



Executive Summary of 1st Global Report on the Situation of Older Persons with Deafblindness December 2023

Acknowledgements and Disclaimers

This report was coordinated by The World Federation of the Deafblind (WFDB). The qualitative and quantitative research and report compilation was led by senior independent consultant, Igor Kusin. Technical support was provided by Lucía D'Arino (WFDB Programme Advisor) and Sanja Tarczay (WFDB President).

We would like to thank everyone who contributed to the report, in particular, those involved in the SHAPES Project in one way or another, WFDB members, and allies for sharing literature sources and participating in WFDB's survey on older people with deafblindness. We also appreciate the contributions made by WFDB board members and participants during the WFDB technical meeting in June 2023 in Brussels, Belgium, as well as other workshops organised within the framework of the SHAPES Project.

The report was made possible thanks to the technical support of the International Disability Alliance (IDA) as well as the SHAPES project which received funding from the European Union's Horizon 2020 research and innovation programme, under grant agreement No 857159.

The information and views set out in this document are those of the author(s) and do not necessarily reflect the official opinion of the International Disability Alliance (IDA), the SHAPES project partners, or other funding or collaborating parties.

Introduction

In 2018, WFDB launched its 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 outcomes¹.**

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 programmes². – World Federation of the Deafblind, *At Risk of Exclusion from CRPD and SDG Implementation: Inequality and Persons with Deafblindness*

¹ 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/>.

² *Ibid.*

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) and Agenda 2030 and the Sustainable Development Goals (SDGs) have triggered greater attention to 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 issues, as well as their specific inclusion requirements”³.

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

³ *Ibid.*

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, the subsequent GDS in 2022 hosted remotely, as well as networks and mechanisms, such as the Global Action on Disability (GLAD) Network and Assistive Technology (AT) 2030⁴. These events and mechanisms have provided valuable space to raise awareness of disability inclusion and serve to advance the global

⁴ 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 that tests what works to improve access to assistive technology, <https://at2030.org/>, May 2022.

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.

In 2023, WFDB launched its Second Global Report on the Situation of Persons with Deafblindness, [*Good Practices and Recommendations for the Inclusion of Persons with Deafblindness*](#). This second global report sought to build on the findings and recommendations of the first global report and to consolidate evidence from different regions and diverse groups, including persons with deafblindness and professionals. Moreover, it 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 thematic areas. The aim of that report was 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 included 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.

This report is the first global report issued by WFDB that focuses on older persons with deafblindness, an underrepresented group, also when it comes to research and literature on them.

Within the group of older persons with deafblindness four subgroups are usually identified:

- 1. Those who have acquired deafblindness earlier in life and not due to ageing**
- 2. Those who were primarily deaf and started losing their vision due to ageing**

3. Those who were primarily blind and started losing their hearing due to ageing
4. Those who were both sighted and hearing until they started losing both senses due to ageing

The fourth group is the largest one, and its members are usually unfamiliar with the experience of being Deafblind and with alternative means of communication, and therefore experience more difficulties to communicate, read, access information, and move independently. Because of this, the fourth group is the least equipped to bridge the communication gap that is opening between them and their surroundings. At the same time, this group is the one that is covered by the majority of the existing literature on older people with deafblindness. The support and assistance needed by the members of the fourth group are more general than those needed by the members of the first three groups. However, all persons ageing with deafblindness share the same experiences: ongoing impairment alongside ageing-related changes, and the resultant need for enduring adaptation. It is important to acknowledge a particular relationship between ageing and deafblindness, with one exacerbating

the other. Individuals often experience ageing as a “second disability,” as well as a sense that whilst one can learn adaptive strategies having lived with deafblindness for a long time, it does not necessarily get easier, and there is often anxiety related to maintain independence. Because of this relationship, there is also a necessary relationship with care and support services.

Regarding the incidence of deafblindness among older people, the numbers vary and are likely to be outdated or inaccurate. In European countries, it is estimated that there are 150 older people with deafblindness for every 100,000 older people. In Finland, the estimates range between 700 and 718 per 100,000. In Norway, it is between 130 and 188 per 100,000. In the Netherlands, 125 per 100,000. In the Aarhus district of Denmark, 130 per 100,000, and in Leicestershire, England 970 per 100,000⁵. However, what all research can agree on is that prevalence of dual sensory impairment (hearing and vision loss) increases substantially with age.

⁵ Matthews 1988a: 28; Svingen & Saarinen 1988a; Balder 1988: 102.

Context: The 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 social 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.

This programme spans across 14 EU countries and engages 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 report has been developed within the context of the SHAPES Project, where WFDB's participation has provided an excellent platform to collect data, feedback, findings on the situation of older persons with deafblindness, as well as identify key challenges, gaps and barriers. WFDB has decided to assemble the information produced during the project, combined with existing research and literature, with the intention of producing a living document that will outlive the project and can be used for multiple purposes by different stakeholders.

In a nutshell, the report attempts to paint a picture on the situation of older persons with deafblindness and its most recurrent themes, using the SHAPES Project as a starting point to raise awareness and encourage future research and documentation on this very specific and often neglected group. This report must be seen as a living document that should be updated and modified in time.

Case Study: SHAPES Project as an Example of how to Include Older Persons with Deafblindness

The SHAPES Project can be referred to as an example of a good practice on how to ensure the participation of older persons with deafblindness in mainstream programmes. Persons with deafblindness of varying ages have been involved in activities to collect data, such as interviews, focus groups, and workshops, to inform on the situation and experiences of older 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 for persons with deafblindness, the testing the digital tools, and solutions being developed for the project. This data has provided valuable insights.

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. 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.

Best practices and lessons learnt from WFDB's participation in the SHAPES Project include:

- Ensuring a rights-based perspective with a CRPD-compliant approach both within SHAPES as a project and its outputs, to

advance the rights of persons with disabilities, including those with deafblindness

- The central importance of adopting accessibility and inclusion as a cross cutting requirement, ensuring accessibility standards and reasonable accommodations amongst others, including a budget for interpreter-guides/Deafblind interpreters and information in accessible formats
- Involving a wide range of OPDs, including those 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. However, these individuals should maintain ownership and decision-making of the project
- OPDs play a key role as right-holders to guide priorities and validate projects results, as well as in building awareness and technical support on accessibility and inclusion measures in mainstream projects. They should be allocated a budget and explicit responsibilities, so they are able to perform their role adequately and make meaningful contributions

- Training for project partners at the beginning of a project on accessibility and inclusion encourages shared responsibility between OPD partners and mainstream partners
- Ensuring that all documents and materials (including overall approach, findings, lessons learnt, etc.) are available in multiple accessible formats and languages in all dissemination efforts to maximise reach

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.

Methodology

This report is based on existing literature on older persons with deafblindness, interviews with older

persons with deafblindness, and the answers sent by respondents to an online survey launched in July 2023 (further details are included in section titled “WFDB’s 2023 Survey on Older People with Deafblindness”).

Information from all three sources have been grouped together and presented as different chapters, gathered around the same or similar problems, barriers, best practices, and possible solutions. Sometimes a chapter was based on just one of the three sources.

A statistical approach was implemented where relevant.

Qualitative Research

The qualitative research focuses on data gathered from the literature review, which was analysed and categorised according to the topic they covered. Each topic was then structured in a different paragraph representing all the views, sometimes supporting and sometimes opposing each other, in an attempt to portray a wide a range of opinions on the situation of older persons with deafblindness and professionals who work with them.

The open answers to the questions in the online survey were examined in a similar manner, grouping together those that referred to the same topic and presenting the most frequent as well as the most elaborated ones for each question.

Quantitative Research

The quantitative research was extracted from the survey questions was analysed statistically and is often represented in a graphical form. The same is valid for some other answers in which numerically and statistically representable data were contained.

A detailed summary of the results can be found in the [full version of the report](#), as well as findings from literature.

2023 WFDB Survey on Older Persons with Deafblindness

WFDB launched in July 2023 an online survey with the purpose of gathering information on older persons with deafblindness for this report. The survey was intended for WFDB members, persons with deafblindness, organisations by and for persons with deafblindness, and other

organisations and professionals in the field of deafblindness. It was made available online for a month and shared widely with WFDB's network. This survey was organised as part of the SHAPES Project and counted on the collaboration of the International Disability Alliance (IDA).

Eighty-six persons from 24 countries responded to the survey: Angola (1 respondent), Australia (2 respondents), Austria (1 respondent), Bangladesh (1 respondent), Brazil (1 respondent), Bulgaria (1 respondent), Canada (4 respondents), Denmark (4 respondents), Ethiopia (2 respondents), Hungary (2 respondents), India (7 respondents), Indonesia (1 respondent), Italy (1 respondent), Kenya (2 respondents), Malawi (1 respondent), Norway (4 respondents), Palestine (1 respondent), Russia (5 respondents), Rwanda (1 respondent), Slovenia (3 respondents), Spain (28 respondents), Tanzania (1 respondent), Uganda (5 respondents), UK (1 respondent) and USA (7 respondents); that is: 49 from Europe, 13 from Africa, 11 from North America, 10 from Asia, 2 from Oceania and 1 from South America.

WFDB SHAPES Technical Workshops

WFDB, in collaboration with the International Disability Alliance (IDA), has held three technical workshops within the context of SHAPES.

Participants include WFDB Executive Council members and Regional Representatives, as well as European Deafblind Union (EDbU) representatives and respective guide-interpreters/Deafblind interpreters.

The main outcomes of the workshops include:

- Ensure proper knowledge of, and ownership of the ongoing work of SHAPES
- Consultation and feedback gathering on the current situation, challenges, and barriers faced by older persons with deafblindness, good practices and recommendations, physical accessibility of public areas and services, digital accessibility and the use of technology to improve quality of life, etc.
- Strengthen ties between Deafblind representative organisations and SHAPES partners.
- Test digital solutions being developed or improved in the project

- Engage in events or meetings to promote the SHAPES Project and raise awareness on WFDB’s participation in the project

These workshops have provided an opportunity to validate the findings from the SHAPES Project and generated insights on older persons with deafblindness, which has fed into this report.

Definition of Deafblindness

Deafblindness is a distinct disability, as stated in the Nordic definition from 1980⁶, revised in 2007 (Gullacksen et al. 2011: 13–14):

“Deafblindness is a distinct disability and a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree, that society is required to facilitate specific services, environmental alterations and/or technology.”

⁶ There are other definitions, legal, clinical, etc. (Simcock & Manthorpe 2021: 97) but this functional definition is the one accepted by the organisations of persons with deafblindness. The existence of different definition just underlines the complexity of deafblindness as a condition (Simcock 2016: 1704).

For instance, in their research, Jaiswal et al. (2020: 3) used the medical criteria for deafblindness laid out by the Quebec Health Insurance system: for vision – a visual acuity less than 20/70 (6/21) or a visual field of less than 60° in the better eye with best standard correction, or hemianopia (loss of half the visual field due to stroke or nerve/brain damage); and for hearing – an unaided average pure-tone threshold hearing level (HL) of more than 26 decibel (dB) across four frequencies (0.5, 1, 2, and 4 kHz) in the better ear.

Needs of Older Persons with Deafblindness

The findings of a study⁷ on the needs of older people from their own perspective and how those needs were met or why they were not met, might be equally, if not even more, be applicable on older persons with deafblindness.

They can be categorised as:

- 1. Practical needs** (includes everyday needs such as grocery shopping, home chores, etc.).
- 2. Emotional needs**, grouped as:
 - a) Feelings of anxiety and insecurity
 - b) Feelings of insignificance and of being neglected
 - c) Feelings of sorrow and grief
- 3. Existential needs**, listed as:
 - a) To find a meaning in life from now until death
 - b) To find a meaning with life as a whole and to be able to contribute with one's own knowledge and experiences

⁷ Ojan Thoreaus Olsson. 1990. "After 80, a Study of Older People's Requirements for Social Care, and of Their Care Situations." *Report of Social Work* no. 48. Stockholm: University of Stockholm.

c) To prepare for one's own death.

Challenges or Barriers for Older Persons with Deafblindness

The following section focuses on the most recurrent topics or themes that were identified in the research and where relevant, links have been drawn with CRPD articles.

One respondent to the survey classified the barriers into two groups:

- 1. Attitudinal barriers:** The barriers due to perceptions from persons with deafblindness themselves and society around them. Some of them are perceived as persons with deafblindness being unable to involve in their daily activities.
- 2. Environmental barriers:** The environment is not supported for or adapted to persons with deafblindness.

Legal Recognition of Deafblindness as a Distinct Disability

Political and legislative decisions influence the everyday life of persons with disabilities,

including those of older persons with deafblindness. The legal recognition of deafblindness as a unique disability, of Deafblind persons and their needs and communication systems is the primary goal of every association of persons with deafblindness. However, recognising just one of the four categories mentioned above does not imply that all the others are automatically recognised as well. Countries that officially recognise deafblindness as a distinct disability and/or have adopted an official definition of deafblindness are more likely to provide specific support services. This is particularly the case in low and middle-income countries. In 2004, The Parliament of the European Union adopted a *Declaration on the Rights of Deafblind People*. The UN *Principles for Older Persons* from 2019 cover both political and social participation. Article 29 of CRPD promulgates the effective and full participation in political and public life of persons with disabilities. Unfortunately, the World Health Organisation still does not recognise deafblindness as a distinct disability in its *International Classification of Functioning, Disability and Health (ICF)* (2001). In 2021, Slovenia was the first country to include the language of the Deafblind into its constitution. Italy has also recognised deafblindness by

passing the Law n. 107 from 24 June 2010, subtitled *Misure per il riconoscimento dei diritti delle persone sordocieche (Measures for the Recognition of the Rights of Deafblind People)*. Both lingua dei segni italiana (LIS) and lingua dei segni italiana tattile (LIST), Italian Sign Language and Italian Tactile Sign Language respectively, are also recognised. The *United Convention on the Rights of Persons with Disabilities (UN CRPD)*, ratified by 186 states worldwide, offers only limited references to deafblindness, and those concern the education of children with deafblindness. The recognition of the impairment and of the language is a significant step but is far from the end of the struggle.

It is evident that there is little evidence of older persons with deafblindness participating in the co-production of policies and services that promote their well-being. The right to interpreter-guides/Deafblind interpreters should be one of the basic rights of persons with deafblindness, but it is hard to imagine that anyone would provide interpreter services until compelled to do so, only straightforward political action by the government can ensure that such a service be available to all the persons with deafblindness who need it. One important thing connected to

legislation is that as deafblindness cannot be described as a simple sum of deafness and blindness, older persons with deafblindness cannot be described as a simple sum of older persons and persons with deafblindness. Again, we have a sum that is greater than the parts. The respondents to the survey suggested that the governments should increase their funding towards services for the Deafblind, that the numbers of hours per month that a person with deafblindness would be assigned an interpreter-guide/Deafblind interpreter should be increased, that the government should collect disaggregated data on how many persons with deafblindness live in the country and their needs, that educating and training persons with deafblindness should be organised, enabling them to have a job, and consequently some financial security, with a promise of a pension one can live on when retired, and that access to urgent and emergency care services should be adapted for persons with deafblindness to use at all times.

Response to Emergencies

Respondents to the survey tackled the question of contacting emergency services. Access to urgent and emergency care services should be

adapted for persons with deafblindness to use at all times. It is suggested that appropriate application (app) and technology should be developed for this purpose, in collaboration with persons with deafblindness and their representative organisations.

This issue became extremely important during the recent COVID pandemic that has particularly impacted older persons.

In the Second Global Report (World Federation of the Deafblind 2023) some of the key concerns for persons with deafblindness raised during the COVID pandemic are mentioned:

- Access to information in accessible formats
- Access to essential services
- Accessible communication
- Accessible guidance for the public
- Accessible meeting platforms used for remote working, health appointments, or education
- Lack of community outreach to check on individuals with high support needs

Those key concerns can be applied to any of the abovementioned emergency situations. Article 11 of CRPD includes measures to ensure the

protection and safety of persons with disabilities in situations of risk.

Interpreter-Guides/Deafblind Interpreters and Other Forms of Live Assistance

Interpreter-guides/Deafblind interpreters are a crucial service which enables the person with deafblindness to reach the level of independence needed to fully participate in society. However, those interpreter-guides/Deafblind interpreters may be not always available. There are many reasons for this, including an insufficient number of interpreter-guides/Deafblind interpreters and administrative challenges. According to the World Federation of the Deafblind (WFDB 2023, 67–69), many states, especially low- and middle-income states, do not possess a system of interpreter-guides/Deafblind interpreters, but this is also valid for those states that do not recognise deafblindness as a distinct disability and/or in which Sign Language is not recognised as a minority language. The usual obstructions in environments where an interpreting service does exist include the assignment to every single person a specific and limited number of interpreting hours per month based on the

severity of the person's impairment, usually calculated on the strictly medical, numeric basis and has no relation to the actual needs of each individual. Additional obstructions include local officials who simply do not understand the situation and needs of the older person with deafblindness, often being uneducated on deafblindness. Oftentimes, a person with deafblindness is only represented as an entry in the spreadsheet to follow. Moreover, services require a considerably advanced booking, which is not always possible, particularly in emergency situations. Finally, providing a salary for the interpreter-guide/Deafblind interpreter by the Deafblind person serves as an obstruction. The lack of appropriate live assistance can affect almost all aspects of a person with deafblindness, which can have a direct impact in their quality of life.

Isolation and Loneliness

Isolation is a problem mentioned by virtually all the interviewed persons with deafblindness, authors and texts. Isolation proved to be an especially grave burden during the COVID pandemic because touching and closeness, methods used by most persons with

deafblindness to communicate and access information, were not allowed. Loneliness could be defined as not having anyone to communicate with in one's own language and as not having any or only very few relationships in life. Isolation is one of those difficulties experienced by persons with deafblindness that can be caused by several instances at the same time: the person with deafblindness withdraws from public life, frustrated by his/her inability to communicate or be understood successfully, by mishearing, by responding inappropriately, and by consequently appearing foolish, even in a well-known environment. Oftentimes, the person's immediate surroundings, family and friends, begin avoiding him/her because of difficulties in communication, perceiving the older person with deafblindness as an outcast. Professionals and specialists rarely know anything about deafblindness or how to communicate with persons with deafblindness, so they reduce their own activities to the necessary minimum, not having time or patience to communicate with their patient/client. Moreover, the community at large rarely notices persons with "invisible" disabilities and ostracise those identified as such. The severity of the problem of isolation lies in it being the slippery slope that leads to loneliness, which often leads

to depression, leading to a person being forcibly placed in an institution where he/she are given pharmacotherapy to induce a vegetative state. Older persons with deafblindness in general seem not to fear so much isolation itself, but rather, the inability to cope with it. In any case, social isolation experienced by older adults, experiencing deafblindness or not, is a public health concern.

Sight and Hearing Loss due to Ageing

Many older persons with deafblindness remain “hidden” because they simply accept that having visual and hearing problems is a normal consequence of ageing, affecting all individuals and something that simply must be dealt with. Consequently, they will not identify as persons with deafblindness, therefore, not seek appropriate Deafblind specific services, institutions, and associations for assistance, and will remain deprived of appropriate support and help. However, it is unimportant whether the dual sensory loss is the result of ageing or a disease. What is important is to recognise it and realise that action can and should be taken.

Identity

As mentioned, many individuals with a dual sensory loss, not only older individuals, reject the label “Deafblind” for multiple reasons, even when aware of mobility, communication, and information accessing problems. When it comes to older persons with dual sensory impairment not perceiving themselves as persons with deafblindness, key players such as health care workers, social workers and other professionals can be a part of the problem. This is because many oversimplify and blame it on ageing, refusing to recognise deafblindness as a unique and distinct disability, with its own specific challenges, barriers, support, and inclusion requirements.

Not identifying oneself as a person with deafblindness can have serious consequences, for example, limited or no access to exclusive services for persons with deafblindness, in a condition where separate services for the deaf and for the blind are not sufficient or adequate, i.e.: interpreters for the deaf and guides for the blind cannot replace interpreter-guides/Deafblind interpreters. Also, peer-to-peer counselling is not an option when one does not accept a peer as such. This will also mean that they will not be accounted for in statistical and data research

practices, which can affect the Deafblind community in general by representing them as less frequent than is the actual situation. Therefore, their specific needs and preferences are less likely to be accounted for.

Socialising with Other Persons with Deafblindness

Meeting other persons with the same condition is of extreme importance for any person with deafblindness, but especially for an older individual. Finding new people with whom it is possible to communicate directly, as well as through an interpreter, might present a fingerpost for the way out of one's complete isolation. Such encounters and gatherings within the Deafblind community often replace the friendships and relationships lost over the communication problems of the older person with deafblindness. The presence of other persons with the same condition is beneficial in rehabilitation, as well.

Deafblindness Misdiagnosed as Dementia

While people around older persons with deafblindness may interpret his/her misunderstanding in communication as a sign of

reduced mental abilities due to ageing, they can also jump to the conclusion that he/she is experiencing cognitive debilitation, that he/she is senile, demented, or having cognitive difficulties in keeping up. Unfortunately, misdiagnosed dementia may lead to actual dementia, because deafblindness in older persons can be related to cognitive decline, functional decline, depression, and participation challenges. Of course, an older person with deafblindness can also actually experience dementia. What is important here is to be able to tell the two apart since the problem of diagnosing dementia is extremely pronounced in persons with deafblindness. Namely, it may be difficult to determine whether a person is dealing with the consequences of deafblindness or signs of dementia without appropriate testing and knowledge.

Deafblindness Combined with Other Disabilities and Illnesses

The term used in psychological literature for a combination of disabilities and illnesses is “multiple vulnerability.” Psychiatric or psycho-geriatric symptoms are likely to develop with older persons with deafblindness when faced

with their own condition and the consequences of isolation, especially if the condition was acquired at older age. Sometimes, deafblindness can incur for other disabilities or illnesses, while in other cases, multiple disabilities have no mutual causal relationship but can influence each other negatively. This situation is often experienced by older persons with deafblindness, which can impact their quality of life and general wellbeing.

Adapting to New Circumstances

Deafblindness is not a static condition as the level of hearing and sight can vary during a person's lifetime with no fixed pattern. Within the older Deafblind population, changes in impairment occur concurrently with changes associated with ageing as a "second disability." Moreover, persons with deafblindness may experience changes associated with ageing sooner than those without impairments, a phenomenon named *accelerated ageing*. Older persons with deafblindness might feel forced to make multiple, repeated, ongoing, permanent, and constant adjustments to their daily life. The range of adjustments for older person with deafblindness includes psycho-social adaptation

and emotional acceptance of deteriorating senses, changes in relationships, including personal relationships and relationships with social care services, having to learn new ways to complete everyday activities, the use of modern assistive technologies and access to information.

There are two main types of adaptations that are ongoing when talking about older person with deafblindness: learning new communication methods or adapting existing ones and learning new skills with new assistive technology.

Communication becomes more difficult with constant changes in hearing and vision, making existing communication methods unsatisfactory. However, many older persons with deafblindness prefer to maintain already adopted communication methods rather than learning alternative communication techniques, being more interested to retain or regain use of their hearing and vision to the greatest extent possible. As far as functioning assistive technology is concerned, such as hearing aids, many older persons with deafblindness consider it to be of the utmost importance to be able to remain independent, maintain social relationships and to live an active life. Unfortunately, one of the problems with developing technology in general

is that it strives towards diminution. This can be a major challenge for older persons with deafblindness, since many lose their fine motor ability, have the sense of feeling in the fingers reduced, which can present a particularly hard problem. For example, these challenges can be seen when it comes to handling ever smaller and smaller modern hearing aids controls. Lack of accessible information about available technology is another major problem. Further problems related to assistive technology are cost, training, maintenance, and adaptation of the device as per individual, specific needs. Some older persons with deafblindness deem themselves to be too old to learn new skills. However, if it is not easy for an older person to learn how to use new technologies, it does not mean that it is impossible. One of the best ways is to be taught by someone who understands his/her needs and not by a skilled IT expert, as it is often the case. An older person with Deafblindness should learn in small steps, at a slow pace, and avoid information overload. On the other hand, there are other older persons with Deafblindness who engage actively in rehabilitation services and enjoy the opportunity to learn new skills and how to use new assistive and mainstream technologies, even in a much

later life. This directly challenges the negative and stereotypical construction of old age as a period of inevitable decline and withdrawal. A different problem presents in the form of receiving more means of assistance than necessary, when the professional in the field simply ignores the service that is needed. The only evaluation criteria in deciding this service should be the evaluation of the situation by the older person with deafblindness him/herself by assessing how much is this is contributing to his/her Quality of Life (QOL), to a pleasant, positive, happy, and safe existence. The life adjustment model acknowledges that adjustments are not just an individual response to impairment, but that people with deafblindness also need the social environment and service providers to adjust as they age, which is not always acknowledged in the literature.

Moreover, another issue is providing unsolicited for help to older persons with deafblindness, which can be a double-edged sword. On one hand, it can be interpreted not as a noble intention, but as a patronising. On the other hand, some older persons with deafblindness are grateful for such help because it demonstrates the helper's intuitive knowledge what is he/she

supposed to do. So, people willing to help might find themselves on a slippery slope. Thus, it is important for the person with deafblindness to make it clear to the service provider when does he/she need help and when not and for service providers to ask if and what kind of assistance is needed.

Health and Care Personnel

Article 25 of CRPD is all about the right of persons with disabilities to equal treatment when dealing with health issues. Unfortunately, insufficient or lack of knowledge on deafblindness, persons with deafblindness, and their needs and methods of communication seems to be the greatest problem persons with deafblindness face when meeting professionals who should provide services for them such as health care staff, social workers, etc. Health and social care systems are often designed around individual medical conditions rather than conditions involving multimodality. For example, ophthalmology is separated from audiology and not treated in conjunction. The person with deafblindness acquires two medical reports for his/her unique condition, only reinforcing the

“deafblindness is the mere sum of deafness and blindness” fallacy. Even hospitals sometimes refuse to include people with deafblindness in therapy sessions because of “impossibility of communication.” Many older persons with deafblindness do not feel that they can express their own needs and wishes without being misunderstood or not understood at all by others. Because of this, these individuals often wait as long as possible before contacting the healthcare system, because they mistrust it and do not feel safe in a doctor’s office, infirmary, or hospital. In most cases, neither medical specialists nor family doctors possess enough knowledge about how to assist older persons with deafblindness, the former possibly because their specialisation is too narrow, the latter because their knowledge is too broad. On the other hand, Deafblind services often do not meet the needs of older persons with deafblindness just like mainstream older people’s services do not have the ability to meet their needs as persons with deafblindness. Furthermore, single sensory impairment services are inadequate when meeting the needs of those acquiring a second sensory impairment.

In short, the experiences of older persons with deafblindness in healthcare include inaccessible

information, lack of awareness on deafblindness among frontline staff, and limited communication support, which deeply affects the confidence of the older person with deafblindness in his/her self-management of health conditions. With a nursing home staff not familiar with the specifics of deafblindness or multiple existing communication methods used by the Deafblind, a person with deafblindness remains alone, isolated, and without adequate support and care. This can lead to a rapid mental and general health deterioration, and a decline in the quality of life, caused by the denial of the guaranteed fundamental rights to a dignified life, communication, and ageing. The life in such a nursing home is often limited to meals, sleep, and idleness with no interaction with other humans. They might also be increasingly exposed to neglect, mistreatment, and condescension, which is treatment contrary to CRPD Article 15 - Freedom from torture or cruel, inhuman, or degrading treatment or punishment.

It has been reported that older persons with deafblindness are often expected to be grateful for whichever level of assistance they receive and accept it without question. Many older persons with deafblindness show a preference

for living in a nursing and/or residential homes adapted for person with deafblindness where they could meet other people with the same impairment, exchange experiences, have a good time, and receive accessible older care.

However, this option is rarely available and can be easily labelled as institutionalisation, something both the EU and UN strongly oppose.

In short, an older person with deafblindness should be able to freely choose how and where to live if his/her rights are not compromised, in accordance with existing legislation, including CRPD Article 14 – Liberty and security of person, Article 17 – Protecting the integrity of the person, Article 19 – living independently and being included in the community and Article 25 – Health, amongst others Last, but not least, in contrast to the professionals who come in contact with older persons with deafblindness, a special mention should be made of carers, especially unpaid workers, since they play a key role in the ecosystem of older persons with deafblindness. More programmes and research are needed to address unpaid care work within households and communities where older persons with disabilities live with the aim to support quality, affordable, and accessible care services across sectors and

improve the situation for both care receivers and the people caring for them. It is important to acknowledge the gendered distribution of unpaid care work, identify trends and patterns, and provide recommendations on how to reduce and redistribute unpaid work.

Empowerment

Four main themes may shape the concept of empowerment at the individual level⁸:

1. Having a sense of personal identity
2. Having a sense of choice and control
3. Having a sense of usefulness and being needed
4. Retaining a sense of worth

There are multiple barriers and challenges to empowerment in decision-making at the individual level (e.g., level of literacy and confidence on the domain when a decision is requested; psychological barriers; age, disability, gender, sexual orientation, ethnicity, and their

⁸ SHAPES Project, 2022. Deliverable 2.4 Empowerment of Older Individuals in Health and Care Decision-making. Accessible at: <https://shapes2020.eu/wp-content/uploads/2023/09/SHAPES-D2.4-Decision-making-and-empowerment-2022-10-17.pdf>

intersections; as well as individual characteristics such as personality and life experiences). Notably, the process of empowerment addresses the social, cultural, political, and economic determinants. The main challenge to empowerment is the impossibility of the outside world to communicate with the person with deafblindness and vice-versa. When it comes to empowering people, socio-economic and educational status, cultural backgrounds, and generational factors, as well as institutionalised ageism are greatly impactful. When focusing on older persons with deafblindness, the dynamics of empowerment in decision-making are heavily affected by ageist and ableist attitudes, environments, and structures, leading to discrimination, exclusion, and denying rights of people as they age. Moreover, age intersects with gender and disability, as well as other characteristics. Person-centred care and shared decision-making are both possible only if the communication flows correctly, in an accessible and inclusive way.

Sustaining empowerment across the lifespan relates to four principles (4Ps):

1. Participation

2. Process
3. Practices
4. Purpose

In order to empower persons with deafblindness, Article 3 of CRPD prohibits all discrimination on the basis of disability, while Article 21 states that persons with disabilities can exercise the right to freedom of expression and opinion.

Access to Information

Access to information in our modern society is important for three reasons: 1.) to be able to build the basis to make one's own decisions and to maintain independent living, 2.) to be able to maintain communication with others, and 3.) to be able to participate in discussions and conversations. The constant stream of new information might be difficult to deal with for an ageing person when his/her vision and hearing is deteriorating. Problems with vision and hearing make it hard to keep up in with a society that is constantly changing and putting new demands on the individual. Acquiring information about things that are occurring, both in the close environment and in the world in general may be a problem for older persons with deafblindness.

Today, both information and even more misinformation are available by moving one's fingertips over a keyboard and moving and clicking a computer mouse. Several conditions must be met for older persons with deafblindness to have a better access to information. These conditions include the education of older persons with deafblindness on how to use the digital technology, simplified digital technology to be more efficient, the contents of digital technology must be delivered in a way that can be accessible to persons with deafblindness, and technology itself should be affordable for the Deafblind user. This must all be in line with CRPD Article 4, Article 9 – Accessibility and 21 – Freedom of expression and opinion, and access to information.

Rights and Independence

Independence might mean different things for different people. For some persons with deafblindness, there can be no independence if a person is dependent on interpreter-guides/Deafblind interpreters and other assistive personnel, but other persons with deafblindness are of the opinion that it is exactly the interpreter-

guides/Deafblind interpreters and other assistive personnel who enable the person with deafblindness to be independent. For the latter, being independent does not mean to refuse assistance or to have no need for it but stands for being in control of how and when that assistance is provided. Remaining autonomous and in control for them is as important as being able to care for oneself, in line with the CRPD.

Abuse and Mistreatment

Persons with disabilities are more likely to be subject to abuse than their peers without disabilities, and this is of course the case for persons with deafblindness, especially older individuals. Unfortunately, it is still true that persons with deafblindness are deemed to be one of the most vulnerable groups in society, including vulnerability to exploitation, all types of abuse, and harm. Increased vulnerability indicates loss of dignity, while equal treatment means that dignity is maintained. Among the persons with deafblindness, older women with deafblindness are more likely to be subject to abuse, and violence. Due to their intersecting and multiple sources of discrimination, they may

be subjected to discrimination based on their gender, on their disability, specifically on their deafblindness, and on their age. Access to justice is a key matter, in order to ensure accountability and avoid impunity. Relevant CRPD articles include Article 6, which focuses on the rights of women with disabilities, obliging the signatories to take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms. Additionally, Articles 13 to 17 speak explicitly about access to justice, liberty and security of person, freedom from torture or cruel, inhuman, or degrading treatment or punishment, freedom from exploitation, violence and abuse, and the protection the integrity of the person.

Work, Employment and Retirement

The sense of isolation and loneliness may be enhanced by the change in the employment status of the person with deafblindness. Such a person is usually forced into an early retirement due to his/her low vision and hearing. Older persons with deafblindness belong to two stigmatised and marginalised groups with high levels of exclusion from the labour market. Thus, persons with deafblindness are more likely to be

unemployed than those with other impairments. Although older persons, those with deafblindness in particular, experience discrimination in the workplace and multiple barriers to engage in paid employment, many older persons either work or have a desire to work. Within five years of retiring, one in four older persons “unretire,” or return to work. Routine is sometimes a very important factor in a person’s life and losing that routine can lead into depression and mental deterioration. Inclusive schooling has enabled persons with disabilities to a greater variety of job opportunities, including jobs with university degrees. Now, the problem for the employer becomes adapting the workplace for a person with deafblindness, which means additional expenses. Article 27 of CRPD, *Work and employment*, recognises the right of persons with disabilities to work on an equal basis with others and prohibits “discrimination on the basis of disability with regard to all matters concerning all forms of employment.”

Poverty

Across the globe, and specially in middle- and low-income countries, poverty is stressed as the major obstacle for persons with deafblindness.

Older persons with deafblindness rarely benefit from retirement pensions or from the national funds which support older persons after retirement. Due to the barriers faced due to their disability, fewer people can access high education levels which would give them access to formal employment and social protection services available. Most persons with deafblindness in such countries are illiterate, thus education needs, communication needs, and health care needs of the Deafblind should be prioritised for their meaningful participation in society. Governments often don't give any attention concerning accessibility of education, medical service, and service provisions for the Deafblind community. Two articles of CRPD address this issue: Article 28 mentions explicitly "the right of persons with disabilities to an adequate standard of living for themselves and their families," while Article 24 recognises the right of persons with disabilities to education and to the full development of human potential.

Creativity and Leisure

The right of persons with disabilities to take part on an equal basis with others in cultural life, the

right of persons with disabilities to have the opportunity to develop and utilise their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society, and the right of persons with disabilities to participate on an equal basis with others in recreational, leisure, and sporting activities are all included in Article 30 of CRPD. Creative activities have been proven to be one of the most efficient outlets for persons with deafblindness, in general, and older persons with deafblindness, in particular, to express themselves. Creative workshops organised by associations of the Deafblind or by organisations for the Deafblind attract individuals who find fulfilment in something they can do with their own hands. Enrolling in new activities, especially creative ones, can prevent that passiveness and give the person new opportunities to fill his/her schedule. Unfortunately, for persons with deafblindness, and especially those who are older, living outside major urban centres makes these workshops difficult to access. The situation is even worse in lower-income states, where there is often no organised activity for persons with deafblindness at all. This limits their chances to learn something new, meet others, and most of all – to feel useful, and to feel that their lives have a meaning.

Participation in Activities, Projects and Programmes

The work/projects/programmes focused on older persons with deafblindness done by various organisations may be roughly divided in four groups: 1.) leisure, 2.) training, 3.) political activity, and 4.) material help. In the leisure department, the most frequent activities are excursions and specialised Deafblind camps and retreats, offering different training options for older persons with deafblindness, as well as intergenerational programmes, in which persons with deafblindness of all ages can meet, socialise, and exchange experiences.

Types of training offered to older persons with deafblindness are of two-fold nature. The first type of training involves them into cooking, handicraft workshops and other skills needed in everyday life. The second type of training is more socially oriented, preparing them for jobs, education on rehabilitation services, personal autonomy and mobility, access to technology, adjustment to deafblindness and optimisation of communication. Political activity is aimed both at older persons with deafblindness and society at large. Organisations assist the Deafblind in legal

matters, campaign to improve remote communication for emergency and assistance calls, help them break isolation and loneliness, carry out personalised projects aimed at promoting social participation, respect, and inclusion. Political activities include spreading awareness, disseminating and communicating information related to deafblindness, government support for persons with deafblindness, and workshops on adapted environments, sensory loss, and communication possibilities. Helping older Deafblind persons materially is an activity restricted in low-income countries.

Moreover, some older persons with deafblindness engage in voluntary work, most often within local organisations of or for the Deafblind. These individuals demonstrate lower levels of depression compared to both non-sensory impaired older persons who volunteer and older persons with deafblindness not engaged in such activity. This is because volunteering is done in contact with other persons, so it increases control over one's life, and gives a person with deafblindness a sense of being needed, resulting in reduced social isolation and loneliness.

Recreation and Participation in Social Life

These events partly overlap with those concerning leisure activities from previous section, especially when it comes to one- and multi-day excursions, social retreats, picnics, visiting recreation and other places, and summer holidays. Celebrations are also organised for days and weeks related to deafblindness. Simple gathering and socialising events, or club events, with no specific programme, but regular meetups for persons with deafblindness are also organised. Visits are organised to different places: museums, galleries, cultural events, shopping malls, sensory gardens, zoological gardens, and more. More “formal” events include local experience groups, conferences, or training events. The Deafblind should be encouraged to plan and organise these activities for themselves and their peers and provide intervention and literacy support in the planning process.

Possible Solutions

Possible solutions for the barriers and challenges met by older persons with deafblindness encompass several topics. The first and most

important is raising awareness and education on deafblindness. Education should be provided for the person with deafblindness, those in his/her immediate environment, and professionals, frontline workers, and service providers with whom he/she often comes into contact. The second type of solution is focused on mobility problems, caused both by deafblindness and age, as mentioned in Article 10 of CRPD. Then, there are solutions focused on organised activities for older persons with deafblindness, human and technology facilitators, social and political activity by both organisations of persons with deafblindness and branches of the government. Finally, there are several solutions to the problems with health care workers and other professionals.

Recommendations

In the second global report, some initial steps to bridge the gaps outlined in WFDB's first and second global are listed in the form of recommendations. These recommendations include:

1. Establishing international, national, and sub-national **recognition of deafblindness** as a

unique and distinct disability with its own specific challenges, barriers, and support and inclusion requirements

2. Establishing a **system for information resources and continuous training on deafblindness for essential frontline workers** (e.g., health, rehabilitation, education, social work, etc.) to understand how to identify, rehabilitate, educate, and support persons with deafblindness and how to adapt services as best practice models evolve
3. Establishing **publicly funded live 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
4. Providing **funding for further research** and data to support an evidence base of CRPD-compliant, disability-specific, and disability-mainstreamed services with the active participation of persons with deafblindness and their representative organisations

Some additional recommendations expressed by older persons with deafblindness have been listed below:

1. Establishing centres and resources that provide specific and adequate services and support to older persons with deafblindness
2. Creation of sites for older persons with deafblindness only, where they can socialise and communicate with their peers and where the staff would be educated in deafblindness and Deafblind methods of communication
3. Funding of accessible and public local transport and other specific services for older persons with deafblindness
4. Organisation of workshops, projects, activities, and programmes for older persons with deafblindness, counting on their involvement and collaboration, to enable them to learn new skills, socialise with their peers, participate in leisure activities, and strengthen community building
5. Including the voices and perspective of older persons with deafblindness both within disability mainstream activities and in organisations of persons with deafblindness, by involving them in decision making processes

Conclusion

Building on the first and second global report, WFDB has expanded quantitative and qualitative analysis of the situation of persons with deafblindness, focusing on older persons with deafblindness using data from available literature, interviews, and a survey.

There has been progress in raising awareness on the situation of persons with deafblindness with the first and second global report. However, governments, funders, NGOs, OPDs, and other development stakeholders must develop a firm grasp of the concrete measures and interventions to address the situation of persons with deafblindness, specifically, of older groups. Although more robust research is required across all areas, this global report provides these stakeholders with good practices and inspiration for improved services that are inclusive of persons with deafblindness.

Older persons with deafblindness must cope with the same barriers as all the other Deafblind persons: mobility, communication, and access to information, amongst others. However, they face additional obstacles related to age. For older persons with deafblindness, the effects of disability and ageing interact with each other, often multiplying the discrimination, disadvantage, and inequality. This combination can be enhanced by other disabilities and illnesses that can occur in old age, as well as ableism, ageism, other attitudinal barriers and intersecting sources of identity.

This Global Report described some of those barriers, obstacles and gaps, as well as some suggested solutions, recommendations and some examples of best practices.

This document is an executive summary of a full report. [You can access the report in different formats and languages here.](#)