

In addition, assessments must always be a flexible, holistic process based on the latest

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<sup>64</sup> Sense International, *End of Project Early Intervention Services for Infants with Sensory Impairments in Kenya and Uganda*, July 2019, p. 64-70.

research and experience within the field of deafblindness<sup>65</sup>. For identification screenings and assessments for deafblindness, a range of functional capacities should be included (i.e., hearing, vision, cognition, mobility, and orientation). Professional guidelines ensure consistent professional standards are met and help to prevent assumptions made by professionals) (e.g., if a child cannot hear and see, it does not mean that they have low cognitive potential)<sup>66</sup>.

In low-resource countries where these services do not exist, piloting of identification, assessment, and referral services tailored to the context can form a starting point. For example, a pilot programme can help to build knowledge of medical professionals on deafblindness, establish community access points for service provision, and initiate procurement of the necessary equipment to undertake assessments, while tapping into the existing government-supported health services<sup>67</sup>.

To overcome the challenges of centralised or limited services for identification, assessment, and

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<sup>65</sup> Weber, Ines, *Assessment of the Functional Hearing of Children with Deafblindness*, June 2020.

<sup>66</sup> Nordic Welfare Centre, *Revealing hidden potentials: Assessing cognition in individuals with congenital deafblindness*, <https://nordicwelfare.org/publikationer/hidden-potentials/>, August 2020.

<sup>67</sup> Sense International, *End of Project Early Intervention Services for Infants with Sensory Impairments in Kenya and Uganda*, July 2019, p. 64-70.

referral, pilot programmes may be initiated in other regions. Data analysis from pilot programmes can be used as evidence to highlight the impact of such services and influence local government development plans to ensure services are delivered locally in health centres and clinics<sup>68</sup>.

## Recommendations

### Governments

- Ensure that identification, assessment, and referral systems for persons with disabilities include services for persons with
  - deafblindness in all age groups and integrate them into existing government-supported health services
- Establish, for example through pilots, early identification and intervention services for infants and young children with
  - deafblindness and identification and assessment services for older persons to identify individuals who are at risk
- Work with deafblindness professionals and persons with deafblindness to establish
  - protocols and professional standards and guidelines for identification, assessment, and referral services

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<sup>68</sup> Sense International, *A Case for the Adoption of the Screening and EI Model for CWDB as a Priority in the Wakiso District Local Government Development Plan*, 2020, p. 19-22.

Incorporate identification, assessment, and referral services into local government

- › development plans to initiate these services across all regions, especially in decentralised systems

Increase training for health care

professionals on the risk factors for

deafblindness so that they are better

- › equipped to identify it and ensure that there are systems for assessing risk of deafblindness built into health checks

### **OPDs and NGOs**

Build alliances with persons with

deafblindness, health care professionals,

including specialists, and families to build

- › capacities on the requirements of persons with deafblindness for identification, assessment, and referral services

### **Donors and Research Institutes**

Ensure that funded programmes, including

pilot programmes, and research on the

- › identification, assessment, and referral services of persons with disabilities include persons with deafblindness

## **Rehabilitation and Communication**

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To obtain the maximum independence, full physical, mental, social, and vocational ability, and

full inclusion and participation in all aspects of society, persons with disabilities have a right to habilitation and rehabilitation<sup>69</sup>. Habilitation and rehabilitation are a set of interventions designed to optimise the functioning of individuals with impairments in interaction with their environment. Habilitation aims to assist individuals who acquire impairments congenitally or in early childhood to learn how to better function with these impairments. Rehabilitation aims to assist those who acquire an impairment so that they can relearn how to perform daily activities and regain maximal function<sup>70</sup>. For the purposes of brevity, the term rehabilitation used in this report refers to both rehabilitation and habilitation under Article 26 of the CRPD.

Deafblindness – whether pre-lingual or post-lingual – often results in social isolation and dependence on others because of the barriers to communicating, accessing information, learning, moving around, and remembering and because it is difficult for the senses to compensate for one

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<sup>69</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 26. “Habilitation refers to a process aimed at helping people gain certain new skills, abilities, and knowledge. Rehabilitation refers to regaining skills, abilities, or knowledge that may have been lost or compromised as a result of acquiring a disability, or due to a change in one’s disability or circumstances.” Sourced from <http://hrlibrary.umn.edu/edumat/hreduseries/TB6/pdfs/HRYes%20-%20Part%20%20-%20Chapter%209.pdf>, accessed May 2022. For the purposes of this report, rehabilitation services include habilitation services.

<sup>70</sup> United Nations Special Rapporteur of the Human Rights Council on the Rights of Persons with Disabilities, Report on habilitation and rehabilitation under article 26 of the Convention on the Rights of Persons with Disabilities, A/HRC/40/32, 21 January 2019, para. 4.

another. One of the biggest barriers is communication, which affects all aspects of social life, including education and learning, work, family life, social interactions, access to services, access to information, and relationships. Language acquisition is an essential element for those with pre-lingual deafblindness in the early intervention stages. Similarly, persons with deafblindness who have not benefited from early intervention may still require language acquisition support. Daily life skills, such as feeding, bathing, dressing, and using the toilet, may also be difficult for some persons with deafblindness, particularly pre-lingual persons with deafblindness because young children learn these daily tasks through watching and listening to others. The impact of isolation and dependence can also result in emotional and mental health difficulties for persons with deafblindness.

Without rehabilitation services, persons with deafblindness either do not learn how to fully communicate or develop a type of ‘home sign’, often called ‘adaptive signs’, that are agreed by family members or individuals who come in contact with them<sup>71</sup>. Without early intervention, children with pre-lingual deafblindness are unable to

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<sup>71</sup> Deasy, K. & Lyddy, F., “Potential for Communication in Individuals Who Are Congenitally Deafblind: It’s in the Eye of the Beholder”, *The Irish Psychologist*, Vol. 35 No. 8, March 2009, p. 205-210.

communicate with their parents and can experience significant developmental delays.

Rehabilitation services, often referred to as community-based rehabilitation (CBR), are services specially designed for persons with disabilities. They are cross-disciplinary and cross-sectoral and are delivered across a range of health and social service delivery models, including through hospitals and health clinics, schools, NGOs, home-based supports, businesses, etc. They are also considered part of Universal Health Coverage (UHC)<sup>72</sup>, and thus are essential for persons with disabilities. CBR services in many low- and middle-income countries are inadequately staffed and underfunded<sup>73</sup>.

The WFDB survey revealed that where CBR services for persons with disabilities exist, they often lack the deafblindness-specific elements, namely professionals from a range of disciplines who are trained on deafblindness and a focus on developing communication methods combined with social interaction to improve and support both communication and social engagement for persons with deafblindness. Moreover, rehabilitation for persons with deafblindness often

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<sup>72</sup> Bright, T., Wallace, S., and Kuper, K. "A systematic review of access to rehabilitation for people with disabilities in low- and middle-income countries", *International Journal of Environmental Research and Public Health*, Vol. 15 Issue 10, 2165, 2 October 2018.

<sup>73</sup> *Ibid.*

focuses on the impairment instead of the environment and the major areas of life, such as work, family, and social life<sup>74</sup>.

## Good Practices

CBR services should be flexible, person-centred (i.e., supporting the requirements of the individual), and available through the various stages of life adjustment. Empowerment, autonomy, independence, and social inclusion should be at the centre of rehabilitative approaches. The focus should be on the lived environment of the individual and not on the impairment (i.e., deafblindness) and should result in an individualised plan that is adjusted over time. Approaches will be different for each individual but may include:

- › Coordination with rehabilitation services
- › Surviving and coping with everyday life (i.e., dealing with urgent sport needs)
- › Recognising the need for life adjustment
- › Exploring new ways to cope with everyday life
- › Developing or adapting communication methods
- › Developing stabilising strategies and new life goals

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<sup>74</sup> National Centre on Combined Vision and Hearing Impairment / Deafblindness, *Eikholt Annual Report*, October 2021, p. 6.



- › Finding ways to maintain and manage new routines and stabilising strategies
- › Dealing with the emotional factors<sup>75</sup>.

**Giving people a chance to learn, to discover, to choose – this is very important. If people think I cannot do something, they will not tell me or show me, and I will never know about it... I learned to roller skate and climb trees and fly kites. I was never told this is not for you... This is my message to all parents and teachers... You cannot know what a person is capable of. Have high expectations, understand their support, and push them to discover themselves.**



– Zamir Dhale, Founder of the Society for the Empowerment of the Deafblind, India<sup>76</sup>

Persons with deafblindness are best served by a team of cross-disciplinary rehabilitative professionals. It is useful for professional groups to establish and document good clinical or technical practices for working with persons with deafblindness, how they will work with other

<sup>75</sup> Goransson, Lena. Deafblindness in a Life Perspective: Strategies and Methods for Support, [www.skane.se/dovblindteam](http://www.skane.se/dovblindteam), 2008, p. 49-50.

<sup>76</sup> Dhale, Zamir. *My life as a person with deafblindness*, [www.sedbIndia.org](http://www.sedbIndia.org), October 2021.

rehabilitative professional groups, and how they will work with other services, such as education, social work, social care, etc.<sup>77</sup>. Rehabilitative professionals should have proper education, training, and qualifications, as well as continuing professional development, and should understand the following:

- › Pre-lingual and post-lingual deafblindness
- › How the senses work together
- › Visual and auditory testing and treatment options
- › The impact of dual sensory loss on various areas of functioning across a wide range of functional areas
- › A range of communication methods for persons with deafblindness and how to select communication methods for individuals
- › Strategies to support orientation and mobility, including support with assistive devices and technology, where relevant
- › Strategies for supporting the autonomy of persons with deafblindness and how to support their choices

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<sup>77</sup> See, for example, Royal College of Speech and Language Therapists, Deafblindness – overview, <https://www.rcslt.org/speech-and-language-therapy/clinical-information/deafblindness/#section-4>, accessed May 2022.

- Strategies for supporting basic life skills, youth transition, and adjustments to daily
- › tasks at all life stages, as well as social inclusion and how to prevent social exclusion
  - › Assessment options and tools
  - › Intervention options
  - › Access to research and evidence on persons with deafblindness
  - › Understanding of health and care duties, including risk factors, such as abuse, exploitation, etc.
  - › Strategies for working with family members
  - › Team approach with other professionals
  - › Person-centred decisions and considerations<sup>78</sup>.

Importantly, it is good practice for rehabilitation professionals working with persons with deafblindness to directly communicate with persons with deafblindness, and not just observe or use interpreter-guides/Deafblind interpreters. This practice increases the rehabilitation professional's understanding of the unique communication methods required for each individual.

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<sup>78</sup> Royal College of Speech and Language Therapists, Deafblindness – overview, <https://www.rcslt.org/speech-and-language-therapy/clinical-information/deafblindness/#section-4>, accessed May 2022.

For children with deafblindness, CBR must combine health, education, and rehabilitation services and should provide support and learning in the following areas:

- › Sensory perception and stimulation
- › Communication
- › Mobility
- › Orientation
- › Life skills
- › Overall child development
- › Preparation for school
- › Family life, including working with families to involve them in their child's development<sup>79</sup>.

Sensory stimulation toys specifically designed or selected for children with deafblindness can help to stimulate residual hearing and vision and help them to develop gestures and communication<sup>80</sup>. Support for parents and family members should include information on deafblindness, emotional and practical life adjustments, communication methods, methods for ensuring peer support, and information on how children with deafblindness learn and develop since parents facilitate learning that is ordinarily observed by children without

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<sup>79</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 32.

<sup>80</sup> Sense International, Sensory support for Isabela, <https://senseinternational.org.uk/our-impact/isabela-s-story/>, accessed May 2022.

deafblindness. Services for parents need to be joined up, coordinated, and easy to navigate because without adequate, structured support, families face considerable burdens raising a child with deafblindness<sup>81</sup>.

For adolescents, CBR should focus on self-image, social interaction and development, personal relationships, transition into adult life, vocational training to enable employment opportunities, increased independence, autonomy, and decision-making. Young persons with deafblindness face considerable barriers to employment. Therefore, CBR should aim to prepare them for work and on how to seek employment, given the many barriers they face. Finally, young persons with deafblindness need to gain and/or increase their understanding of deafblindness in order to develop adaptive strategies for a changing environment<sup>82</sup>.

For adults, CBR should focus on how to access interpreter-guide/Deafblind interpreting services, charting their environments, maintaining employment (e.g., through vocational rehabilitation), setting or adjusting life goals, and personal relationships, while working with their existing network of family and friends. It is

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<sup>81</sup> Goransson, Lena. Deafblindness in a Life Perspective: Strategies and Methods for Support, <https://nkcdb.se/wp-content/uploads/2018/11/Deafblindness-in-a-Life-Perspective.pdf>, 2008, p. 63-83.

<sup>82</sup> *Ibid.*, p. 85-97.

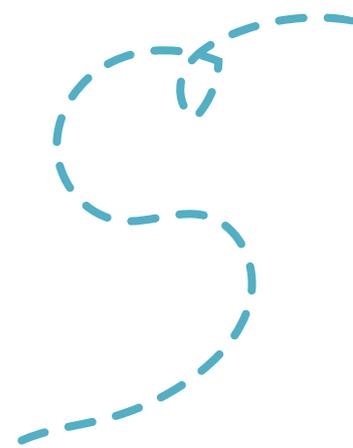
important to combine social interaction and communication as a comprehensive topic to strengthen the network around persons with deafblindness, rather than working on communication in isolation<sup>83</sup>.

For older persons, it is important to distinguish those who acquired deafblindness through ageing versus those who have deafblindness and have aged, as their needs will differ. CBR should provide information on how to adjust to life with deafblindness, how to embed deafblindness considerations and awareness into health care (e.g., doctors, carers, nursing homes, etc.), information strategies for strengthening the individual's network of friends and family, access to interpreter-guide/Deafblind interpreting services and assistive devices, training on how to work with interpreter-guides/Deafblind interpreters and assistive devices, and information on daily life adjustments<sup>84</sup>. Social exclusion increases with age, and it increases with deafblindness, compounding the effects of ageing and deafblindness. Therefore, it is essential that CBR services support communication methods in combination with social interaction to prevent isolation.

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83 *Ibid.*, p. 109-127.

84 *Ibid.*, p. 143-161.



## CASE STUDY

### **Communication is a Human Right: Lessons from Sonnia Margarita in Ecuador**

Sonia Margarita is a 68-year-old woman with deafblindness from Ecuador. When she was twelve, she had an accident while playing with other children. She hit her head which resulted in retinal detachment and was unable to access immediate medical care in her region. She was taken to Colombia in an attempt to receive higher quality medical care. After several treatments and procedures, she was prescribed medication that eventually led to hearing loss. By the age of fourteen, she was completely deaf and blind.

It was very emotional to become deafblind as a teenager, during this highly social period of life when the world expands. These traumatic events left her feeling emotionally empty and cut off. However, her family provided her with love and support and made her realise that she was not alone. They played a key role in supporting her social inclusion, for example, to attend parties and dances.

Once she accepted her condition, she was open to the possibility of learning new ways of communicating. She uses combined methods of communication, which is good practice for

persons with deafblindness. She learned how to read Braille, and since there were no rehabilitative services for learning deafblind communication in her area, she developed her own form of tactile communication. Initially, her family served as her first interpreter-guides/Deafblind interpreters, and they also hired tutors to home-school her for much of her education. However, Sonnia Margarita also taught others how to communicate using her form of tactile sign, which made her less dependent on her family. She also uses a 'tele tact' or 'teletouch' machine that enables a person to type words into a keyboard which is then displayed in Braille on a grid for Sonnia Margarita to read. This has been helpful when communicating with people who do not know tactile signs. Since she acquired deafblindness as a teenager, she speaks Spanish, her native language.

Sonia Margarita has four university degrees and has had a successful career as a teacher, teaching a wide range of subjects and age groups. She attributes this to her ability to explain very technical concepts clearly, demonstrating that communication is not just a capability but one of her greatest strengths.

She uses innovative ways to communicate and live independently. For example, the doorbell activates fans throughout the house, which alerts

her that someone is at the door. She puts her hand through security bars, and if it is someone that she knows, they can use tactile signs to communicate with her. She also uses a wireless landline phone to call family or her interpreter-guide/Deafblind interpreter, using the touch tone buttons, which vibrate as a means of sending short messages in case of an emergency.

Sonia Margarita says that persons with deafblindness need the following to ensure communication:

- A positive attitude to draw support from people
- A strong, consistent support system (e.g., family, friends, neighbours, teachers, colleagues, and professionals supporting persons with deafblindness)
- A flexible, tailored approach to teaching new methods of communication, ensuring that it works for the individual and that it maximises any residual vision or hearing
- Stimulation of all the senses to make use of them, especially at a young age
- Exploration of orientation, guidance, distance, and mobility to maximise independence
- To have multiple methods of communication, like Sonia Margarita, so that there is more than one way to communicate.

Communication is a right that is often taken for granted. For persons with deafblindness, it is the key to social inclusion, livelihoods, and living independently, as the example of Sonnia Margarita clearly presents. Some persons with deafblindness have managed to learn communication methods without government support or CBR programmes, but the conditions of their individual circumstances, for example positive experiences of family support and financial means, have often been essential factors for success. Government investment into CBR programmes to support early interventions to develop communication methods and support life adjustments will ensure persons with deafblindness are not left behind.



## Recommendations

### Governments

Legally recognise deafblindness and ensure that deafblindness is included in CBR

- › services that are person-centred, cross-disciplinary, cross-sectoral, and part of Universal Health Coverage

Build the capacities of CBR professionals on

- › deafblindness and deafblindness-specific methods and approaches

Ensure CBR services are person-centred, adapt according to the life cycle of the

- › individual, and are tailored to support persons with both pre-lingual and persons with post-lingual deafblindness

- › Facilitate the participation of persons with deafblindness in developing CBR services

### OPDs and NGOs

Build alliances with persons with deafblindness, health care professionals,

- › and families to build capacities on the requirements of persons with deafblindness for CBR services

## Donors and Research Institutes

- Ensure that funded programmes, including pilot programmes, on CBR services of persons with deafblindness
- Conduct research on the programmatic-effectiveness and cost-effectiveness of CBR service for persons with deafblindness

## Assistive Devices and Technologies and Accessible Technologies

Persons with disabilities, including persons with deafblindness, have a right to access affordable assistive devices and technologies, which are assistive, adaptive, or rehabilitative tools designed to specifically help persons with disabilities with daily tasks. They also have a right to affordable accessible technologies, which are technologies and digital tools aimed at a wider audience, but can be useful for persons with disabilities, including persons with deafblindness<sup>85</sup>. Persons with disabilities who have access to assistive devices and technologies, or accessible technologies are better able to maintain or improve their functioning and independence, thus

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<sup>85</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Articles 4.g, 4.h, 9.2.h, 19.b, 20, 26, and 32.d.

improving their well-being<sup>86</sup>. Although assistive devices and technologies can lead to greater independence, they should not be seen as a replacement for live assistance, such as interpreter-guide/Deafblind interpreting services.

Very few countries have a national assistive technology policy or programme, and even in high-income countries, assistive products are expensive and often rationed or not included in or difficult to obtain through health and welfare schemes, leading to high out-of-pocket payments. In many low-income countries, persons with disabilities rely on donations and/or lower-quality products that may not be suitable for the individual<sup>87</sup>. In addition to access to these devices and technologies, regular maintenance, parts (such as batteries), and ongoing adjustments to properly fit the device or to make it work for the person as they adjust to it and as their condition changes over time are barriers, especially in middle and low-income countries.

Furthermore, persons with deafblindness often need to purchase assistive technologies to add to existing technology available to everyone. For example, computers are usually not built with

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<sup>86</sup> World Health Organisation, Assistive technology, <https://www.who.int/news-room/fact-sheets/detail/assistive-technology>, 18 May 2018.

<sup>87</sup> *Ibid.*

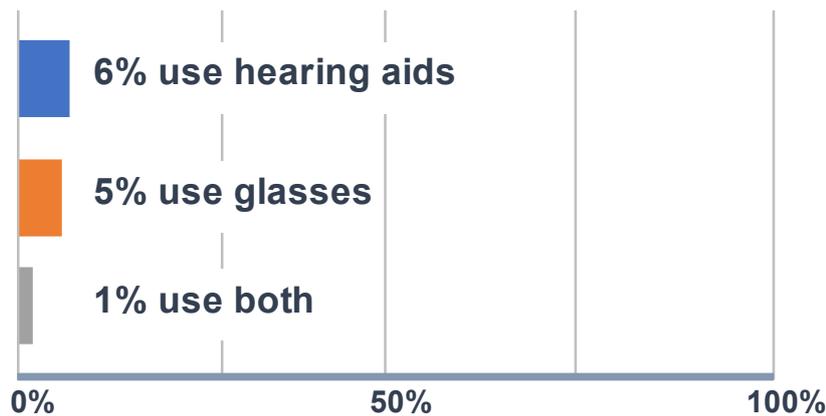
screen reading software. People who require screening reading technology often have to purchase screen reading software separately, uninstall the operating system, and install a new operating system that is compatible with the screen reading software.

Persons with deafblindness are diverse, and therefore, the range of assistive devices and technologies and accessible technologies that they require vary considerably. Most commonly, these devices and technologies aid in communication, information, mobility, and/or memory. Some examples include wheelchairs, hearing aids, spectacles, red and white canes, screen reading software, smartphone technologies, Braille displays and notetakers, sensory toys for children, etc. There is also the potential to expand the range of devices and technologies for persons with deafblindness with new and emerging technologies that are available but are not currently being utilised for persons with deafblindness.

WFDB's quantitative data analysis revealed that access to assistive devices is very low for children with deafblindness. Across the 36 countries in the MICS analysis, 6% of children used hearing aids, 5% used glasses, and only 1% used both glasses and hearing aids. Access to assistive devices was

highest in upper middle-income countries. For the complete data table, see Table 2 in Annex 1.

## ACCESS TO ASSISTIVE DEVICES FOR CHILDREN WITH DEAFBLINDNESS

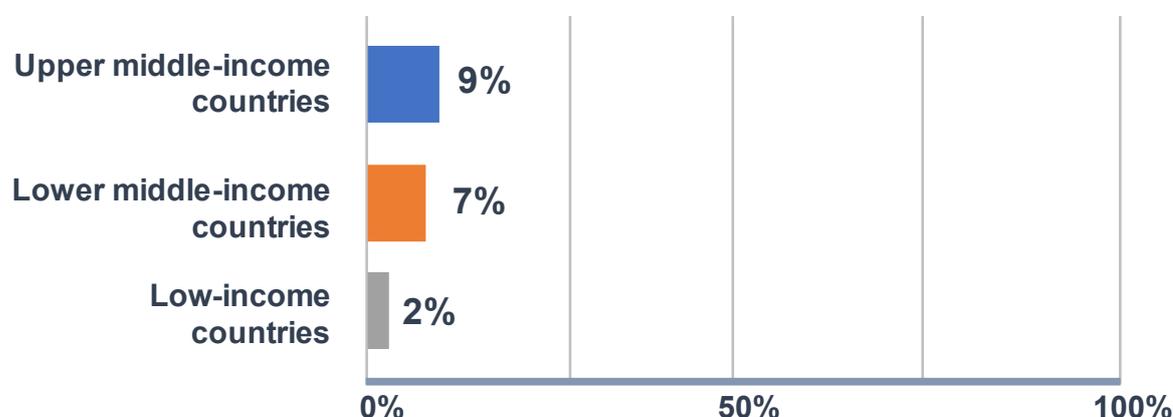


In WFDB's survey, respondents commonly stated that assistive devices and technologies are unaffordable or unavailable with very few choices and only limited training on how to use them. Many social protection schemes do not cover the costs of assistive devices and technologies and do not recognise them as a necessity or as an extra cost due to disability<sup>88</sup>.

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<sup>88</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 19.

## ACCESS TO GLASSES FOR CHILDREN WITH DEAFBLINDNESS BY LEVEL OF COUNTRY INCOME



### Good Practices

“Addressing the unmet need of assistive products is crucial to achieve the Sustainable Development Goals, to provide Universal Health Coverage (UHC), and to implement the CRPD”<sup>89</sup>. WHO’s Global Cooperation on Assistive Technology (GATE) initiative, which aims to assist governments to access assistive technology as part of UHC, sets out good practices across five interlinked areas, which is adapted below to apply to persons with deafblindness:

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<sup>89</sup> World Health Organisation, Assistive technology, <https://www.who.int/news-room/fact-sheets/detail/assistive-technology>, 18 May 2018.

## PEOPLE



Involve persons with deafblindness in decision-making about assistive devices and technologies and a person- / user-centred approach that addresses the diverse needs of persons with deafblindness

## POLICY



Develop national policies and programmes with minimum standards to ensure that persons with deafblindness can access assistive products, including a sustainable financing mechanism and universal access

## PRODUCTS



Identify the priority products for persons with deafblindness and enhance production, procurement, and service provision and support the innovation of new and emerging technologies for persons with deafblindness

## PROVISION



Develop a model for free and affordable service provision that integrates assistive devices and technologies into health and / or rehabilitative services or specialist referral centres, making it easier to access services from a single point

## PERSONNEL



Ensure training for professionals on how to use assistive devices and technologies and on how to advise persons with deafblindness on their use, including on maintenance and repairs<sup>90</sup>.

*Francisco (Frank), a man with deafblindness uses a Braille during a meeting in Nairobi, Kenya, which shows the importance of assistive devices to facilitate participation.*

*At the same time, he is assisted by two interpreter-guides/Deafblind interpreters in Spanish tactile sign language.*

**Photo taken by WFDB**



## CASE STUDY

### **The Role of Assistive Devices and Accessible Technology: Lessons from Alegría in the Canary Islands**

Alegría (pseudonym) is a 72-year-old woman with deafblindness from the Canary Islands, Spain. She is almost completely blind and can hear with a hearing aid if spoken to loudly and as long as there is no background noise.

When Alegría goes out on her own, she uses a pedestrian device that is installed at the pedestrian crossing which, when activated, makes a sound audible to her to indicate when it is safe for her to cross the road. This sound activation tool is essential to Alegría's safety and independence as well as her ability to move around freely and independently. Unfortunately, not all traffic lights in her area have this system activated, and there is more that can be done to make the streets more accessible to people like Alegría. She often relies on an interpreter-guide/Deafblind interpreter or family member, as they provide useful information that goes beyond street crossings and if she is taking a route not supported by the pedestrian device.

Alegría received training and support from local OPDs on how to live independently, including

advice on navigating with her red and white cane and training her memory to learn new routes, which builds self-confidence. She also received free, one-to-one training on using accessible technology. For example, she uses a screen reader and a voice-activated command on her mobile phone. She also uses voice-activated virtual assistant technology to check the weather, play a song, or set reminders.

She has been able to participate in online social gatherings that use accessible video calling software, which helps her to connect with others and to stimulate her memory and cognition. One of the activities she enjoys the most is joining her weekly online reading club. Prior to each meeting, Alegría reads the assigned book using an audiobook device. She then shares her thoughts with the moderator and other members.

These are just some of the examples of accessibility features, assistive devices, accessible technologies, and programmes to facilitate independence of persons with deafblindness.

## Recommendations

### Governments

In line with WHO's GATE initiative, integrate affordable, quality assistive devices and technologies and accessible technologies for persons with deafblindness into plans, programmes, and services, for example, as part of Universal Health Coverage, and make these services available across the country and easy to navigate

- Put pressure on technology companies to adopt universal design principles and incorporate assistive programmes into digital devices (e.g., magnification, screen readers, speech-to-text, etc.)

- Provide training to persons with deafblindness on how to use assistive devices or technologies and accessible technologies, in collaboration with their representative organisations to ensure that trainings meet the requirements of persons with deafblindness

- Ensure assistive devices and technologies are adapted according to the requirements of the individual

- Facilitate the participation of persons with deafblindness in developing policies and

programmes on assistive devices and technologies

Increase international cooperation and technical assistance between countries to

- › share information and good practices on assistive devices and technologies and accessibility technologies.

## Interpreter-guides/Deafblind interpreters and Other Forms of Live Assistance

Persons with deafblindness have a right to access a range of in-home, residential, and other communication supports, including live assistance to support independence, autonomy, and inclusion in the community and to prevent isolation or segregation<sup>91</sup>. Most often, this requires access to interpreter-guides/Deafblind interpreters. However, some persons with deafblindness may use personal assistants for more basic mobility support, and children with deafblindness may require teaching assistants in schools.

**Interpreter-guides/Deafblind interpreters are uniquely trained and qualified professionals that are responsive to the compounded support requirements of persons with deafblindness, including communication,**

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<sup>91</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Articles 4.h, 9.2.e, 9.2.f, 19.b, 20, 23.2, 28.2.a, and 29.a.iii.

**interpretation, access to information, description, orientation, guiding, and mobility support adapted to the person**<sup>92</sup>. Crucially, they are trained on the appropriate communication methods that are used by persons with deafblindness. Interpreter-guides/Deafblind interpreters are an essential support that enable persons with deafblindness to work, go to school or advance their education, attend medical appointments, access other services, exercise, socialise with family and friends, run errands, shop, respond to correspondence, and enjoy cultural events and recreation.

According to the WFDB survey, many countries, especially low- and middle-income countries, do not have a system for interpreter-guides/Deafblind interpreters, forcing persons with deafblindness to rely on family members. While families form a significant role in the support networks of persons with deafblindness, it is unsustainable to rely exclusively on friends and families to provide this service. This is because families are not always available and rarely trained to provide the service, which means that persons with deafblindness are dependent on the availability of family members

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<sup>92</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 5-6. Interpreters for persons with deafblindness may be referred to in many ways, including interpreter-guides, deafblind interpreters, communicator-guides, intervenors, and more. In this report, interpreter-guides/Deafblind interpreters refer to the form of live assistance unique to persons with deafblindness.

who have sufficient knowledge of deafblind communication. Family members may also interfere with the task, affecting the independence or autonomy of the person with deafblindness. For example, relying on a family member to interpret during a medical visit may compromise privacy, or the family member may try to intervene as a proxy decision-maker on health decisions.

Persons with deafblindness use a variety of methods of communication, depending on their residual hearing or vision. There is not one way for all persons with deafblindness to communicate. Some persons with deafblindness may effectively be able to use the live assistance supports available to the deaf (e.g., captioning services or sign language interpreters) or the blind (e.g., personal assistance). However, it is a common misperception that services for the deaf or services for the blind will be sufficient for persons with deafblindness. More commonly, persons with deafblindness have no other option than to use services for the deaf or blind because there are no services available for persons with deafblindness. Services for the blind or deaf are usually not fit for purpose for persons with deafblindness and may place a burden on these services for other groups<sup>93</sup>.

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<sup>93</sup> *Ibid.*, p. 12.

Where interpreter-guide/Deafblind interpreting services are provided, they are often expensive, restrictive, inconsistent, and have limited availability across the country, according to respondents in WFDB's survey. For example, one respondent commented that their interpreter-guide/Deafblind interpreting service only allows for two hours to go to the bank, including travel time. These types of restrictions limit independence and make daily living very rigid. Similarly, requiring considerably advanced booking, such as 72 hours' notice, is unrealistic in modern society and forces persons with deafblindness to not utilise services that are available but place too many restrictions. Where these services are not free, the cost, according to another respondent, is akin to paying the salary of another person, which is an impossible barrier for many persons with deafblindness.

WFDB members have reported that cuts to free or low-cost services are an increasing threat to existing services and often lead to a reduction in the number of hours interpreter-guides/Deafblind interpreters are available or a reduction in the number of interpreter-guides/Deafblind interpreters available within a service, stretching services. Persons with deafblindness are unable to absorb these cuts since interpreter-guide/Deafblind interpreting services are essential for work, school, and accessing other services. These cuts force

persons with deafblindness to work less and not access essential services, resulting in increased dependency.

## Good Practices

The first step to ensuring quality interpreter-guide/Deafblind interpreting services is to recognise deafblindness and interpreter-guide/Deafblind interpreting services within a legislative and policy framework<sup>94</sup>. This also includes recognition of sign languages where they are still not recognised, as sign language is one element of deafblind communication and ensures standardisation. The legislative and policy framework should also set out or refer to minimum standards and budgetary measures for the service, including the number of hours that are available for free, which should be based on consultations with OPDs of persons with deafblindness. This should be based on consultations with persons with deafblindness and may depend on the national and local environment as well as individual requirements. The legal and policy framework should also specify how local provision of services will be carried out (e.g., through legislation and budgetary measures)<sup>95</sup>.

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<sup>94</sup> Zevallos-Arevalo, Ricardo. *Peru Promotes Training of Interpreter Guides for Persons with Deafblindness*, Article prepared for DBI Ibero-Latin American Network, 3 August 2021.

<sup>95</sup> Jaiswal, Atul. *Deafblind Ontario Services, Stakeholder Consultation Project*, August 2019, p. 6.

Interpreter-guides/Deafblind interpreters must also be seen as a reasonable accommodation for persons with deafblindness to work, attend education, access health, and other services, as well as for social interaction<sup>96</sup>.

**The provision of free interpreter-guides/Deafblind interpreters is an essential service for persons with deafblindness, and therefore, the provision of interpreter-guide/Deafblind interpreting services is an immediate obligation of States to ensure the right to live independently and be included in the community<sup>97</sup>.** However, this right is also subject to progressive realisation, and States should strive to ensure a full interpreter-guide/Deafblind interpreting service for all persons with deafblindness over time<sup>98</sup>. Moreover, since it is an essential service, budgetary cuts should be seen as retrogressive<sup>99</sup>. It can take several years to set up interpreter-guide/Deafblind interpreting services where there currently are no services,

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<sup>96</sup> Australian Deafblind Council, *Response to National Disability Insurance Scheme Eligibility and Reasonable and Necessary Support*, 25 September 2012.

<sup>97</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 19.

<sup>98</sup> International Covenant on Economic, Social, and Cultural Rights, resolution 2200A (XXI), 16 December 1966, Article 2.1.

<sup>99</sup> Committee on Economic, Social, and Cultural Rights, General Comment No. 3: The nature of States parties' obligations (art. 2, para. 1 of the Covenant), 14 December 1990, para. 9.

and informal mechanisms, such as voluntary services or interpreter-guides/Deafblind interpreters-in-training, may serve as an interim measure while services are being developed.

Guidelines and criteria to regulate the delivery of services should be developed in consultation with persons with deafblindness and their representative organisations and should include information on training, certification, and ethical codes of conduct<sup>100</sup>. The purpose of interpreter-guide/Deafblind interpreting services should be to support autonomy, independent living, communication, mobility, and access to information, reflecting the capabilities and diverse needs of individuals, across different aspects of life<sup>101</sup>. Interpreter-guide/Deafblind interpreting services should prioritise essential functions, such as work, education, health care, emergency services, etc., and recreation and social engagement should be considered essential to persons with deafblindness to ward against social isolation<sup>102</sup>. It is, therefore, essential that persons with deafblindness have a say about what is

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<sup>100</sup> United Nations Special Rapporteur of the Human Rights Council on the Rights of Persons with Disabilities, report on disability inclusive policies, A/71/314, 9 August 2016, para. 49.

<sup>101</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 13; Dhale, Zamir. *My life as a person with deafblindness*, [www.sedbndia.org](http://www.sedbndia.org), October 2021.

<sup>102</sup> Gerencer, S., & Lusina, U. *Performance of Personal Assistance in Persons with Deafblindness*, July 2021.

essential when accessing services because access to interpreter-guides/Deafblind interpreters for many is the difference between communicating or not communicating, which is fundamental to all human beings.

The elements for interpreter-guide/Deafblind interpreting services should include:

- **Guidelines covering technical and behavioural competencies** – Technical competencies include knowledge of deafblindness, deafblind communication skills, guiding skills, training qualifications and certification, etc. Behavioural competencies ensure that interpreter-guides/Deafblind interpreters are flexible, emotionally attuned, work as a team, etc.
- **Training and certification programme** – Once the competencies are agreed upon, the training and certification programme can be developed to meet them. An accreditation system of non-formal interpreter-guides/Deafblind interpreters, such as volunteers or interpreter-guides/Deafblind interpreters-in-training, may also be considered.
- **Registry and booking system** – This should include a role profile for interpreter-guides/Deafblind interpreters and a system for recruiting and registering interpreter-

guides/Deafblind interpreters as well as methods for requesting their services. Payment to interpreter-guides/Deafblind interpreters should be based on fair compensation and should form part of the role profile. Persons with deafblindness should be able to choose from the available interpreter-guides/Deafblind interpreters, and they must be able to book more than one at a time, as some persons with deafblindness require more than one interpreter-guide/Deafblind interpreter, depending on the situation (e.g., to enable breaks for interpreter-guides/Deafblind interpreters during a long event). Coordination between interpreter-guide/Deafblind interpreting services and services for the deaf and blind may help to ensure individuals are able to utilise the most suitable form of live assistance based on individual need

- **Quality control measures** – This includes a complaints mechanism, a feedback mechanism, continuous professional learning for interpreter-guides/Deafblind interpreters, safeguarding mechanisms, monitoring measures to ensure services maintain standards, and data collection and review systems to ensure services meet demand

- **Professional body of interpreter-guides/Deafblind interpreters** – Interpreter-guides/Deafblind interpreters need to share and exchange learning, research latest practices in deafblind communication and guiding, and seek advice, and a professional body can facilitate this and advance the profession<sup>103</sup>.

Interpreter-guide/Deafblind interpreting services, assistive devices and technologies, and accessible technologies make up the portfolio of disability support services to overcome and eliminate social exclusion, and persons with deafblindness may use any combination of these services, depending on individual needs.

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<sup>103</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 12; Intervenor Services, *Coaching Resources for Behavioural Competencies: Intervenor Services Human Resource Strategy*, 2017-2018; and *Technical Competencies Training Resource Guide: Intervenor Services Human Resource Strategy*, 1 February 2019; Zevallos-Arevalo, Ricardo. *Peru Promotes Training of Interpreter Guides for Persons with Deafblindness*, Article prepared for DBI Ibero-Latin American Network, 3 August 2021



*A man and a woman with deafblindness (on the left side) communicate with each other through the assistance of their interpreter-guides/Deafblind interpreters (on the right side), using tactile communication.*

**Picture taken by WFDB during a meeting in Geneva, Switzerland**

## CASE STUDY

### **Autonomy and Independence Through Flexible and Free Interpreter-guide/Deafblind interpreting services: Lessons from Randi Torgunn Myren in Norway**

Interpreter-guide/Deafblind interpreting services began in Norway in 1980, and when Randi Torgunn Myren acquired deafblindness in 1985, she took the opportunity to apply for their services. Access to these services meant that she didn't need to rely on family members for all of her communication needs.

“The first time I used one was for a summer meeting for the Norwegian Deafblind Association (FNDB). I requested a specific interpreter-guide/Deafblind interpreter, and we hit it off and had good chemistry. She put me in contact with other persons with deafblindness so that I could make new friends and so that I learned about deafblindness.”

Randi studied at university and worked in a governmental department which supported the deaf and deafblind with the support of interpreter-guide/Deafblind interpreting services.

“(The service) is free in Norway. There used to be a limited number of hours that you could use the service, but now there is no restriction on the

number of hours to use the service. The only restriction is the availability of interpreters.”

Randi books interpreter-guides/Deafblind interpreters and then meets them close to her home. She is retired now and uses them primarily to support her in organising, facilitating, and participating in a peer group of persons with deafblindness that meet in a local café.

“We talk, read the newspapers, and sometimes we have a quiz. We may also go out to dinner at a restaurant together.”

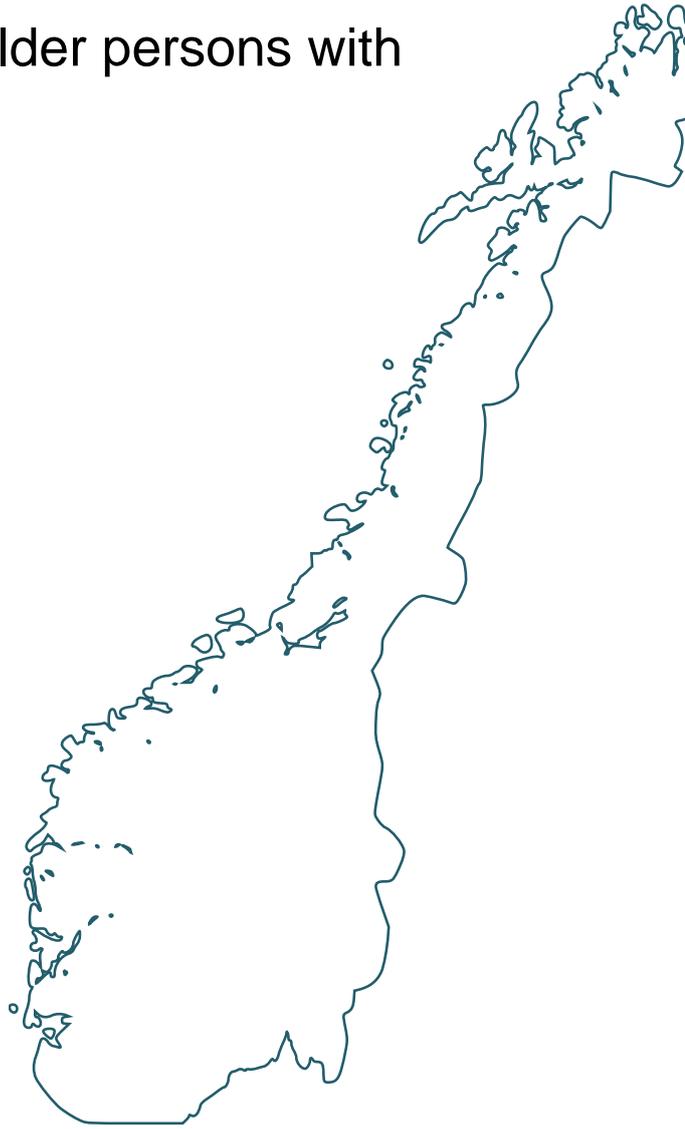
Randi also uses interpreter-guides/Deafblind interpreters to hike in the mountains, go on holiday, and to attend international meetings for FNDB. She has to pay the travel expenses, such as the hotel, for the interpreter-guide/Deafblind interpreter when going abroad, but the government covers their professional fees.

The service in Norway offers sign language interpretation services for the deaf and interpreter-guide/Deafblind interpreting services for the deafblind housed within a combined service. Interpreter-guides/Deafblind interpreters can be booked via phone or email, and urgent matters, such as hospital or doctor visits are made a priority. There are usually enough interpreter-guides/Deafblind interpreters available, and you can often choose the

interpreter-guide/Deafblind interpreter that you want to work with if they are not already booked. The service directly employs some interpreter-guides/Deafblind interpreters that have fixed working hours (e.g., 9:00 am – 5:00 pm), but there are also freelancing interpreter-guides/Deafblind interpreters, who are just as qualified but often work more flexible hours. For example, when Randi travels abroad, she uses freelancing interpreter-guides/Deafblind interpreters because their flexible hours enable them to travel, whereas interpreter-guides/Deafblind interpreters directly employed by the service cannot travel because of their fixed hours. Freelancing professionals help to fill the demand gaps and bring greater flexibility to the service.

Flexible and free interpreter-guide/Deafblind interpreting services have ensured that Randi has been able to remain fully active in employment, obtain further educational qualifications, engage as an active member of her national organisation of persons with deafblindness (FNDB), socialise, travel abroad, and enjoy her favourite recreational activities. Randi has been supported to fully participate in society and has enjoyed independence and autonomy without needing to rely heavily on family members. Moreover, she has avoided the

social isolation that many older persons with deafblindness experience.



## Recommendations

### Governments

- Consult with OPDs of persons with deafblindness and develop partnerships with
  - OPDs, NGOs, training institutes, and private sector to explore interpreter-guide/Deafblind interpreting models
- Develop a legislative and policy framework for interpreter-guide/Deafblind interpreting services for persons with deafblindness as an essential service
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- Establish a sustainable funding mechanism to progressively make interpreter-guide/Deafblind interpreting services free to all persons with deafblindness
  -
- Establish guidelines on interpreter-guide/Deafblind interpreting competencies, a training and certification programme, a registry and booking system, and quality control measures in consultation with OPDs of persons with deafblindness
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- Link interpreter-guide/Deafblind interpreting services to relevant ministries and departments (e.g., health, education, employment, etc.), to ensure that civil servants and frontline staff recognise interpreter-guides/Deafblind interpreters so
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that persons with deafblindness can access them in mainstream services

## OPDs and NGOs

OPDs of persons who are deaf and hard of hearing should collaborate with OPDs of persons with deafblindness to advocate for shared goals in achieving sign language

- interpretation and interpreter-guide/Deafblind interpreting services and to optimise synergies and agree on cost-savings strategies

Advocate for interpreter-guide/Deafblind interpreting services for persons with deafblindness as an essential disability

- support service and facilitate the participation of persons with deafblindness in all processes during the design phase

Support the development of a professional body of interpreter-guides/Deafblind

- interpreters in line with other disability support service models

Develop mechanisms and networks, like AT2030, to research, advocate, and fund

- live assistance for all persons with disabilities, including interpreter-

guides/Deafblind interpreters for persons with deafblindness

## Donors and Research Institutes

- Increase international technical cooperation on interpreter-guide/Deafblind interpreting services and increase funding to establish disability support services for persons with deafblindness
- Support the development of networks or mechanisms to improve the provision of live assistance to all persons with disabilities, including interpreter-guides/Deafblind interpreters for persons with deafblindness
- Generate research on the cost, cost effectiveness, and return on investment of interpreter-guide/Deafblind interpreting services to tackle financial barriers.

## Participation of Persons with Deafblindness

Participation of persons with disabilities is a cross-cutting precondition to ensure the enjoyment of all their rights as well as being a standalone right<sup>104</sup> and is covered in more detail in the chapter on Participation in Public and Political Life. The active

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<sup>104</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, preamble and Articles 1, 3, 4, 7, 9, 19, 21, 24, 26, 29, and 32-35.

and informed participation of persons with deafblindness upholds the disability movement's motto 'nothing about us without us' and replaces the common practice of decisions being made on behalf of persons with deafblindness, ensuring good governance and a human rights-based approach<sup>105</sup>.

The lack of participation of persons with deafblindness stems from dual barriers:

Communication supports are needed to demonstrate the capabilities of persons with deafblindness

Misperceptions about capabilities of persons with deafblindness often lead to a lack of communication supports

- Lack of sufficient accessibility measures and reasonable accommodations, such as communication supports, including
- 1 access to affordable interpreter-guide/Deafblind interpreting services, assistive devices and technologies, information in accessible formats, etc.

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<sup>105</sup> Committee on the Rights of Persons with Disabilities, General Comment No. 7 on the participation of persons with disabilities through their representative organisations, CRPD/C/GC/7, 9 November 2018, para. 2.

- 2 The misperception that persons with deafblindness cannot participate or that it is too difficult to include them.

These two barriers compound one another because the misperceptions about the capabilities of persons with deafblindness often lead to a lack of reasonable accommodation and accessibility measures to improve communication supports. Yet, the communication supports are needed to demonstrate the capabilities of persons with deafblindness<sup>106</sup>. In low-income countries, persons with deafblindness may also experience economic barriers to participation because they are facing poverty and are preoccupied with coming up with ways to generate income.

Moreover, OPDs of persons with deafblindness often do not have the capacity to monitor opportunities to contribute to legislative and policy processes because they do not have access to affordable communication support, often due to a lack of affordable interpreter-guide/Deafblind interpreting services. For example, the literature review revealed that even where persons with deafblindness are mentioned in global reports (e.g., reports from the UN Special Rapporteur on

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<sup>106</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 9.

the rights of persons with disabilities or OPD shadow reports to the CRPD Committee), they lack the specificity in comparison with other groups of persons with disabilities, including other underrepresented groups of persons with disabilities, or may be excluded entirely. This leads to underrepresentation of persons with deafblindness in essential standard-setting tools, such as General Comments and Concluding Observations of the CRPD Committee.

Where persons with deafblindness are explicitly mentioned in reports or decisions, they are often not consulted. For example, the National Human Rights Commission in Mexico recently demanded the invalidity of various provisions of the General Education Law, including provisions on inclusive education that explicitly referred to persons with deafblindness, because persons with deafblindness were not consulted on the legislation. The Supreme Court of Justice of the Nation determined that by directly affecting the rights of persons with disabilities, there was an obligation to consult these groups prior to the issuance of the law, in accordance with the General Constitution<sup>107</sup>. This example demonstrates that by overlooking the participation

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<sup>107</sup> Supreme Court of the Justice of the Nation, The SCJN Invalidates Several Articles of the General Education Law Due to Lack of Prior Consultation, press release on No. 189/2021, Mexico City, 29 June 2021, <https://www.internet2.scjn.gob.mx/red2/comunicados/noticia.asp?id=6497>, accessed May 2022.

of persons with deafblindness, regardless of the reason, these processes will likely need to be revisited to understand the express requirements, as set out directly by persons with deafblindness. It is, therefore, more cost-effective and time-efficient to include persons with deafblindness from the outset, even if it requires additional time and/or money.

## Good Practices

Participation should be active, free, and meaningful, ensuring a systematic and timely approach. There must be a guarantee of reasonable accommodations to consultative processes, consultative processes must be free from stigma, and everyone's legal capacity should be recognised<sup>108</sup>. To ensure equitable access to information and equitable opportunities for the participation of persons with deafblindness, proactive steps must be taken. Through their representative organisations, persons with deafblindness should be:

- **Actively invited to join decision-making processes at the outset**, since they may not have the capacity to monitor such emerging opportunities

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<sup>108</sup> UNPRPD, *The preconditions necessary to ensure disability inclusion across policies, services, and other interventions*, <https://unprpd.org/sites/default/files/library/2020-08/Annex%20%20UNPRPD%204th%20Funding%20Call%20Preconditions%20to%20disability%20inclusion%20ACC.pdf>, accessed May 2022, p. 5.

- Asked about their information and communication requirements** with plenty of notice prior to the consultation process (e.g.,

  - access to interpreter-guides/Deafblind interpreters, sharing information in advance in accessible formats, an accessible venue, captioning, etc.)

**Given opportunities to provide feedback on adjustments** and whether these adjustments

  - are working through a disability focal point or directly with the organisers

**Allowed time for interpretation or other adjustments** to ensure information is

  - exchanged and understood to enable participation and sensory breaks in long sessions<sup>109</sup>.

Interpreter-guide/Deafblind interpreting services should be paid for by the organisers and not by the person with deafblindness since this is a necessary adjustment to ensure their participation<sup>110</sup>, and costs should include the professional fees for interpreter-guides/Deafblind interpreters as well as reasonable travel expenses, if applicable. In addition, organisers of participatory

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<sup>109</sup> Deafblind Scotland, *An Inclusive Communication Guide for Engaging with Deafblind People*, <https://dbscotland.org.uk/wp-content/uploads/2021/03/Inclusive-Communication-Guide-for-Engaging-with-Deafblind-People-accessible-final.pdf>, accessed May 2022; and Jaiswal, Atul. Deafblind Ontario Services, *Stakeholder Consultation Project*, August 2019, p. 28.

<sup>110</sup> Jaiswal, Atul. Deafblind Ontario Services, *Stakeholder Consultation Project*, August 2019, p. 28.

processes could benefit from increased awareness of deafblindness (i.e., what it is and how people are affected by it) as well as participation tools, such as deafblind communication guides or manuals, which are often developed by OPDs of persons with deafblindness<sup>111</sup>.

Proxies, or substitute representatives without deafblindness, should not be used in place of persons with deafblindness without their express consent and should only be considered after exploring all avenues for direct participation. This is because others who speak on behalf of persons with deafblindness often miss essential elements or details and do not have the lived experience of deafblindness. Where proxies are used, persons with deafblindness should be supported to review the final versions or decisions to ensure that it truly reflects their views. Proxies should also only be viewed as a one-off arrangement unless OPDs of persons with deafblindness instruct otherwise.

An essential way to ensure the participation of persons with deafblindness in low-income countries is to urgently address the extreme poverty of persons with deafblindness so that they can focus their attention on the participatory process.

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111 See for example, Deafblind Scotland, An Inclusive Communication Guide for Engaging with Deafblind People, [https://D\\_bscotland.org.uk/wp-content/uploads/2021/03/Inclusive-Communication-Guide-for-Engaging-with-Deafblind-People-accessible-final.pdf](https://D_bscotland.org.uk/wp-content/uploads/2021/03/Inclusive-Communication-Guide-for-Engaging-with-Deafblind-People-accessible-final.pdf).

## CASE STUDY

### **The Participation of Persons with Deafblindness in Mainstream Programmes: Lessons from the EU-Funded SHAPES Project**

The Smart and Healthy Ageing through People Engaging in Supportive Systems, or SHAPES project, is a four-year project (2019-2023) that intends to build, pilot, and deploy a large-scale, standardised open platform for the European Union (EU), integrating a broad range of technological, organisational, clinical, educational, and societal solutions for long-term, health, and active ageing. More specifically, this project looks at technology in the home and in local communities to reduce health and social care costs, hospitalisations, and institutional care of older persons.

WFDB is one of 36 consortium partners, composed of researchers, technology companies, and civil and public organisations aimed at helping older persons, across 14 EU countries and engaging with over 2,000 older persons, caregivers, and service providers. The main objective is to improve the long-term sustainability of health and social care systems in Europe and improve the independence and autonomy of older persons.

This project focuses on two main outputs:

- › 15 digital solutions, such as devices or products to improve independent health and social care that are being developed and tested through collaborative approaches. For example, one tool is a robot to assist with rehabilitation activities and to support daily life, and other tools include a smart phone/tablet app of maps providing information on the accessibility of public places and businesses
- › A digital platform of good practices and learning from the project, which is currently available to SHAPES partners but may be used for other purposes going forward.

Persons with deafblindness have been involved in activities to collect data, such as interviews, focus groups, and workshops, on the following areas to inform digital solutions:

- › The situation and experiences of persons with deafblindness
- › The barriers to accessing health and technology
- › Recommendations on how technology can be used to improve health and independence

- › Recommendations on how technology could be more accessible
- › Testing the digital tools and solutions being developed for the project.

A number of measures were adopted to ensure the inclusion of persons with deafblindness in the project. WFDB advocated for a budget line for interpreter-guides/Deafblind interpreters for meetings and travel to ensure that the participation of persons with deafblindness was meaningful and equal to project participants without deafblindness. Persons with deafblindness worked with interpreter-guides/Deafblind interpreters to participate in the data collection activities, and some of these activities worked with smaller cohorts to adapt to the communication requirements of the group. For example, focus groups usually involved 2-3 participants with deafblindness, and workshops comprised of 7-10 participants with deafblindness.

Many of the project events were integrated so that WFDB could connect with other project partners and to raise the profile of persons with deafblindness among mainstream partners. For example, at one of the online meetings, a person with deafblindness presented on a panel while another person with deafblindness moderated the panel. WFDB also provided guidance and

technical support across the project on how to make information accessible (e.g., through accessible formats) and ensured use of CRPD-compliant language. For instance, WFDB provided advice on a promotional video to improve the colour contrast and add subtitles.

WFDB hired a project coordinator without deafblindness for this fast-paced, complex project, but this coordinator filtered all decisions through WFDB's president and regional representatives to maintain ownership by persons with deafblindness. For example, WFDB's senior leadership selected the participants for the data collection activities to ensure diversity of communication methods among cohorts. Having a project coordinator helped to ensure activities were implemented in a timely manner, but persons with deafblindness drove the project and project-related decisions.

The good practices for including persons with deafblindness in mainstream projects learned from SHAPES include:

- The central importance of ensuring **accessibility standards and reasonable accommodations**, including a budget for interpreter-guides/Deafblind interpreters and information in accessible formats
- Involve OPDs of persons with deafblindness in the **early planning stages**, including the

proposal development, to avoid making changes to the project at later stages

- › Persons with deafblindness may require additional support, such as a project coordinator, to manage daily activities and communication, but they should **maintain ownership and decision-making of the project**
- › **Inclusion and accessibility should be adopted as a cross-cutting requirement** for the project at the outset, in the same way as ethical guidelines or safeguarding measures are often integral to projects at the conceptual stage
- › OPDs play a key role in **building awareness and technical support on accessibility and inclusion measures** in mainstream projects and should be allocated a budget and explicit responsibilities for taking on this role, rather than providing free advice on their own time
- › **Training for project partners** at the beginning of a project on accessibility and inclusion encourages shared responsibility between OPD partners and mainstream partners
- › **Activities should be integrated** with participants with and without disabilities, but some activities may need to be specific for

persons with disabilities, depending on the needs of the group.

The SHAPES project has provided a platform for persons with deafblindness to come together on health and technology issues, resulting in a positive exchange with mainstream organisations, new connections and partnerships with mainstream organisations, and peer-to-peer learning between persons with deafblindness. WFDB plans to consolidate learning from the SHAPES project and produce a final report highlighting learning on project participation of persons with deafblindness as well as insights on health and technology for older persons with deafblindness.



*Sonnia Margarita, an older woman with deafblindness, is using a braille line to navigate through her mobile device to access and test different applications (Apps) produced by the SHAPES project in her mobile device.*

**Picture taken by WFDB in Nairobi, Kenya**

## Recommendations

### All

- Set up a system to notify OPDs of persons
  - › with deafblindness about upcoming consultation processes
- Try alternate means of communicating with OPDs of persons with deafblindness if they
  - › are unresponsive, as it may be due to communication barriers rather than lack of interest or availability to participate
- Guarantee the provision of a system for making reasonable accommodation
  - › requests and adopt accessibility measures to ensure that participatory processes are easier to navigate for persons with deafblindness

### Governments

- Recognise the value and capabilities of persons with deafblindness, develop
  - › partnerships with OPDs of persons with deafblindness and support their active participation, including reasonable accommodations
- Ensure that persons with deafblindness are
  - › actively consulted whenever they are mentioned in laws, policies, guidelines,

reports, and other implementation tools and on services that affect them

Develop a service of interpreter-guides/Deafblind interpreters to reduce

- barriers to participation for persons with deafblindness

Question OPDs and NGOs that represent

- the interests of persons with deafblindness without their direct participation

Recognise poverty as a barrier to participation and develop programmes to

- generate income for persons with deafblindness so that they can focus their attention on participatory processes

## **OPDs and NGOs**

Support the development of deafblind communication guides and meeting

- accessibility guidelines that include persons with deafblindness, in consultation with persons with deafblindness

Increase awareness of government and other stakeholders on the importance of

- including the participation of persons with deafblindness and facilitate linkages accordingly

- Ensure that OPDs with deafblindness
- › maintain autonomy over decisions in joint programmes and projects

## Donors and Research Institutes

- › Ensure funded programmes enable the direct participation of persons with deafblindness, including the provision of interpreter-guide/Deafblind interpreting services and the necessary time to enable their inclusion
- › Make inclusion and accessibility a cross-cutting requirement of funded programmes at the outset and ensure this is integrated into the design of mainstream programmes.

## Data Collection and Research

The lack of legal recognition of deafblindness by States as well as other international, national, and sub-national actors, leads to the invisibility of persons with deafblindness in statistics, research, policies, programmes, and mainstream services for the general population and disability-specific services<sup>112</sup>. Data and research on persons with deafblindness help decision makers to pay attention to the specific supports required by

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<sup>112</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 8.

persons with deafblindness and inform planning and budgeting processes.

Based on WFDB's experience of preparing the first and second global reports on the situation of persons with deafblindness, there is still a need for more and better-quality data on the situation of persons with deafblindness. For example, many studies on deafblindness are very small scale and do not necessarily reflect the experiences of persons with deafblindness at a national level. Further, many different definitions or measurement tools have been used for identifying persons with deafblindness, which can make it difficult to compare findings across time and place. Similarly, national surveys have often used tools for measuring disability that do not allow for the identification of persons with deafblindness (e.g., based on categories of impairments where deafblindness is not an option). Even when surveys do include tools, like the Washington Group Questions, analyses may not be disaggregated to include deafblindness as a unique category of disability. Many surveys may also not have sufficient sample sizes to explore many outcomes amongst persons with deafblindness, particularly children with deafblindness.

In addition, persons with deafblindness are a diverse group, which can create challenges when

trying to classify or quantify the group<sup>113</sup>. Not having deafblindness as a distinct disability or choice in surveys means that persons with deafblindness often must choose between deaf or blind options on surveys, which skews the data.

Deafblindness can even be neglected within disability-specific research. This is because persons with deafblindness are often left out of wider research on persons with disabilities and because of a lack of funding and/or links with research institutes. Smaller groups, like persons with deafblindness, are often deprioritised due to their numbers. However, because deafblindness is a low-incidence, high support needs disability, there is a very limited understanding of the requirements of persons with deafblindness and, therefore; a high demand for evidence and information on what works for persons with deafblindness.

## Good Practices

Greater international cooperation is needed to formulate an international research agenda, bringing persons with deafblindness and researchers together<sup>114</sup>. In addition, persons with

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<sup>113</sup> Damen, Saskia, “The challenge of identifying deafblindness”, *British Journal of Visual Impairment*, 2019, Vol. 37(2) 77-80; National Centre on Combined Vision and hearing Impairment / Deafblindness, *Eikholt Annual Report*, October 2021, p. 6.

<sup>114</sup> Damen, Saskia, “The challenge of identifying deafblindness”, *British Journal of Visual Impairment*, 2019, Vol. 37(2) 77-80.

deafblindness can contribute to research in a variety of ways, including:

- › Identifying research topic priorities
- › Providing advice during the commissioning or tendering process
- › Advising on the study design, study tools and analysis plans for the research, including research questions and questions to include in surveys
- › Taking part in the research, as subjects. Persons with deafblindness should directly participate with the support of interpreter-guides/Deafblind interpreters rather than asking questions to family members or other proxies as much as possible
- › Taking part in data collection as members of the research team
- › Analysing results or contributing to analysis plans
- › Developing conclusions or recommendations
- › Disseminating results<sup>115</sup>.

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<sup>115</sup> SUITCEYES, Best Practice Recommendations for Engaging Deafblind Participants in Research, [https://suitceyes.eu/wp-content/uploads/2020/12/D8\\_D2.3-Best-practice-recommendations-for-engaging-deafblind-participants-in-research.pdf](https://suitceyes.eu/wp-content/uploads/2020/12/D8_D2.3-Best-practice-recommendations-for-engaging-deafblind-participants-in-research.pdf), accessed May 2022, p. 7.

Persons with deafblindness will require communication support, such as interpreter-guides/Deafblind interpreters, and other accessibility requirements and reasonable accommodations to participate in research activities and may require training, depending on their roles and experience.

Large surveys, such as national censuses, should include the Washington Group Questions, to support disaggregation by disability and increase the visibility of persons with disabilities in data, including persons with deafblindness. WFDB in partnership with ICED has established a method for identifying the number of persons with deafblindness in survey data that uses the Washington Group Questions, which are outlined in detail in the chapter on Prevalence.

However, it is important to note that many mainstream surveys may not have sufficient sample sizes to explore the experience of persons with deafblindness in detail, particularly children with deafblindness. For example, it was not possible to explore outcomes such as access to health and education in children at a national level using the MICS data, as most countries identified fewer than 10 children with deafblindness and some countries did not identify any children with deafblindness.

Censuses, which attempt to gather information from all people in a population, are most likely to have sufficiently large sample sizes to measure outcomes amongst persons with deafblindness, however, they are conducted infrequently (typically every 10 years). Additional data collection on the situation of persons with deafblindness may be needed to complement these mainstream surveys.

Additionally, mainstream surveys need to be accessible and inclusive in their design so that the experiences of persons with deafblindness can be accurately collected. For example, in the MICS, literacy and numeracy are determined through children performing a task that is based on written materials (e.g., reading out a sentence for literacy or performing mathematical calculations described in the text) and oral instructions. Since these tasks are not provided in accessible formats (e.g., Braille, instructions delivered with tactile signing, etc.), it does not provide a true picture of the literacy and numeracy of children with deafblindness. Training of data collectors and the provision of supports (e.g., Braille, sign language) are needed during data collection.

Most importantly, there needs to be research and evidence that specifically focuses on and prioritised by persons with deafblindness (i.e., globally available evidence on the effectiveness of models and/or services that maximise

independence and autonomy and improve the quality of life of persons with deafblindness)<sup>116</sup>.

This research needs to align with the CRPD and reflect the latest understanding of deafblindness. Key research priorities include the continuous assessment and revision of interpreter-guide/Deafblind interpreting services, assistive devices and technologies, and good practices on what works for persons with deafblindness in both disability-specific and mainstream services.

## Recommendations

### Governments

- Support research on good practices for services and social inclusion of persons with
  - deafblindness, ensuring their participation in the focus of the research

- Support the development of research on the models and/or services that maximise independence and autonomy of persons
  - with deafblindness to inform service provision. As research and evidence emerges, ensure that policies and programmes align with the latest findings

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<sup>116</sup> Jaiswal, Atul. Deafblind Ontario Services, *Stakeholder Consultation Project*, August 2019, p. 28.

## OPDs and NGOs

- Include persons with deafblindness in
- research initiatives at all levels and data collection advocacy
- Support direct participation of persons with
- deafblindness in the monitoring and evaluation of programmes

## Donors and Research Institutes

- Invest in research to better support an evidence-base for disability-specific and disability- mainstreamed services for
- persons with deafblindness, including on the provision of interpreter-guide/Deafblind interpreting services
- Encourage international cooperation to develop a global research agenda on
- persons with deafblindness, working with OPDs of persons with deafblindness to set the agenda
- Invite OPDs of persons with deafblindness to academic and research conferences and
- earmark time to discuss and evaluate the gaps in research for persons with deafblindness
- Actively include persons with deafblindness
- and their OPDs in research activities, from study design to data collection and

dissemination and use inclusive data collection methods whereby they can share their own experiences directly (rather than as a default through a proxy, such as family members) as much as possible.

# DISABILITY MAINSTREAMING OF LAWS, POLICIES, AND SERVICES

Persons with deafblindness should have access to the same services as persons without disabilities, but often, they are excluded based solely on the grounds of their disability. These mainstream services include education, employment, social protection, recreational facilities, voting, vocational training, emergency services, the courts, the justice system, etc.

These services should be mainstreamed to ensure the inclusion of all persons with disabilities with a particular focus on underrepresented groups, including persons with deafblindness.

Services that are ordinarily available to the public should not be segregated or separate services for persons with disabilities because this leads to isolation and social exclusion and increases stigma and discrimination. These mainstream services should link with the preconditions for disability inclusion and disability-specific services for persons with deafblindness, such as services for disability identification, assessment, and referral; rehabilitative / CBR services; disability support services (such as interpreter-guides/Deafblind interpreters); access to assistive

devices and technologies; and accessibility measures.

Additionally, these mainstream services should also ensure the participation of persons with deafblindness and be based on data and research on good practices for persons with deafblindness<sup>117</sup>.

The following section reviews good practices for persons with deafblindness in mainstream services.

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117 UNPRPD, *The preconditions necessary to ensure disability inclusion across policies, services, and other interventions*, <https://unprpd.org/site/default/files/library/2020-08/Annex%20%20UNPRPD%204th%20Funding%20Call%20Preconditions%20to%20disability%20inclusion%20ACC.pdf>, accessed May 2022, p. 4.



*A female child with deafblindness and a woman chat and have a good time.*

*Courtesy of Sense International*

## **Inclusive Education**

Children with deafblindness have a right to an inclusive, free, quality education to meet their full potential and cannot be prohibited from education due to their disability, regardless of their support needs. This includes the right to individualised support measures, facilitation of learning deafblind communication methods, delivery of education in modes and means of communication for the individual, facilitation of orientation and mobility,

access to assistive devices and technologies, and access to live assistance<sup>118</sup>.

However, the reality is that many children with deafblindness are not enrolled in school, often due to lack of parental support and/or schools' refusals to accept children with deafblindness because of their high support requirements, according to WFDB's survey. Data from 36 countries in the MICS<sup>119</sup> showed that only 7% of young children with deafblindness (aged 3-4 years) were enrolled in early childhood education programmes.

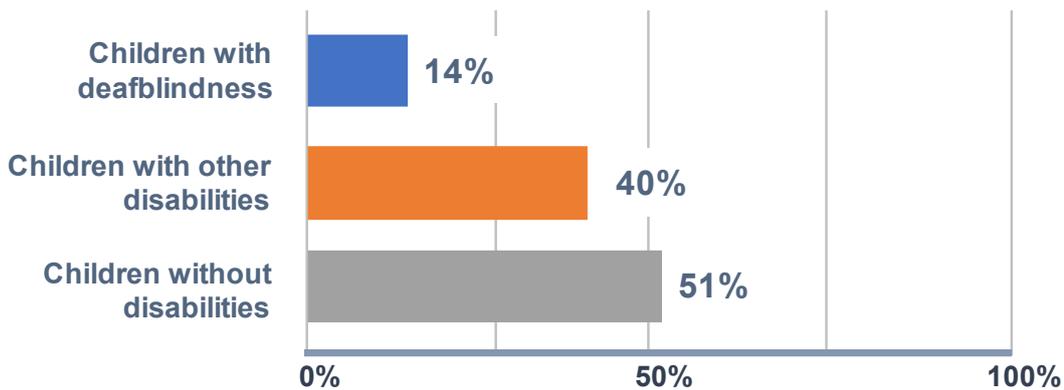
Children with deafblindness were less likely to be enrolled in early childhood education compared to children with other disabilities (20%) or children without disabilities (31%). The proportion of children with deafblindness that were attending early childhood education increased with country income level, which was similar to children with other disabilities and children without disabilities.

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118 Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 24; Committee on the Rights of Persons with Disabilities, General Comment No. 4 on Article 24 – the right to inclusive education, CRPD/C/GC/4, 25 November 2016, para. 35.c.

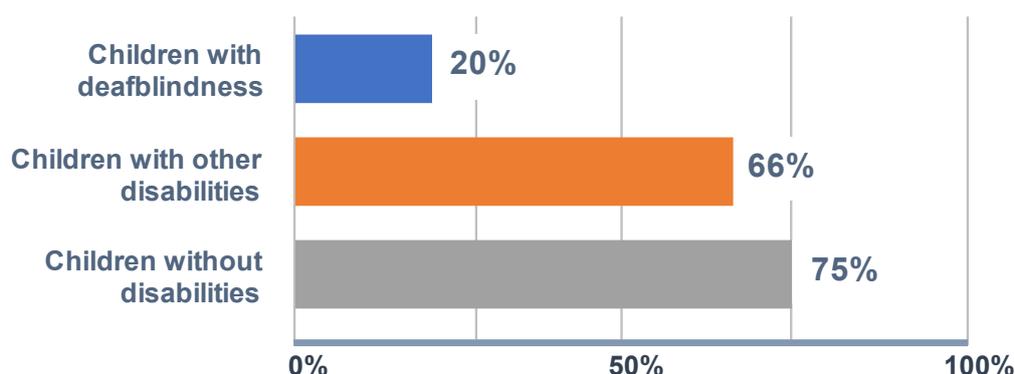
119 Please note that different measures of school enrolment are different than those used in the 1<sup>st</sup> Global Report. These measures are in line with indicators used by UNICEF and for the Sustainable Development Goals

## ENROLLMENT IN EDUCATION



Enrolment improves at the primary school level, but the trend remains. The data revealed that only 20% of children with deafblindness of primary school age attended school. Children with deafblindness of primary school age were two to three times less likely to be enrolled in primary school compared to children with other disabilities (66% enrolled) and children without disabilities (75% enrolled).

## ENROLLMENT IN PRIMARY



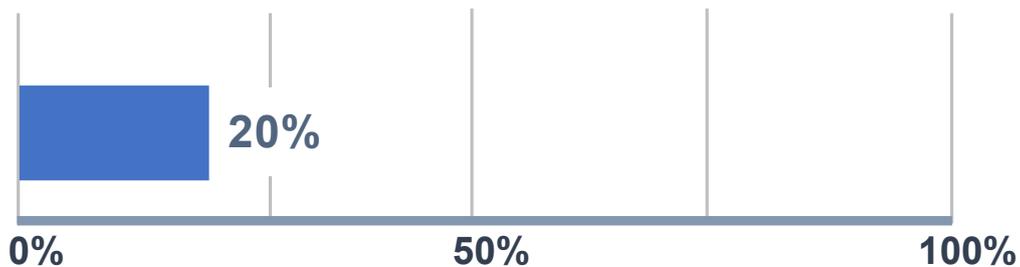
## SCHOOL

Similarly, only 16% of children with deafblindness attended secondary school. Children with deafblindness of secondary school age were half as likely to be enrolled in secondary school as children with other disabilities (36% enrolled) and three times less likely to be enrolled compared to children without disabilities (49%). For data on individual countries, see Table 3, Annex 1.

For those children with deafblindness that are in school, many are only offered places in ‘special schools’ which are segregated from the general population, and which increase social exclusion and isolation. The quantitative research did not indicate whether children with deafblindness or children with disabilities were in segregated or mainstream education. Also, it did not explore the attendance or retention rates for children with deafblindness.

The quality of education is difficult to measure statistically for children with deafblindness. For example, literacy and numeracy are determined through children performing tasks that are based on written materials, such as reading a sentence or performing mathematical calculations. Because these tasks are not provided in accessible formats, such as Braille or through tactile signing, they do not provide a true picture of the quality of education for children with deafblindness. In addition, learners with deafblindness have diverse

requirements, for example, pre-lingual and post-lingual learners may require different learning strategies, and many curricula are fixed and inflexible, making it difficult for teachers to meet the individual needs of learners. Moreover, teachers are often not trained in deafblind communication, which significantly affects learners with deafblindness<sup>120</sup>. Finally, learners with deafblindness often require assistance in their learning, recreational and social activities, basic care, and in moving around the school.



**only 20% of all children with deafblindness are developmentally on track**

Among children with deafblindness (aged 3-4 years), only 20% were considered to be developmentally on track, according to the Early Childhood Index. This index is used to track the implementation of the SDGs and includes the domains of literacy-numeracy, physical functioning, social-emotional development, and learning. Children with deafblindness were almost

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<sup>120</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 28.

half as likely to be developmentally on track compared to children with other disabilities and three times less likely compared to children without disabilities. The proportion of children with deafblindness that were developmentally on track decreased by country income level, from 40% in the upper middle-income countries to 13% in low-income countries – a trend that was similar for children with other disabilities and children without disabilities.

### Good Practices

Many countries are transitioning from segregated education to inclusive education models and updating education laws and policies to comply with the CRPD, and children with deafblindness must not be left out of the discourse on the transition from segregated education to inclusive mainstream education. However, placing children with deafblindness in mainstream schools **without** the appropriate supports is **not** inclusive education. This includes appropriate rehabilitation supports (e.g., the ability to communicate or to perform basic life skills) and educational and social supports (e.g., teaching assistants, adapted curricula, family sensitisation, etc.). Therefore, the definition of inclusive education for children with deafblindness includes individualised support measures, learning deafblind communication methods, education delivered in modes and

means of communication for the individual, facilitation of orientation and mobility, access to assistive devices and technologies, and access to live assistance<sup>121</sup>. Educational systems transitioning from segregated models should ensure these measures are in place in order to ensure a smooth transition for children with deafblindness.

Because children with deafblindness are at higher risk of exclusion from education than others<sup>122</sup>, legal and policy frameworks should make explicit reference to learners with deafblindness, and their requirements based on input from persons with deafblindness and their families. In addition, laws, policies, or administrative procedures that prohibit or have the effect of blocking the enrolment of children with deafblindness in mainstream inclusive schools, such as a blanket capitation on learners with disabilities, should be rescinded and replaced with an inclusive model of education<sup>123</sup>.

Early identification and referral programmes should link with early childhood education

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<sup>121</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 24; Committee on the Rights of Persons with Disabilities, General Comment No. 4 on Article 24 – the right to inclusive education, CRPD/C/GC/4, 25 November 2016, para. 35.c.

<sup>122</sup> Committee on the Rights of Persons with Disabilities, General Comment No. 4 on Article 24 – the right to inclusive education, CRPD/C/GC/4, 25 November 2016, para. 6.

<sup>123</sup> Ezzat, Amal, “Advocating for the Right to Education for Learners with Deafblindness and Multiple Disabilities in Egypt”, DBI Review, Number 61, July 2018, p. 5-8.

programmes because early intervention is critical for improving educational, cognitive, and social outcomes for children with deafblindness and to ensure that children have basic life skills and the ability to communicate<sup>124</sup>. Where early education is in short supply, community-based support to transition children with deafblindness to primary school may be needed, especially if intervention programmes have been insufficient or if identification of deafblindness or rehabilitation was delayed. Home-based education with support from special education teachers from local schools and an adapted curriculum can enable parents and caregivers to help their children become school-ready, learn essential life skills, and help to establish links between families and schools at the earliest stages in low-resource settings where early childhood education programmes are oversubscribed<sup>125</sup>. Guidelines for parents, teachers, and rehabilitation professionals on this home-based support model will help to ensure quality standards are met. However, steps should be made to include children with deafblindness in inclusive mainstream early education programmes

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<sup>124</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 28.

<sup>125</sup> Sense International, *A Baseline Survey on the Inclusive Education Project in Greater Masaka: Final Report*, 8 October 2020; Sense International, *A Review of Sense International Tanzania's teaching Assistant Approach to Inclusive Education: Research Summary Report*, 2020; VIHEMA, *Report on Findings from the Assessment of Care Givers of Children with Deaf-Blindness in Malawi: A Case of Machinga District*, 28 October 2020.

and ensure early intervention is integrated into them.

In addition, some children with deafblindness, such as children who use sign languages, require adapted teaching practices to ensure social and cultural development in respect to their language. Sign language users are a linguistic minority group, and teaching practices should adopt a bilingual framework to address the linguistic, social, and cultural factors that affect children with deafblindness. Most importantly, all children with deafblindness must not be deprived of language exposure during the critical period of language acquisition<sup>126</sup>.

WFDB aspires to achieve the inclusion of persons with deafblindness in education systems and society, whilst also respecting the individual decisions and preferences of every person with deafblindness in that matter. It is vital to respect the freedom of choice of every individual and ensure that no child or adult with deafblindness is without the necessary supports and adaptations.

The main elements for inclusive education of children with deafblindness in mainstream schools at all levels of education include:

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<sup>126</sup> Higgins, Michale, and Lieberman, Amy. "Deaf Students as a Linguistic and Cultural Minority: Shifting Perspectives and Implications for Teaching and Learning", *J Educ* (Boston), Vol 196, Issue 1, January 2016, p. 9-18.

- Identification, assessment, and referral services, and access to assistive devices and technologies** with linkages and coordination between these services and schools, as well as access to essential
- medicines, and nutritional support, as needed on an individual basis. Children with deafblindness require proper identification and assessment to ensure that the right supports are identified for each child
- Communication and basic life skills** through rehabilitation services or a suitable alternative, such as, a home-based programme. This is to ensure children have the necessary communication, orientation,
- mobility, and basic life skills (e.g., feeding, dressing, going to the toilet, etc.) to attend school. This also requires language acquisition, especially for children with pre-lingual deafblindness
- Adaptation of the curricula** to ensure **teaching methods and learning outcomes** for children with deafblindness are appropriate. Children with deafblindness should not, however, be excluded in
- adapted curricula from learning essential skills to promote autonomy and economic opportunities, such as learning digital technology skills. Children with deafblindness must be supported to learn

and discover, which includes taking risks, to build their confidence and independence, and adolescents should be supported in transitioning into adult life. A **bilingual framework** should be adopted to address the social, cultural, and linguistic development of children with deafblindness who require this level of support

- Development of **individualised education plans** tailored to the specific requirements of individual learners, maximising their full potential

- Sensitisation on deafblindness for teachers and adequate training** on supporting the requirements of children with deafblindness, including a variety of deafblind communication methods and inclusive learning methods, with access to information resources and professional development. Training teachers in multiple deafblind communication methods is more likely to lead to higher communication levels in children with deafblindness. Teacher training can be provided centrally and/or as a mobile unit that works directly with teachers and learners with deafblindness in the classroom, and it should respond to gaps in the teaching pool to help with high teacher turnover.

➤ **Provision of accessible teaching and learning materials**, including learning materials in accessible formats, appropriate to learners with deafblindness and **physical accessibility of school buildings and facilities**

➤ **Provision of live assistance, such as teaching assistants**, trained in deafblind communication and inclusive learning methods for children with deafblindness. The models for teaching assistants vary, and teaching assistants may work one-on-one or in small clusters of children with different types of disabilities, providing targeted, individualised support within a mainstream classroom. Teaching assistants support the implementation of the curriculum under the supervision of the teacher.

➤ **Sensitisation on deafblindness for parents, school staff, and the community** to combat stigma and discrimination and the barriers to education from within the family, school, and community. In addition, parents need advice on how to support their children's education, and **home visits** from education and rehabilitation staff help to facilitate the progress of children with deafblindness and to troubleshoot developmental delays

## Data on students with deafblindness

- integrated into education management
- information systems (EMIS) to inform planning<sup>127</sup>.

Teaching assistants are as essential to learners with deafblindness as interpreter-guides/Deafblind interpreters are to adults with deafblindness. Cadres of teaching assistants do not exist within all free education systems. As with interpreter-guides/Deafblind interpreters, technical and ethical guidelines, training and certification programmes, role profiles, service agreements, and formal professional status need to be established for teaching assistants, and pilot programmes can help to demonstrate their added value while these systems are being developed. In addition, education ministries should liaise with OPDs on the diverse needs of different groups of persons with disabilities, as teaching assistants can be

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<sup>127</sup> Brady, L. Beth. "Quantitative Analysis of Classroom Communication Environments for Learners with Deafblindness", *The Journal of Special Education*, Hammill Institute on Disabilities, 1-12, 2021; Carter, Gill. "Lessons on deafblindness form research in East Africa", *DBI Review*, Issue 63, April 2020, p. 52-54; Dhale, Zamir. *My life as a person with deafblindness*, [www.sedbindia.org](http://www.sedbindia.org), October 2021, p. 3; Haga, Frederick, Literature Review on Schemes for Service of Learning Support Assistants, supplied by Sense International, accessed May 2022; Higgins, Michale, and Lieberman, Amy. "Deaf Students as a Linguistic and Cultural Minority: Shifting Perspectives and Implications for Teaching and Learning", *J Educ* (Boston), Vol 196, Issue 1, January 2016, p. 9-18; Ireland's National Council for Special Education, *Information for Parents/Guardians of Children and Young People who are Deafblind / with dual sensory loss*, <https://ncse.ie/wp-content/uploads/2019/09/NCSE-Deafblind-Information-for-Parents-Guardians-002.pdf>, accessed May 2022; Sense International, *A Review of Sense International Tanzania's teaching Assistant Approach to Inclusive Education: Research Summary Report*, 2020; Sense International, *Monitoring Report on Implementation of Early Years Competence Based Curriculum for Learners with Diverse Disabilities*, May 2020; Sense International Romania, E-Sense, <https://surdocecitate.ro/en/e-sense/>, accessed May 2022; and VIHEMA, Report on Findings from the Assessment of Care Givers of Children with Deaf-Blindness in Malawi: A Case of Machinga District, 28 October 2020.

utilised to support children with all types of disabilities<sup>128</sup>.

Even when education is provided to children with deafblindness, as adults, they often miss out on many of the skills and benefits of education. Therefore, learning programmes for adults with deafblindness can support employment, apprenticeship, secondary school credit, post-secondary education, and further independence. These learning programmes for adults are most successful if delivered as one-on-one or small group instruction using the communication modality used by the student and not one that is imposed upon them. For example, in Canada, the curriculum for a literacy programme for persons with deafblindness covers basic computer training, numeracy, measurement, recognition and classification, data management and probability, filling out forms, reading comprehension, writing skills, job readiness, managing schedules, working with others, budgeting, problem solving, resume writing, and community partner referrals and resources. Methods of communication are also covered as well as using assistive technologies. While the programme has some similarities to vocational training, it is aimed at learners whose literacy skills are below Grade 12 (upper

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<sup>128</sup> Haga, Frederick, Literature Review on Schemes for Service of Learning Support Assistants, supplied by Sense International, accessed May 2022.

secondary) but who are older than school age<sup>129</sup>. These programmes can help persons with deafblindness to fill key gaps in their education and qualifications should be involved in developing adult education programmes.

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<sup>129</sup> CNIB, *Literacy Programme*, <https://deafblindservices.ca/programs-and-services/literacy-program/>, accessed May 2022.

## CASE STUDY

### Teaching Assistants Are the Key to Inclusive Education: Lessons from Tanzania

Inclusive education was well established in laws and policies in Tanzania, like many other countries in Sub-Saharan Africa. However, very few practical steps had been taken to ensure the inclusive education of children with deafblindness.

From 2016-2020, Sense International Tanzania piloted a programme in the Dar es Salaam and Kilimanjaro regions to challenge the misbelief that children with deafblindness cannot be educated in mainstream classrooms due to their unique needs. The programme was based on a two-step model for inclusive education for children with deafblindness:

#### **STEP I**

Using an adapted curriculum, children with deafblindness were prepared for school through home-based education that was provided by parents or caregivers and supported by teachers from a nearby school

Children with deafblindness transitioned from home-based education to mainstream schools with the support of teaching assistants. Parents, teachers, and teaching assistants were trained in pedagogical skills for teaching children with deafblindness in inclusive classrooms. Teachers were also taught how to manage the diverse needs of children with deafblindness, how to manage the classroom, and how to work with teaching assistants.

In addition, SI Tanzania worked with the Education Support Resource and Assessment Services (ESRAC) on educational assessments to determine children's disability status, suggest referrals, support school placements, and support individual education plans. This is because many children with deafblindness in Tanzania have not been properly assessed and have not accessed rehabilitative services, demonstrating how disability-specific services link to education services.

Children with deafblindness were not placed in mainstream schools without being ready for school. Home-based education filled a gap in rehabilitation and early education services in Tanzania by enabling parents and teachers to support children with deafblindness to become

ready for classroom-based learning, for example, by teaching children communication methods and daily living skills. Home-based education also helped parents to facilitate, support, and reinforce their child's learning, while demonstrating to parents their child's potential to learn. Many parents overcame reluctance to send their children to mainstream schools through this home-based support.

Teaching assistants provided learning and one-to-one communication support to children with deafblindness in the classroom. They also facilitated social interaction and provided support with mobility and orientation in activities outside the classroom, such as eating lunch, playing with other children, and using the toilet.

There was no system for teaching assistants in Tanzania prior to this programme. Therefore, SI Tanzania had to work with the Ministry of Education, Science, and Technology and the President's Office, Regional Administration and Local Government, to pilot the use of teaching assistants to support children with deafblindness in inclusive education. Teaching assistants are now recognised in Tanzania, with some commitments by the government to establish a cadre of teaching assistants and develop guidelines with qualifications for suitable candidates for training and job placement, as well

as a budget to fund them within the education system.

SI Tanzania has further achieved the following under this programme:

- Class management with teaching assistants has been added to the syllabus of the Patandi Teachers' College<sup>130</sup>
- A flexible, competency-based curriculum at the primary school level has been established to meet the diverse needs of children with complex disabilities, including deafblindness<sup>131</sup>
- Inclusion of teaching assistants in the National Strategy on Inclusive Education (2021-2026) with plans to develop national guidelines.

It has been challenging to demonstrate the value for money of a new system of teaching assistants where it did not previously exist, especially when

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<sup>130</sup> See further, The addition of class management with teaching assistants added to the syllabus of National's Patandi Special Needs and Inclusive Teacher's College, p. 27, <https://tie.go.tz/uploads/files/Muhtasari%20wa%20Somo%20Ia%20Ujifunzaji%20wa%20mwanafunzi%20Mwenye%20Uziwikutoona.pdf>.

<sup>131</sup> See further, A flexible, competency-based curriculum to meet the needs of children with complex disabilities, including those with deafblindness, is available at <https://www.tie.go.tz/uploads/files/MTAALA%20REKEBIFU%20WA%20UZIWIWIKUTOONA%20-%20ELIMU%20YA%20MSIMNGI.pdf>; The competency-based syllabus is available at <https://www.tie.go.tz/uploads/files/MUHTASARI%20REKEBIFU%20%20WA%20ELIMU%20YA%20MSINGI%20-%20%20UZIWIWIKUTOONA%20HATUA%20YA%20I-III.pdf>; The competency-based teacher guide is available at <https://www.tie.go.tz/uploads/files/MWONGOZO%20REKEBIFU%20wa%20UziwiKutoona%20-%20Msingi.pdf>.

there continues to be a national shortage of teachers for mainstream classrooms. However, this programme shows that putting a child with deafblindness in an inclusive school is less expensive than putting them in a special or segregated school. Additionally, the government rightly insists that all children should attend school. For children with deafblindness, teaching assistants are essential. For many, live assistance is as vital to children with deafblindness as assistive devices are to children with physical disabilities. Many simply cannot attend school without them.

Children with deafblindness who attended mainstream school with the support of a teaching assistant achieved key milestones in language, communication, and independence. In many instances, it had a transformative effect in building confidence and in test results. In addition, many families that were at breaking point prior to the programme noted that the stresses of full-time care were alleviated and many saw improvements in their own economic empowerment, since many parents are forced to stay at home to care for children with deafblindness in lieu of community-based supports.

Inclusive education can only be inclusive if children are actually included in what everyone is

learning. To make inclusive education effective, every child with deafblindness needs a quality, inclusive teacher; access to a teaching assistant; and family involvement in developing individual education plans based on individual potential from the point of what the child can do, not what they cannot do<sup>132</sup>.

*Kelvin, a learner with deafblindness; no vision in both eyes, no hearing on his right with very minimal ability to sound perception on the left. He is stretching his left hand towards his mother to locate an electronic tablet provided by Sense International Tanzania and used as assistive learning technology.*

**Photo credit:  
HDIF, 2019**



<sup>132</sup> Adapted from the National Strategy on Inclusive Education (NSIE), 2018-2021, and Sense International Tanzania, *Cooperation that Counts: The Impact of Inclusive Education on Learners and their Families*, August 2020.

## Recommendations

### Governments

- Amend education laws and policies to align with CRPD Article 24, the right to inclusive education, and explicitly outline the supports
  - for learners with deafblindness, including access to teaching assistance and provision to learn and use deafblind communication methods
- Develop a cadre of teaching assistants in mainstream schools for children with disabilities, including children with
  - deafblindness, and initiate pilot programmes to get children with deafblindness into schools
- Develop training modules for teachers and teaching assistants on deafblind
  - communication, how to work with teaching assistants / teachers, and inclusive learning methods for learners with deafblindness
- Coordinate between identification and assessment, rehabilitation, and educational
  - services and the relevant ministries and departments
- Establish early intervention programmes
  - linked with early education programmes for children with deafblindness, and flag them

as a priority group. Where early education programmes are lacking, develop community-based solutions, such as home-schooling with an adapted curriculum and support from trained teachers, aimed at making children with deafblindness school ready with the necessary communication and basic life skills

Work with OPDs of persons with deafblindness and deafblindness professionals to adapt curricula, modify school facilities and buildings, develop inclusive learning materials, and community sensitisation programmes to ensure persons with deafblindness are included

Adopt a bilingual framework to support the cultural, social, and linguistic development of children with deafblindness that require it

Where segregated education is transitioning to an inclusive mainstream model, ensure that children with deafblindness have the appropriate supports in place in mainstream schools so that they are not placed in schools that are ill-equipped to support them

## **OPDs and NGOs**

Work with OPDs of persons with deafblindness to develop strategies to adapt curricula, modify school facilities and

buildings, develop inclusive learning materials, and community sensitisation programmes to ensure persons with deafblindness are included. Where necessary, link with cross-border experts to provide technical assistance

- Pool resources to advocate for teaching assistants for all children with disabilities in mainstream schools and include explicit references to deafblind communication and learning methods in advocacy materials

## **Donors and Research Institutes**

- Invest in research to better support an evidence-base for inclusive education of children with deafblindness, at scale, as well as the cost-effectiveness and educational and economic impacts of teaching assistants.

## **Health**

In addition to the right to habilitation and rehabilitation, which are disability-specific services, persons with deafblindness have a right to the highest attainable standard of health, including access to affordable, quality health care, community access to health services, and access to health specialists, including sexual and reproductive health. Discrimination on grounds of

disability or other factors is prohibited, and measures to ensure that dignity and autonomy are upheld should be introduced and maintained<sup>133</sup>.

Persons with disabilities often require more health care, such as additional screenings and check-ups, follow-up visits, medication, and urgent or emergency care where their impairment links to their health (e.g., eye health) or where the impairment could be likely to cause increased health risks (e.g., increased risk of contracting infectious diseases). A common barrier is the lack of understanding of deafblindness and related health conditions among health professionals<sup>134</sup>.

Persons with disabilities are more likely to have co-morbidities because of the influence of behavioural risk factors, such as reduced physical activity<sup>135</sup>, and the lack of understanding of deafblindness is amplified when there are multiple health issues.

There is emerging anecdotal evidence that persons with deafblindness are at increased risk of mental health conditions due to lack of basic supports, social isolation, and communication

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<sup>133</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 25.

<sup>134</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 33.

<sup>135</sup> World Health Organisation, *World Report on Disability*, 2011, p. 59.

challenges, and this may lead to psychosomatic disorders (i.e., physical health conditions because of long-term stress) in addition to mental health conditions in both persons with deafblindness and their family members<sup>136</sup>. Persons with deafblindness spend extra internal resources on adapting to the dual sensory impairment and interacting with the environment, which can drain the body and mind of energy. Social expectations and the brain's inclination to want information can play a role in mental health daily. Furthermore, the energy spent in dealing with unsupportive communication strategies or lack of deafblindness-specific approaches during interactions also affects mental health<sup>137</sup>. More research is needed on the mental health of persons with deafblindness to better understand the prevalence of mental health conditions, short- and long-term effects, and approaches for improving and managing mental health outcomes for persons with deafblindness. In addition, public health information (e.g., on vaccinations and disease prevention) is often not available to persons with deafblindness in

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<sup>136</sup> The Association of the Swedish Deafblind (FSDB), *Tools for Better Health*, <http://www.fsdb.org/Verktyg-forbattrehlsa.html>, accessed October 2021; World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 36.

<sup>137</sup> Danish Association of the Deafblind (FDDB), *Finding the balance: Report on deafblind people's stress and well-being*, <https://www.fddb.dk/tilbud-til-dig/pjecer-boeger-og-andre-udgivelser/boeger-og-rapporter/at-finde-balancen-en-undersogelse-om-doevblindes-stress-og-trivsel/>, 2013.

accessible formats<sup>138</sup>. For example, during the recent COVID-19 pandemic, accurate, up-to-date information that was accessible to persons with disabilities, especially persons with deafblindness, was often not available<sup>139</sup>. Persons with deafblindness often require an interpreter-guide/Deafblind interpreter to access health services. Respondents to WFDB's survey suggested that where there are no interpreter-guide/Deafblind interpreting services, health professionals often talked to family members, which created an intermediary between the health care professional and persons with deafblindness that may not always be impartial or objective. It can result in discussions and decisions taking place without the direct involvement of the person with deafblindness. This can affect diagnosis and treatment options and may result in serious health consequences (e.g. if the person's health history is not accurately described)<sup>140</sup>.

The health of children with deafblindness is of particular concern. Data from 36 countries in the MICS shows that children with deafblindness have

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<sup>138</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 34.

<sup>139</sup> International Disability Alliance, *Reaching Persons with Deafblindness during the Covid-19 pandemic*, <https://www.internationaldisabilityalliance.org/covid-deafblind>, 19 April 2020.

<sup>140</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 34.

poorer health outcomes compared with children with other disabilities and children without disabilities.

For example, children with deafblindness (aged 2-4 years) were 20% more likely to have had an acute respiratory infection in the last two weeks and 48% more likely to have experienced diarrhoea in the last two weeks compared to children without disabilities. Further, 22% of children with deafblindness experienced wasting, a sign of malnutrition, which was twice as high as children without disabilities. Children with deafblindness were also 24% more likely to have stunted growth compared to children without disabilities.

## HEALTH OUTCOMES

Compared to children without disabilities, children with deafblindness are:

**20%**

more likely to have had an acute respiratory infection

**24%**

more likely to have stunted growth

**48%**

more likely to have experienced diarrhoea

**2x**

twice as likely to experience malnutrition

The data also revealed that despite having higher health needs, children with deafblindness were equally likely to have health insurance compared to other groups. Overall, access to health insurance was very low in the sampled countries at less than 15% for all groups. The likelihood of seeking health care among children who had diarrhoea or an acute respiratory infection in the last two weeks was similar across groups. For the full data in each country, see Table 4, Annex 1.

## Good Practices

Gaps in national health systems affecting the general population affect persons with deafblindness. Even where there are limited resources, specific measures should be addressed. For example, persons with deafblindness should be legally recognised and identified as a priority group in accessing affordable health insurance or state-funded health care (i.e., universal health coverage) because of their disability-related health needs and increased risks of developing other health conditions. In addition, health services should link with disability-specific rehabilitation services to facilitate the identification, assessment, treatment, and rehabilitation of persons with deafblindness. The causes of deafblindness should be researched, as the risk factors may vary across countries.

Key elements to improve health outcomes for persons with deafblindness include:

- **Conduct training and sensitisation of frontline health care workers** on deafblindness and common misperceptions, related health conditions, communication methods, and measures to ensure interpreter-guides/Deafblind interpreters are used

- **Establish a deafblindness team located within health and rehabilitation systems**  
that can advise other health care professionals
- **Link health appointment procedures with interpreter-guide/Deafblind interpreter booking**
- **Provide communication aids**, such as personalised cards and/or an alert on the medical records, stating that the person has deafblindness, their communication requirements, and basic health information to help facilitate communication. These cards can be developed cheaply and can facilitate a more productive and efficient health appointment and can be lifesaving in health emergencies
- **Include mental health screening and assessments** for persons with deafblindness into basic health and rehabilitation services
- Advocate for **measures to be adopted that prevent family members from serving as a proxy** where persons with deafblindness are not incapacitated (e.g., through legislation, policy, patients' bill of rights, or other similar mechanisms)

- Provide public health information in**
- **accessible formats** and through alternative communication methods<sup>141</sup>.

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The Association of the Swedish Deafblind (FSDB), *Tools for Better Health*, <http://www.fsdb.org/Verktyg-forbattrehlsa.html>, accessed October 2021; Deaf Scotland et al, *Mental Health, Sensory Loss, and Human Rights: A Transition Report Call for Sensory Literate Services*, 10 February 2021, p. 11; World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 34-35.

## **SEXUAL AND REPRODUCTIVE HEALTH: An Example of Applying Good Practices**

These good practices should be applied across different areas of health and may require further tailoring of interventions to ensure that persons with deafblindness are able to access services. For example, good practices in sexual and reproductive health (SRH) services for persons with deafblindness include:

- Training of health care workers on how to communicate with persons with deafblindness, including tips on communication methods, how to treat persons with deafblindness on an equal basis with others in SRH services, how to handle and respond to situations of abuse, prevention and awareness of fertility sterilisation, etc. SRH of persons with deafblindness should not exclude any SRH information available to the public, and steps should be taken to address the stigma that results in omitting persons from deafblindness from receiving full information on SRH
- Training of local government officials to raise awareness and ensure that persons with deafblindness are included in local level programmes

- Training of family members on how to support persons with deafblindness in their SRH decisions and coordination with families and teachers on a common understanding of SRH, especially where cultural barriers exist
- Integrating SRH education into education programmes at an early stage and improving and updating knowledge as children with deafblindness get older. Content should cover the full range of SRH issues, such as anatomy, menstruation, sex and sexual health, contraception, pregnancy, sexual health risks, safe access to SRH services, safeguarding, violence, abuse, and harmful traditional practices (e.g., forced marriage). Learning should be routine and repeated to reinforce the content, included in individualised learning plans, and adapted to meet the learning needs of each person, including the communication requirements of individuals. For example, use anatomically correct dolls with tactile information to help children with deafblindness understand the material
- Putting persons with deafblindness at the heart of all actions and decisions about their SRH needs

- Financial support on livelihoods, as resolving economic issues are essential for well-being and helps with financial independence, especially if abuse is in the family or community
- Media outreach to raise awareness in the community so that key factors linked to SRH are identified (e.g., safe access to water, mobility and getting around safely) and access to communication and orientation support<sup>142</sup>.

## CASE STUDY

### **Pilot Programme to Support Mental Health: Lessons from India**

During the COVID-19 pandemic, Sense International India (SI India) conducted a small questionnaire-based study with adults with deafblindness and their families to better understand how they were coping mentally and emotionally with the challenges of the pandemic. Many reported emotional or behavioural difficulties, such as feeling lost, unable to connect, and tensions with their families. Family members increasingly requested specialist mental health supports for children and young people with deafblindness.

Consequently, SI India took a strategic decision to prioritise the mental health of persons with deafblindness as a new area of work.

They started by increasing awareness among special education teachers and CBR workers about mental health and reviewed existing research on the topic. However, there was not much literature or research on the mental health of persons with deafblindness.

SI India initiated a pilot project in April 2022 to better understand the existing mental health issues that children and young people with deafblindness experience. This two-year pilot

project, underway at the time of drafting this report, aimed to benefit 1,000 persons with deafblindness across 22 states in India.

SI India developed a screening checklist influenced by the World Health Organisation's (WHO) Five Well-Being Index (WHO-5), WHO's self-reporting questionnaire-20 (SRQ-20), and other tools available and considered the communication barriers and behaviours specific to persons with deafblindness. To address the language barrier, the checklist was translated into various regional languages. The screening checklist used a five-point scale and covered five key aspects, including:

- Behaviour
- Emotion
- Cognitive and physiological regulation
- Social aspects

SI India trained CBR workers and special education teachers to use the screening checklist in schools, rehabilitation centres, and in the community with children and young people with deafblindness.

The next stage of the project will involve analysis of the screening checklist and the implementation of interventions following a two-pronged approach:



A special Educator is collecting data from the parent of a child with deafblindness using the Mental Health Screening Checklist developed by Sense International India.

***Courtesy of Sense International India***

The main challenges of developing and delivering this pilot project so far have been the lack of existing literature on mental health and deafblindness, translating the checklist accurately into local languages to ensure its validation, and the stigma among parents and caregivers around mental health issues. Although parents were sensitised on mental health within the pilot project, some parents did not want to answer questions truthfully due to the lack of understanding of its importance and the stigma

associated with mental health conditions. In addition, many parents who recognise the need for mental health supports for their children want a quick solution. The pilot project is still developing the referral pathways, but even once they are developed, the interventions will be dependent upon the existing mental health services available in India, which may not provide quick access to support. However, Sense International India will continue to work towards increased support to persons with deafblindness and their families on access to mental health services.

Going forward, SI India hopes to work with others in the deafblind community to validate the checklist, further integrate mental health considerations into its programmes and advocacy work and collaborate with civil society in India with a focus on mental health advocacy for policy-level changes.

## Recommendations

### Governments

Legally recognise deafblindness as a distinct disability and identify persons with deafblindness as a high priority group for

- access to affordable or state-funded health care, especially children with deafblindness, in low-income settings

Prioritise children with deafblindness in

- nutrition programmes and work with families to identify health risks and health advice

Form linkages between health and rehabilitation services for persons with

- disabilities and establish a deafblindness team that can serve as a resource for other health professionals

Develop standardised training and sensitisation modules for health care

- workers on deafblindness, related conditions, and communication methods to address stigma and knowledge gaps

Establish a system for booking interpreter-guide/Deafblind interpreting services for health appointments and inform health care

- staff on the practicalities of the booking service and how to work with interpreter-guides/Deafblind interpreters

Develop protocols on specialised health areas, such as SRH, to adapt services to

- meet the requirements of and ensure inclusion of persons with deafblindness

## **OPDs and NGOs**

Include measures to protect persons with deafblindness in a patient bill of rights, such

- as measures to prevent family members serving as a proxy

Advocate for health ID cards and updated health records stating that the person has

- deafblindness, their communication requirements, and basic health information

Advocate for and advise on accessible formats for public health information and

- include persons with deafblindness in consultations on access to information

## **Donors and Research Institutes**

Conduct national research on the causes of deafblindness to better understand the

- situation across countries and contexts and adapt prevention strategies based on evidence

Conduct research on the mental health of

- persons with deafblindness to better understand the prevalence of mental health

conditions, short- and long-term effects, and good practices / approaches for improving and managing mental health outcomes for persons with deafblindness.

## **Work, Employment, and Technical and Vocational Training**

Persons with deafblindness have the right to work on an equal basis with others, which includes the opportunity to gain a living through work that is freely chosen or accepted in the labour market. This includes the right to access technical and vocational training, equal opportunities for career advancement, opportunities for employment in the public sector, reasonable accommodation, and just and favourable conditions of work, such as equal remuneration for work of equal value, safe and healthy working conditions, and protection from harassment<sup>143</sup>.

However, the attitudes of employers, family members, technical and vocational education and training (TVET) institutes, local government officials organising livelihood programmes, and others are often the biggest barrier, as there are many misperceptions about the capabilities of persons with deafblindness and a lack of

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<sup>143</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 27.

understanding of their communication requirements<sup>144</sup>. Other barriers include lack of educational opportunities, transitioning from school to work, lack of opportunities for TVET, lack of reasonable accommodation or access to interpreter-guide/Deafblind interpreting services, and forced retirement due to the acquisition of deafblindness<sup>145</sup>.

One respondent from WFDB's survey noted that "the majority of people with deafblindness (in my country) work independently or in a family business or small business". This is because TVET is often provided without access to interpreter-guides/Deafblind interpreters or teaching assistants, making it only accessible to persons with deafblindness who have a high degree of functioning in communication. Many rely on courses and programmes offered by NGOs, encouraging self-employment through communication skills, training in a specific trade, coaching, and/or seed money to set up income-generating activities<sup>146</sup>. These programmes are often in the form of sheltered workshops (i.e., segregated programmes) that are not aimed at the

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<sup>144</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 24.

<sup>145</sup> *Ibid.*, p. 21.

<sup>146</sup> *Ibid.*, p. 23.

formal job market. While persons with deafblindness should be supported in seeking self-employment if freely chosen, working in the informal sector should not be the only option for persons with deafblindness. This is because sheltered workshops isolate persons with disabilities from the rest of the workforce, rarely result in independence or social inclusion, and often do not provide marketable skills or fair wages<sup>147</sup>.

The lack of legally recognising deafblindness, gaps in legislative and policy frameworks to ensure employers provide reasonable accommodations, and inadequate or non-existent interpreter-guide/Deafblind interpreting services leads to the systematic exclusion of persons with deafblindness in work. Furthermore, barriers to accessing banking services (e.g., due to restrictions of legal capacity) may also prohibit access to employment that is not on a cash-only basis.<sup>148</sup> In addition, some social protection systems eliminate the disability allowance if persons with disabilities receiving the benefit get a

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<sup>147</sup> Carter, Gill. "Lessons on deafblindness from research in East Africa", *DBI Review*, Issue 63, April 2020, p. 52-54; Neumann, Erik. *BBC World Service*, "Sheltered Workshops for People with Disabilities: A Reliable Opportunity or an Outdated System?", <https://www.kuer.org/health-care/2019-04-08/sheltered-workshops-for-people-with-disabilities-a-reliable-opportunity-or-an-outdated-system>, 8 April 2019.

<sup>148</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 24.

job. This is because social protection systems often do not distinguish between the effects of unemployment and the extra costs of having a disability (e.g., many employers do not provide reasonable accommodation for interpreter-guide/Deafblind interpreting services, accessible transportation, assistive devices or technology, etc.)<sup>149</sup>.

Tax incentives and national quotas are an increasing trend to encourage employers to hire persons with disabilities but are unlikely to lead to the employment of persons with deafblindness, especially if other measures are not in place to support their employment. This is because some employers will hire them to claim the tax break and either not provide meaningful work or tell them to stay home due to stigma and the lack of reasonable accommodations and access to interpreter-guide/Deafblind interpreting services<sup>150</sup>.

## Good Practices

Employers should be encouraged to support mainstream, waged employment of persons with deafblindness. This starts with education, and if persons with deafblindness do not receive a good education, they are unlikely to be prepared for

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<sup>149</sup> *Ibid.*, p. 19.

<sup>150</sup> *Ibid.* p. 24.

work. Education builds the confidence, soft skills, and independence required for the workplace. Adolescents with deafblindness may require additional supports in education to understand how to transition from secondary school into work, and some adults with deafblindness may require remedial or adult education on communication methods, literacy, numeracy, basic skills, job-readiness, and secondary school qualifications<sup>151</sup>. Adolescents and adults with deafblindness are also likely to require rehabilitation services from a cross-disciplinary team across all aspects of independent living related to employment, such as support for communication, orientation, mobility, learning to use assistive devices and technologies, and vocational training. The rehabilitation support may vary for each individual (e.g., some may require advice on how to interview for a job or how to address issues or barriers in the workplace). The key elements to supporting persons with deafblindness in work include:

- **Legal recognition of deafblindness as a distinct disability** so that the disability-specific supports are easy for persons with deafblindness to access

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<sup>151</sup> *Ibid.*, p. 28. See the chapter on Inclusive Education for more information on remedial education of adults with deafblindness.

**Strong anti-discrimination laws and legal and policy provisions that require employers to provide reasonable accommodation** for persons with disabilities, including deafblindness. This includes ensuring that employers

- understand their obligations and how to
- apply a reasonableness test to individual cases, which may require tools, trainings, and impartial advice from UN agencies, private consultants, government departments, statutory bodies, national disability councils, national human rights institutions, OPDs, and/or trade unions

Access to **affordable interpreter-guide/Deafblind interpreting services and assistive devices and technologies**, and

- acknowledgement of interpreter-guide/Deafblind interpreting services and accessible technologies as a reasonable
- accommodation for persons with deafblindness. Because interpreter-guide/Deafblind interpreting services are costly for employers, governments should provide a free service to persons with deafblindness to enable their employment and independence beyond work

- **National accessibility standards and guidelines for employers** to make

workplaces and work environments more accessible to persons with disabilities, including persons with deafblindness

- **CBR services linked with employment programmes** to ensure that persons with deafblindness have the communication skills, independence, confidence, and strategies for adapting to a new working environment and to provide support in retaining work

- Targeted **training for employers, family members, TVET providers, local government, and other employment stakeholders** on reasonable accommodations and the capabilities of persons with deafblindness to tackle stigma and misperceptions. For example, employers may be targeted through Business Disability Networks (i.e., networks comprised of OPDs and local employers aimed at increasing employment of persons with disabilities)

- Access to **inclusive mainstream TVET and employment programmes**, including career advice, employment pathways with a gradual approach for those that are hard to reach, and assistance in finding work that matches individual profiles and aspirations. TVET and employment programmes must

move away from sheltered workshops or programmes that segregate persons with deafblindness from those without disabilities, and persons with deafblindness may require teaching assistants or interpreter-guides/Deafblind interpreters to access TVET or employment programmes. **CBR services** may be integrated to support persons with deafblindness who require a targeted approach to increase autonomy and independence, allowing for a more gradual transition

- Removal of barriers to **access banking and other financial services** (e.g., loans to start a business)

**Access to TVET and employment programmes for family members in tandem with persons with deafblindness.**

- Family members often are unable to work for long periods because of caring responsibilities. As persons with deafblindness transition into work, carers
- should also receive support to help them transition into work, as family members may take control of employment and TVET programmes intended for persons with deafblindness, especially in countries with few economic opportunities. To support the wider family and the independence and

autonomy of persons with deafblindness, a more holistic approach may be required<sup>152</sup>.

Some persons with deafblindness may wish to run their own businesses, and this should be encouraged and supported if it is freely chosen. Entrepreneurial programmes aimed at self-employment should include business management skills, such as budgeting, procurement, record keeping, advertising, etc., and should be aimed at entrepreneurship in the formal economy rather than mere labour market participation. This also involves ensuring that information about self-employment is available in accessible formats<sup>153</sup>.

Some tips for employers to make their workplaces more inclusive of persons with deafblindness include:

- Commit to equality and non-discrimination
- through policies and explicit reference to this in job adverts and recruitment processes

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152 International Labour Organisation, *Disability Inclusion Makes Good Business Sense*, <http://www.businessanddisability.org/>, accessed June 2022; Light for the World, “Skills development for youth with deafblindness: fostering inclusion through skills training”, Disability Inclusion Insight Series No. 5, 2019; National Centre on Combined Vision and hearing Impairment / Deafblindness, *Eikholt Annual Report*, October 2021, p. 8; Pertoff, Jerry, “Transition from school or quality adult life for youth with deafblindness”, *DBI Review*, Issue No. 63, April 2020. p. 23-24; World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 24-28.

153 Kitching, John. “Entrepreneurship and Self-Employment by People with Disabilities”, *Background Paper for the OECD Project on Inclusive Entrepreneurship*, <https://www.oecd.org/cfe/leed/background-report-people-disabilities.pdf>, 2014, p. 10 & 20; Sense International, Mwanaasha Case Study, <https://senseinternational.org.uk/our-impact/mwanaasha-story/>, accessed October 2021.

- Conduct **internal sensitisation trainings**
  - for staff on persons with deafblindness to tackle stigma
- Develop **reasonable accommodation policies and procedures and accessibility standards** for a more
  - inclusive recruitment process and workplace, including access to interpreter-guides/Deafblind interpreters
- Adopt a more **flexible work environment**, including flexible hours and opportunities to
  - work from home, which can help to include persons with deafblindness
- Identify **internal ‘mentors’** or peers that are available to persons with deafblindness to
  - ask informal questions and to ensure they are included in the workplace culture
- Provide **planned and supported employment experiences** for persons with deafblindness who are hard to reach and
  - provide a community-based approach to ensure supports are in place for communication, transportation, transition into work, safeguarding policies, etc.
- Link with OPDs of persons with deafblindness** to better understand their accessibility requirements, reasonable

accommodations, and advice on retaining persons with deafblindness<sup>154</sup>.

In addition, because of technology's increasing importance in the workplace, technology companies should take steps to make digital tools and equipment more accessible to persons with disabilities. For example, many computer-operating systems are not compatible with screen reading software programmes and often need to be uninstalled and replaced by another operating system. By adopting a more inclusive approach to technology innovation and development, persons with deafblindness can more easily use workplace technology.

## Recommendations

### All

- Adopt measures to increase the employment of persons with deafblindness as an example to other employers (e.g., reasonable accommodation policies, sensitisation trainings, accessibility standards, flexible work environments, mentors, links with OPDs, and a planned

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154 Pertoff, Jerry, "Transition from school or quality adult life for youth with deafblindness", *DBI Review*, Issue No. 63, April 2020. p. 23-24; World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 24-25.

and supported work experience for persons with deafblindness)

- Amend NGO-, OPD-, and government-led TVET and employment programmes to move away from sheltered workshops and adopt more inclusive models for persons with deafblindness
- Ensure that entrepreneurial programmes aimed at self-employment of persons with deafblindness are focused on the formal economy, and not aimed at mere labour market participation, for a more sustainable impact

## **Governments**

- Develop a strong legal and policy framework prohibiting discrimination in employment on the grounds of disability, recognising the requirement of employers to provide reasonable accommodations, establishing accessibility standards for employers, and
- recognising deafblindness as a distinct disability and the need for interpreter-guide/Deafblind interpreting services. These measures should be prioritised over tax incentives or affirmative action programmes requiring quotas of persons with disabilities

so that persons with deafblindness have a fair chance of securing and retaining work

- Strengthen inclusive education in mainstream schools for children and young people with deafblindness

Form linkages between employment and CBR services for persons with

- deafblindness and adopt a gradual employment pathway for those that are hardest to reach

Require the banking sector to remove barriers to banking and financial services

- and strengthen legislation and regulations on legal capacity to be in line with CRPD Article 12

Establish interpreter-guide/Deafblind interpreting services and ensure affordable

- access to assistive devices and technologies for persons with deafblindness

Ensure that social protection benefits for persons with disabilities are separate from

- unemployment benefits and are aimed at covering the extra costs of disabilities

Adopt a holistic approach to employment programmes for persons with deafblindness

- to help family members who were carers transition into work

## OPDs and NGOs

- Work with government and other stakeholders (e.g., Business Disability Networks) to sensitise employment stakeholders on the capabilities and requirements of persons with deafblindness in the workplace
- Develop information tools and resources on accessibility requirements, reasonable accommodations, and advice on retaining persons with deafblindness in employment to share with government and employers
- Advocate to technology companies to make digital tools more accessible to persons with disabilities, including persons with deafblindness, and to adopt a more accessible and inclusive approach to technology innovation and development

## Donors and Research Institutes

- Conduct research on the common barriers to employment and challenges within work for persons with deafblindness
- Transition away from funding sheltered workshops or livelihood programmes that are segregated and aim for the informal economy. Instead, establish programmes aimed at tackling the main barriers, such as

access to interpreter-guides/Deafblind interpreters, awareness raising on stigma, anti-discrimination measures, and reasonable accommodations.

## Social Protection

Persons with deafblindness have a right to an adequate standard of living for themselves and their families, including food, housing, water, clothing, and the continuous improvement of living conditions. This involves access to social protection schemes and poverty reduction programmes that are mainstream (e.g., public housing, retirement age pension, unemployment assistance, etc.) and disability-specific (e.g., assistance with disability-related expenses or extra cost of disability and respite care)<sup>155</sup>.

Based on WFDB's research in 2018, households with persons with deafblindness in some countries were more likely to be in the bottom 40% in terms of socio-economic status compared to households with no members with disabilities<sup>156</sup>. Based on data from 36 countries in the MICS, children with deafblindness were 30% more likely to live in

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<sup>155</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 28.

<sup>156</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 18.

poverty compared to children without disabilities in upper middle-income countries. A household with a person with deafblindness affects the whole family, especially where there are limited or no community-based or social supports<sup>157</sup>.



**It requires a lot of time and money to care for children with deafblindness and in some cases it means employing somebody... to directly take care of the child if you are employed. In terms of medication, these children often need frequent medical check-ups, catering for medical bills, and transport. If the child is enrolled in school, it will require the caregiver to provide that child with communication and mobility (devices), or an interpreter-guide(/Deafblind interpreter), which escalates the cost.**



- Key informant from Sense International Uganda's study on caring for a child with deafblindness<sup>158</sup>

In most low- and middle-income countries, social protection schemes tend to focus on basic poverty-related issues or being able to work and

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<sup>157</sup> Sense International Uganda, *The Economic Impact of Caring for a Child with Deafblindness / Multi-Sensory Impairment*, November 2019, p. 32.

<sup>158</sup> *Ibid.*, p. 29-30.

do not cover the extra costs related to disability<sup>159</sup>. Extra costs of having deafblindness vary depending on individual needs and whether services are provided by the State, but some examples include:

- Assistive devices (e.g., glasses, magnifiers,
- Braille machines and supplies, hearing aids, red and white cane, etc.)
- Live assistance (e.g., interpreter-guides/Deafblind interpreters, personal assistants, private carers, private tutor /
- teaching assistant, childcare, family member serving as a carer and taking time off work, etc.)
- Accessible transportation
- Adaptations to the home
- Tuition at a private school and school meals,
- especially if public schools will not enrol a child with deafblindness
- Health and rehabilitation expenses (e.g., diagnosis, check-ups, screenings and
- assessments, tests, communication and rehabilitation services, medication, surgery, etc.)<sup>160</sup>.

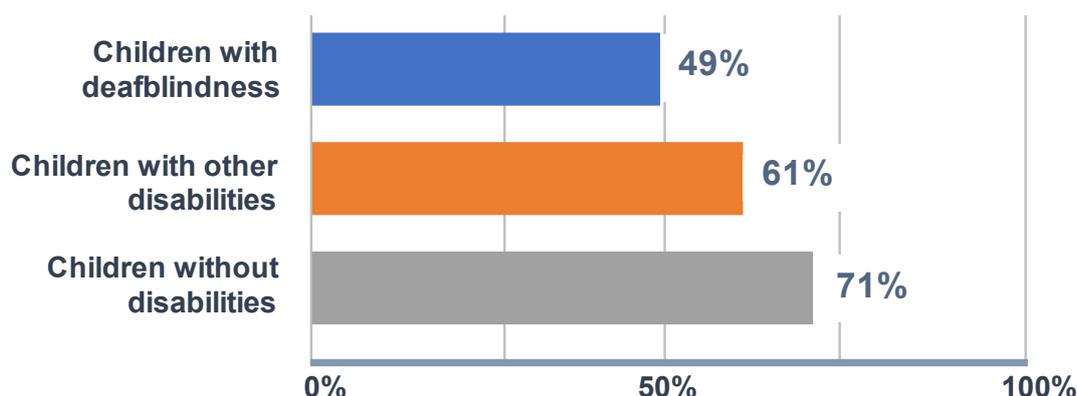
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<sup>159</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 19.

<sup>160</sup> Sense International Uganda, *The Economic Impact of Caring for a Child with Deafblindness / Multi-Sensory Impairment*, November 2019, p. 31-32.

To receive social protection benefits to cover these costs, children and adults with deafblindness are usually required to provide proof of eligibility, including proof of identity and proof of disability. Data from 36 countries in the MICS showed that approximately half of young children with deafblindness aged 2-4 years had their birth officially registered compared to 61% of children with other disabilities and 73% of children without disabilities. This varied widely by region with 28% in Sub-Saharan Africa to 100% in North Africa and West Asia. Registration also varied by country income level, with almost all children with deafblindness registered in middle-income countries but only 26% registered in low-income countries. The research did not explore the reasons for unregistered births. For the full country data, see Table 5, Annex 1.

## REGISTRATION OF BIRTH



Lack of personal identification, such as birth certificates, creates a barrier for individuals and

families in accessing social protection. In addition, if deafblindness is not legally recognised or not understood by health providers, their disability may not be accurately identified for social protection eligibility, which can affect the application of social protection supports. This often happens when deafblindness is not recognised and persons with deafblindness are forced to choose their disability identification between deaf or blind. In these instances, the social protection interventions are often tailored to the chosen group (e.g., free access to guiding services for the blind or entitlement to sign language interpretation for the deaf), which are insufficient for most persons with deafblindness. Disability identification can affect the types of social protection supports as well as the amount of money that certain groups are entitled to. For example, if deafblindness is recognised as a vulnerable group, they may have faster access to support in an emergency.

The analysis of the data from 36 countries in the MICS did not reveal a difference between children with deafblindness and children with other disabilities or no disabilities in terms of having both biological parents present in households. However, this data does not match the literature or WFDB's or Sense International's field experience. For example, a study in Uganda revealed that parental abandonment and single-parent households were often the result of conflict related

to the identification of deafblindness in the child and blame for the disability attributed to mothers. The capacity of single-parent households with children with deafblindness to meet basic needs is significantly reduced due to the caring responsibilities<sup>161</sup>. More targeted research is needed to better understand the links between poverty and persons with deafblindness, including the prevalence and impact of deafblindness in single-parent households.

Where social protection measures are in place, respondents to WFDB's survey noted that information on available schemes and guidance on eligibility requirements are often difficult to navigate.

## Good Practices

The first step to ensuring persons with deafblindness enjoy the right to an adequate standard of living is to **ensure that deafblindness is legally recognised as a distinct disability**.

This enables the development of tailored information, guidance, and eligibility of social protection schemes and paves the way for targeted interventions in other disability-specific and mainstream services, such as health, education, CBR, etc., as disability identification

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<sup>161</sup> *Ibid.*, p. 36.

cards are used in many countries to access tailored supports. In addition, measures should be taken to increase birth registrations and access to official identification, such as birth certificates, for children with deafblindness.

The following measures reflect good practices for the social protection of persons with deafblindness:

- Social protection schemes consider both the **poverty-related aspects of persons with deafblindness and their families as well as the extra costs of having**
- **deafblindness**, particularly in relation to the availability of free or affordable, inclusive services, including health, education, TVET, CBR, etc.
- **A holistic, targeted approach for households with persons with deafblindness** and for those with high support requirements is more likely to lead to greater independence and autonomy while addressing poverty. This should
- include **specific guidance to social workers and information to persons with deafblindness** and their families on the schemes and programmes that they are entitled to, as well as linkages to community-based supports from OPDs, NGOs, schools, health centres, etc.

## **Some specific considerations for social**

- **protection**, depending on the situation in the country, include:
  - health costs for identification, assessment, and treatment of health conditions related to deafblindness
  - Rehabilitation services
  - Access to assistive devices and technologies
  - Access to live assistance, including interpreter-guides/Deafblind interpreters, respite care, carers, etc.
  - Additional education costs (e.g., tutoring, teaching assistants, accessible learning materials, etc.)
  - Access to livelihoods for persons with deafblindness and their caretakers, including loss of income
  - Accessible infrastructure (e.g., transportation, housing, etc.)
  - Access to a support network, as many individuals and families become isolated

Additional **Linkages with mainstream and disability-specific services** to ensure that

- social protection measures address poverty and address the costs of disability as these costs link to access to services

- **Accessible information and eligibility guidance** on the types of social protections supports available

- **Training for frontline social protection workers** and government officials on deafblindness, the measures that address their poverty issues, and the administrative barriers to accessing these measures

- **Improved data collection on persons with deafblindness** to inform planning<sup>162</sup>.

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162 Sense International Uganda, *The Economic Impact of Caring for a Child with Deafblindness / Multi-Sensory Impairment*, November 2019, p. 29-30 & 53-54; World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 20.

## CASE STUDY

### **The Path to Tailored Supports Through Legal Recognition, Disability Identification Cards, and the Social Protection System: Lessons from Bangladesh**

There are a range of social protection supports for persons with disabilities in Bangladesh, including a disability pension of 750 Bangladeshi taka per month. There is also a smaller student stipend based on the number of students per household. In addition, tailored supports are linked to the social protection system, such as supports in education. These social protection measures are essential for persons with deafblindness, as many live below the poverty line and because of the extra costs of having a disability.

To access social protection measures and other tailored supports, persons with disabilities must be certified by a doctor and apply for a Disability Identification (ID) card, which is issued by the Department of Social Services.

Deafblindness was not legally recognised until 2013 in Bangladesh, and as a result, most persons with deafblindness were inaccurately categorised as having ‘multiple disabilities’ on

their Disability ID cards. The Centre for Disability in Development (CDD) in partnership with Sense International began advocating for deafblindness to be recognised as a distinct disability in 2007, and under the Disability Act of 2013, deafblindness was finally recognised as a distinct disability.

This did not lead to immediate changes for persons with deafblindness because many people, including social workers and government officials, still thought of deafblindness as a condition of multiple disabilities rather than a distinct disability. Now that deafblindness is recognised on ID cards, persons with deafblindness are better able to advocate for tailored supports, which was very difficult to do with the categorisation of “multiple disabilities”. For example, a student with deafblindness who has an ID card listing deafblindness may be in a better position to request to learn deafblind communication methods and receive communication supports in school than a student with deafblindness who has an ID card listing “multiple disabilities”.

CDD aimed to increase awareness so that deafblindness as a distinct disability could be better integrated and utilised within the social protection system and to ensure that social

protection benefits match the requirements of persons with deafblindness.

With support from Sense International, CDD trained social service officers in eight districts, since they are the entry point for issuing Disability ID cards and social protection benefits. Slowly, persons with deafblindness have been recognised through the ID cards.

This has led to concrete steps in improved support for persons with deafblindness. For example, during the COVID-19 pandemic, persons with deafblindness were given priority during relief (i.e., distribution of basic food items, hygiene kits, and financial support) because social service officials were sensitised and because persons with deafblindness were easier to identify. At the community level, there is greater awareness of deafblindness and improvements in identifying deafblindness and understanding the condition, including among teachers. Furthermore, as the disability movement in Bangladesh advocates for the introduction of standardised tailored supports for each disability, persons with deafblindness are more likely to be included in government plans because there is increasing data on persons with deafblindness through the ID card scheme.

Many challenges remain. For example, persons with deafblindness who have ID cards listing

‘multiple disabilities’ need to be better informed on how to change their status to ‘deafblindness’ and the benefits of doing so. Family members, doctors, and social service officials require continuous sensitisation on the importance of deafblindness as a distinct disability, the link between disability status on ID cards and the eligibility of social protection measures, and their role in facilitating the process. In addition, the disability pension and student stipend need to be increased, particularly for people with high or complex needs.

Nevertheless, CDD has demonstrated that ‘one size does not fit all’ regarding social protection mechanisms, and that there is a link between legal recognition of deafblindness, understanding of deafblindness, its importance as a distinct disability, and access to tailored social protection supports.

Noori, a 10-year-old student with deafblindness from Jashore District in Bangladesh, is holding her Subarna Nagorik Card, Disability ID card, where deafblindness is specifically mentioned.

***Courtesy of National Resource Centre on Deafblindness (NRCDB) and Centre for Disability in Development (CDD)***



## Recommendations

### Governments

- Legally recognise deafblindness as a

  - › distinct disability

Strengthen birth registration, disability identification, and other administrative
  - › processes for children and adults with deafblindness to enable them to access social protection schemes and programmes

Amend social protection schemes to consider both the poverty-related aspects of persons with deafblindness and their families, as well as the extra costs of having
  - › deafblindness, and create linkages with other mainstream and disability-specific services to reduce dependency on social protection mechanisms

Adopt a holistic approach to working with
  - › families with persons with deafblindness with high support requirements

Train social workers on deafblindness, the measures that address their poverty issues, and the administrative barriers. Create
  - › guidance for social workers to enable their continued support for persons with deafblindness

Make eligibility guidance and information on
  - › social protection schemes available in accessible formats

- Collect reliable data on persons with
- › deafblindness to inform planning

## **OPDs and NGOs**

- Document the extra costs of having deafblindness and make recommendations
- › to the social protection system based on the findings
- Develop sensitisation and training resources
- › for social workers on deafblindness and their requirements
- Work with persons with deafblindness, families, and social workers to design specific guidance and information for social workers supporting persons with deafblindness and their families on the
- › social protection schemes and programmes that they are entitled to. Establish linkages between community-based supports from OPDs, NGOs, schools, health centres, etc., and government-run social protection schemes and programmes

## **Donors and Research Institutes**

- Conduct research on the links between poverty and deafblindness, including the
- › extra costs of having deafblindness and the burden this places on households and the

prevalence and impact of single-parent households for children with deafblindness.

## Participation in Public and Political Life

Participation is a principle of the CRPD as well as a standalone right. This is because persons with disabilities, especially persons with deafblindness who experience communication barriers, are often excluded from making decisions that affect them. Persons with deafblindness have a right to participate in political and public life on an equal basis with others directly or through freely chosen representatives. This right includes the right to vote, the right to stand for election, and the right to participate in public affairs through participation in NGOs and associations, including through their own representative organisations<sup>163</sup>. In addition, OPDs should be involved in and participate fully in national CRPD monitoring processes<sup>164</sup>. Representation of persons with deafblindness should reflect their diversity of gender, age, communication preferences, ethnicity, and other aspects, and they should be represented at local, national, and international levels. The right to participate is a civil and political right and is,

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<sup>163</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 29.

<sup>164</sup> *Ibid.*, Article 33.c.

therefore, immediately applicable, and not subject to budgetary restriction<sup>165</sup>.

Voting systems, administrative procedures, and information on the practicalities of voting and candidate information are often inaccessible to persons with deafblindness. This can lead to family members believing that they are incapable of voting<sup>166</sup>. According to WFDB survey respondents, many rely on a ‘trusted person’ or family member to support them in voting. However, there is rarely a way to check whether the ‘trusted person’ has genuinely voted according to the person’s wishes. On the other hand, many countries do not provide any reasonable accommodations to support voting, such as allowing or providing live assistance, and where it is permitted, some persons with deafblindness do not trust family members to vote according to their wishes<sup>167</sup>.

Persons with deafblindness are rarely represented in politics, whether elected or appointed. Stigma plays a major role, but lack of access to accessible

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<sup>165</sup> Committee on the Rights of Persons with Disabilities, *General Comment No. 7 on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation of the Convention*, CRPD/C/GC/7, 9 November 2018, para. 28.

<sup>166</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 36.

<sup>167</sup> *Ibid.*

information, assistive devices, and reasonable accommodations, such as affordable interpreter-guides/Deafblind interpreters, as well as social isolation all, contribute to their exclusion<sup>168</sup>.

*Riku, a man with deafblindness, participates in a voting process during WFDB's General Assembly in Nairobi, Kenya in October 2022, with the support of his interpreter-guides/Deafblind interpreters. He is overseeing the counting process to ensure it is fair and transparent.*

**Photo taken by WFDB**



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168 *Ibid.*, p. 36-38.

One of the most effective ways for persons with deafblindness to participate in public life is through OPDs. WFDB has 75 national and associate members from 62 countries around the world (i.e., national OPDs of persons with deafblindness). However, these representative organisations often face barriers in maintaining registration through complex, expensive national processes, leading to inconsistent activity and barriers to funding. National disability movements also often fail to recognise OPDs of persons with deafblindness or to take steps to ensure their participation, leaving them on the fringes of national, regional, and international disability movements<sup>169</sup>.

The literature review included a review of shadow report submissions to the CRPD Committee State reporting process and revealed that very few shadow reports mentioned persons with deafblindness, demonstrating a significant gap in their participation of CRPD monitoring processes at the national level. The reasons for their exclusion are not entirely clear; however, communication barriers and lack of interpreter-guides/Deafblind interpreters, stigma about the capabilities of persons with deafblindness, and inconsistent functioning of OPDs of persons with deafblindness may all be contributing factors.

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<sup>169</sup> *Ibid.*

WFDB survey respondents noted that many OPDs of persons with deafblindness face barriers to funding, technical support, access to information, and interpreter-guides/Deafblind interpreters, which all facilitate their participation. For example, if an OPD for persons with deafblindness cannot track policy developments and opportunities to participate in consultation processes because they do not have access to interpreter-guide/Deafblind interpreting services, then the organisation will miss opportunities to influence decision-making.

## Good Practices

If deafblindness is recognised as a distinct disability, then voting systems are more likely to be required to adopt accessibility measures and make reasonable accommodations for voters with deafblindness.

Some good practices to ensure persons with deafblindness can vote on an equal basis with others include:

- **Provide guidance on the requirements of persons with deafblindness in the voting process**, including specific advice to election officials and training for electoral commission members and other election officials

- › **Ensure access to free interpreter-guide/Deafblind interpreting services to support the voting process**
- › **Create accessible voting information and materials** (e.g., Braille, large print, etc.)
- › **Provide accessible polling sites, voting machines, and ballots**, taking steps to ensure voting secrecy. For example, ballots can be made with tactile cues to align voting ballots within a template and tactile cues to vote yes or no. Persons with deafblindness may require training on how to use accessible voting machines and ballots from election officials. Accessible polling sites should include removal of physical barriers, accessible signage, and staff to provide support
- › **Ensure reasonable accommodations for individuals that require it**, such as allowing interpreter-guides/Deafblind interpreters or other live assistance to accompany persons with deafblindness throughout the process, accessible postal voting, or accessible e-voting that can be done remotely or in advance of the election day
- › **Create accessible information on candidates**, including debates (e.g., through captioning, accessible transcripts,

etc.). This may involve setting standards for political parties and TV / radio networks on providing accessible information

- **Enable observation** of the voting process by persons with disabilities or third parties to audit and assess the accessibility of the voting process, ensuring that the requirements of persons with deafblindness are considered, or appoint a person with deafblindness to the **independent body that oversees elections**<sup>170</sup>.

To enable persons with deafblindness to serve as elected or appointed representatives on an equal basis with others, government at all levels must adopt policies and procedures to support reasonable accommodations, such as access to interpreter-guides/Deafblind interpreters and accessible technologies, regardless of whether these roles are paid or voluntary.

Appointing a representative from an OPD of persons with deafblindness to serve on a local or national development committee or similar body is a good starting point and provides practical experience for persons with deafblindness in

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<sup>170</sup> SZBLIND, Voting secrecy – a right for everyone,

[https://www.szblind.ch/fileadmin/pdfs/Medien/PMT\\_Abstimmungsschablonen.pdf](https://www.szblind.ch/fileadmin/pdfs/Medien/PMT_Abstimmungsschablonen.pdf), 15 September 2021; World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 36-38.

public policy making<sup>171</sup>. Similarly, national umbrella OPDs should increase the involvement of persons with deafblindness in the leadership of the national disability movement and provide reasonable accommodations to facilitate their active participation. Steps should be taken to ensure the diversity of persons with deafblindness in a representational capacity. In addition, political parties should reach out to OPDs of persons with disabilities to learn how to mainstream their processes so that they can be more inclusive.

Participation of persons with deafblindness in OPDs is a good vehicle for facilitating their political participation. It is not uncommon for persons with deafblindness to join OPDs of the deaf or blind, especially if they had single sensory impairments and have acquired the dual sensory impairment. If there is not an OPD of persons with deafblindness in the country, then umbrella OPDs or OPDs of the deaf and/or blind may have members who are deafblind. Moreover, other OPDs (e.g., of the deaf or blind) are ideally placed to provide financial, technical, or logistical supports for OPDs of persons with deafblindness that require it. OPDs of the deaf or blind should not, however, be used as proxies for OPDs of persons with deafblindness.

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<sup>171</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 37.

Because OPDs of persons with deafblindness face significant communication barriers, they often struggle to maintain consistent operations.

However, they are the authoritative voice of persons with deafblindness. OPDs of persons with deafblindness can be supported in the following ways to strengthen their participation in decisions that affect them:

- **Removal of barriers for official registration** (e.g., providing communication supports for OPDs to register, free or sliding scale registration fees, and removal of unnecessary re-registration procedures to ensure greater accessibility). Registration should not be a pre-requisite for taking part in consultation processes. However, where these regulations are slow to change, other OPDs and NGOs should help OPDs of persons with deafblindness to address the gaps and ensure they can consistently function, as official recognition is often a requirement for participating in official consultation processes and may be necessary for funding
- **Increased funding and support to obtain funding.** Funders can set up OPDs of persons with deafblindness to use fiscal sponsors, be involved in partnership grants, apply for small grants, and should remove

administrative barriers or eligibility criteria that are likely to affect funding opportunities (e.g., submission of an annual report). If funding is through a partner organisation or fiscal sponsor, steps should be taken to ensure that OPDs of persons with deafblindness are making decisions, including financial decisions, that affect them. Additionally, it is crucial to ensure fiscal sponsors are building their capacities. Funding should include accessibility costs (e.g., interpreter-guides/Deafblind interpreters) to make sure participation is genuine

- **Support in tracking consultation opportunities** provided by umbrella OPDs, UN agencies, national disability councils, and others. For those OPDs that do not have access to interpreter-guide/Deafblind interpreting services, a system can be devised in partnership with other organisations to help to facilitate their participation, which may also include assisting with reasonable accommodations and communications between parties. Government and UN stakeholders that regularly seek input from OPDs should develop systems for reaching out to OPDs of persons with deafblindness to ensure

their participation. National disability councils can play a key role in improving the participation of OPDs of persons with deafblindness and addressing the gaps, and they should promote the appointment of persons with deafblindness on committees and working groups

- **The inclusion of accessibility measures and reasonable accommodations,** especially interpreter-guides/Deafblind interpreters, in consultative processes. This may also include planning with plenty of advance notice to enable booking for interpreter-guides/Deafblind interpreters, providing information in accessible formats, sending information in advance or preparing ‘pre-event sessions’ to cover some of the content prior to the event, and moving at a slower pace to ensure interpreter-guides/Deafblind interpreters have sufficient time to interpret. Accessibility guides can ensure the smooth participation of persons with deafblindness in consultation processes. In some countries where there are very few supports for deafblind communication, **linkages between OPDs of persons with deafblindness and CBR services** may be needed to ensure that persons with deafblindness have the

necessary communication skills to participate

- **Increased technical support to improve organisational functioning** in organisational development (e.g., leadership and governance development, financial management, strategic planning, programme or project planning, monitoring and evaluation, membership growth and retention, etc.) and in methods for effectively representing persons with deafblindness (e.g., advocacy and lobbying, campaigning and communications, research, evidence-based reporting, CRPD monitoring, etc.)
- **Use OPDs of persons with deafblindness and not proxies for the voice of persons with deafblindness.** The wider deafblindness community includes many allies, such as organisations of parents and family members of persons with deafblindness, deafblindness experts and professionals, service providers, disability NGOs, and deafblindness networks. WFDB and its members rely on and work in partnership with these allies. Habits and linkages can form, resulting in consultation processes that usurp the voice and direct input from OPDs of persons with deafblindness. This can affect policy and

programmatic decision-making, for example, on the priorities and approaches used in services. Governments, UN agencies, and others that lead consultation processes have a responsibility to directly invite and support the participation of OPDs of persons with deafblindness in decisions that affect them, and allies should take steps to adjust their roles and serve as facilitators to encourage and support the participation of persons with deafblindness, using a partnership model<sup>172</sup>.

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<sup>172</sup> Committee on the Rights of Persons with Disabilities, *General Comment No. 7 on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation of the Convention*, CRPD/C/GC/7, 9 November 2018; World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 36-38.

## CASE STUDY

### **A Consortium of Solidarity and Support to Establish an Organisation of Persons with Deafblindness: Lessons from Nepal**

The Deafblind Association of Nepal (DAN) was established in 2012 and has been working in partnership with the national parents' association, the Society of Deafblind Parents (SDBP), to establish and strengthen the legal definition of deafblindness based on the views of persons with deafblindness and their families. The Disability Rights Act of 2017 in Nepal includes deafblindness as one of the ten categories of disability. However, the language in the law inadequately describes deafblindness, which leads to barriers in accessing the correct identity card and access to services for persons with deafblindness.

This barrier has arisen because persons with deafblindness and their families were not fully included in the government process to develop the law. Therefore, DAN and SDBP have been advocating to improve the participation of persons with deafblindness in decision-making at the local, provincial, and national levels.

A consortium of DAN, SDBP, the National Federation of the Deaf Nepal (NDFN), and the

Nepal Association of the Blind (NAB), was formed in collaboration with Sense International to promote greater participation of persons with deafblindness in decision-making at all levels. DAN and SDBP bring the voice and lived experiences of persons with deafblindness, while NDFN and NAB bring stronger links with the government and greater influence in policy-making based on experience. For example, NDFN is represented on the Disability ID Card Committee, advising the government.

Partnerships with other OPDs are a good way to strengthen the voice and capacities of OPDs of persons with deafblindness and their members. Many persons with deafblindness have links with OPDs of persons with single sensory impairments. The single sensory OPDs may have members who were originally deaf or blind and have acquired deafblindness, which has helped these OPDs to better understand deafblindness. While the services for single sensory impairments are usually insufficient for persons with deafblindness, the single sensory OPDs may share similar goals with persons with deafblindness on some advocacy issues, which can lead to natural alliances.

Members of DAN and SDBP discussed and debated the definition of deafblindness through a series of workshops, and a task force was

created to amend the legal definition. This definition was ultimately validated in a national workshop that had a broader representation than the members of DAN and SDBP. This amended definition was presented to the government's Disability ID Committee by persons with deafblindness. Members of DAN and SDBP also met with the Ministry of Women, Children, and Senior Citizens to advocate for the amended definition of deafblindness. This is currently under review and further advocacy aimed at the Cabinet or Parliament may be needed.

The consortium also advocated to have persons with deafblindness represented on the national High-Level Committee on Disability, an advisory body on policy and programming established by the Disability Rights Act, and on the provincial-level committees. The consortium has been successful in achieving representation at the national level and in two of the seven provinces. They continue to advocate for further representation at the local level.

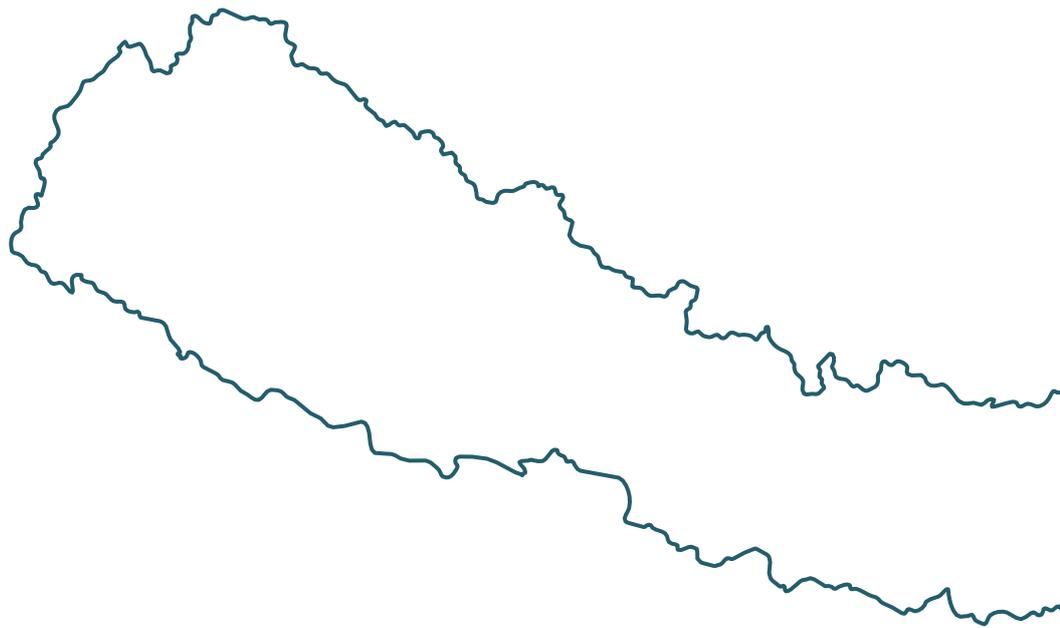
Because these advocacy efforts were OPD-led, they reflected the priorities and views of persons with deafblindness, which is extremely important for a group that often experiences marginalisation of their voice due to communication barriers. These communication barriers were addressed through the following measures:

- › A support system for providing interpreter-guide/Deafblind interpreting services
- › Providing documents and communications in accessible formats
- › Identifying the reasonable accommodations of participants and making adjustments according to the requirements of individuals
- › On-going capacity building support by NDFN and NAB to strengthen the deafblind movement and their networks.

Persons with deafblindness have become more visible within the disability community in Nepal as a result of this project. The government also started to recognise persons with deafblindness as a distinct group and allocated some funds to support them with their advocacy at the local, provincial, and national levels, which has helped them to expand their reach to new districts. The government has also invited the participation of persons with deafblindness in policy meetings and provided reasonable accommodations to enable participation, especially communication support.

Meaningful participation of persons with deafblindness in decision-making requires accessibility considerations, reasonable accommodations, and communication supports,

including interpreter-guide/Deafblind interpreting services. In addition, capacity building and partnerships with other organisations help OPDs of persons with deafblindness to achieve their goals, overcome barriers, and build their knowledge and experience. Most importantly, it is essential to evaluate how effectively the voices of persons with deafblindness are being heard by assessing whether their voices are being recognised and if their rights are fulfilled.



## Recommendations

### Governments

Develop guidance and advice for persons with deafblindness and election officials on

- measures and supports to enable persons with deafblindness to vote

Provide access to interpreter-

guide/Deafblind interpreting services for

- voting, serving in appointed or elected roles, and participating in public consultation processes, including for OPD members

Provide voting information, including

information on candidates / parties, and

- information open to public consultation available in accessible formats

Support reasonable accommodations of persons with deafblindness for voting,

- serving in an appointed or elected role, and participating in consultation processes

Remove barriers for official registration of

- OPDs of persons with deafblindness to enable their full and effective participation

Enable observation of the voting process by persons with disabilities or third parties to

- audit and assess the accessibility of the voting process, ensuring that the requirements of persons with deafblindness

are considered, or appoint a person with deafblindness to the independent body that oversees elections

- Establish mechanisms and guides for informing OPDs of persons with deafblindness about consultation opportunities and support them throughout the consultation process

## **OPDs and NGOs**

- Provide tailored technical support to OPDs of persons with deafblindness based on the evolving learning needs of the group, rather than on disability sector trends

- Create partnership models that increase the capacity and exposure of OPDs of persons with deafblindness and mentor OPDs to take on increasing responsibilities with demonstrated achievements

- Track opportunities for consultation for OPDs of persons with deafblindness and establish procedures for ensuring their direct input, including the CRPD and SDG monitoring processes

- Express the requirements of persons with deafblindness, especially of interpreter-guides/Deafblind interpreters, in all disability advocacy tools (e.g., briefings, reports,

submissions, etc.) where the requirements and recommendations of persons with disabilities are mentioned

Advocate to political parties to adopt disability mainstreaming to make their

- processes more inclusive and to encourage more persons with disabilities to participate in political processes

## **Donors and Research Institutes**

Increase funding opportunities for OPDs of persons with deafblindness and adapt administrative procedures to remove barriers for them (e.g., through fiscal

- sponsorship, reduced grant sizes for small or emerging organisations, and partnership funding models that ensure agency of persons with deafblindness)

Encourage funding programmes and proposals on persons with disabilities to

- include OPDs of persons with deafblindness as a priority underrepresented group

Support the technical assistance to OPDs of persons with deafblindness based on the

- evolving learning needs of the group, rather than on disability sector trends.

## Recreation and Participation in Social Life

Social life is an integral part of the human experience and essential to well-being and the capacity to thrive. The rights directly affecting the social life of persons with deafblindness include:



Accessibility



Living independently and being included in the community



Personal mobility



Freedom of expression and opinion, and access to information



Respect for home and the family



Participation in cultural life, recreation, leisure, and sport<sup>173</sup>.

Notably, persons with deafblindness have the right to marriage, family, parenthood, and relationships on an equal basis with others<sup>174</sup>. They also have the right to take part on an equal basis with others in cultural life, recreation, leisure, and sport. For

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<sup>173</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Articles 9, 19, 20, 21, 22, and 30.

<sup>174</sup> *Ibid.*, Article 22.

children with deafblindness, this includes the right to play<sup>175</sup>.

Social isolation among persons with deafblindness at all ages is a common challenge. Communication barriers reduce or alter interactions with people and impact social networks, including the support network of persons with deafblindness. Difficulties in being understood lead to fatigue, frustration, and stress in social situations<sup>176</sup>. Barriers to accessing information, developing independent living skills, mobility issues, and caregiver dependency combined with the communication barriers obstruct social contact and reduce participation in social activities<sup>177</sup>. Therefore, persons with deafblindness are more likely to experience decreased participation in everyday activities, which can lead to stigma about the social capabilities of persons with deafblindness, low self-esteem, lack of support, and a lower quality of life<sup>178</sup>.

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175 *Ibid.*, Article 30.

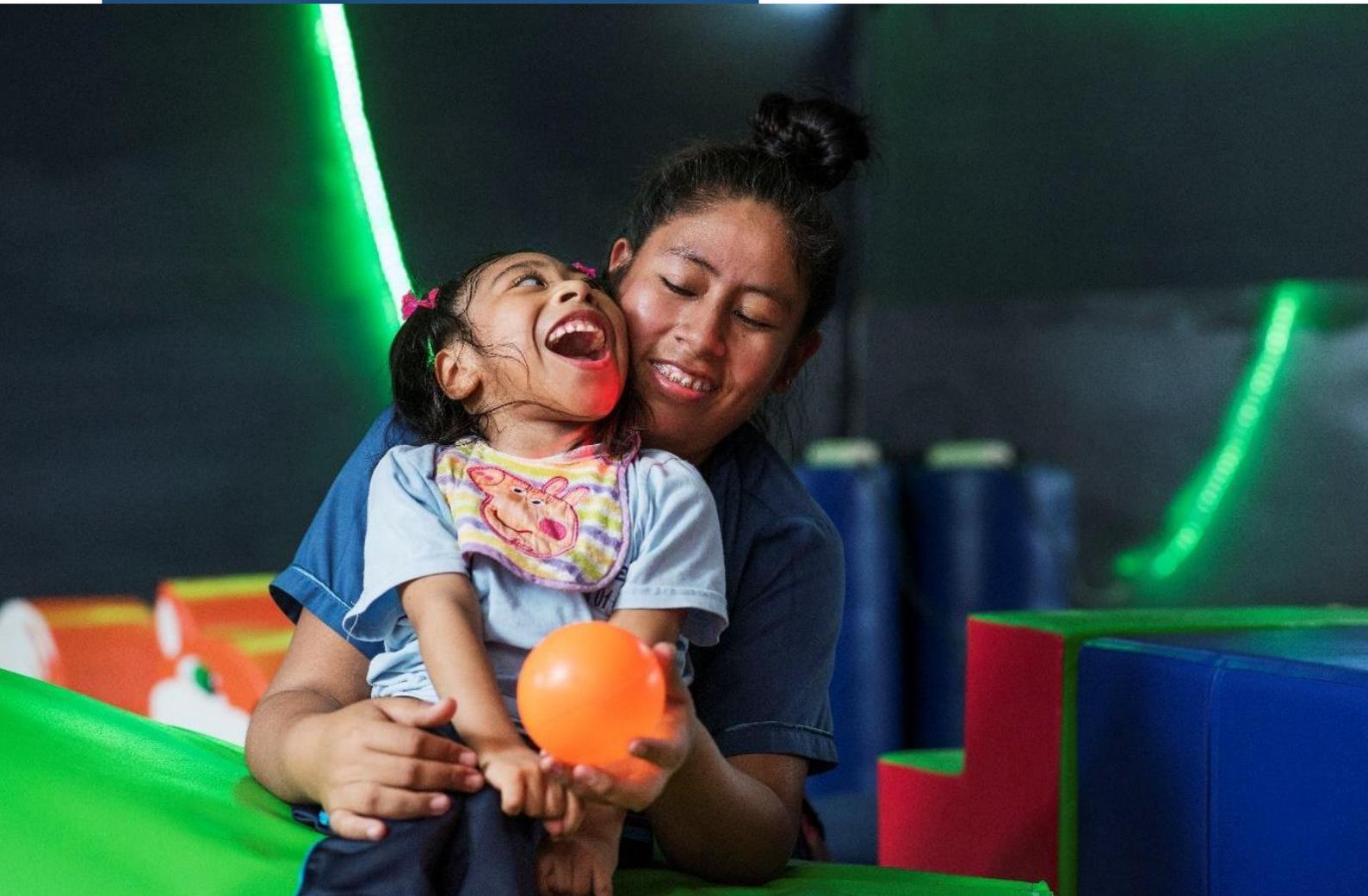
176 World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 40.

177 *Ibid.*, p. 41; Choudhary, V., *Connecting Youth and Adults with Acquired Deafblindness: An Action Research Study to Gain Insights into the Benefits of Age Diversity in Peer-Matching*, 29 July 2020, p. 2.

178 World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 40-41.

*A woman and a child with deafblindness are playing at an indoor playground.*

***Courtesy of Sense International***



Particularly, family life for persons with deafblindness and their families can be drastically affected by the stresses and strains of caring responsibilities, stigma, and general lack of support. Caregivers can significantly empower or

disempower persons with deafblindness in social settings<sup>179</sup>. In extreme cases, these stresses can result in violence, neglect, and abuse of persons with deafblindness by caregivers (e.g., some may be locked away or medicated to sleep all day). Caregivers can sometimes be overly protective and risk avoidant, preventing persons with deafblindness from participating socially<sup>180</sup>. Conversely, a highly supportive family can provide a safe, accepting space for persons with deafblindness that encourages learning, exploration, and personal growth.

However, persons with deafblindness should not rely exclusively on families for social interaction. People who acquire deafblindness may go from having social networks that focus on friends and family members to social networks largely comprised of professionals who support them and have reduced contact with family and friends<sup>181</sup>. Moreover, for those that acquire deafblindness, especially in older persons, it is often the social isolation that can be an indicator of the prevalence of acquired deafblindness. Persons with prelingual

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<sup>179</sup> Prause, D. et al, *Balancing on a knife-edge: Experiences of older patients with acquired DB when receiving existential care*, provided by author, accessed October 2021.

<sup>180</sup> World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 41.

<sup>181</sup> Goransson, Lena. *Deafblindness in a Life Perspective: Strategies and Methods for Support*, [www.skane.se/dovblindteam](http://www.skane.se/dovblindteam), 2008, p. 57-58.

deafblindness may struggle to find people beyond family and professionals supporting them who can communicate with them, significantly limiting the scope of possible social interactions. This, in turn, can affect social development as well as the development of communication skills due to the low- exposure to diverse people.

According to WFDB survey respondents, the rules for using interpreter-guides/Deafblind interpreters often prioritises 'essential' activities, such as education, employment, health visits, etc., and may limit the available hours, requiring persons with deafblindness to prioritise the tasks they wish to complete that require assistance. Social interaction is often overlooked as an essential aspect for live assistance. For example, the Norwegian Association of the Deafblind (NADB) highlighted that persons with deafblindness over the age of 67 (i.e., the age of retirement) are not entitled to interpreter-guide/Deafblind interpreting services for social activities, implying that a social life is irrelevant to older persons with deafblindness. WFDB survey respondents noted that OPDs are often the only entity in countries providing support for social inclusion, but many are limited in what they can organise due to the costs.

## **Good Practices**

Recent experiences of the COVID-19 pandemic have brought to light the impact of social exclusion

through the barriers of enforced restrictions on social interaction and the impact that this has on people's lives. In a post-pandemic world, there are opportunities to increase awareness of the impacts of social isolation on persons with deafblindness, as well as opportunities for greater social empathy and understanding of the core human right to socially interact with others on a regular basis<sup>182</sup>.

Social networks and activities are essential for maintaining positive health in persons with deafblindness, especially in older persons, because it strengthens their support networks, and improves their quality of life, health outcomes, and mental health. Patience and sufficient time to allow for communication are important factors to ensure a smooth social experience. Some key elements and measures to enhance and improve social inclusion for persons with deafblindness include:

- ▶ **Access to interpreter-guide/Deafblind interpreting services** for social interactions and recreational activities, recognising these
- ▶ as 'essential', as well as access to **assistive devices and technologies** to improve personal independence and mobility
- ▶ **CBR services that address barriers to social interaction** as a priority for persons

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<sup>182</sup> Ebuenyi, I., et al. "COVID-19 as social disability: the opportunity of social empathy for empowerment", *BMJ Global Health*, 2020, 5:e0003039. Doi: 10.1136/bmjgh-2020-003039.

with deafblindness to identify and amend strategies in individual plans, including individualised education plans for children with deafblindness, that are updated over the individual's course of life. This includes working with the social networks of persons with deafblindness, including families, on strategies for supporting social inclusion

- **Accessible information** on social, cultural, and recreational activities and opportunities

- **Accessibility standards and guidance** for public recreational venues and transportation operators to increase inclusion of persons with deafblindness in accessing recreational activities

- **Support to OPDs of persons with deafblindness to arrange and enhance social activities** for persons with deafblindness. This may include the development of **peer networks or mentoring programmes** so that persons with deafblindness can share learning on social inclusion with other persons with deafblindness. This support should also include **schemes to develop networks of support**, such as mediators, coordinators, volunteers, companions, and others, who are sensitised on deafblind communication and can play a role in facilitating social

interaction and recreational activities. Where possible, multi-party engagement should be encouraged to develop more advanced social interactions and to build peer relationships

**Sensitisation training for caregivers** on methods for increasing autonomy and positive social interactions for persons with deafblindness and to overcome stigma. This

- can be delivered by parents' groups, OPDs, CBR services, schools, and other service providers, depending on the situation in the country

**Information and guidance to support the participation of persons with**

**deafblindness** in social, recreational, and cultural activities. For example, the Danish Association of the Deafblind (FDDDB) developed a hiking course and nature guide

- for families focusing on interpretation, visual descriptions, and techniques for hiking with a companion. These guides can be developed by museums, libraries, cinemas, theatres, sports venues, parks, and other sites<sup>183</sup>.

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Ardura Rod, A. et al. *Leisure Activities and Free Time: Planning and Development According to Levels*, <http://www.asocide.org/publicaciones/>, accessed October 2021; Danish Association of the Deafblind (FDDDB), *Close to Nature: with new methods for hiking and sight description report*, <https://www.fddb.dk/tilbud-til-dig/pjecer-boeger-og-andre-udgivelser/boeger-og-rapporter/taet-paa-naturen-med-nye-metoder-til-vandring-og-synsbeskrivelse-rapport/>, accessed October 2021; Liston,

Lastly, caregivers and organisations involved in the social activities of persons with deafblindness should be mindful of the authenticity of the social interaction. Persons with deafblindness need to have trust in the activities, including the motivations for the orchestrated social activity. While some planned group activities among persons with deafblindness are often welcomed, they should not be forced as a means of finding solutions to limited social interactions, as this can detract from the autonomy and the authentic qualities of social engagement<sup>184</sup>.

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Lilias. "How to Become a Bridge, not a Barrier: Building Peer Relationships for a Young Man with Congenital Deafblindness Using Multiparty Interactions in the Tactile Modality", *DBI Review*, Issue No. 65, April 2021, p. 20-24; Pertoff, Jerry. National Transition Follow-Up of Youth Identified as Deafblind: Parent Perspectives, <https://www.govinfo.gov/content/pkg/ERIC-ED465234/pdf/ERIC-ED465234.pdf>, August 2001; Prause, D. et al, *Balancing on a knife-edge: Experiences of older patients with acquired DB when receiving existential care*, provided by author, accessed October 2021; World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 40-41–

184 Choudhary, V., *Connecting Youth and Adults with Acquired Deafblindness: An Action Research Study to Gain Insights into the Benefits of Age Diversity in Peer-Matching*, 29 July 2020, p. 12.

## CASE STUDY

### **Social Connection Through Dance: Lessons from Kerry in the United States**

I have been a dancer for 18 years but learning to dance took longer for me since I was the only deaf person in the classroom. I wanted others who are deaf to have an easier, more accessible experience. I started Silent Rhythms, Inc., a dance class that I taught for the deaf in Boston, Massachusetts, USA. As I became blind, I knew that I wanted to expand the classes to reach those, who like myself, are deafblind.

Over time, I saw that dance was a wonderful way to bring people of different backgrounds together both on and off the dance floor, so things evolved. Silent Rhythms' mission is to promote the inclusion of persons with disabilities in the arts and to promote wider inclusion in society. We make the dance fit the person rather than trying to fit the person to the dance.

Since 2008, more than 6,000 persons with disabilities have taken in-person dance lessons, and 10,000 people without disabilities have also participated, learning more about how to include persons with disabilities in dance. The deafblind community in Boston is small, but we have taught 40 persons with deafblindness from various

backgrounds, ages, communication preferences, etc.

All dance classes are free to persons with disabilities and are taught by a dance teacher who knows sign language. Before all dance classes, there is a pre-workshop that teaches everyone how to communicate with persons who are deaf or deafblind, and there are interpreters on-site to support communications. We arrange the lessons so that persons with deafblindness are paired with persons without disabilities, who support orientation and mobility.

We hold our events near public transportation to make it easier for people to access, but we sometimes arrange transportation for persons with deafblindness. We also try to diversify the location of events. For example, older persons with deafblindness prefer a familiar location, whereas younger persons with deafblindness enjoy our outdoor community events. We also work with persons with deafblindness to help them realise their own potential, since many do not feel confident that they can learn to dance.

There are many barriers preventing persons with deafblindness from participating in social activities, including communication, cost, transportation, and attitudes. Many social events in Boston that are accessible only consider the needs of people who are either deaf or blind and

do not consider the unique requirements of persons with deafblindness. Also, because the deafblind community is small and diverse with individualised communication needs, it is harder for persons with deafblindness to come together as a single community.

Silent Rhythms was built on my connections with the dance community in Boston, and we have had a lot of support from them, including from the dance company that taught me to dance. We also have links with OPDs and disability organisations and reach out to them to advertise our events.

Because Silent Rhythms was founded by a person with deafblindness, we have understood their needs. We also work closely with our dance students with deafblindness, seeking their feedback and strengthening our programmes. One of my students with deafblindness has been coming to our events for ten years and has been learning how to teach others. It is, therefore, important to give persons with deafblindness the opportunities to not only participate, but to also plan, teach, and lead social activities.

Being deafblind can lead to extreme isolation. Social activities help to bring us out of this isolation and to interact with others. It also helps the world to learn about deafblindness. One of the key benefits of the arts has been the

promotion of well-being and positive mental health, which is important for persons with deafblindness. It is also my way of staying connected. I hope to be dancing well into my eighties.

Kerry Thompson, Founding Executive Director of Silent Rhythms, Inc., dancing at one of their events.

*Photo taken by Maureen White*



## Recommendations

### Governments

- Rescind legislation and policies that hinder the right to form a family for persons with deafblindness
- Adopt measures to support families with persons with deafblindness (e.g., social protections, respite care, etc.) to alleviate stresses and strengthen families as part of the support network
- Provide interpreter-guide/Deafblind interpreting services for social, recreational, and cultural activities for persons with deafblindness to prevent isolation and exclusion and provide access to assistive devices and technologies to enable independence
- Establish accessibility guidance tools (e.g., on accessible communications) for public recreational, cultural, and sporting activities
- Ensure CBR, education, mental health, and other essential services facilitate social inclusion and social development for persons with deafblindness throughout their life cycle
- Support civil society programmes to advance the social engagement of persons

with deafblindness in line with the CRPD (e.g., through funding NGOs, OPDs, and others) to organise activities, peer networks, mentoring and volunteer programmes, etc.

## **OPDs and NGOs**

- Develop partnerships with OPDs of persons with deafblindness and parents' groups to establish interventions to increase social interactions and to combat isolation of persons with deafblindness
- Arrange and enhance authentic social activities for persons with deafblindness (e.g., peer networks, mentoring programmes, and schemes for mediators, coordinators, volunteers, companions, and others) who are sensitised on deafblind communication and who play a role in facilitating social interaction and recreational activities
- Deliver sensitisation training for families and caregivers on methods for increasing autonomy and positive social interactions for persons with deafblindness and to overcome stigma

- Work with social, recreational, sports, and cultural institutions to develop information and guidance on how to support the participation of persons with deafblindness in activities and reach out to the deafblind community to advertise inclusive venues and activities

## **Donors and Research Institutes**

- Conduct research on the social isolation of persons with deafblindness and the community-based interventions that effectively tackle loneliness and isolation of persons with deafblindness
- Provide grants to community-based groups and social enterprises, especially those led by persons with deafblindness, to develop interventions to increase social interaction and access to recreational activities of persons with deafblindness, recognising the central importance of social interaction on wellbeing.

## **Preventing and Responding to Violence, Abuse, and Exploitation**

Several rights protect the safety and integrity of persons with deafblindness, including:

- Freedom from torture or cruel, inhuman, or degrading treatment or punishment
- Freedom from violence, exploitation, and abuse
- Protecting the integrity of the person<sup>185</sup>.

There was a lack of literature in the literature review on violence, exploitation, and abuse of persons with deafblindness, and the quantitative research did not show significant findings on the supervision of children with deafblindness. This was largely because of the way that the quantitative data was captured (e.g., by asking caregivers) which results in underreporting. However, even if there is underreporting of incidents of violence, this does not mean that violence is not happening.

The field experiences of WFDB and Sense International are that persons with deafblindness are at increased risk of violence, including forced sterilisation, gender-based violence, bullying and harassment, sexual violence, emotional violence and neglect, and physical violence in the home, at work, in institutions and residential facilities, and in the community. Data on children with disabilities show that they are three to four times as likely to

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<sup>185</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Articles 15, 16, and 17.

be survivors of violence than children without disabilities<sup>186</sup>, and women with disabilities experience up to ten times more violence than women without disabilities<sup>187</sup>. There is little data on violence against persons with deafblindness. However, this data on persons with disabilities, in general, demonstrates the pervasive nature of violence and the risks to persons with deafblindness, as a highly marginalised group within the wider group of persons with disabilities. Some of the key risk factors affecting persons with deafblindness include:

- Lack of support to develop communication skills or access to information or reporting mechanisms. For example, families may hide persons with deafblindness from the community, blocking access to reporting mechanisms. In addition, they may lack awareness of what constitutes violence, which can be difficult if they rely on touch for communication

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186 UNICEF, *The State of the World's Children 2013 – Violence against Children with Disabilities*, <https://www.un-ilibrary.org/content/books/9789210597593>, p. 11-29.

187 UNFPA, *Young Persons with Disabilities: Global Study on Ending Gender-Based Violence, and Realising Sexual and Reproductive Health and Rights*, [https://www.unfpa.org/sites/default/files/pub-pdf/Final\\_Global\\_Study\\_English\\_3\\_Oct.pdf](https://www.unfpa.org/sites/default/files/pub-pdf/Final_Global_Study_English_3_Oct.pdf), 2018.

- Caretaker dependency may result in domestic abuse, child abuse, or institutional abuse. A lack of supports for families can add to the stresses and lead to harmful practices of ‘managing’ persons with deafblindness, especially in poor families. For example, a child with deafblindness in Uganda may be left at home unattended or locked up, if the parent needs to work but has no access to childcare, leaving them at risk and subjecting them to inhuman conditions
- Exclusion from sexual and reproductive education programmes that provide information on gender-based violence and sexual violence<sup>188</sup>.

Though there is increasing awareness of violence against persons with disabilities, there is little attention to the deafblindness-specific risk factors and little awareness raising within deafblind communities across all countries.

## Good Practices

To understand the prevalence and nature of violence against persons with deafblindness, more targeted quantitative and qualitative research is

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<sup>188</sup> Sense International Uganda, *The Economic Impact of Caring for a Child with Deafblindness / Multi-Sensory Impairment*, November 2019, p. 58; World Federation of the Deafblind, *At risk of exclusion from CRPD and SDG implementation: Inequality and Persons with Deafblindness*, <https://wfdb.eu/wfdb-report-2018/>, September 2018, p. 35, 41, and 43-46.

needed. Research that is conducted on violence against persons with disabilities should include persons with deafblindness to ensure that they are not excluded from the research. This may require time-consuming and costlier steps to identify persons with deafblindness and to overcome the communication barriers and stigma of discussing violence. However, working with OPDs of persons with deafblindness, service providers, and parents' groups can help identify persons with deafblindness in the community that have experienced violence. In some instances, persons with deafblindness may require sensitisation on what constitutes violence, depending on their communication abilities and existing understanding of violence.

Research on violence should consider the programmatic interventions to prevent and respond to situations of violence once identified as part of the research programme. Some elements for preventing and responding to violence against persons with deafblindness include:

- **Supports for families and caregivers** to address the risks of violence (e.g., social protection / caregivers' salaries, child- or adult-care services, access to education to ensure children with deafblindness are not out of school, respite care, and other community-based supports)

- **Guidance to social workers, schools, health centres, etc.** on recognising the risks, patterns, and signs of abuse of persons with deafblindness
- **Information on how to report violence** available in accessible formats and targeted education programmes aimed at persons with deafblindness to raise their awareness
- **Inclusive and accessible sexual and reproductive health education programmes** that consider the requirements of persons with deafblindness (e.g., interpreter-guides/Deafblind interpreters, accessible information, assistive devices, etc.)
- **Inclusive measures in violence prevention and response programmes** for the wider community, including access to interpreter-guides/Deafblind interpreters, information in accessible formats, assistive devices, etc.
- **Training for interpreter-guides/Deafblind interpreters, CBR workers, teachers, and other intermediaries** on their responsibilities in identifying the risks and interventions to prevent and respond to violence

- **Training and guidance for professionals within the justice system**, such as police, lawyers, and judges to facilitate access to justice<sup>189</sup>.

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189 Sense International Uganda, The Economic Impact of Caring for a Child with Deafblindness / Multi-Sensory Impairment, November 2019, p. 58; World Bank, Five facts to know about violence against women and girls with disabilities, <https://blogs.worldbank.org/sustainablecities/five-facts-know-about-violence-against-women-and-girls-disabilities>, 5 December 2019.

## CASE STUDY

### **Empowering Women Tackle Violence and Abuse of Persons with Deafblindness: Lessons from Uganda**

In 2021, Sense International Uganda (SI Uganda) joined a consortium led by the Uganda Society for Disabled Children and Peace and Humanitarian Security Resources in a peacebuilding project aimed at removing barriers to women's meaningful participation in violence and conflict prevention.

The project focused on women with disabilities and female caregivers of persons with disabilities, and SI Uganda facilitated the inclusion of women with deafblindness and mothers and female caregivers of children with deafblindness. Leaders at the local and national level, the media, and family members were active stakeholders in the programme.

The project sought to improve the meaningful participation of the beneficiaries in early conflict warning at both the national and district levels. Violence and conflict were broadly interpreted to include all types of violence, such as collective violence (e.g., violent gangs), interpersonal violence (e.g., domestic violence, child abuse, etc.), and economic violence (e.g., property

seizures, exclusion from development programmes, etc).

The beneficiaries were empowered as Fem Wise-Africa mediators, a network of African women in conflict prevention and mediation and a subsidiary mechanism of the African Union.

This two-year project used a range of activities, including trainings and community dialogue, to ensure that:

- › Key decision-makers develop favourable attitudes towards women as mediators
- › Women and children with disabilities establish early warning systems to prompt dialogue and a mechanism for addressing it
- › Conflict and violence prevention mechanisms led by parents' groups for children and youth with disabilities that are linked to the national mainstream mechanisms
- › Mainstreaming of conflict prevention and peacebuilding programmes to ensure that they include persons with deafblindness.

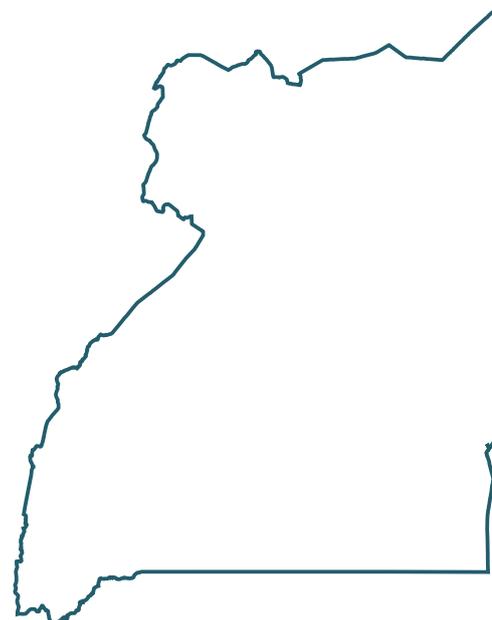
Some key learnings from the project include:

- › Persons with deafblindness need to be sensitised about violence so that they understand how to identify violence and so that they can be empowered

- › Persons with deafblindness should be involved so that they can learn to express and share their concerns about violence in a safe environment
- › Stigma in the community needs to be addressed so that persons with deafblindness are not hidden in their communities, which puts them at higher risk of violence and exclusion
- › Both men and women need to be involved in peacebuilding programmes to understand the gender dynamics of conflict and violence
- › Leaders and decision-makers at local and national levels need to clearly understand the types of violence affecting persons with deafblindness, including the ways in which they are at risk of violence, abuse, and exploitation and the interventions that address violence
- › There are good laws and policies in place to prevent and respond to violence, but a proactive approach is needed to implement these policies, particularly for groups like persons with deafblindness
- › The network / community approach helps to provide a safe environment and helps women to speak out

- Poor economic conditions and lack of social protection supports contribute significantly to the incidence of conflicts and violence
- More research and data are needed on violence against persons with deafblindness.

By mainstreaming persons with deafblindness into broader disability programmes and mainstream mechanisms, like Fem Wise-Africa, there is greater awareness of the daily violence that persons with deafblindness face - the aggression they encounter, not being taken seriously, dismissive responses, refusals to accommodate them, and overall exclusion. In this project, peacebuilding went beyond the absence of violence and focused on meeting the daily needs, including economic needs, of persons with deafblindness and the enjoyment of their rights while creating a network for advocacy and inclusion.



## Recommendations

### All

- Ensure all programmes aimed at preventing and responding to violence include persons with disabilities, including deafblindness-specific interventions, such as access to
- › interpreter-guides/Deafblind interpreters, accessible information, and teaching approaches to build understanding and resilience of persons with deafblindness who are at risk

### Governments

- › Recognise the links between lack of supports to persons with deafblindness and their families and increased risks of violence
- › Improve access to interpreter-guides/Deafblind interpreters and information in accessible formats for persons with deafblindness on systems for reporting and responding to violence
- › Incorporate information into education, health, and CBR programmes, including sexual and reproductive health education, to help persons with deafblindness to recognise and report violence. This includes training and guidance for professionals working with persons with deafblindness on

identifying the risks, patterns, and signs, as well as good practice for responding to violence

- Provide support to persons with deafblindness to respond to violence and ensure continuity of care and support to rebuild their networks (e.g., through community-based interventions and independent living programmes), if affected

## **OPDs and NGOs**

- Work with intermediaries of persons with deafblindness (e.g., interpreter-guides/Deafblind interpreters, teachers, health and rehabilitation worker, etc.) to build their capacities on safeguarding approaches and how to identify and respond to violence
- Provide training to the justice sector on methods for supporting persons with deafblindness within the system
- Increase internal awareness of violence against persons with deafblindness and establish programmatic approaches and procedures for serving as a 'safe haven' or 'first response' for persons with deafblindness. This may involve discussing violence with persons with deafblindness,

offering advice and information, and liaising with police, health centres, and other stakeholders relevant to cases of violence

- Work with research institutes to encourage research on violence against persons with deafblindness

## **Donors and Research Institutes**

- Conduct targeted quantitative and qualitative research on violence against persons with deafblindness and ensure that research aimed at violence against persons with disabilities includes persons with deafblindness
- Fund pilot programmes to test interventions that prevent and respond to violence against persons with deafblindness and to bring it out of the shadows.

## **Response to Emergencies**

Persons with deafblindness must be protected in situations of risk, including armed conflict, humanitarian emergencies, and natural disasters. This includes measures to protect access to essential services, information that is available in

accessible formats, and access to live assistance during and in response to emergencies<sup>190</sup>.

Persons with disabilities are more likely to be left behind or abandoned during evacuation from disasters or conflict, often due to a lack of planning and preparation and inaccessible information, facilities, services, and transportation systems. Most shelters or refugee camps are not accessible and may turn away persons with disabilities, especially those with complex requirements or high support needs, like persons with deafblindness. In addition, disruption to physical, social, and economic networks and support systems can leave persons with disabilities at high risk of suffering the impact of the disaster or conflict but also at risk of not meeting basic human needs, such as nutrition, health care, access to medicines, rehabilitation, personal care, etc. When help arrives or recovery is initiated, persons with disabilities are often deprioritised because of their disabilities or overlooked as a vulnerable group<sup>191</sup>. There is emerging evidence on the experiences of and interventions for persons with deafblindness in

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<sup>190</sup> Convention on the Rights of Persons with Disabilities, A/RES/61/106, 13 December 2006, Article 11; Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, Joint Statement: Persons with Disabilities and COVID-19, 1 April 2020

<sup>191</sup> United Nations Department of Economic and Social Affairs, Disability Inclusive Disaster Risk Reduction and Emergency Situations, <https://www.un.org/development/desa/disabilities/issues/disability-inclusive-disaster-risk-reduction-and-emergency-situations.html>, accessed June 2022.

emergencies arising from the COVID-19 pandemic, which can inform future emergencies beyond global health crises. Some of the key concerns for persons with deafblindness raised during the pandemic include:

- Access to information in accessible formats.
  - The information during the pandemic, including individual guidance, changed rapidly and was often not available in accessible formats
- Access to essential services, including health care, education, food, and rehabilitation services. Interpreter-guides/Deafblind interpreters and other forms of live assistance, such as carers, were also reduced or closed for periods. In some countries, family members were restricted from visiting or supporting family members, which affected persons with deafblindness who live independently, yet rely on family members for assistance (e.g., food shopping or interpreting). Parents of children with deafblindness were not equipped with the methods for teaching them, and could not take time off, as learners with deafblindness require more direct support
- Communication became even harder for persons with deafblindness due to lack of

access to interpreter-guide/Deafblind interpreting services or family members who could interpret. In addition, personal protective equipment (PPE), such as masks and gloves, obstructed communication. For some persons with deafblindness, phones and digital communications were simply not possible or were inaccessible due to a lack of access to assistive or accessible technologies

- Guidance for the public was not always realistic for persons with deafblindness who rely on touch and close proximity to communicate. People often reacted negatively when persons with deafblindness did not follow social distancing guidance due to their communication methods
- Meeting platforms used for remote working, health appointments, or education often did not include captioning, speech-to-text technology, or interpretation, limiting participation. In addition, safety, confidentiality, and individual support to use online systems were lacking
- Lack of community outreach to check on individuals with high support needs<sup>192</sup>.

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<sup>192</sup> Dhale, Zamir. "Experiences of Deafblind Persons during the CVODI-19 Outbreak", *NewsZhook*, reprinted on <https://www.internationaldisabilityalliance.org/content/experiences-deafblind-amid-covid->

## Good Practices

The approaches for supporting persons with deafblindness depend very much on the nature of the emergency, the duration, the circumstances within the country and local area, as well as the needs of individuals. However, there are some good practices that apply to a range of situations. Some key elements include:

- **Reasonable accommodations** for persons with deafblindness in emergencies are immediate, tailored solutions for individuals. For example, access to interpreter-guides/Deafblind interpreters, and using tactile forms of communication are common reasonable accommodations for persons with deafblindness. Because reasonable accommodations combat discrimination, they are not subject to suspension in emergencies. However, if a request cannot be reasonably accommodated, alternatives should be sought
- **Accessible information** (e.g., large print, Braille, captioning, accessible social media,

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[19-outbreak](#), accessed October 2021; International Disability Alliance, “COVID-19 in Mexico: the experience of deafblind children told by their mothers”, *Voices of People with Disabilities during COVID-19 Outbreak series*, <https://www.internationaldisabilityalliance.org/deafblind-mexico>, accessed October 2021; International Disability Alliance, “Reaching Persons with Deafblindness during the Covid-19 pandemic”, *Voices of People with Disabilities during COVID-19 Outbreak series*, <https://www.internationaldisabilityalliance.org/covid-deafblind>, accessed October 2021; Wittich, W. et al, “Living with deafblindness during COVID-19: An international webinar to facilitate global knowledge transfer”, *British Journal of Visual Impairment*, 2021, p. 1-13.

etc.) and **accessible distribution sites, transportation, and facilities** (e.g., in refugee camps). Persons with deafblindness may also require access to assistive devices or technologies that were left behind, such as a Braille machine, red and white cane, hearing aid, etc.

- **Community outreach to identify those that require additional protection or help.** For example, those that cannot go places, such as distribution sites, evacuation routes, etc., and those who require additional care or support for basic needs
- **Maintaining access to essential services,** such as health care, education, rehabilitation, food, medicine, interpreter-guide/Deafblind interpreting services, access to carers for basic needs, etc. If services are adapted due to the emergency, they may require further adaptations or reasonable accommodations for individuals. For example, teleservices for health appointments may not be possible for all persons with deafblindness
- **Adaptable public guidance from authorities** (e.g., on evacuation routes, public health and/or safety guidance, etc.). This is to ensure that blanket guidance does not exclude or harm persons with

deafblindness. For example, guidance during the COVID-19 pandemic to socially distance prevented persons with deafblindness from communicating. Reasonable accommodations for exemptions to official guidance may be necessary for persons with deafblindness

- **Guidance and training for frontline staff** on the requirements of persons with deafblindness and on how to communicate with them. Because this is a low-incidence group, frontline staff should be armed with information on what to do if they do not know how to help persons with deafblindness
- **Safeguarding measures** to protect persons with deafblindness from violence, abuse, exploitation, or other harms. For example, enabling access to live assistance, awareness raising of frontline workers on safeguarding, responding quickly to safeguarding concerns, expediting family reunions, ensuring access to accessible redress mechanisms, etc.
- **Identification cards** that provide basic information, including that the person is deafblind and their methods of communication, as well as any other essential information, such as medications,

medical conditions, or contact details of family members. This will help persons with deafblindness to interact with first responders, hospitals, and others on the frontlines

- **Participation of OPDs of persons with deafblindness in emergency response and planning** to ensure they are not left behind and to help establish protocols for communicating with persons with deafblindness in emergencies. Umbrella OPDs that serve as focal points in emergencies should ensure that persons with deafblindness are included in the consultation, planning, implementation, and monitoring and evaluation of humanitarian programmes and represented in committees or bodies responding to emergencies. This may require meetings, consultations, or conferences to take stock of the challenges and interventions from recent emergencies<sup>193</sup>.

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193 Dhale, Zamir. "Experiences of Deafblind Persons during the COVID-19 Outbreak", *NewsZhook*, reprinted on <https://www.internationaldisabilityalliance.org/content/experiences-deafblind-amid-covid-19-outbreak>, accessed October 2021; Inter-Agency Standing Committee, *Guidelines: Inclusion of Persons with Disabilities in Humanitarian Action*, July 2019; International Disability Alliance, "COVID-19 in Mexico: the experience of deafblind children told by their mothers", *Voices of People with Disabilities during COVID-19 Outbreak series*, <https://www.internationaldisabilityalliance.org/deafblind-mexico>, accessed October 2021; International Disability Alliance, "Reaching Persons with Deafblindness during the Covid-19 pandemic", *Voices of People with Disabilities during COVID-19 Outbreak series*, <https://www.internationaldisabilityalliance.org/covid-deafblind>, accessed October 2021; Sense International, *COVID-19 Rapid Response for People with Deafblindness, their Families, and Schools in Kenya: Final Evaluation Report*, March 2021; Sense International Romania, *Abstracts:*

In addition, persons with deafblindness should be included in recovery programmes, as they may be disproportionately affected by the social, economic, psychosocial, and logistical impacts of emergencies<sup>194</sup>.

## Recommendations

### Governments

Legally recognise deafblindness and classify persons with deafblindness as a

- vulnerable group in emergencies that require prioritisation and targeted support

Prioritise persons with deafblindness in evacuation and establish protocols for

- ensuring support during evacuations, especially in regions prone to natural disasters

Develop humanitarian, disaster risk reduction, and emergency service plans to establish accessibility standards and to

- enable reasonable accommodations for persons with deafblindness, including access to interpreter-guides/Deafblind interpreters, accessible information, and

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*Deafblindness During the Pandemic*, 2020; Wittich, W. et al, "Living with deafblindness during COVID-19: An international webinar to facilitate global knowledge transfer", *British Journal of Visual Impairment*, 2021, p. 1-13.

<sup>194</sup> Inter-Agency Standing Committee, *Guidelines: Inclusion of Persons with Disabilities in Humanitarian Action*, July 2019, p. 19-21.

guidance to frontline staff on how to communicate with persons with deafblindness. This may include reasonable accommodations to official guidance.

- Include OPDs of persons with deafblindness in consultation processes for emergency planning and implementation
- Train frontline staff (e.g., first responders, humanitarian agencies, etc.) on the requirements of persons with deafblindness in emergencies, including safeguarding measures

- Maintain access to essential services during emergencies and identify interpreter-guides/Deafblind interpreters as an essential service

- Work with NGOs, OPDs, and others to encourage community-based supports and checks on persons with deafblindness during emergencies

## **OPDs and NGOs**

- Include OPDs of persons with deafblindness in actions on emergency planning for persons with disabilities
- Develop community-based solutions for checking on and supporting persons with

deafblindness in the community during emergencies

## **Donors and Research Institutes**

Conduct research on the situation of persons with deafblindness in emergencies and humanitarian action to better

- understand the impacts and ensure research on persons with disabilities in emergencies includes persons with deafblindness.

# CONCLUSIONS AND RECOMMENDATIONS

Building on the first global report, WFDB has expanded quantitative analysis of the situation of persons with deafblindness, focusing on children with deafblindness using data from the MICS, and advanced the dialogue on what works for persons with deafblindness in line with the CRPD across a wide range of policy areas.

There has been progress in raising awareness on the situation of persons with deafblindness with the first global report. However, governments, funders, NGOs, OPDs, and other development stakeholders must develop a firm grasp of the concrete measures and interventions that work for persons with deafblindness. Although more robust research is required across all areas, this second global report provides these stakeholders with good practices and inspiration for improved services that are inclusive of persons with deafblindness.

Persons with deafblindness are frequently excluded from disability-specific and mainstream services due to a vicious cycle of stigma and misperceptions about their capabilities, lack of

access to interpreter-guide/Deafblind interpreting services and accessible information, low-incidence rates combined with high support needs, complexity of deafblindness interventions, lack of technical understanding and resources, and isolation. This report seeks to improve the positions of persons with deafblindness within the disability movement as well as within broader mainstream services.

A systematic review of the preconditions for disability inclusion is key to ensuring mainstream services are inclusive of persons with deafblindness. Deafblindness must be accurately recognised to establish deafblindness-specific interventions and services. A global mechanism to address systemic gaps in access to live assistance, including interpreter-guides/Deafblind interpreters, in solidarity with other groups of persons with disabilities, could generate the momentum that OPDs of persons with deafblindness may not be able to achieve on their own. However, interpreter-guide/Deafblind interpreting services may be difficult to implement if rehabilitation services are not in place. Furthermore, rehabilitation services may not include persons with deafblindness if health and rehabilitation workers do not have access to information and training resources on good practices for persons with deafblindness in local languages.

This overlapping nature of the preconditions creates planning challenges. However, this should not lead to inaction or inertia. As many of the case studies demonstrate, pilot programmes that systematically address the preconditions combined with good practices of mainstream services for persons with deafblindness are a good starting point.

The literature review revealed that there are many good practices to facilitate the inclusion of persons with deafblindness being used in diverse settings across the globe. However, WFDB's survey highlighted a lack of consistency in implementing good practices across countries and regions, indicating that good practices are often restricted to small projects in a limited number of countries. In addition, this report did not review or analyse practices that are not aligned with the CRPD, such as segregated education, employment, and residential services or services that exclude or disempower persons with deafblindness, which is a major concern of the deafblind community, as many outdated and bad practices need to be terminated and replaced with CRPD-compliant services and approaches.

The recommendations in this report are numerous. However, broken down into essential components for individual services and policy areas, it creates a roadmap for OPDs of persons with

deafblindness and their allies to advocate for concrete change and to overcome the question of what works for persons with deafblindness.

The initial steps to bridge the gaps that were outlined in WFDB's first global report remain relevant, and this report builds on those recommendations to identify four urgent priorities to ensure persons with deafblindness are not left behind:

- . Establish international, national, and sub-national **recognition of deafblindness**
  - 1 as a unique and distinct disability with its own specific challenges, barriers, and support and inclusion requirements

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- . Establish a **system for information resources and continuous training on deafblindness for essential frontline workers** (e.g., health, rehabilitation,
  - 2 education, social work, etc.) to understand how to identify, rehabilitate, educate, and support persons with deafblindness and how to adapt services as good practice models evolve

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- . Establish **publicly funded live**
  - 3 **assistance** for persons with deafblindness as an essential service, in particular trained **teaching assistants** in

educational institutions and **interpreter-guide/Deafblind interpreting services** for all persons with deafblindness that require it

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- . Provide **funding for further research** and data to support an evidence base of CRPD-compliant disability-specific and
- 4** disability-mainstreamed services with the active participation of persons with deafblindness and their representative organisations.

Persons with deafblindness are a broad and diverse group that require reasonable accommodations for individuals, accessibility standards as a group applied across all services and facilities, tailored deafblindness-specific services, as well as inclusion in mainstream services. These are the key factors for ensuring social inclusion, participation, independence, and autonomy.

## ANNEX 1 – DATA TABLES

**Table 1. Prevalence of Deafblindness**

Country/Area	Severe (n, survey)	Severe (%)	Severe (n, total pop.)	Moderate (n, survey)	Moderate (%)	Moderate (n, total pop.)	Mild (n, survey)	Mild (%)	Mild (n, total pop.)
<b>Pooled</b>									
All countries	229	0.05	114,393	748	0.14	297,789	3,444	0.66	1,430,356
Low-income	105	0.06	46,541	396	0.15	113,894	1,616	0.80	596,678
Lower middle-income	92	0.04	45,241	261	0.12	125,647	1,137	0.55	567,156
Upper middle-income	32	0.06	22,611	91	0.15	58,248	688	0.70	266,498
<b>Central and South Asia</b>									
Pooled	34	0.05	28,654	81	0.11	69,527	219	0.31	186,091
Bangladesh	23	0.05	23,471	56	0.11	54,143	131	0.27	127,107
Kyrgyzstan	2	0.05	1,001	2	0.05	1,003	6	0.09	1,859
Nepal	8	0.04	3,866	21	0.15	13,696	77	0.60	55,157
Turkmenistan	1	0.02	316	2	0.04	685	5	0.10	1,968
<b>East and Southeast Asia</b>									
Pooled	6	0.07	709	17	0.23	2,286	69	0.75	7,568
Mongolia	6	0.07	709	17	0.23	2,286	69	0.75	7,568
<b>Latin America and the Caribbean</b>									

Country/Area	Severe (n, survey)	Severe (%)	Severe (n, total pop.)	Moderate (n, survey)	Moderate (%)	Moderate (n, total pop.)	Mild (n, survey)	Mild (%)	Mild (n, total pop.)
Pooled	24	0.05	9,888	82	0.17	35,778	609	0.83	170,735
Argentina	4	0.07	7,630	14	0.22	25,352	51	0.57	66,719
Cuba	2	0.00	56	4	0.01	160	143	2.49	49,010
Dominican Republic	2	0.01	270	9	0.04	1,288	73	0.47	14,889
Guyana	2	0.01	23	6	0.13	300	125	2.12	4,952
Honduras	14	0.06	1,909	45	0.27	8,599	187	1.06	34,331
Suriname	0	n/a	n/a	4	0.05	79	27	0.49	810
Turks and Caicos Islands	0	n/a	n/a	0	n/a	n/a	3	0.22	24
<b>North Africa and West Asia</b>									
Pooled	46	0.07	23,628	119	0.17	60,030	501	0.75	259,451
Algeria	17	0.06	7,785	45	0.17	22,448	198	0.84	110,770
Georgia	1	0.01	57	3	0.04	316	18	0.31	2,555
Iraq	17	0.09	13,369	45	0.19	29,167	206	0.77	120,692
State of Palestine	6	0.05	991	12	0.11	2,120	36	0.40	7,908
Tunisia	5	0.05	1,426	14	0.20	5,979	43	0.59	17,526
<b>North America and Europe</b>									
Pooled	3	0.04	890	3	0.04	894	26	0.21	4,797
Belarus	1	0.05	782	1	0.05	785	15	0.21	3,575
Kosovo	1	0.02	85	1	0.02	86	7	0.22	1,122
Montenegro	1	0.02	23	1	0.02	23	4	0.08	100
<b>Oceania</b>									

Country/Area	Severe (n, survey)	Severe (%)	Severe (n, total pop.)	Moderate (n, survey)	Moderate (%)	Moderate (n, total pop.)	Mild (n, survey)	Mild (%)	Mild (n, total pop.)
Pooled	0	n/a	n/a	3	0.02	19	39	0.39	438
Samoa	0	n/a	n/a	2	0.02	12	25	0.44	332
Tonga	0	n/a	n/a	0	n/a	n/a	4	0.11	35
Tuvalu	0	n/a	n/a	1	0.18	7	10	1.77	71
<b>Sub-Saharan Africa</b>									
Pooled	116	0.05	50,624	443	0.13	129,255	1,981	0.82	801,276
Central African Republic	19	0.11	2,402	38	0.29	6,276	182	1.41	30,610
Chad	38	0.05	4,007	228	0.34	25,577	712	1.79	135,057
Democratic Republic of Congo	23	0.08	30,635	48	0.14	55,209	198	0.61	244,778
Ghana	1	0.00	258	7	0.02	2,856	131	0.93	109,022
Guinea-Bissau	0	n/a	n/a	3	0.01	123	15	0.15	1,241
Lesotho	4	0.05	373	13	0.20	1,419	64	1.06	7,616
Madagascar	8	0.04	4,154	24	0.12	13,523	159	0.90	100,914
Malawi	14	0.06	4,646	33	0.12	10,052	202	0.77	64,793
Sao Tome and Principe	2	0.12	113	8	0.23	211	35	1.09	1,015
Sierra Leone	2	0.02	690	17	0.09	3,034	127	0.54	17,790
The Gambia	1	0.00	7	5	0.01	100	21	0.14	1,495
Togo	4	0.10	3,339	13	0.18	6,120	56	1.02	34,753
Zimbabwe	0	n/a	n/a	6	0.07	4,755	79	0.81	52,192

**Table 2. Access to assistive devices children with deafblindness compared to children with other disabilities and no disabilities**

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
<b>Has both hearing aids and glasses</b>					
All	3/228 (1)				
Girls	3/120 (2)				
Boys	0/108 (0)				
Central and South Asia	0/34 (0)				
East and Southeast Asia	0/6 (0)				
Latin America and the Caribbean	0/23 (0)				
North Africa and West Asia	2/46 (4)				
North America and Europe	1/3 (33)				
Sub-Saharan Africa	0/116 (0)				
Upper middle-income	1/31 (3)				
Lower middle-income	2/92 (2)				
Low-income	0/105 (0)				
<b>Has glasses</b>					
All	11/229 (5)				
Girls	6/120 (5)				
Boys	5/109 (5)				

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
Central and South Asia	0/34 (0)				
East and Southeast Asia	0/6 (0)				
Latin America and the Caribbean	4/24 (17)				
North Africa and West Asia	2/46 (4)				
North America and Europe	1/3 (33)				
Sub-Saharan Africa	4/116 (3)				
Upper middle-income	3/32 (9)				
Lower middle-income	6/92 (7)				
Low-income	2/105 (2)				
<b>Has hearing aids</b>					
<i>All</i>	13/226 (6)				
Girls	8/119 (7)				
Boys	5/107 (5)				
Central and South Asia	0/34 (0)				
East and Southeast Asia	0/6 (0)				
Latin America and the Caribbean	1/22 (5)				
North Africa and West Asia	6/46 (13)				
North America and Europe	1/3 (33)				

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
Sub-Saharan Africa	5/115 (4)				
Upper middle-income	5/31 (16)				
Lower middle-income	3/91 (3)				
Low income	5/104 (5)				

<sup>1</sup>Prevalence ratio (PR) is adjusted by age.

**Table 3. Education outcomes for children with deafblindness, children with other disabilities, and children with no disabilities**

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
<b>Early Childhood Development Index</b>					
All	13/66 (20)	1831/4841 (38)	0.60 (0.38 to 0.95)	75476/109331 (69)	0.35 (0.22 to 0.55)
Girls	9/30 (30)	829/2121 (39)	0.93 (0.56 to 1.54)	38548/54298 (71)	0.53 (0.33 to 0.87)
Boys	4/36 (11)	1002/2720 (37)	0.33 (0.15 to 0.73)	36928/55033 (67)	0.20 (0.09 to 0.42)
Central and South Asia	2/4 (50)	118/297 (40)	1.26 (0.50 to 3.15)	11153/14805 (75)	0.71 (0.26 to 1.98)
East and Southeast Asia	1/3 (33)	70/134 (52)	0.66 (0.08 to 5.59)	5843/6832 (86)	0.39 (0.05 to 2.85)
Latin America and the Caribbean	3/5 (60)	147/314 (47)	1.35 (0.75 to 2.45)	11131/12951 (86)	0.73 (0.38 to 1.39)
North Africa and West Asia	1/9 (11)	181/428 (42)	0.26 (0.05 to 1.48)	13735/17065 (80)	0.14 (0.03 to 0.77)
Sub-Saharan Africa	6/45 (13)	1241/3544 (35)	0.48 (0.25 to 0.92)	30128/53551 (56)	0.29 (0.15 to 0.54)
Upper middle-income	4/10 (40)	245/484 (51)	0.88 (0.47 to 1.66)	18884/21754 (87)	0.49 (0.26 to 0.93)

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
Lower middle-income	3/11 (27)	611/1395 (44)	0.64 (0.19 to 2.21)	32621/43227 (75)	0.36 (0.11 to 1.19)
Low-income	6/45 (13)	975/2961 (33)	0.48 (0.25 to 0.92)	23838/44206 (54)	0.29 (0.15 to 0.55)
<b>Early Childhood Education</b>					
<i>All</i>	<i>4/57 (7)</i>	<i>779/3983 (20)</i>	<i>0.62 (0.25 to 1.54)</i>	<i>29458/96112 (31)</i>	<i>0.44 (0.17 to 1.19)</i>
Girls	2/25 (8)	331/1726 (19)	0.89 (0.30 to 2.66)	14877/47754 (31)	0.56 (0.18 to 1.68)
Boys	2/32 (6)	448/2257 (20)	0.55 (0.19 to 1.59)	14581/48358 (30)	0.37 (0.12 to 1.16)
Central and South Asia	1/5 (20)	52/302 (17)	1.20 (0.22 to 6.55)	4962/15054 (33)	0.69 (0.11 to 4.18)
East and Southeast Asia	1/3 (33)	47/142 (33)	1.17 (0.45 to 3.07)	3613/6838 (53)	0.74 (0.18 to 3.08)
Latin America and the Caribbean	2/5 (40)	107/360 (30)	1.07 (0.70 to 1.64)	6201/14699 (42)	0.94 (0.52 to 1.68)
North Africa and West Asia	0/12 (0)	49/419 (12)	0.00 (0.00 to 0.00)	3221/16219 (20)	0.00 (0.00 to 0.00)
Sub-Saharan Africa	0/32 (0)	486/2627 (19)	0.00 (0.00 to 0.00)	9039/39028 (23)	0.00 (0.00 to 0.00)
Upper middle-income	2/11 (18)	150/539 (28)	1.08 (0.64 to 1.82)	9367/23797 (39)	0.97 (0.53 to 1.75)

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
Lower middle-income	2/14 (14)	414/1362 (30)	0.87 (0.29 to 2.62)	15009/41836 (36)	0.54 (0.15 to 1.91)
Low-income	0/32 (0)	214/2081 (10)	0.00 (0.00 to 0.00)	4944/30328 (16)	0.00 (0.00 to 0.00)
<b>Primary School Net Attendance Rate</b>					
<i>All</i>	12/59 (20)	13387/20231 (66)	0.30 (0.18 to 0.50)	75888/101157 (75)	0.28 (0.17 to 0.47)
Girls	8/33 (24)	6267/9474 (66)	0.35 (0.21 to 0.58)	38246/50766 (75)	0.33 (0.20 to 0.55)
Boys	4/26 (15)	7120/10757 (66)	0.24 (0.10 to 0.54)	37642/50391 (75)	0.22 (0.09 to 0.50)
Central and South Asia	0/12 (0)	1100/1939 (57)	0.00 (0.00 to 0.00)	14262/19205 (74)	0.00 (0.00 to 0.00)
Latin America and the Caribbean	0/7 (0)	966/1911 (51)	0.00 (0.00 to 0.00)	5669/10928 (52)	0.00 (0.00 to 0.00)
North Africa and West Asia	2/13 (15)	3298/3998 (82)	0.19 (0.05 to 0.66)	13747/16238 (85)	0.18 (0.05 to 0.63)
Sub-Saharan Africa	8/23 (35)	7408/11653 (64)	0.53 (0.30 to 0.94)	35398/47361 (75)	0.50 (0.28 to 0.89)
Upper middle-income	1/8 (12)	2779/3204 (87)	0.14 (0.02 to 0.82)	16323/18027 (91)	0.13 (0.02 to 0.79)
Lower middle-income	6/32 (19)	5120/7577 (68)	0.28 (0.18 to 0.45)	35321/48170 (73)	0.26 (0.17 to 0.42)

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
Low-income	5/19 (26)	5469/9429 (58)	0.46 (0.21 to 0.98)	24040/34753 (69)	0.42 (0.20 to 0.90)
<b>Secondary School Net Attendance Rate</b>					
<i>All</i>	<i>9/56 (16)</i>	<i>5676/15798 (36)</i>	<i>0.42 (0.20 to 0.87)</i>	<i>46770/96415 (49)</i>	<i>0.35 (0.17 to 0.71)</i>
Girls	5/30 (17)	2707/7384 (37)	0.38 (0.22 to 0.66)	23505/47405 (50)	0.33 (0.19 to 0.56)
Boys	4/26 (15)	2969/8414 (35)	0.45 (0.12 to 1.75)	23265/49010 (47)	0.37 (0.10 to 1.45)
Central and South Asia	2/11 (18)	1002/2111 (47)	0.41 (0.08 to 2.17)	17814/27289 (65)	0.32 (0.06 to 1.76)
Latin America and the Caribbean	0/10 (0)	490/1481 (33)	0.00 (0.00 to 0.00)	3514/9177 (38)	0.00 (0.00 to 0.00)
North Africa and West Asia	3/14 (21)	2398/4086 (59)	0.35 (0.17 to 0.72)	11387/17038 (67)	0.29 (0.14 to 0.62)
Sub-Saharan Africa	3/19 (16)	1351/7403 (18)	0.62 (0.22 to 1.79)	8884/35518 (25)	0.49 (0.18 to 1.34)
Upper middle-income	1/8 (12)	1450/2510 (58)	0.21 (0.04 to 1.03)	11576/16731 (69)	0.18 (0.04 to 0.89)
Lower middle-income	6/35 (17)	3328/7546 (44)	0.41 (0.17 to 1.00)	29382/52985 (55)	0.34 (0.14 to 0.84)
Low-income	2/13 (15)	884/5726 (15)	0.84 (0.24 to 2.92)	5691/26559 (21)	0.58 (0.17 to 1.99)

<sup>1</sup>Prevalence ratio (PR) is adjusted by age.

**Table 4. Health outcomes amongst children with deafblindness compared to children with other disabilities and no disabilities**

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
<b>Acute Respiratory Infection (ARI) in past two weeks</b>					
All	35/105 (33)	2709/8083 (34)	0.96 (0.76 to 1.22)	39697/157307 (25)	1.20 (0.97 to 1.49)
Girls	16/51 (31)	1167/3594 (32)	0.93 (0.63 to 1.38)	19637/77888 (25)	1.11 (0.75 to 1.64)
Boys	19/54 (35)	1542/4489 (34)	1.00 (0.69 to 1.44)	20060/79419 (25)	1.29 (0.93 to 1.80)
Central and South Asia	0/10 (0)	114/443 (26)	0.00 (0.00 to 0.00)	3898/19956 (20)	0.00 (0.00 to 0.00)
East and Southeast Asia	1/4 (25)	83/234 (35)	0.72 (0.12 to 4.34)	2355/10765 (22)	1.21 (0.19 to 7.79)
Latin America and the Caribbean	4/6 (67)	178/526 (34)	1.77 (1.02 to 3.08)	4210/19476 (22)	2.77 (1.71 to 4.49)
North Africa and West Asia	1/16 (6)	219/661 (33)	0.20 (0.03 to 1.46)	6325/26036 (24)	0.28 (0.04 to 1.97)
Sub-Saharan Africa	29/69 (42)	2071/5964 (35)	1.16 (0.89 to 1.51)	21808/75885 (29)	1.36 (1.07 to 1.74)
Upper-middle-income	3/13 (23)	204/734 (28)	0.81 (0.31 to 2.16)	6010/29054 (21)	1.17 (0.46 to 2.96)
Lower-middle-income	4/24 (17)	828/2400 (34)	0.51 (0.19 to 1.36)	16076/66154 (24)	0.72 (0.27 to 1.89)

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
Low-income	28/68 (41)	1663/4898 (34)	1.13 (0.87 to 1.47)	17410/61558 (28)	1.33 (1.04 to 1.70)
<b>Diarrhoea in the past two weeks</b>					
<i>All</i>	<i>23/104 (22)</i>	<i>1437/8043 (18)</i>	<i>1.09 (0.81 to 1.46)</i>	<i>16216/156941 (10)</i>	<i>1.48 (1.09 to 2.00)</i>
Girls	13/50 (26)	624/3569 (17)	1.26 (0.83 to 1.90)	7748/77699 (10)	1.71 (1.13 to 2.59)
Boys	10/54 (19)	813/4474 (18)	0.91 (0.53 to 1.59)	8468/79242 (11)	1.25 (0.72 to 2.18)
Central and Southern Asia	1/10 (10)	56/443 (13)	0.61 (0.17 to 2.26)	1167/19937 (6)	1.41 (0.38 to 5.20)
Latin America and the Caribbean	2/6 (33)	73/523 (14)	2.31 (0.89 to 5.99)	1543/19420 (8)	3.65 (1.34 to 9.92)
North Africa and West Asia	1/16 (6)	84/658 (13)	0.48 (0.11 to 2.11)	1882/25994 (7)	0.86 (0.20 to 3.70)
Sub-Saharan Africa	19/68 (28)	1174/5932 (20)	1.18 (0.84 to 1.66)	10820/75671 (14)	1.47 (1.04 to 2.07)
Upper-middle-income	2/13 (15)	104/728 (14)	1.01 (0.43 to 2.36)	2221/28996 (8)	1.85 (0.74 to 4.65)
Lower-middle-income	2/24 (8)	318/2398 (13)	0.62 (0.23 to 1.66)	4911/66043 (7)	1.15 (0.39 to 3.37)
Low-income	19/67 (28)	1006/4866 (21)	1.20 (0.85 to 1.68)	9025/61366 (15)	1.49 (1.05 to 2.11)
<b>Stunted</b>					

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
All	40/88 (45)	3000/7793 (38)	1.07 (0.90 to 1.28)	40996/154102 (27)	1.24 (1.03 to 1.50)
Girls	18/43 (42)	1355/3471 (39)	0.91 (0.66 to 1.25)	20011/76358 (26)	1.11 (0.83 to 1.49)
Boys	22/45 (49)	1645/4322 (38)	1.23 (1.01 to 1.50)	20985/77744 (27)	1.39 (1.11 to 1.72)
Central and South Asia	1/5 (20)	167/416 (40)	0.59 (0.14 to 2.58)	5775/21509 (27)	0.77 (0.19 to 3.13)
East and Southeast Asia	0/1 (0)	16/62 (26)	0.00 (0.00 to 0.00)	415/3625 (11)	0.00 (0.00 to 0.00)
Latin America and the Caribbean	2/4 (50)	105/481 (22)	2.42 (0.99 to 5.96)	2170/18591 (12)	6.13 (1.98 to 19.01)
North Africa and West Asia	3/11 (27)	96/599 (16)	1.69 (0.55 to 5.21)	2376/24726 (10)	2.77 (0.93 to 8.29)
Sub-Saharan Africa	33/65 (51)	2475/5832 (42)	1.05 (0.86 to 1.27)	27123/74744 (36)	1.15 (0.94 to 1.41)
Upper-middle-income	3/9 (33)	105/691 (15)	1.74 (0.71 to 4.30)	2344/29199 (8)	3.60 (1.35 to 9.55)
Lower-middle-income	4/15 (27)	656/2235 (29)	0.90 (0.37 to 2.20)	14756/63471 (23)	1.28 (0.52 to 3.17)
Low-income	33/64 (52)	2219/4802 (46)	1.06 (0.87 to 1.28)	23725/60766 (39)	1.17 (0.95 to 1.42)
<b>Wasted</b>					

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
All	19/87 (22)	587/7799 (8)	2.08 (1.47 to 2.96)	7663/153779 (5)	2.79 (1.99 to 3.92)
Girls	6/42 (14)	261/3478 (8)	1.38 (0.71 to 2.68)	3450/76212 (5)	1.99 (1.09 to 3.66)
Boys	13/45 (29)	326/4321 (8)	2.77 (1.95 to 3.92)	4213/77567 (5)	3.47 (2.46 to 4.89)
Central and South Asia	1/6 (17)	50/413 (12)	1.14 (0.32 to 4.02)	1765/21480 (8)	2.32 (0.69 to 7.78)
East and Southeast Asia	1/3 (33)	16/224 (7)	4.84 (1.10 to 21.39)	590/10423 (6)	5.88 (1.45 to 23.92)
Latin America and the Caribbean	0/3 (0)	16/481 (3)	0.00 (0.00 to 0.00)	482/18505 (3)	0.00 (0.00 to 0.00)
North Africa and West Asia	2/10 (20)	18/592 (3)	6.36 (1.97 to 20.53)	389/24576 (2)	11.58 (3.11 to 43.15)
Sub-Saharan Africa	15/65 (23)	474/5847 (8)	2.00 (1.30 to 3.06)	4365/74796 (6)	2.52 (1.63 to 3.90)
Upper-middle-income	0/8 (0)	23/683 (3)	0.00 (0.00 to 0.00)	673/29054 (2)	0.00 (0.00 to 0.00)
Lower-middle-income	4/15 (27)	132/2256 (6)	3.06 (1.28 to 7.30)	3063/63483 (5)	5.47 (2.33 to 12.84)
Low-income	15/64 (23)	428/4810 (9)	2.02 (1.32 to 3.10)	3900/60722 (6)	2.55 (1.65 to 3.94)
<b>Health insurance</b>					

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
All	19/229 (8)	5911/50534 (12)	1.18 (0.84 to 1.65)	44167/387809 (11)	1.10 (0.78 to 1.54)
Girls	11/120 (9)	2572/23382 (11)	1.54 (1.06 to 2.25)	21888/192368 (11)	1.39 (0.94 to 2.06)
Boys	8/109 (7)	3339/27152 (12)	0.88 (0.53 to 1.45)	22279/195441 (11)	0.85 (0.52 to 1.41)
Central and South Asia	1/34 (3)	49/4915 (1)	2.70 (0.48 to 15.09)	536/72679 (1)	2.58 (0.37 to 17.97)
East and Southeast Asia	0/6 (0)	0/508 (0)	1.00 (0.41 to 2.43)	0/10685 (0)	1.00 (0.41 to 2.44)
Latin America and the Caribbean	1/24 (4)	1451/6158 (24)	0.42 (0.07 to 2.49)	15805/56874 (28)	0.37 (0.06 to 2.22)
North Africa and West Asia	16/46 (35)	2638/9726 (27)	1.36 (0.99 to 1.88)	16168/62978 (26)	1.25 (0.91 to 1.71)
North America and Europe	0/3 (0)	2/474 (0)	0.00 (0.00 to 0.00)	58/9646 (1)	0.00 (0.00 to 0.00)
Sub-Saharan Africa	1/116 (1)	1609/27870 (6)	0.65 (0.18 to 2.31)	9738/168819 (6)	0.65 (0.20 to 2.14)
Upper-middle-income	2/32 (6)	1625/9094 (18)	0.78 (0.21 to 2.94)	17666/86810 (20)	0.69 (0.18 to 2.64)
Lower-middle-income	17/92 (18)	4058/18928 (21)	1.33 (0.99 to 1.78)	24733/169592 (15)	1.24 (0.93 to 1.65)
Low-income	0/105 (0)	194/22471 (1)	0.00 (0.00 to 0.00)	1201/130786 (1)	0.00 (0.00 to 0.00)

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
<b>Sought care for ARI in past two weeks</b>					
All	18/34 (53)	1457/2649 (55)	1.12 (0.84 to 1.50)	22062/37146 (59)	1.14 (0.86 to 1.53)
Girls	11/21 (52)	604/1150 (53)	1.11 (0.72 to 1.71)	10787/18291 (59)	1.11 (0.76 to 1.63)
Boys	7/13 (54)	853/1499 (57)	1.24 (0.81 to 1.91)	11275/18855 (60)	1.22 (0.80 to 1.86)
Central and South Asia	2/3 (67)	96/141 (68)	0.99 (0.44 to 2.22)	2950/4331 (68)	0.95 (0.43 to 2.13)
Latin America and the Caribbean	1/1 (100)	99/146 (68)	1.06 (0.94 to 1.19)	2640/3790 (70)	1.21 (1.16 to 1.27)
North Africa and West Asia	1/1 (100)	136/184 (74)	1.57 (1.26 to 1.95)	3167/4502 (70)	1.40 (1.34 to 1.46)
North America and Europe	0/0 (NA)	3/4 (75)	NA (NA to NA)	307/383 (80)	NA (NA to NA)
Sub-Saharan Africa	14/29 (48)	1069/2080 (51)	1.13 (0.80 to 1.60)	11667/22056 (53)	1.15 (0.81 to 1.65)
Upper-middle-income	2/2 (100)	140/191 (73)	1.23 (0.92 to 1.66)	3710/5090 (73)	1.31 (1.19 to 1.44)
Lower-middle-income	2/3 (67)	495/752 (66)	0.98 (0.45 to 2.11)	9019/13768 (66)	0.96 (0.43 to 2.15)
Low-income	14/29 (48)	821/1697 (48)	1.12 (0.79 to 1.59)	9262/18152 (51)	1.15 (0.81 to 1.65)

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
<b>Sought care for diarrhoea in past two weeks</b>					
All	10/23 (43)	815/1437 (57)	0.79 (0.44 to 1.41)	8970/16199 (55)	0.83 (0.47 to 1.49)
Girls	5/13 (38)	336/624 (54)	0.72 (0.32 to 1.58)	4291/7738 (55)	0.76 (0.36 to 1.60)
Boys	5/10 (50)	479/813 (59)	0.90 (0.46 to 1.75)	4679/8461 (55)	0.91 (0.47 to 1.79)
Central and South Asia	1/1 (100)	38/56 (68)	1.56 (0.94 to 2.58)	756/1167 (65)	1.43 (1.31 to 1.57)
Latin America and the Caribbean	0/2 (0)	53/73 (73)	0.00 (0.00 to 0.00)	938/1540 (61)	0.00 (0.00 to 0.00)
North Africa and West Asia	0/1 (0)	39/84 (46)	0.00 (0.00 to 0.00)	1007/1881 (54)	0.00 (0.00 to 0.00)
North America and Europe	0/0 (NA)	0/1 (0)	NA (NA to NA)	45/69 (65)	NA (NA to NA)
Sub-Saharan Africa	9/19 (47)	655/1174 (56)	0.89 (0.48 to 1.64)	5823/10807 (54)	0.95 (0.51 to 1.76)
Upper-middle-income	0/2 (0)	66/104 (63)	0.00 (0.00 to 0.00)	1322/2218 (60)	0.00 (0.00 to 0.00)
Lower-middle-income	1/2 (50)	202/318 (64)	0.75 (0.18 to 3.02)	2867/4909 (58)	0.82 (0.24 to 2.86)

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
Low-income	9/19 (47)	542/1006 (54)	0.89 (0.48 to 1.64)	4759/9013 (53)	0.95 (0.51 to 1.76)

<sup>1</sup>Prevalence ratio (PR) is adjusted by age.

**Table 5. Well-being outcomes for children with deafblindness, children with other disabilities and children with no disabilities**

	Deafblind (%)	Other disability (%)	aPR (95% CI), other disability <sup>1</sup>	No disability (%)	aPR (95% CI), no disability <sup>1</sup>
<b>Child's birth is registered</b>					
All	51/105 (49)	4919/8062 (61)	0.90 (0.72 to 1.12)	113373/156467 (72)	0.87 (0.71 to 1.07)
Girls	22/51 (43)	2101/3580 (59)	0.87 (0.66 to 1.15)	55740/77446 (72)	0.84 (0.65 to 1.08)
Boys	29/54 (54)	2818/4482 (63)	0.93 (0.74 to 1.18)	57633/79021 (73)	0.90 (0.72 to 1.13)
Central and South Asia	9/10 (90)	316/467 (68)	1.22 (1.01 to 1.47)	16622/22269 (75)	1.20 (1.02 to 1.40)
East and Southeast Asia	2/4 (50)	152/234 (65)	0.79 (0.28 to 2.19)	7903/10743 (74)	0.72 (0.25 to 2.08)
Latin America and the Caribbean	5/6 (83)	511/526 (97)	0.87 (0.60 to 1.27)	19189/19478 (99)	0.85 (0.59 to 1.22)
North Africa and West Asia	16/16 (100)	629/631 (100)	1.00 (1.00 to 1.01)	24356/24462 (100)	1.00 (1.00 to 1.01)
Sub-Saharan Africa	19/69 (28)	3140/6005 (52)	0.76 (0.45 to 1.29)	42256/76076 (56)	0.72 (0.44 to 1.20)
Upper-middle-income	12/13 (92)	711/728 (98)	0.94 (0.80 to 1.12)	28114/28454 (99)	0.93 (0.79 to 1.10)

Lower-middle-income	21/24 (88)	1808/2390 (76)	1.06 (0.89 to 1.28)	52955/66042 (80)	1.04 (0.87 to 1.24)
Low-income	18/68 (26)	2397/4941 (49)	0.75 (0.43 to 1.32)	32079/61744 (52)	0.71 (0.41 to 1.22)

<sup>1</sup>Prevalence ratio (PR) is adjusted by age.

# GLOSSARY

**Accessibility** A precondition for persons with disabilities to live independently, actively participate in society, and have unrestricted enjoyment of all rights on an equal basis with others. It involves the extent to which products, systems, services, environments, and facilities can be used by people with diverse requirements to achieve identified goals in identified contexts of use.

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**Accessible formats** Information provided in a variety of formats to meet the needs of persons with sensory disabilities. This includes but is not limited to Braille, tactile graphics, large print, text-to-speech, oral presentation, electronic files compatible with screen reading software, captioned or sign language interpreted videos, icons or animations, image description, etc.

**Accessible technologies**

Technologies and digital tools aimed at a wider audience, but which can be useful for persons with disabilities (e.g., smartphones , digital assistants, etc.).

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**Assistive devices and technologies**

Assistive, adaptive, or rehabilitative tools designed to specifically help persons with disabilities with daily tasks (e.g., wheelchairs, hearing aids, Braille displays , screen readers , assistive canes, magnifiers, text-to-speech systems, vibrating alarm clocks, etc.).

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**Community-based rehabilitation (CBR)**

Cross-disciplinary and cross-sectoral services specifically designed for persons with disabilities that are delivered across a range of health and social service delivery models, including through hospitals and health clinics, schools, NGOs, home-based supports, businesses, etc., to obtain maximum independence, full physical, mental, social, and vocational ability, and full inclusion and participation in all aspects of society.

**Deafblindness** 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/Deafblind interpreters, among others.

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**Disability** An evolving concept that results from the interaction between persons with impairments and environmental and/or attitudinal barriers that hinder their full and effective participation in society on an equal basis with others.

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**Disability mainstreaming** A comprehensive and holistic approach to remove barriers and improve access and opportunities in services available to the public for persons with disabilities on an equal basis with persons without disabilities.

**Disability  
resource centre  
or hub**

An independent organisation or network of organisations with the primary focus of providing information and technical resources to persons with disabilities, families, and professionals working with persons with disabilities across a range of services. These information and technical resources may be delivered through a resource library, an online repository of information and technical guidance, training courses and other learning events, and links with technical experts.

**Disability-specific services**

Specially designed community-based services to meet the requirements of persons with disabilities, usually involving identification of the impairment, assessment, and testing of the impairment to understand functioning, referral services to receive further advice or supports, community-based rehabilitation or habilitation services to attain maximum independence and participation in society, and disability support services to provide access to live assistance, assistive devices and technologies, modifications to the home, etc. For this report disability-specific services include deafblindness-specific services as well as disability-specific services aimed at multiple groups of persons with disabilities.

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**Disability support services**

Direct help or live assistance for persons with disabilities so that they can perform daily activities (e.g., access to assistive devices, live assistance, sign language interpretation, accessibility modifications in the home, and more).

**Discrimination** Any distinction, exclusion, limitation, or preference which, being based on race, colour, nationality, ethnicity, social or economic status, language, religion or similar belief, political or other opinions, gender, gender identity, sexual orientation, family or civil status, disability, or other characteristic, has the purpose or effect of nullifying or impairing equality

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**Human rights or social model of disability** Recognises the systemic barriers in the environment, negative attitudes, and social exclusion as the factors that impede the full participation of persons with disabilities, not the person's condition. It requires adaptations to the environment and reasonable accommodations to ensure equal opportunities. It is also grounded in the principles of the CRPD, including respect for autonomy, non-discrimination, full and effective participation, acceptance of difference and diversity, equal opportunity, and accessibility.

**Identification, assessment, and referral**

Services that are specially designed to identify disabilities (usually through screening, risk factor questionnaires, or health checks), assess the condition and individual functioning through tests and comprehensive evaluations, and refer individuals for additional testing, health and rehabilitation specialists so that they receive information on their condition, advice on how to make adjustments, and support services.

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**Inclusion**

The meaningful participation of persons with disabilities in all of their diversity, the promotion of their rights, and of disability-related perspectives in line with the CRPD.

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**Interpreter-guide/Deafblind interpreter**

Uniquely trained and qualified professional that is responsive to the compounded support requirements of persons with deafblindness, including communication, interpretation, access to information, description, orientation, guiding, and mobility support, adapted to the person. Other terms may be used, depending on the context and translation into native languages.

**Medical model of disability**

Viewing disability as a problem that belongs to the individual, which has dominated approaches and responses to disability. It includes a perception that something is wrong with the person, which affects attitudes and behaviours directed toward them and leads to stigma and exclusion. For example, the belief that persons with disabilities need to be looked after rather than empowered, that they are not capable of making decisions or doing things that others can do, or that they are to be feared.

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**Organisation of persons with disabilities (OPD)**

Organisations comprising a majority of persons with disabilities (i.e., more than half of their membership) and governed, led, and directed by persons with disabilities rooted in, committed to, and fully respectful of the principles of the CRPD.

**Orientation** The action of understanding the environment, for example, orienting someone or something relative to a specified position. For persons with deafblindness, this orientation relates to mobility, looking for and finding things or people, navigating an environment, understanding what is going on in their environment, etc.

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**Reasonable accommodation** Necessary and appropriate modifications and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure persons with disabilities the enjoyment of rights on an equal basis with others.

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**Post-lingual deafblindness** When vision and hearing loss is acquired after the development of a language, including spoken or sign languages.

**Preconditions for inclusion**

The essential building blocks or foundational aspects that are indispensable in addressing the requirements and views of persons with disabilities that should be considered in public policy-making and programming across all sectors.

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**Pre-lingual deafblindness**

When vision and hearing impairment is acquired at birth or in the early years before a child develops a language.

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**Sensory disability**

Characterised by barriers to communication and/or accessing information through sight, hearing, smell, touch, taste, and/or spatial awareness.

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**Stigma**

A mark of disgrace associated with a particular circumstance or quality, resulting in being treated differently, marginalised, and discriminated against. This is usually based on false assumptions or cultural or religious beliefs. Disability stigma is often associated with disease, dependence, helplessness, and curses.

## **Twin- track approach**

Integrating disability-sensitive measures into the design, implementation, and monitoring and evaluation of all policies and programmes. This involves providing both targeted, disability-specific measures as well as mainstreaming strategies to bring about the inclusion of persons with disabilities.

## **Washington Group Questions**

Questions specifically designed to be used in surveys or censuses to count persons with disabilities (i.e., replacing the yes/no question on whether a person has a disability). The questions focus on functional domains, such as difficulty performing basic universal activities (e.g., walking, seeing, self-care, etc.) and are used in measurement tools, such as large surveys, alongside other questions to enable disaggregation by disability status. There is a Short Set of six questions and several Extended Sets to better include functions missing in the Short Set. There is also a set of questions adapted for children to account for their evolving development - the Washington Group-UNICEF Modules for Child Functioning for children aged 2-17 years.

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## The World Federation of the Deafblind (WFDB)

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## REGIONAL REPRESENTATIVES



**European Deafblind Union  
(EDbU)**



**Federación Latinoamericana  
de Sordociegos (FLASC)**  
*(Latin American Federation of  
Deafblind)*



**African Federation of  
Deafblind (AFDB)**