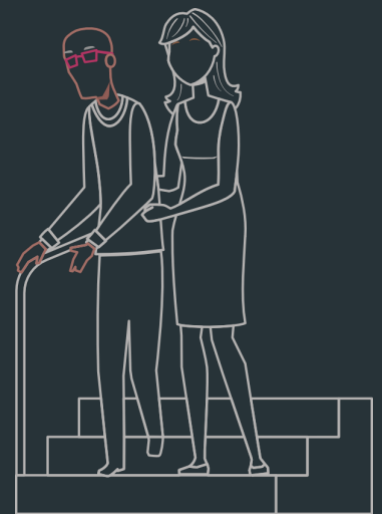
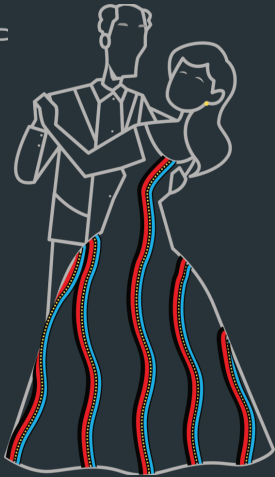
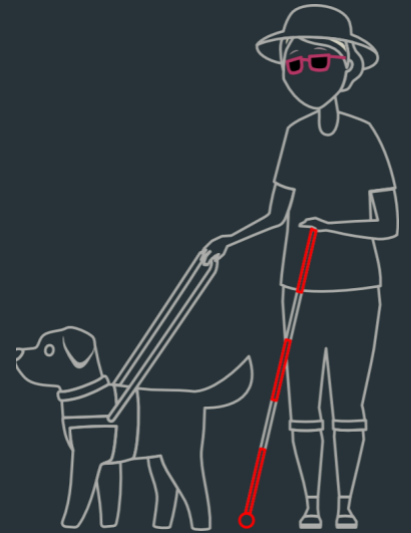


**The World Federation of the Deafblind (WFDB)**

# **Global Report on the Situation of Older Persons with Deafblindness**

**December 2023**





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**<https://wfdb.eu/wfdb-global-report-on-older-people-with-deafblindness/>**

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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 nor other funding and collaborating parties.



## Abbreviations

<b>A</b>	<b>ADF</b>	African Disability Forum
	<b>ADL</b>	Activities of daily living
	<b>ALS</b>	Amyotrophic lateral sclerosis
	<b>APASCIDE</b>	<i>Asociación Española de Padres de Sordociegos</i> (Spanish Association of Family Members of Deafblind Persons)
	<b>ASOCIDE</b>	<i>Asociación de Sordociegos de España</i> (Spanish Association of Deafblind Persons)
<b>C</b>	<b>CNIB</b>	Canadian National Institute for the Blind
	<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>D</b>	<b>DSI</b>	Dual sensory impairment
	<b>DSL</b>	Dual sensory loss
<b>E</b>	<b>EC</b>	Executive Council
	<b>EDBU</b>	European Deafblind Union



<b>F</b>	<b>FASOCIDE</b>	<i>Federación de Asociaciones de Personas Sordociegas de España</i> (Federation of Associations of Deafblind People of Spain)
	<b>FDDB</b>	<i>Foreningen Danske DøvBlinde</i> (Danish Association of Persons with Deafblindness)
<b>I</b>	<b>IADL</b>	Instrumental activities of daily living
	<b>ICF</b>	WHO's International Classification of Functioning, Disability and Health
	<b>IDA</b>	International Disability Alliance
	<b>IGP</b>	Income Generation Programme
<b>L</b>	<b>LIS</b>	<i>Lingua dei segni italiana</i> (Italian Sign Language)
	<b>LIST</b>	<i>Lingua dei segni italiana tattile</i> (Italian Tactile Sign Language)
<b>M</b>	<b>MEP</b>	Member of the European Parliament
<b>N</b>	<b>NADbBg</b>	National Association of the Deafblind in Bulgaria
	<b>NADBU</b>	National Association of the Deafblind in Uganda

**NGO** Non-governmental organization  
**NSSF** National Social Security Fund

**O** **ONCE** *Organización Nacional de Ciegos Españoles* (Spanish National Organisation of the Blind)

**OPD** Organisation of Persons with Disabilities

**P** **PLI** Protactile language interpreting

**Q** **QOL** Quality of life

**S** **SDG** Sustainable Development Goal  
**SHAPES** Smart and Healthy Ageing through People Engaging in Supportive Systems

**SSP** Special service provider(s)

**U** **UBB** Union of the Blind in Bulgaria  
**UDB** Union of the Deaf in Bulgaria  
**UDHR** Universal Declaration of Human Rights

**UN CRPD** United Nations Convention on the Rights of Persons with Disabilities

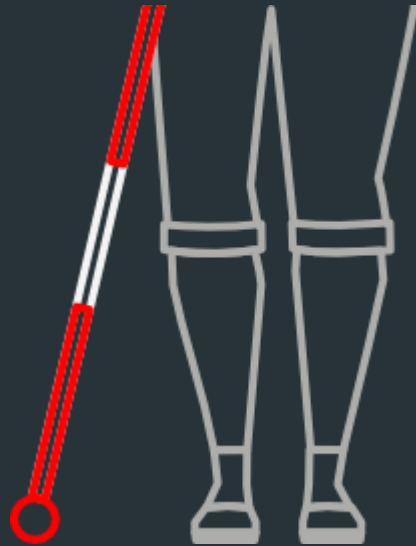
**V** VI Visually impaired

**W** **WFDB** World Federation of the Deafblind  
**WFDB EC** World Federation of the Deafblind  
Executive Council  
**WHO** World Health Organisation





# INTRODUCTION





# INTRODUCTION



Why are we so worried about ageing? Living longer is something we want, provided we are living longer with good health and quality of life. So, we need to know whether our ageing population involves people living longer in good health, followed by a short period of ill health and disability, followed by death, or whether increased longevity means a longer period of disability, too.

Matthews 1988a: 27



We who are not there yet, who are not 80 or over, have probably a lot of preconceived apprehensions about old people, their situations, needs, and problems. BUT what do they really think, feel, dream about, and what do they really want and need from us in our roles as daughters, sons, grandchildren, relatives, neighbours, friends or professionals?

Svensson 1988: 95





Older individuals with deafblindness face unique challenges in their daily lives. Their dual sensory impairment significantly impacts their communication, mobility, and access to information, amongst other aspects that impact their daily routines. It is crucial to provide these individuals with appropriate support and accommodations to enhance their quality of life. However, as each person with deafblindness is unique, their preferences, requirements, and abilities may vary. It is important to establish an open communication between the older persons with deafblindness and all the individuals and organisations that encounter and have an impact on this group, including policy makers, and build individualised strategies based on their specific needs, capabilities, and goals.

In addition to understanding how these individuals interact in the world, having a thorough comprehension of how carers, especially unpaid carers, play a role in the ecosystem of older individuals with deafblindness is critical to offering the most effective solutions and recommendations. However, before one can understand the unique situations older individuals with deafblindness encounter, there must be an understanding of the previous research on deafblindness as a whole.



## WFDB's First Global Report on Deafblindness (2018)

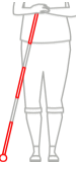
In 2018, the World Federation of the Deafblind (WFDB) launched its first global report on the situation of persons with deafblindness, [\*At Risk of Exclusion from CRPD and SDG Implementation: Inequality of Persons with Deafblindness\*](#). This report sought to open a dialogue between national and international disability rights and development stakeholders and drew attention to one of the most marginalised and underrepresented groups in the world.

2%



Representing 0.2% to 2% of the population, persons with deafblindness are a very diverse yet hidden group, and are more likely to be poor, unemployed, and have low education outcomes.

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 of persons with disabilities, including older individuals



with deafblindness. Underscoring the importance of ‘leave no one behind’, there is growing momentum for greater disability inclusion. However, the first global report highlighted the fact 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”<sup>ii</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 and foster a more inclusive environment for those with deafblindness:

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

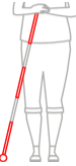




inclusion requirements

- 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 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) 2030<sup>iii</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.



## WFDB's Second Global Report on Deafblindness (2023)

In 2023, the World Federation of the Deafblind (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 best 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.

The report also includes multiple sections on the SHAPES Project, which is an EU innovation programme on technology, ageing and health focusing on older persons, including those with deafblindness. More information can be found in subsequent sections.

This report is the first global report issued by the World Federation of the Deafblind (WFDB) that focuses on older persons with deafblindness, an underrepresented group, when it comes to research and literature.

## **Existing Research on Older Persons with Deafblindness**

At first glance, it might seem that the literature on older persons with deafblindness is not as rich as on children with deafblindness. However, thorough research reveals there are papers and books, addressing this topic, but it is true that the quantity of literature on children with deafblindness is more significant. Despite the minimal existing literature,



research on the situation of older persons with deafblindness is imperative for creating an inclusive and accessible world.

In the following sections, we will present the findings of the existing research on older people with deafblindness, information obtained by individually interviewed older persons with deafblindness, and answers to an online survey completed by individuals with deafblindness and organisations of and for persons with deafblindness.

In 1998, Deafblind International's Acquired Deafblind Network organised its third European Conference in Marcelli di Numana, in Marche, Italy, with its main topic being *Older Deafblindness*. The proceedings of the conference were published the year after containing 27 papers presented on the occasion (*Older Deafblindness* 1988).

In 2008, Lena Göransson published the book *Deafblindness in a Life Perspective. Strategies and Methods for Support* containing the results of a four-year project to develop qualified psychosocial and pedagogical habilitation and rehabilitation for children, adolescents, and adults with deafblindness, as well as for their families. The final part of the book (before "Discussion") is titled "Ageing with Deafblindness" and presents the

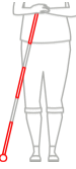


views of older persons with deafblindness, their condition and needs (Göransson 2008: 143–162). However, the section concerning ageing is significantly shorter than those sections concerning individuals experiencing deafblindness in childhood, adolescence, and adult life (Simcock 2016: 1727).

In 2021, Sonja Milošević's book *Život gluhoslijepih osoba u Republici Hrvatskoj (The Life of Deafblind Persons in the Republic of Croatia)* presented the findings of a research carried out as part of the project »UVIJEK ZAJEDNO – sprječavanje diskriminacije i izolacije gluhoslijepih osoba te osiguravanje dostojanstvenog starenja« (“ALWAYS TOGETHER – Preventing Discrimination and Isolation of Deafblind Persons and Ensuring Dignified Aging”), a research that included older Deafblind individuals as well (Milošević 2021).

Moreover, the Croatian Association of Deafblind Persons *Dodir*, the publisher of the volume, has addressed the topic in several issues of its official journal, also titled *Dodir*, as well as in several other publications.

Finally, a dozen online papers and articles on the topic can be retrieved, whose literature provided multiple sources that scrutinised the condition and needs of older persons with deafblindness<sup>v</sup>. As



many of these sources cover the situation of the deafblind population in different countries and regions, their insights are very valuable when trying to compile an overview of the realities of older persons with deafblindness worldwide.

## Definition of Deafblindness

Deafblindness is a distinct disability, as stated in the Nordic definition from 1980<sup>v</sup>, revised in 2007 (Gullacksen et al. 2011: 13–14):

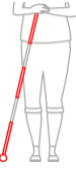
“ Deafblindness is a distinct disability and a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree, that society is required to facilitate specific services, environmental alterations, and/or technology.”

---

Gullacksen et al.

The comments below are a clarification to the definition above of deafblindness:

- Vision and hearing are central in getting information. Therefore, a decrease in the function of these two senses that carry



information from distance, increases the need to use senses that are confined to information within reach (tactile, kinaesthetic, haptic, smell, and taste), as well as leaning on memory and deduction.

- The need for specific alterations regarding environment and services depends on
  - a. The time of onset in relation to communicative development and language acquisition
  - b. The degree of the hearing and vision disability, whether it is combined with other disabilities and whether it is stable or progressive.
- A person with deafblindness may be more disabled in one activity and less disabled in another activity. Therefore, each activity and participation in it needs to be assessed separately. Variation in functioning within each activity and participation may also be caused by environmental conditions and by internal personal factors.
- Deafblindness causes varying needs for co-creating alterations in all activities and especially in:



- Access to all kinds of information
  - Social interaction and communication
  - Orientation and moving around freely
  - Activities of daily life and effort demanding near-activities including reading and writing
- An interdisciplinary approach including specific know-how related to deafblindness is needed in service delivery and environmental alterations.

Deafblindness is a heterogeneous condition. Persons with deafblindness do not represent a homogeneous group of persons with disabilities, even if they are sometimes perceived as such (Simcock, Manthorpe and Tinker 2022: 16).

According to the Coppersmith matrix, there are four subgroups of Deafblind persons grouped by the status of their vision and hearing impairment (Smith 1994), making deafblindness a continuum of combined hearing and sight loss (Simcock & Manthorpe 2021: 97):



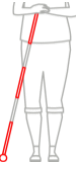


## COOPERSMITH MATRIX

	HEARING	HARD OF HEARING	DEAF
SIGHTED			
PARTIALLY SIGHTED		<b>DEAFBLIND</b>	
BLIND			

What must be kept in mind at all times is that the sum (deafblindness) is greater than the parts (hearing and vision impairment). Because of this, the way that both impairments interact, or the synergy of the impairments, is considered to be a defining feature of deafblindness (Simcock & Wittich 2019: 3).

Therefore, persons with deafblindness have different degrees of hearing and vision impairment, and accordingly, use different methods of communication, both in receiving and in transmitting information. There are a wide range of causes for deafblindness (Simcock & Manthorpe 2021: 97). These causes are often grouped into two overly simplistic and arguably artificial distinction of congenital or pre-lingual versus acquired or post-lingual deafblindness. However, this divide is of less importance when addressing



older persons with deafblindness and their needs (Simcock & Manthorpe 2021: 99–100). Finally, the development of the condition differs from individual to individual (Simcock *et al.* 2022a: 1–2). These factors make the Deafblind community even more complex and internally divided. This heterogeneity results in persons with deafblindness remaining marginalised and, in many ways, invisible (World Federation of the Deafblind, 2018: 3). This marginalisation is especially seen in statistics, policies, programmes, services, and in the specific support required by persons with deafblindness (World Federation of the Deafblind, 2018: 8).

Despite their differences, there are two main aspects that all persons with deafblindness have in common (Simcock 2016: 1704; Simcock and Manthorpe 2021: 97):



Deprivation in use of hearing and sight  
(the distance senses)



Difficulties with communication, accessing  
information and mobility, and activities of  
daily life

(Olesen 2012: 10).



## Older Persons with Deafblindness

A group considered particularly disadvantaged within the Deafblind community are older persons with deafblindness.

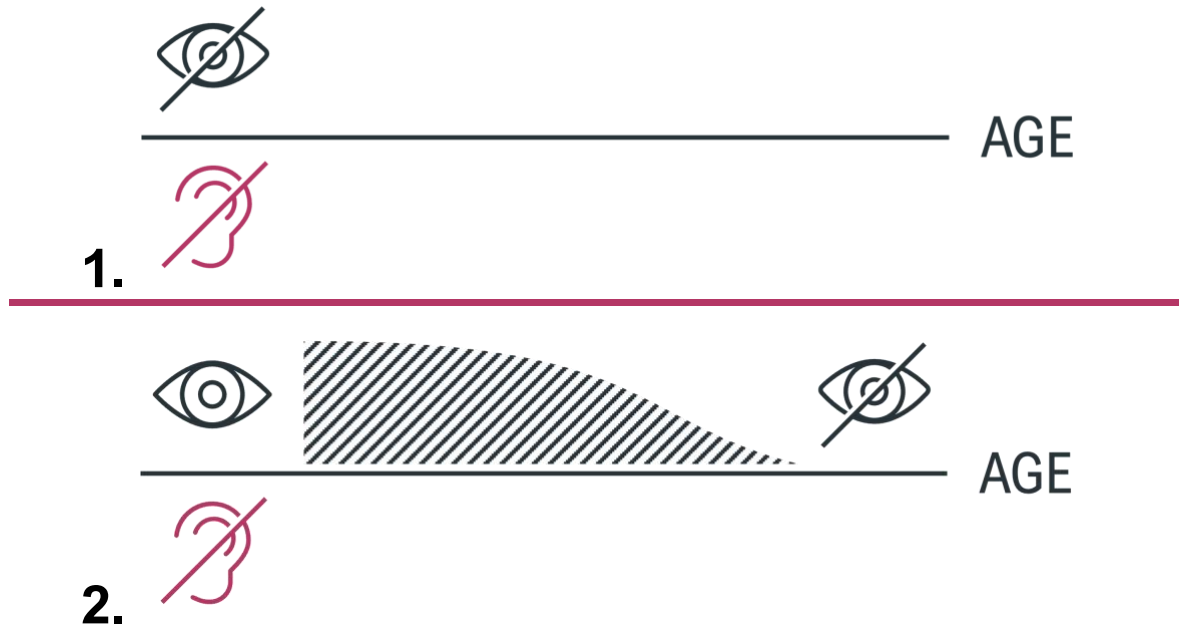
The term “older person” is defined by the European SHAPES Project as a person of sixty-five years of age or older<sup>vi</sup>. However, representatives of persons with deafblindness from low-income countries flagged during a workshop held in Kenya in 2021<sup>vii</sup> that life expectancy varies across regions in the world. For example, in some areas, a forty-year-old person may be considered an older person, since the age of sixty-five is rarely reached.

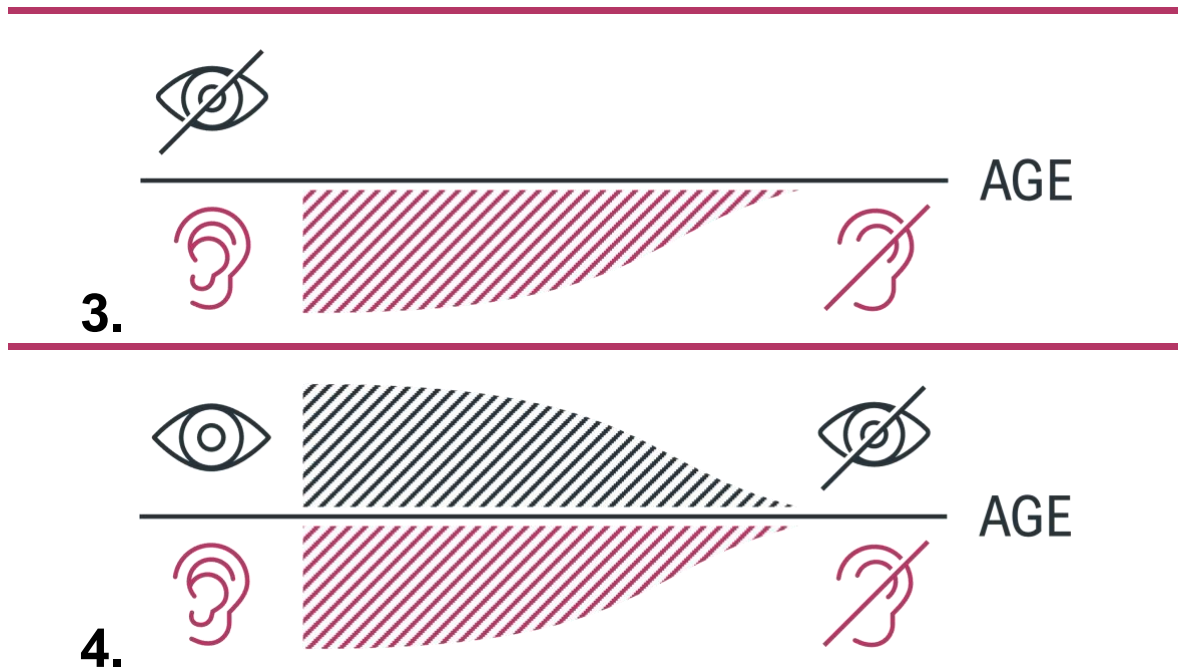
This remark asks us to leave the often-adopted Europe-centric vision of the world and re-think the definition of an older person in a more flexible way, so that it conforms to the situation and context around the globe. For example, an older person could be defined as an individual who reaches 75% of the life expectancy in the region where he/she lives. For instance, in Japan, life expectancy in 2019 was 84.3 years, which would set the threshold at 63 years and older. Whereas in DR Congo, life expectancy is 62.4 years, which would set the threshold at 46 years<sup>viii</sup>.



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 first group are likely to have lived their whole life or a major part of their life with deafblindness and are aware of all the adjustments and strategies needed. The second and third groups have lived all their lives with a primary impairment and acquired the second one due to ageing. Those three groups are usually equipped with knowledge of some alternative method of communication and access to information like Braille or Sign Language and its various modes (tactile, frame, guided, etc.). However, the fourth group, the largest one according to Göransson (2007: 154), is often unfamiliar with the experience of being Deafblind and has rarely been exposed to alternative means of communication, and therefore experiences more



difficulties to communicate, read, access information, and move independently. Because of this, they are considered the least equipped to bridge the communication gap that is opening between them and their surroundings. Göransson also reported on a project focused on capturing each individual persons' description of their life situations and to use them as a basis when developing and creating good means of support (2007: 5). The findings of this project showed only a couple of persons with deafblindness had not had any functional methods for communicating with others (2007: 146–147). The communication problem of this fourth group does not lie in the area of producing messages, but in the one receiving them, and this is the field where they have to learn and adopt new communication techniques (Bagley 1988a: 63). Concerning this classification of older persons with deafblindness, it is important to note that this fourth group, persons with late-life acquired deafblindness, is the one that is covered by the majority of literature on older people with deafblindness (Simcock 2016: 1703–1704; Simcock & Manthorpe 2021: 98).

While all four groups need support and assistance in their everyday life, the support needed by the first three groups are usually of a more specific nature, like support in finding strategies for



communication, support and cultural mediation in contact with different authorities, and emotional support to cope with the loss of senses. All of these methods of support presume the existence of staff with specific knowledge of deafblindness as well as knowledge of how to communicate in order to meet the needs through dialogues with the individual person (Göransson 2007: 154, 161).

The support and assistance that the fourth group requires are more general than the other groups, including transport services, assistive devices and technology, and an environment with knowledge of the impairment, and of how to treat a person with a combined visual and hearing impairment (Göransson 2007: 154, 161). As Simcock (2016: 1736) frames it, “in order to ensure appropriate care and support services, it is important to develop knowledge and understanding of the unique experience of those ageing with impairment, and to recognise the differences between this population and those ageing into disability.” Those ageing with deafblindness tend to experience the following: ongoing change, both impairment- and ageing-related, and the resultant need for enduring adaptation; a particular relationship between ageing and deafblindness, with one exacerbating the other; experiencing ageing as a “second disability;” a sense that whilst



one can learn adaptive strategies having lived with deafblindness for a long time, it does not necessarily get easier; a particular relationship with care and support services; and anxiety related to maintaining their independence (Simcock 2016: 1733, 1737).

With such heterogeneity within the older population with deafblindness, it comes as no surprise that a question of identity of individuals comprising it arises (Balder 1988: 102). Sometimes, a single individual with deafblindness even adopts multiple identities (Simcock & Walter 2019: 4). Not all older persons with dual sensory impairment identify themselves as Deafblind. Some might identify as Deaf with visual problems, or Blind with hearing problems, and some might not identify as either, but rather, as individuals that experience both visual and hearing problems, not accepting the persons with deafblindness designation. Because of this, those who research deafblindness might find materials on younger Deafblind persons more easily than older ones (Simcock 2016: 1727).

Concentrating on the needs of older persons with deafblindness is a relatively new concern among organisations in the field of deafblindness since it was not until the 1980s that these organisations explicitly highlighted those needs, the first shared

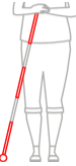




concern being the needs of Deafblind children (Simcock & Manthorpe 2021: 98).

Regarding the incidence of deafblindness among older people, the numbers vary and are likely to be outdated or inaccurate<sup>ix</sup>. According to an estimate made by researcher Ole Mortenson, based on surveys in several European countries, 150 older people per 100,000 older people are Deafblind (Matthews 1988a: 28). According to authors Svingen & Saarinen (1988a), the prevalence in Finland is 718/100,000<sup>x</sup>, while in Norway it was estimated at 130–188/100,000. Svingen & Saarinen also convey data from similar surveys made in other countries: 125/100,000 in the Netherlands, 130/100,000 in Aarhus district, Denmark, and 970/100,000 in Leicestershire, England.

Jaiswal et al. (2020: 2) estimate that between 1.7 and 33% of persons over the age of 50 have been reported to live with deafblindness. The differences in numbers are the consequence of the fact that all of the cited surveys did not use the same methodology, nor the same criteria to decide which older person belongs to the category of persons with deafblindness and which one does not. Due to the definitional complexity of deafblindness as a condition (and to the willingness or unwillingness of persons living with this condition to accept their



own deafblindness) establishing its prevalence is challenging. However, what all research can agree on is that prevalence of dual sensory impairment (hearing and vision loss) increases substantially with age (Simcock & Manthorpe 2021: 97).

Moreover, as Balder (2008: 102) correctly notices: “Statistics – Governments will naturally seek their own; however, statistics are only part of the picture, governments must understand the implications of any level of combined hearing and vision loss”.

One of the problems faced by those who conduct research on persons with deafblindness population lies in the range of languages and methods of communication that respondents use, because it necessarily involves interpretation and translation, and oftentimes multiple interpreters or translators. This means that within the answers to the surveys, not only the worldview and experiences of persons with deafblindness are included, but also those of his/her interpreter and possible translator into another (spoken) language (Simcock 2016: 1725–1726).

Deafblindness does not affect only persons with deafblindness but can have a significant impact on the situation of the entire family, because providing care for an older Deafblind person can be intensely demanding and distressing for the whole family.



Unfortunately, the effect it has on couples or other family members, is unsatisfactorily researched so far (Simcock & Wittich 2019: 8).

Persons with deafblindness are especially disadvantaged among persons with disabilities, and older Deafblind persons are especially vulnerable among them. Simcock, Manthorpe and Tinker (2022b: 6) classify those vulnerabilities as vulnerable *about* (broad matters such as one's job or health, the future, etc.), vulnerable *to* (physical harm, further sensory loss, isolation, etc.) and vulnerable *when* (in times of worry, fear, and panic, etc.), but remark that persons with deafblindness feel vulnerability as multi-layered, in which those three categories overlap (Simcock, Manthorpe and Tinker 2022: 17).

Some of the difficulties that persons with deafblindness meet in their everyday life represent the reaction of persons with deafblindness to their own condition, some stem from the person's immediate surroundings (friends and family), some from the professionals coming into contact with persons with deafblindness (health and care workers, care providers, social workers, etc.), and some are imposed by the society at large. However, there is some overlap in this classification as well.



Richard Howitt, a MEP from the UK notes “Deafblind persons are the most excluded population of persons with disabilities. They are excluded from the excluded” (Tarczay 2014: 1). With this in mind, can we postulate that older persons with deafblindness are excluded even further?

In the light of everything stated on older persons with deafblindness, Simcock (2016: 1704) rightfully points out that our aim should be answering the question: what is known about the experiences, views, and key features of old age and ageing for Deafblind people?

### **Context: The SHAPES Project**

The Smart and Healthy Ageing through People Engaging in Supportive Systems, or SHAPES Project<sup>xi</sup>, 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 costs, social care costs,



hospitalisations, and institutional care 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, and findings on the situation of older persons with deafblindness, as well as identify key challenges, gaps and barriers. WFDB is one of 36 consortium partners, composed of researchers, technology companies, and civil and public organisations aimed at helping older persons.

They do this across 14 EU countries and engage 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.

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.

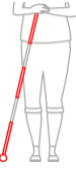
In a nutshell, the report attempts to paint a picture on the situation of older persons with deafblindness and its most recurrent themes, using



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 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, including interviews, focus groups, and workshops. This data has provided valuable insight and has been used 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, and testing the digital tools and solutions being developed.



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 had the intention of connecting WFDB 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. Specific examples of WFDB's involvement in the SHAPES Project include:

- WFDB involved a variety of older persons with deafblindness with multiple communication



systems that have been directly involved and fully participated in different activities such as interviews, focus groups, and workshops

- WFDB has raised awareness on the project, contributing to dissemination efforts and advocating for the importance of advancing the rights of older persons with deafblindness. Events that help further these goals include the 16th session of the Conference of States Parties to the Convention on Rights of Persons with Disabilities (COSP16) in New York and an event titled “Presentation of WFDB 2nd Global report on the inclusion of persons with deafblindness and the SHAPES Project”, co-hosted with two MEPs at the European Parliament in Brussels
- WFDB assisted in the publication and dissemination of internal reports<sup>xii</sup>, highlighting accessibility issues and recommendations for SHAPES consortium on how to make information, communication tools, promotion materials, and events accessible for all
- WFDB contributed to a section on accessibility and inclusion that was added on a deliverable template<sup>xiii</sup>, which all SHAPES Partners must follow when completing a deliverable. WFDB has also provided feedback to many

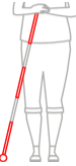




deliverables to ensure both their accessibility and perspective of persons with disabilities is included

- WFDB contributed to the publication of a page on accessibility on SHAPES' website<sup>xiv</sup>
- WFDB provided many resources and provision of checklists to guarantee diversity, accessibility, and inclusion<sup>xv</sup>
- WFDB aided in the creation of a fictional profile of a "persona" with deafblindness to reflect the reality of the needs of many older persons with deafblindness, which is used as an example to ensure the digital solutions and platforms are inclusive of the Deafblind community
- WFDB provided feedback provisions from the disability and Deafblind community specifically on digital solutions created by SHAPES Partners such as Access Earth App by Access Earth (Ireland), I Can See App by SciFi (Greece) and eCtouch App by Omnitor (Sweden)

WFDB provided assessments on SHAPES' multiple resources as well as recommendations for the implementation, adoption, and scale-up



of the SHAPES Platform and its digital solutions across Europe

- WFDB encouraged multiple collaborations with SHAPES Partners, for example, WFDB has cooperated with Agile Ageing Alliance (AAA) on an International Standard (ISO) focusing on smart multi-generational neighbourhoods by providing recommendations, a check list, and best practices for creating accessible and inclusive communities

More examples of WFDB's work and a list of publications can be found on WFDB's website<sup>xvi</sup>.

The 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

- Highlighting 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
- Acknowledging that persons with deafblindness may require additional support, such as a project coordinator, to manage daily activities and communication, but the individual with deafblindness should maintain ownership and decision-making of the project
- Realizing that OPDs play a key role as right-holders to guide priorities and validate project results, as well as in building awareness and technical support on accessibility and inclusion measures in mainstream projects. OPDs should be allocated a budget and explicit responsibilities, so they are able to perform their role adequately and make meaningful contributions
- Encouraging training for project partners at the beginning of a project on accessibility and inclusion to promote shared responsibility

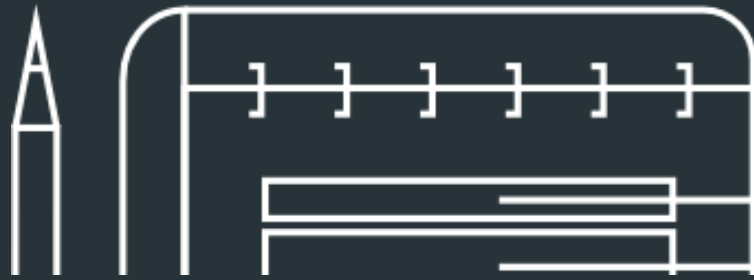


between OPD partners and mainstream partners

- 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.





# REPORT LAYOUT





# REPORT LAYOUT

## 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” for more information).

Information from all three sources have been grouped together and presented as different chapters that focus on 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. This was done 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 answers for each question.

## **Quantitative Research**

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

The survey questions were divided into four groups. The first group included questions on the informant, such as country, age, involvement in organisations and what type of organisation, and the respondents' link to persons with deafblindness. The second group consisted of questions on older persons with deafblindness, their greatest challenges and barriers,



how to overcome them, the availability of assistive technology, how to improve the integration and participation of older persons with deafblindness in society, and how the government can improve the lives of older persons with deafblindness. The third group included questions on the work of the respondent's organisation, the existence of any work/project/programme focused on older persons with deafblindness, the existence of regular social events for persons with deafblindness, the existence of regular creative workshops for persons with deafblindness, and the type of older persons with deafblindness who attend these events. The fourth group focused on resources, sharing case studies about older persons with deafblindness, examples of best practices for older persons with deafblindness, sharing resources or materials on older persons with deafblindness, sharing any other documents related to older persons with deafblindness, and sharing any other relevant information about older people with deafblindness.

## **WFDB's 2023 Survey on Older People with Deafblindness**

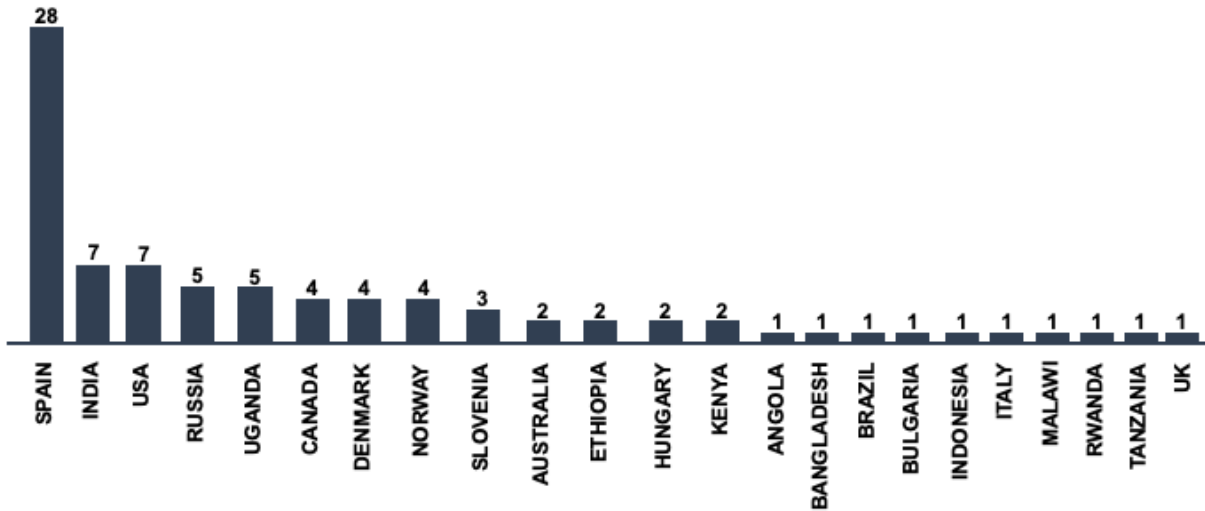
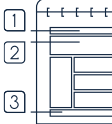
In July 2023, WFDB launched an online survey with the purpose of gathering information on





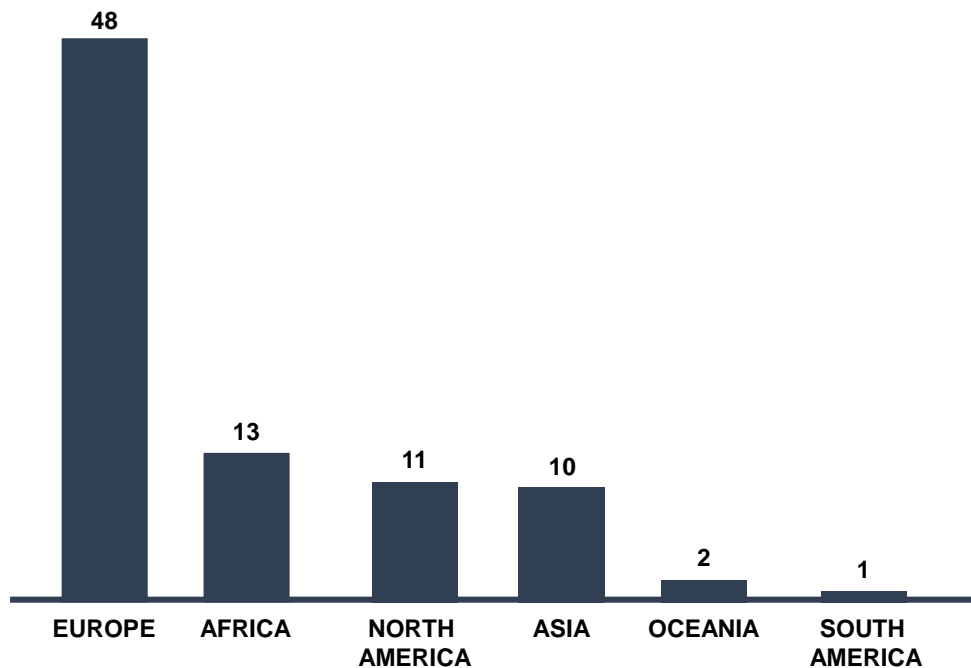
older persons with deafblindness for this report. The survey was intended for WFDB members, persons with deafblindness, organisations by and for persons with deafblindness, and other organisations and professionals in the field of deafblindness. It was made available online for a month and shared widely 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 responses to the survey were received from 24 countries: 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) (**Figure 1**).



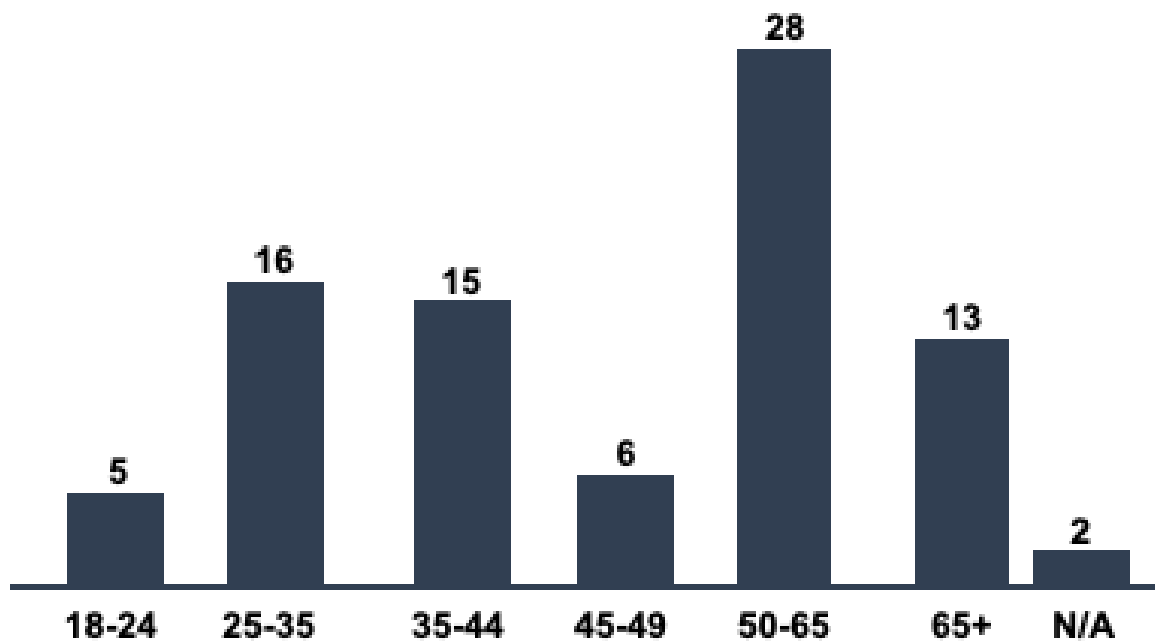
**Figure 1 - Distribution of respondents by country.**

By continent, the distribution is as follows: 49 from Europe, 13 from Africa, 11 from North America, 10 from Asia, 2 from Oceania, and 1 from South America (**Figure 2**).



**Figure 2 - Distribution of Respondents by Continent.**

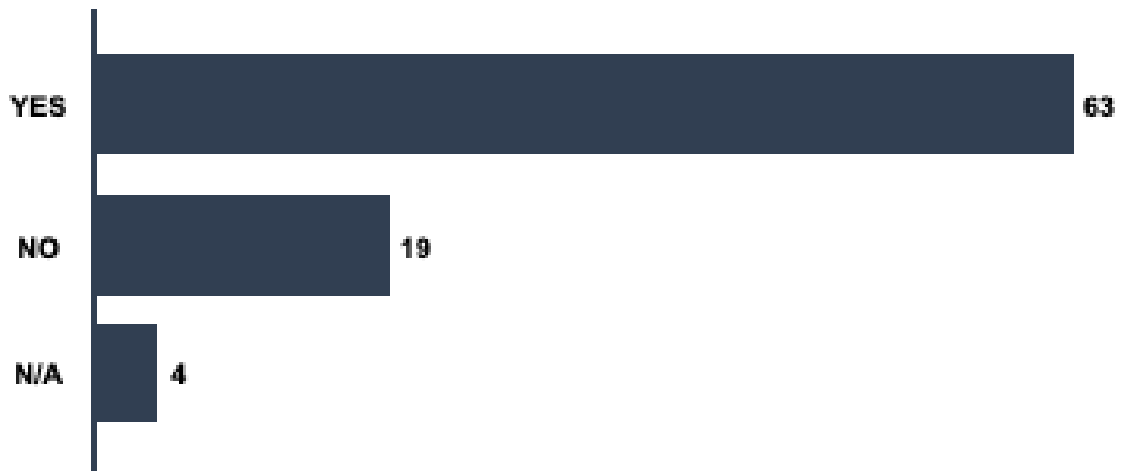
The age of the respondents is distributed as follows: 5 respondents were between the age of 18 and 24, 16 between 25 and 35, 15 between 35 and 44, 6 between 45 and 49, 28 between 50 and 65, and 13 older than 65 years, while two respondents have not answered the question (**Figure 3**).



**Figure 3 - Distribution of Respondents by Age.**

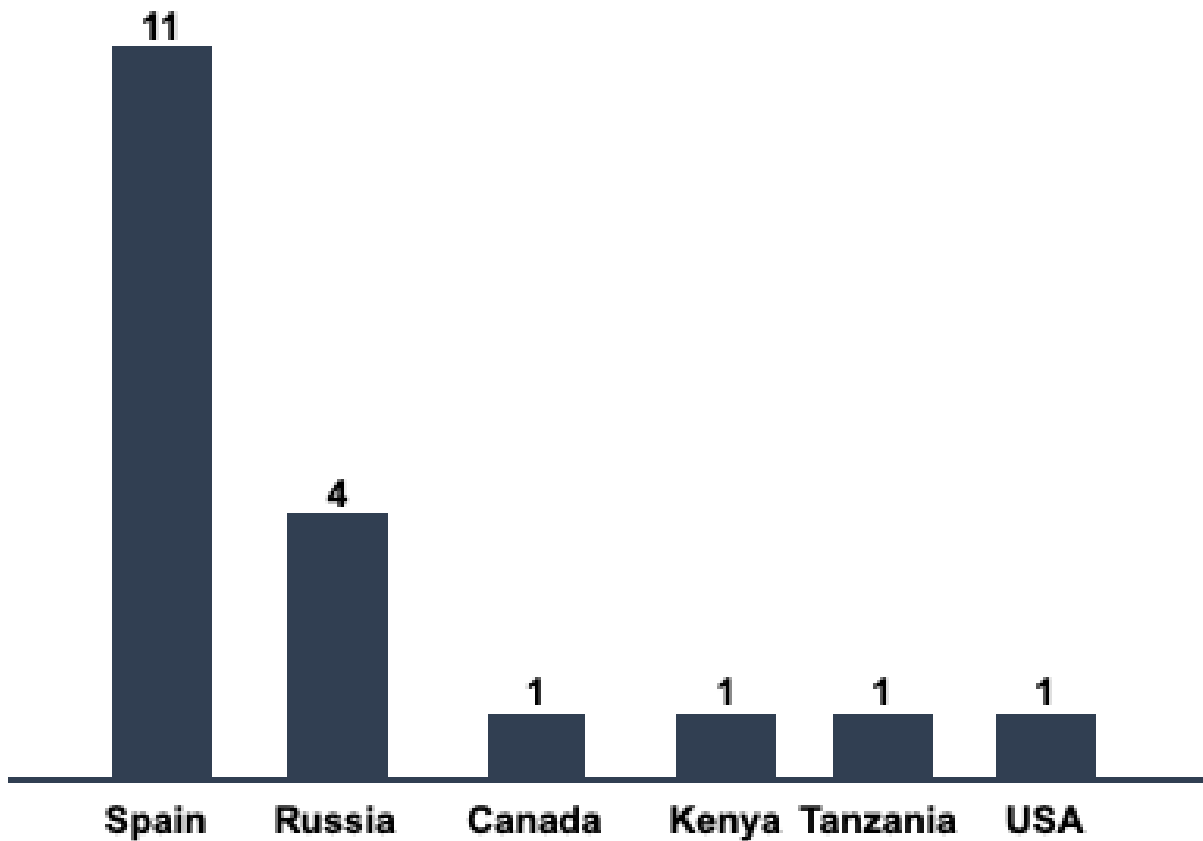
The age group defined as older persons in this report (65+) represents 15,3% of all the respondents.

Of all the respondents, 63 are involved in or represent an organisation, 19 are not, and 4 have not answered that question (**Figure 4**).



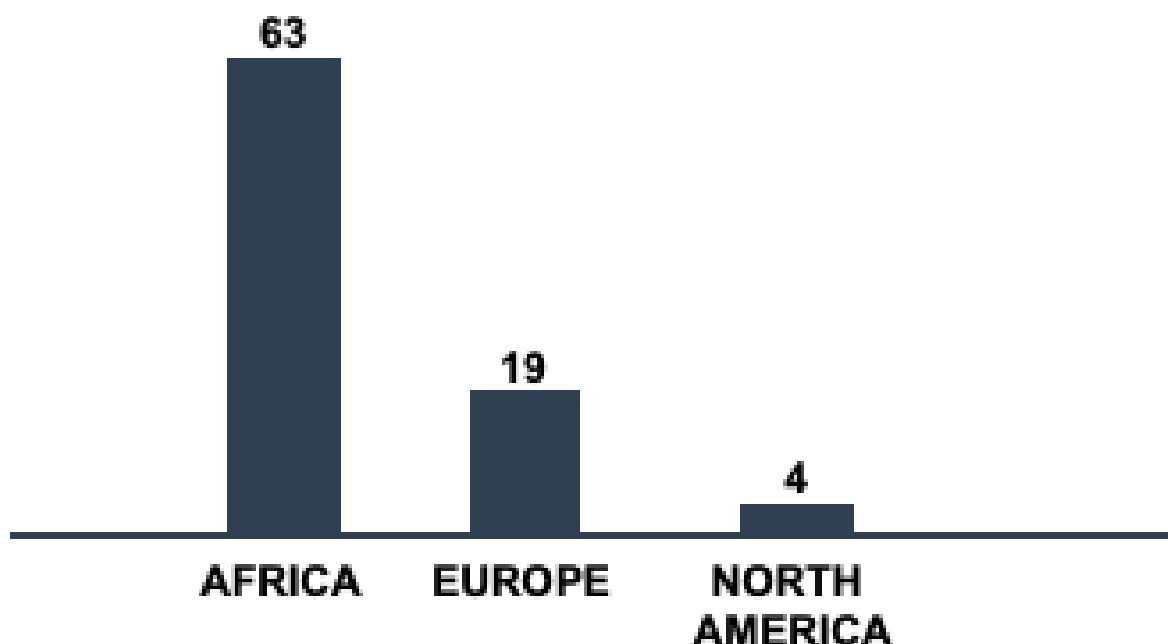
***Figure 4 - Respondents Involved or Representing an Organisation.***

Of those who are not involved in or do not represent any organisation, most come from Spain, which is not such a surprising result, considering that the greatest number of answered surveys (28) came from that country. However, it still represents almost 40% of all the Spanish respondents, which is significant. The other negative answers came from all 4 of the Russian respondents, and one respondent each from Canada, Kenya, Tanzania, and the USA (**Figure 5**).



***Figure 5 - Respondents not Involved in or not Representing any Organisation by Country.***

The distribution of these by continent is as follows: 15 from Europe, 2 from Africa and 2 from North America (**Figure 6**).



***Figure 6 - Respondents not Involved in or not Representing any Organisation by Continent.***

Of those respondents who are involved in or represent an organisation, the vast majority (41 of them), are involved in an organisation for persons with deafblindness, 6 in an NGO working in the field of disability, and 5 in an organisation for persons with disabilities (other than deafblindness). One respondent from the latter group has answered “other” but specified it as an organisation for persons with blindness, which is an organisation of persons with disabilities (other than deafblindness), after all. One respondent is involved in a government body and one in an education institute, specified as a university. The answer “other” was given by 6 persons



(not including the one involved in an organisation for persons with blindness); 3 of them with no specification; 1 in a government funded organisation that provides services to people who are Deafblind; 1 as a service provider for persons who are Deafblind as well as people who are Deaf, hard of hearing, and non-verbal with a developmental disability; and 1 as a special educator.

As expected, most respondents (47 of them), are persons with deafblindness; however, one each is at the same time a professional service provider that directly supports persons with deafblindness (e.g., rehabilitation, education, interpreter-guide/Deafblind interpreter, etc.), a family member of a person with deafblindness, and a professional that indirectly supports persons with deafblindness (i.e., OPD or NGO staff member, programme manager, researcher, fundraiser, advocate, etc.). There are 14 professional service providers that directly support persons with deafblindness (e.g., rehabilitation, education, interpreter-guide/Deafblind interpreter, etc.), and 14 professionals that indirectly support persons with deafblindness (i.e., OPD or NGO staff member, programme manager, researcher, fundraiser, advocate, etc.) with one respondent being both. Two respondents answered “other,” one being the



founder and chair of a national disability peoples forum, and the other a volunteer of a foundation for the support of persons with deafblindness. The volunteer also conducted scientific studies concerning Deafblind people, older persons with deafblindness, and carried out rehabilitation activities.

## **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
- Consult and gather feedback on the current situation of Deafblind individuals, challenges and barriers faced by older persons with deafblindness, best 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. Relevant information and feedback collected during these workshops has been inserted throughout different sections of this report.

## **Needs of Older Persons with Deafblindness**

In her paper, Svensson (1988) presents the findings of a doctoral thesis<sup>xvii</sup> in social work. The purpose was to describe the needs of older people from their own perspective and to see how those needs were met or why they were not met. This thesis did not study older people with deafblindness, but older persons (80+), in general. However, the findings might be equally, if not even more, applicable on older persons with

deafblindness. This is because older persons with deafblindness encounter the same problems as other older persons, only to a somewhat greater degree, because the effects of ageing and those of deafblindness enhance each other. In the thesis three major categories of needs were identified:



### Practical needs

Includes everyday needs such as grocery shopping, home chores, etc.



### Emotional needs

Grouped as:

- a) Feelings of anxiety and insecurity: includes worrying about ageing and its consequences, becoming ill, pain and death, being victims of crime, plus practical sources of anxiety. Feelings of insecurity are often because of a decreased ability to control different kinds of life-situations, including fear of severe memory loss, fear of odd behaviours, and fear of not getting adequate help, fear of radically changed circumstances of life (i.e., having to move away from home, or losing the partner and

friends, etc.). Oftentimes, these fears can result in isolation and not leaving the home

- b) Feelings of insignificance and of being neglected:

When older persons feel that they do not mean anything to anyone anymore, they stop believing in their own life being meaningful and worth living

- c) Feelings of sorrow and grief:

Most older people experience the death of their spouses, sisters, brothers, other relatives or friends



## Existential needs

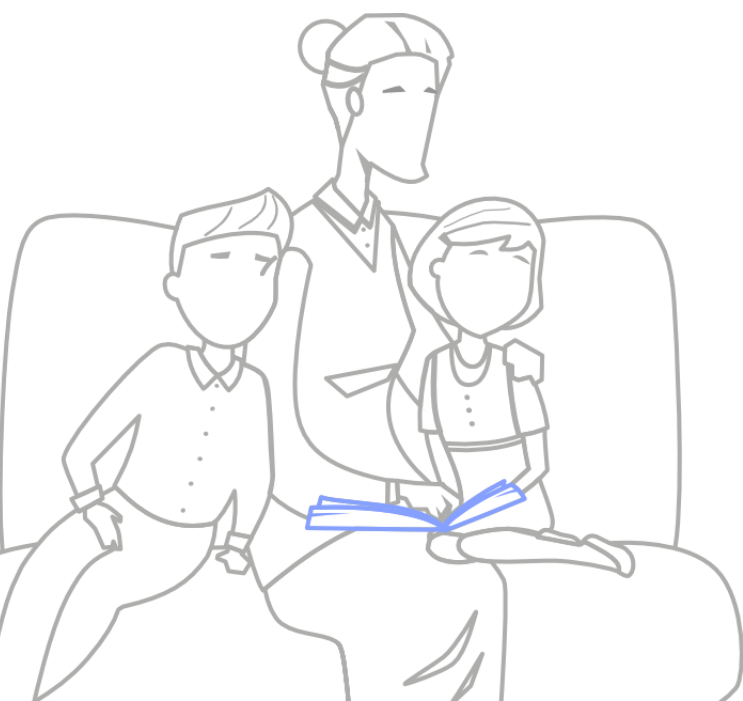
Listed as:

- a) Finding a meaning in life from now until death by overcoming: dissatisfaction with contemporary life, losing a spouse, losing friends and relatives, losing the capability of doing useful things, losing meaning in life, or waiting for death to come
- b) Finding meaning with life as a whole and to be able to contribute with one's own knowledge and experiences. (Older people often wanted to talk about their lives and about times gone by. An important purpose

for the respondents was to evaluate and sum up their lives when they felt that death was coming closer)

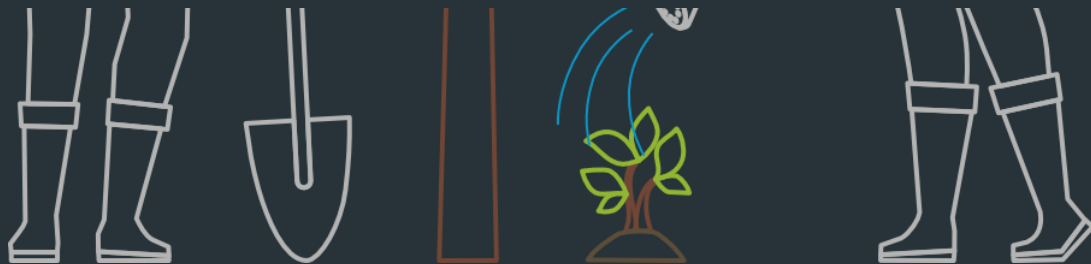
### c) Preparing for one's own death

The author stresses multiple times that there were some interesting differences in the answers, depending on the gender of the respondent, of his/her living area, of the marital status, and several other circumstances. However, all of those needs can be applied to older persons with deafblindness and should be taken into consideration when we approach them as professionals, but also as family members or friends.





# CHALLENGES FACED BY OLDER PERSONS WITH DEAFBLINDNESS





# CHALLENGES OR BARRIERS FACED BY OLDER PERSONS WITH DEAFBLINDNESS ACCORDING TO SURVEY RESPONDENTS

In reference to the online survey, isolation/loneliness, communication and access to information, and mobility are at the top of the list among the answers for challenges affecting persons with deafblindness.

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

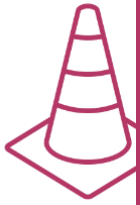
## Attitudinal barriers



These are barriers due to perceptions from persons with deafblindness themselves and society around them. Some barriers are perceived as persons with deafblindness being unable to involve in their daily activities



## Environmental barriers



These barriers refer to an environment not supported for or adapted to persons with deafblindness

This categorisation will be followed when analysing the data obtained from the answers to this question.

Attitudinal barriers can be created both by society and persons with deafblindness themselves. For example, the general public by and large lack knowledge on deafblindness and the needs of persons with deafblindness; however, persons with deafblindness sometimes also lack knowledge on what they, as Deafblind persons, can do and have the right to do. It is true that some persons with deafblindness consciously refuse to acknowledge their condition. However, the general opinion is that awareness about deafblindness should be increased. This includes the recognition of deafblindness as a distinct disability as well as of the rights and needs of persons with deafblindness. Lack of a specific policy concerning deafblindness is also mentioned by some respondents.

Some respondents stressed the problem of mental health issues in older persons with deafblindness



like stress, anxiety, and depression. Deteriorating mental health is a direct consequence of isolation and loneliness.

Misdiagnosis and assuming that difficulties caused by deafblindness are typical and common manifestations of ageing (and therefore, need no extra attention or concern) are also mentioned within the report.

For some older persons with deafblindness, new communication and information technologies are a solution, but others deem them to be too complicated to.

Environmental barriers are roughly grouped into communication barriers and mobility barriers. As Helen Keller famously stated, “Blindness separates people from things; deafness separates people from people.” Persons with deafblindness are isolated from people by not hearing and from things by not seeing.

Barriers to good health care are among these environmental barriers. The impossibility to communicate with health staff causes persons with deafblindness to often neglect their own health problems, causing even more health issues. This includes special care, too.

Poverty, as stressed by several respondents from Africa, is a problem connected to lack of





employment opportunities for persons with deafblindness. They are either declared “incapable” or “unfit” to have a job, or are forced into early retirement, often with meagre pensions, if they used to have a job before their condition deteriorated. This problem is amplified by expensive assistive devices and technologies, which can include hearing aids and spectacles.

Mobility is another barrier, mostly in the form of organised transportation for persons with deafblindness, as public transport is often not accessible or just not practical for persons with deafblindness. Public transport can get them from point A to point B, but the problem lies in reaching point A from their homes and to reach their goal from point B. Transportation problems are not just connected with everyday chores (shopping, etc.), but also with access to services they have the right to as citizens. One respondent quotes the judiciary system as an example, another mentions social public services.

Lack of support service providers such as interpreter-guides/Deafblind interpreters, personal assistants, etc., is a major issue. This issue lies not so much in insufficient numbers of people performing those services. Instead, it lies in not being able to obtain an interpreter-guide/Deafblind interpreter or some other service provider. This



impedes the older person with deafblindness in fulfilling his/her role of active participant in social life, as well as undertaking his/her own personal tasks.

One respondent mentioned in another question that “(i)n many countries, there are certain traditional beliefs associated with the causes of disability, such as curses and contagion,” which result in both the persons with disabilities and their families (primarily their mothers) “being shunned and isolated.” Cultural beliefs, religion, and traditions have an impact on how deafblindness is perceived and treated, and therefore, on the life or situation of a person with deafblindness, including older individuals.

Another question in the survey dealt with suggestions on how to overcome those challenges and barriers. Below is a single response, from a professional that indirectly supports persons with deafblindness from Canada, which subsumes everything mentioned by all the respondents:

“ People in general misunderstand the impact of combined hearing and vision loss on the individual and think of it as one or the other (vision or hearing disability). There is a greater need for educating the public and raising awareness about the unique



disability of DSL (dual sensory loss) while also advocating for Intervenor Services to support people who are deafblind.

DSL is considered a unique disability whereby individuals cannot accommodate for the loss in one sense by using the other sense<sup>xviii</sup>. Like single sensory impairments, it is also important to identify individuals with this impairment since it profoundly influences an individual's ability to gather information about their surroundings and is associated with impaired mobility<sup>xix</sup>, as well as impaired communication function, and social isolation<sup>xx</sup>.

Research highlights that, despite the negative impact of sensory losses, community-dwelling older adults receiving sensory rehabilitation services tend to have good health overall and a high level of independence<sup>xxi</sup>. Therefore, it is important that inter-disciplinary services and funding be provided to support this population.

Simple interventions, such as ensuring regular sight and hearing checks or holding conversations in well-lit areas, can be very effective in improving the quality of life of people with dual sensory impairment. Creating accessible environments can improve the quality of life for adults who experience dual sensory loss as they age.



Examples of simple changes that make an impact might include: altering doors and tables with contrasting colours, access to assistive devices that help people engage in conversations using a pocket talker, and using tactile markers and labelling to create cues that help a person navigate buttons on their stove.

Families, carers, and other 'non-specialists' can play a crucial role in early identification, hopefully leading to appropriate and timely interventions.

Older adults living with dual sensory impairment, or DSI, (i.e., combined hearing and vision impairment) are a highly vulnerable population due to systemic barriers to accessing health care<sup>xxii</sup>.

Hearing and vision care may be addressed using primary, secondary, and tertiary prevention strategies (World Health Organization, 2018)<sup>xxiii</sup>.

Solutions to address barriers that seniors who experience DSL face should include 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<sup>xxiv</sup>.

It is also important to establish 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 good practice models evolve<sup>xxv</sup>.

Dual Sensory Impairment (DSI) is a complex condition that has repercussions on the roles performed by health care professionals who work with this population. Professionals who work with this population might be solicited to perform roles outside of their specific training such as optometrists taking on the role of a counsellor. These additional roles can increase their workload and can lead to expectations for them to perform new and unfamiliar tasks. There is a clear need for counselling services for this population, as well as education concerning this intersection of chronic conditions. It is also evident that a fragmented health system may contribute to the need for these additional roles. A client-centred approach with a multidisciplinary team would best serve the needs of older individuals with DSI while maximizing their independence when possible<sup>xxvi</sup>. Curriculum for training of all health care professional needs to be coordinated to address the needs of seniors with dual sensory loss rather than single sensory loss. To improve care experience of older adults with DSI, there is a dire need for training of healthcare professionals to accommodate the communication



and accessibility needs of older adults living with DSI.

Healthcare administrators and policymakers should consider the distinct accessibility and communication needs of this vulnerable population in order to help them age well.<sup>xxvii</sup>

Research suggests that greater awareness of deafblindness is a priority, particularly as mental health professionals are likely to have very little experience of treating people with dual sensory impairment.

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Sense and Deafblind UK, 2001

Most respondents stressed the importance of government responsibility, raising awareness, educating service providing personnel, as well as other frontline professionals who come in contact with older persons with deafblindness, as well as the importance of becoming familiar with Deafblind communication methods, and greater availability of interpreter-guides/Deafblind interpreters, intervenors, personal assistants, etc.



## 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 and of Deafblind persons and their needs and communication systems are the primary goals for 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. For example, if a given state recognises deafblindness as a unique disability, that does not mean that the needs and communication systems are also automatically recognised.

The World Federation of the Deafblind (2018: 8) reports that from the 50 countries for which data was available, 19 of those (38%) officially recognise deafblindness as a distinct disability. The survey also indicates that countries that do 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* calling on the institutions of the European Union and the Member States to recognise and implement the rights of people who are Deafblind, declaring that persons with deafblindness should have the same rights as are enjoyed by all EU citizens. The declaration goes on to state that these rights should be enforced by appropriate legislation in each Member State and instructs its President to forward this declaration and the list of its signatories to the Council, the Commission, and the governments of the Member States (European Union 2004).

The UN *Principles for Older Persons* from 2019 cover both political and social participation, and describe participation as integration in society, via active involvement in the formulation and implementation of policies that affect well-being (§7), having opportunities to serve the community and volunteer (§8), and being able to form movements or associations (§9). (United Nations 1991)

Furthermore, the World Health Organisation today does not recognise deafblindness as a distinct disability in its *International Classification of Functioning, Disability and Health (ICF)* (2001). Within the category of *Body Functions*,





subcategory *Sensory Functions and Pain* there are distinct *Seeing and Related Functions* (b210 *Seeing Functions*, b215 *Functions of Structures Adjoining the Eye*, b220 *Sensations Associated with the Eye and Adjoining Structures*, b229 *Seeing and Related Functions, Other Specified and Unspecified*), and distinct *Hearing and Vestibular Functions* (b230 *Hearing Functions*, b235 *Vestibular Functions*, b240 *Sensations Associated with Hearing and Vestibular Function*, b249 *Hearing and Vestibular Functions, Other Specified, and Unspecified*), but no (sub)category that would include deafblindness, combining seeing and hearing functions.

Unfortunately, there is little evidence of older persons with deafblindness participating in the co-production of policies and services that promote their well-being if we define participation as “the practice of consulting and involving members of the public in the agenda-setting, decision making, and policy-forming activities of organisations or institutions responsible for policy development”. (Simcock & Wittich 2019: 6)

In 2021, Slovenia was the first country to include the language of persons with deafblindness into its Constitution:





## Article 62a

(Sign Language and language of persons  
with deafblindness)

The free use and development of the Slovenian Sign Language is guaranteed. In areas of municipalities where Italian or Hungarian are also official languages, the free use of Italian and Hungarian Sign Language is guaranteed. The use of these languages and the status of their users is regulated by law. The law regulates the free use and development of the language of persons with deafblindness.

With this formulation, a strict definition of which methods of communication used by persons with deafblindness are legally recognised was astutely avoided.

We know that there is no such thing as a single language of persons with deafblindness. Persons with deafblindness use many different methods of communication based on Sign Language, manual alphabets, and Braille depending on preferences and the residual vision and hearing of the individual, amongst other factors. Instead of listing



all of those factors (and probably unconsciously omitting some), the authors subsumed them all under “language of persons with deafblindness.” However, it could be argued that the communication method in question is indeed the language mentioned in such 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 Nations Convention on the Rights of Persons with Disabilities*, ratified by 186 states worldwide, offers only limited references to deafblindness, and those concern the education of children with deafblindness (United Nations 2006):

- “ 3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of



the community. To this end, States Parties shall take appropriate measures, including:

- (c) Ensuring that the education of persons, and in particular children, who are blind, Deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximise academic and social development



The recognition of the impairment and of the language is a significant step but is far from the end of the struggle.

The right to interpreter-guides/Deafblind interpreters should be one of the basic rights of persons with deafblindness. However, they are available in only 58% of high-income countries and only 42% provide government-funded interpreter services. In the low- and middle-income countries, the situation is worse. Interpreter services are provided only in 10% of countries (N=31; low and upper-middle income countries), with only one country providing government funding (World Federation of the Deafblind 2018: 10). As it is hard to imagine that anyone would provide interpreter services until compelled to do so, it is clear that only straightforward political action by the government can ensure that such a service be



available to all the persons with deafblindness who need it.

However, this section does not only refer to the legal recognition of deafblindness and the rights and needs of persons with deafblindness, but also the rights and needs of older people, including retirement, pensions, personal fulfilment, long-term care, and eligibility for services. There are states in which there is a restriction on access to medical treatment and aids after reaching a certain age. These restrictions happen in developed countries as well, “(i)n the UK you would be unlikely to receive a new hearing aid or assistive device when you are very old.” (Matthews 1988a: 30. 34)

Another thing that contributes to the invisibility of older persons with deafblindness is the tendency of national policies, as well as international ones, to homogenise the ageing experience *de facto*, excluding older persons with deafblindness from welfare policies and development programmes, only adding to the lack of recognition and paucity of research (Simcock & Manthorpe 2021: 102).

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. As previously mentioned, we have a sum that is greater than the parts.

It is interesting what respondents to the survey had to say about how the government could improve the lives of older persons with deafblindness. It comes as no surprise that most respondents feel that the governments should increase their funding towards services such as those of interpreter-guide/Deafblind interpreter, health and other care personnel, transportation for persons with deafblindness, assistive devices and technology, research of deafblindness, organisations of persons with deafblindness, trainings and rehabilitation, projects concerning persons with deafblindness, and medication. Also, increasing the numbers of hours per month that a person with deafblindness would be assigned an interpreter-guide/Deafblind interpreter was encouraged by respondents. Thus, the government should collect disaggregated data on how many persons with deafblindness live in the country and their needs. Some respondents call for an official census that would reveal these numbers to share them openly with service providers and policy makers, amongst others.

Even where there is disability funding, it is not always accessible to older people with deafblindness due to heavy legislation and



limitations between accessing disability and aged care services simultaneously. The system can be difficult for service providers to understand, let alone for those with deafblindness themselves. Additionally, many Deafblind persons do not benefit from government programmes simply because they do not know that they exist, or have not been made aware of the benefits, due to their lack of access and availability of information in multiple formats.

However, in order to achieve the above, it is imperative that governments recognise deafblindness as a distinct, unique disability as well as the multiple communication methods of persons with deafblindness as their languages. Because of this, another important aspect of government action is legislation on all levels, from the constitution to laws, rules, and orders.

Educating and training persons with deafblindness enables them to have a job, financial security, and potentially a promise of a pension. This allows older individuals with deafblindness to live on when retired, increase their opportunities, promote equality, and improve their quality of life. These benefits would be seen when supporting employment of educated and expert Deafblind persons in their field of expertise.



## Response to Emergencies

Respondents to the survey addressed 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 was suggested that appropriate applications (apps) 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 had a disproportionate impact on older persons. During an interview with an older person from Spain called Vicky, she said that she was completely unaware of what was happening in the world due to lack of accessible information. The first information she had about the pandemic was on television, which was not available in sign language interpretation nor accessible formats. When people started talking about it, she was full of doubts and could not believe that that was happening. She was surprised when her friend visiting used sanitising gel to clean their hands and explained her why she should not touch other people. As she got a fever, she was taken to a hospital by ambulance, where they performed some tests and therapy, but





nobody could explain her what was going on. She was not aware of the pandemic, due to a lack of accessible information. An interpreter on video-call was of some help, but staff with protective clothing and facemasks left an impression on Vicky who became very anxious and afraid. Later, a signing friend of hers was summarising all the news about COVID for her, so she finally got a more complete picture of the situation<sup>xxviii</sup>.

As WFDB's Second Report states, persons with disabilities are more likely to be left behind or abandoned during an evacuation from natural disasters, armed conflict, or humanitarian emergencies, 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 older 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 (United Nations Department of Economic and Social Affairs).

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.

## **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, as discussed, those interpreter-guides/Deafblind interpreters may not always be available. The reasons for this are many, from the most banal (an insufficient number of interpreter-guides/Deafblind interpreters) to the administrative reasons for lack of guides and interpreters., E.g., lack of existing laws or other state documents that regulate the right to an interpreter-guide/Deafblind interpreter, laws existing but not specifying who covers the costs of interpretation, or extremely complex bureaucratic processes.

According to the World Federation of the Deafblind (WFDB 2023, 67–69), many states, especially those low- and middle-income ones, do not possess a system of interpreter-guides/Deafblind interpreters. 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. Relying on family members and friends to take over interpreter duties is not a solution to the interpreting and guiding problem, because the availability of family members and friends forces the older person with deafblindness to adapt to the schedules of others instead of the schedules and needs of the person requiring services. Additionally, challenges can arise when family members take on interpretation



duties because they are not trained to provide such a service, and because they can and are likely to interfere, making decisions in place of the older Deafblind person. Furthermore, services provided for either Deaf or Blind persons cannot replace non-existing services for persons with deafblindness, because, as it is already stated multiple times, deafblindness is not the same as the mere sum of deafness and blindness, so neither the separate services combined can substitute for a complete and adequate service for Deafblind persons.

One of the obstructions in this field is the practice in some states of assigning to every single person with deafblindness a specific and limited number of interpreting hours per month based on the severity of the person's impairment. This severity is usually calculated on the strictly medical, numeric basis and has no relation to the actual needs of each individual. For older persons with deafblindness, these restrictions have an even more discouraging effect than on younger ones, because in addition to the proverbial "three more times time needed" by Deafblind persons to accomplish a goal, they need extra time as older individuals. In other words, if a hearing and seeing person might need ten minutes to do accomplish a task, a deafblind person might need three times more time, so thirty



minutes. Some services require considerably advanced booking (e.g., 72 hours in advance), which is not always possible, particularly in emergency situations where older persons with deafblindness might find themselves in more disadvantaged positions than younger ones. Having to pay for this service from one own's pocket, (i.e., providing a salary for the interpreter-guide/Deafblind interpreter) is another burden for older persons with deafblindness, because many of them cannot afford the extra expense. This forces the person to deprive him/herself of an interpreter-guide/Deafblind interpreter.

For many persons with deafblindness, especially older individuals, it is not the condition itself that is central to the experience of being Deafblind, but the lack of support. For older persons with deafblindness, support services are valued, but what they are concerned with is whether those services will always be available, accessible, and funded (Simcock 2016: 1736).

It is not rare that local officials deciding on the allotment of interpreter-guides/Deafblind interpreters do not understand the situation and needs of the older person with deafblindness. Those administrators are rarely educated on deafblindness and for them, a person might just represent an entry in the spreadsheet to follow.



Depriving persons with deafblindness, especially older ones, of interpreter-guides/Deafblind interpreters means divesting them from participating in public life, thus discriminating against them (Göransson 2007: 150–151) and going against the CRPD.

## **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. This resulted in a serious lack of information on the pandemic, partial or even total incomprehension of what was going on, and ignorance about the methods of protection against the virus. Additionally, socialising with other people was brought to a halt by those same measures.

The older population in general feels the consequences of loneliness, social isolation, and reduced social participation, but no one feels these consequences more than older persons with deafblindness (Jaiswal et al. 2020: 2).



Göransson (2007: 149) correctly defines loneliness as “not having anyone to communicate with in one’s own language” and as “not having any or only very few relationships in life.” The communication problem is increased in situations where the person with deafblindness lives with people with whom he/she is unable to communicate or share activities, and this situation can make the person with deafblindness feel even lonelier. The inability to communicate with family and friends also amplifies this issue (Göransson 2007: 149).

Isolation can be caused by several reasons at the same time.

First, the person with deafblindness withdraws from public life, frustrated by his/her inability to communicate successfully, by mishearing, responding inappropriately, and consequently appearing foolish (Simcock et al. 2022: 8), even in a well-known environment. The result is that he/she is, feels, and expects to be misunderstood throughout his/her life (Simcock et al. 2022: 15). With the ability to influence people and social situations lost, self-determination, social contact, and the possibility of participating actively in other areas are limited (Olesen 2012: 14). Isolation brings with itself passivity (Olesen 2012: 14). As failing vision and weakening hearing make his/her



communication and previous activities and skills difficult to perform, the person with deafblindness withdraws from the activities he/she was engaged in before (Olesen 2012: 14; Tarczay 2019: 6).

On the other hand, miscommunication is not the only reason for withdrawal. Isolation is not only a social process, but a spatial one, as well. For example, while for some older persons with deafblindness can navigate their immediate neighbourhood where there is no danger of motorised traffic, going further away from home becomes harder to achieve as this danger increases. As the sense of vision weakens, going out, especially into unfamiliar environments and when it is dark outside, becomes harder. This can make the older person with deafblindness insecure and scared. Thus, many older persons with deafblindness do not dare going out on their own because they feel it to be too risky and they are afraid of the possibility of getting lost.

Added to those are transportation problems, being either unavailable, inaccessible, inadequate, or too expensive, as well as poorly maintained sidewalks and roads, all barriers for a successful participation in public life. As taking initiatives and following conversations becomes more and more difficult, supplemented by not being able to go out alone anymore, isolation is heightened. This causes an





avoidance of social events and even certain domestic tasks, among other everyday activities, including reading a book or a newspaper, watching television, knitting, cooking, going out for groceries, attending concerts, or driving. The result is a decision to stay home which, along with the communication problems, increases the risk of isolation (Göransson 2007: 144, 148, 152–3; Jaiswal et al. 2020: 2, 4, 6; Simcock et al. 2022a: 10).

Isolating oneself becomes a vicious cycle, because not interacting with other people leads to more insecurity, which leads to an even stronger wish not to go out and meet others. As 89-year-old Viola from Sweden noted, “The more I stay at home, the more insecure I feel.” (Göransson 2007: 144)

Secondly, the person’s immediate surroundings, family and friends, begin avoiding him/her because of difficulties in communication, often becoming impatient (Simcock et al. 2022: 13), leading the immediate surroundings of the older person with deafblindness to eventually try to avoid too much communication with him/her (Olesen 2012: 13). This avoidance of communication may lead others to believe that the older person with deafblindness prefers to be left alone (Olesen 2012: 14). The family may perceive the older person with deafblindness as an outcast, since he/she



becomes unable to participate in conversations with, and about, close family members (Olesen 2012: 11).

When family members start breaking their ties with an older person with deafblindness, the older individual experiences a significant loss, left without the support of his/her nearest and dearest. A woman ageing with Usher Syndrome Type I (a condition where an individual is born profoundly Deaf and begins to lose their vision in the first decade of life) reported grandparenthood, a role associated with older age, as challenging, because she could never help her daughter by keeping the baby in her house overnight, which is what (many) grandmothers do (Simcock 2016: 1731).

The feeling of isolation is often well known for those who experience the death of their spouses, sisters, brothers, other relatives or friends. Alfredo, a 76-year-old male with deafblindness from Cordoba, Spain, shares his experience when his wife passed away. “I was alone all the time and as my children had their own life, and I could not communicate with anyone. I (thought) it was normal. I got depressed by feeling lonely”<sup>xxix</sup>.

For primarily Deaf persons who later acquired deafblindness, as it is the case of Alfredo, even communication with Deaf friends becomes difficult



because of the failing vision. This is especially true for persons with Usher Syndrome Type I since as they age, their vision deteriorates (Simcock 2016: 1731). As some Deaf people feel uneasy, uncomfortable, and unwilling to engage in tactile Sign Language, having to hold hands with the person with deafblindness for the whole duration of a conversation can be challenging. There is also a tendency for the Deaf to reduce their contacts with persons with deafblindness. The situation is not so different from the one with hearing interlocutors. Such negative attitudes towards a more physical approach to communication, which is sometimes also regarded as weak and helpless, influence the contents of the conversation or the discussions (Olesen 2012: 12). Because it is difficult for the person with deafblindness to see his/her Deaf friends' signs and it takes him/her more time to understand what they were talking about, his/her Deaf friends perceive the person with deafblindness as difficult to interact with and may make him/her feel left out. (Göransson 2007: 144, Simcock et al. 2022: 8)

To compensate the loss of everyday contacts with friends and family, some older persons with deafblindness find solace in communication with people they interact with in a professional capacity. For example, Nancy, interviewed by Matthews



(1988a: 36) mentions care workers, meal preparation, chiropodist, hairdresser, voluntary agency, with whom she enjoys social interaction.

Unfortunately, it is not easy to create new friendships when you do not socialise with other people (Jaiswal et al. 2020: 4). For many, this may result in isolation and loneliness.

Thirdly, professionals and specialists rarely know anything about deafblindness or how to communicate with persons with deafblindness, so they reduce their interactions to the necessary minimum, not having time or patience to communicate with their patient/client adequately.

Medical personnel and frontline workers are usually so overburdened, that they do not have a lot of time to dedicate to every patient. If that patient is Deafblind and needs more time for a consultation than a hearing and seeing one<sup>xxx</sup>, some doctors and nurses deliver their lines to the interpreter-guide/Deafblind interpreter, if there is one, and send for the next patient. They do not even consider the possibility that a person with deafblindness could have any additional questions for them. This attitude alienates the person with deafblindness, causing him/her to be reluctant when need arises to visit a doctor, and thus furthering their isolation.



Similarly, in nursing homes, the care personnel are rarely educated on deafblindness and the needs and communication methods of a Deafblind individual, so those feel left out of whatever is happening around them.

In both cases the person with deafblindness might often conclude that they are simply not worth the effort and feel further marginalised.

Fourthly, the community at large rarely notices persons with “invisible” disabilities. Thus, public places are not always accessible for persons with such disabilities. Persons with deafblindness need physical access to institutions, as well as access to information in multiple formats, and both are seriously jeopardised for individuals who can neither see well nor hear well in a seeing and hearing world.

In communities worldwide, there is still a stigma on persons with disabilities, including those that make use of visible assistive devices, such as hearing aids and/or red and white canes, which may distance people from the person using them. While these devices may assist an individual in navigating the world, they can also be a reason for the person using them to withdraw from public life, embarrassed both for not being able to hear and see, and needing to depend on others or assistive



devices, thereby affecting their social participation (Jaiswal et al. 2020: 6).

Loneliness is especially felt by older persons with deafblindness who live on their own. This isolation is not alleviated by contacts with their peers, because the moment an older Deafblind person returns home, dismissing their interpreter-guides/Deafblind interpreters, he/she goes back to his/her lone existence. Some persons with deafblindness complain that they might have an interpreter-guide/Deafblind interpreter only a couple of hours per day, lamenting that they have to spend the rest of the day alone at home. This indicates that for the rest of the day, they might not need an interpreter-guide/Deafblind interpreter purely in a professional capacity, but rather someone to communicate and interact with.

Sometimes older persons with deafblindness substitute their families with their interpreter-guides/Deafblind interpreters and employees of persons with deafblindness associations. This dependence on service providers can become a burden for the professionals and some measures must be taken to ensure the deafblind individual understands what service providers are for and what they are not for. In other cases, older Deafblind persons accept them in their



professional capacity, but still treat them with some affection, often as a form of gratefulness.

Isolation, *per se*, is challenging enough, but its severity lies in it being the slippery slope that leads to loneliness, which often leads to depression. This is especially the case with older persons with deafblindness living in remote, rural, and/or smaller towns, who are increasingly faced with growing psychological and mental problems. This can lead to them being forcibly placed in institutions where they are given pharmacotherapy to induce a vegetative state (Tarczay 2019: 5), contrary to the CRPD and respect to human rights. Even if institutional admittance is avoided, an increase in isolation could also lead to dependency, frustration, decline in memory (Jaiswal et al. 2020: 4), limited security, integrity, participation and independence, or eventually even to a change of identity (Olesen 2012: 10, 15).

Isolation also means being cut off from participation in different activities in society and information, be it information about older people's possibilities and rights or dialogues with doctors, district nurses, and home care staff. A lack of communication and information has a negative impact both on the activity and participation of older persons with deafblindness, as well as on



their psychological health (Göransson 2007: 149, 150).

A life of reduced access to information, communication difficulty and potentially high levels of social isolation can cause older persons with deafblindness to face ageing with a sense of uncertainty (Simcock and Manthorpe 2021: 100). Oftentimes, these individuals do not fear isolation itself, but the inability to cope with isolation (Simcock, Manthorpe and Tinker 2022: 9).

Social isolation experienced by older adults is a public health concern. This is no less important for older adults with deafblindness who often experience participation restrictions due to challenges in communication, mobility, and access to information (Jaiswal et al. 2020: 6).

## **Sight and Hearing Loss Due to Ageing**

The situation of persons with deafblindness is often invisible and their isolation means they are hard to reach. Some live in small communities that have no knowledge of what deafblindness is or of the existence of other persons with the same condition and associations that could help them lead a deserving and dignified life. Others simply cannot accept their own deafblindness by identifying themselves either as Blind/low vision





individuals with hearing problems or as Deaf/hard of hearing individuals with sight problems.

Many older persons with deafblindness remain “hidden” because they simply accept that having vision and hearing problems is a normal consequence of ageing (Göransson 2007: 146). They may believe this disability affects all individuals eventually and is something that has just to be put with (Matthews 1988a: 29). Ageing and deafblindness do have many characteristics in common, so it is no wonder that deafblindness is often mistaken for “normal” ageing. Physiological, age-related changes can be indistinct from pathological, disease related ones (Matthews 1988a: 29).

Those who do not identify as persons with deafblindness, but as having “a visual impairment and hearing problems” or “a hearing impairment and visual problems” or simply think that they have “slightly poor vision and hearing” due to their age, consequently, will not address appropriate Deafblind specific services, institutions, and associations for help. Health services and other care givers will often reason in the same way, seeing the dual sensory loss as purely a problem of ageing (Duncan 1988: 65; Göransson 2007: 147). This causes the person in question to remain



undetected and deprived of appropriate support and help.

Not even the serious consequences of the acquired dual sensory loss, such as being limited in travelling outside your home, can convince people that it requires special attention, because it is dismissed as a simple matter of age (Olesen 2012: 10, 13).

It is not of importance whether some impairment is the result of normal ageing or disease related. What is important is to recognise sensory loss and recognise that something should be done about it (Matthews 1988a: 29). It is very important to assess the dual disability and its consequences accurately when it comes to older persons (Edberg 2012: 5).

However, not all older persons with deafblindness reason in the same way. Some perceive reduced social participation as significantly influencing their functional and psycho-emotional well-being and not just as a normal part of ageing (Jaiswal et al. 2020: 4).

Matthews's (1988a: 29–30) words may serve as a perfect conclusion to this issue: "What is important is our cultural understanding of illness and culturally shaped expectations of old age. This determines when we seek medical help, the type



of help that is looked for, and our judgements of appropriate treatment and care. And we need to recognise that we have different cultures across Europe not just between states but between, for example, different classes and ethnic groups. Our attitudes to ageing and to older people need to change. A new attitude is called for as a result of the new demography.”

## Identity

As we have seen in the previous chapter, many individuals with a dual sensory loss do not perceive themselves as a person with deafblindness for multiple reasons (Simcock 2016: 1732). For some individuals, it may take some time to accept their deafblindness as an identify but for others, that might never happen. Health services and other professionals and administrators do not help here with their own view that the dual sensory loss is purely a problem of ageing (Duncan 1988: 65).

For instance, when asked whether she thinks of herself as Deafblind, Hazel, an older woman with deafblindness from UK, answered immediately, “No! No, I don’t.” Adding, “I’ve not mixed with them much you see, persons with deafblindness.” However, she is convinced that she has to accept



her friend Sarah's invitation to socialise more with persons with deafblindness and talk to them because otherwise it is always someone else who is doing the talking when in company, leaving Hazel feeling left out (Matthews 1988a: 35). Here we can see the obvious duality within the person with deafblindness not accepting the label of "Deafblind" on one side but being aware of her communication problems on the other. This issue could be overcome by socialising with persons who accept themselves as Deafblind.

Older persons who struggle with dual sensory loss, but do not identify as Deafblind ignore the fact that deafblindness is not a mere sum of deafness and blindness. These individuals are unaware of the fact that different strategies and skills are required for a double sensory loss than for a single sensory loss. For example, including use of other senses, such as the sense of touch, as well as some other techniques, can greatly assist Deafblind individuals. However, if a person declines to be identified as Deafblind, there is no way that those strategies and skills can be implemented (Matthews 1988a: 36).

Additionally, not identifying oneself as a person with deafblindness can have serious consequences. For example, lack of acknowledgement creates 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. Interpreters for the Deaf and guides for the Blind can never be a replacement for interpreter-guides/Deafblind interpreters, because the former do not know how to guide, and the latter do not know how to communicate with a person with deafblindness. Peer-to-peer counselling is not an option when one does not accept themselves as part of the peer group. This also means 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.

Moreover, if one is not explicitly looking for a second sensory disability, there is a good chance that it will not be found (Jorritsma 1988: 68).

During a discussion as part of the 1988 3<sup>rd</sup> *European Conference of Deafblind International's Acquired Deafblindness Network*, notes, "Terminology, i.e., Deafblind, is not readily applicable to the older group" (Balder 1988: 101). Unfortunately, there is no mention of how this point was adopted nor why<sup>xxxi</sup>.



This point is reflected in the fact that most older persons who develop their sensory loss at old age will not identify with the label “Deafblind”. It is worth clarifying that the term Deafblind in this context is used to refer to sensory loss that is not just hearing loss and vision loss but is about recognising the effect of the combination and that different strategies and skills are required that include use of other senses, for example tactile approaches and other techniques. The term Deafblind is also used to highlight the need for a different discipline that needs resourcing if peoples’ needs are to be met. We might be facing a dilemma if persons with deafblindness do not see themselves as Deafblind; however, we must continue to promote the term and leave the identification aspect to each individual as a free choice.

## **Socialising with Other Persons with Deafblindness**

Meeting other persons with the same condition is of extreme importance for any Deafblind person, but especially for an older one. Meeting other people who face similar barriers due to their reduced vision and hearing may be crucial to more easily accept one’s own deafblindness. 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.

Göransson (2007: 144, 148) mentions the importance of meeting other persons with deafblindness through FSDB (Association of the Swedish Deafblind) in an older Deafblind person's life. Viola, an older woman from Sweden, said that she has never felt left out, because people there understand her. However, she now feels too old to participate to meetings. FSDB is primarily described by older persons with deafblindness as a social network where one can meet others who know what it is like to live with deafblindness and a place where people can socialise on the same terms.

Such encounters and gatherings within the Deafblind community often replace the friendships and relationships lost over the communication problems of the older Deafblind person (Simcock and Manthorpe 2021: 100).

The presence of other persons with the same condition is beneficial in rehabilitation, as well. A well supervised small group with four to six persons with deafblindness has been proven stimulating for both the psycho-social and the practical rehabilitation (Schipper 1988: 85).



## Deafblindness Misdiagnosed as Dementia

While people around older persons with deafblindness may interpret his/her misunderstanding of communication as a sign of reduced mental abilities due to ageing, they can also jump to the conclusion that he/she experiences from cognitive debilitation (Olesen 2012: 14, 15). This conclusion underestimates his/her intellectual ability and cognitive capabilities, thus regarding the older person with deafblindness as helpless and unequal. At the same time, limited communication, social participation, independence, and acquisition of information do influence the cognitive capabilities of the older person in a negative way, due to lack of mental stimulation (Olesen 2012: 14).

When a person with deafblindness cannot properly understand what his/her interlocutors say due to his/her diminished hearing and diminished vision, he/she may often reply with something not in line with the actual topic of the conversation. Others, puzzled by that replica, may conclude that the person with deafblindness is senile, demented, or lacking the cognitive abilities needed to keep up (Göransson 2007: 146; Olesen 2012: 12).

Thus, the condition of the person can be seriously misdiagnosed as dementia, instead of





deafblindness. An erroneous diagnosis leads to an erroneous therapy or approach, which can lead to a serious decline in the older Deafblind person's mental and physical health. Thus, misdiagnosis may lead to it becoming true.

On the other hand, deafblindness in older persons can be related to cognitive decline, as well as depression, functional decline, and participation challenges (Jaiswal et al. 2020: 1).

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. However, "(t)he problem of diagnosing dementia is extremely pronounced in persons with deafblindness. Namely, it is difficult to determine whether a person is dealing with the consequences of deafblindness or signs of dementia. Due to (a) wrong diagnosis, there is a lack of timely and effective help. This problem can be eliminated by educating healthcare workers and frontline staff about deafblindness and the consequences of loss of vision and hearing in different areas of functioning" (Ivasović 2021: 6). Skov Uldall stresses that "(s)ensory loss and dementia may blur each other's existence" (2012: 19). When this happens, care staff should pay special attention to ensure they are well-informed on how to recognise the typical consequences of



late acquired deafblindness and the early signs of dementia (2012: 20).

## **Deafblindness Combined with Other Disabilities and Illnesses**

Deafblindness at older age needs may be accompanied by other illness and disabilities. The term used in psychological literature for this is “multiple vulnerability” (Prickarts 1988a: 91).

As previously stated, psychiatric or psychogeriatric 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 in old age (Prickarts 1988a: 87). Moreover, old age brings with it several experiences of loss. Apart from losing vision and hearing, the person also loses partners, relatives, and friends (Prickarts 1988a: 91).

Prickarts (1988a: 91) reports that most older clients with acquired deafblindness who come to Kalorama, a Dutch centre that provides support for persons with deafblindness, have accompanying problems. Sometimes, it is deafblindness that is responsible for disturbances, while in other cases, multiple disabilities have no mutual causal



relationship, but can influence each other negatively.

## 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. Some older persons with deafblindness can even experience improvements as a result of changes in their condition or medical intervention. This is not limited to those ageing with acquired deafblindness, but also to those ageing with congenital deafblindness. The nature and timing of hearing and vision deterioration varies, and periods of stability alternate with periods of fluctuation (Simcock 2016: 1729). Constant adaptation is not just a need, but a necessity.

Within the older Deafblind population, changes in impairment occur concurrently with changes associated with ageing (considered a "second disability"). Moreover, there is a phenomenon called *accelerated ageing*, which explains how persons with Deafblindness (and those with other impairments) may experience changes associated with ageing sooner than those without impairments. Older persons with deafblindness lose many of the gains they achieved in



rehabilitation as they age, and they may make multiple, repeated, ongoing, permanent, and constant adjustments (Simcock 2016: 1733; Simcock & Manthorpe 2021: 100).

The range of adjustments for older persons with deafblindness includes psycho-social adaptation, emotional acceptance of deteriorating senses, and changes in relationships (including personal relationships and relationships with social care services). Additionally, these individuals will have to learn new ways to complete everyday activities, the use of modern assistive technologies, and access to information (Simcock 2016: 1729).

Some older persons with deafblindness who live with a condition for a long time find it easy to adjust, enabling them to maintain their independence and become increasingly self-reliant. For others, long-time deafblindness does not make maintaining independence or coping any easier, and instead, daily activities become harder with old age (Simcock 2016: 1731, 1732, 1734).

Two main types of adaptations are ongoing with the older persons with deafblindness: 1.) learning new communication methods or 2.) adapting existing ones. Both types of adaptations are also applicable to assistive devices and technology.



Communication becomes more difficult with constant changes in hearing and vision, often making existing communication methods unsatisfactory (Simcock 2016: 1729–1730). As the sight deteriorates and, consequentially, the sense of touch becomes more important, primarily Deaf individuals who used Sign Language now must learn to perceive it in a different way. This can be done either by moving the signer closer to persons with deafblindness, by leading the signer's hands to be within the field of vision of the person with deafblindness, or to learn to “read” tactile Sign Language, a switch which is not so easy to do (Göransson 2007: 144). Primarily Blind individuals who used Braille can continue using it, but in new settings that they did not need before. For instance, typing Braille on the screen of a Smartphone. However, reduced motor abilities resulting in a loss of sensitivity in fingers can make Braille an inaccessible method of communication (Simcock 2016: 1730).

Some signing older persons with deafblindness prefer using what little sight and hearing they have left to continue using Sign Language in the traditional, visual mode, only to switch to a new communication technique when residual sight becomes insufficient to continue with that method. Nevertheless, it is best to introduce new



communication techniques as early as possible (Duncan 1988: 66). Being interested in retaining or regaining the use of their hearing and vision to the greatest extent possibly makes many older persons with deafblindness resistant to adapting their communication preferences. When this occurs, these individuals prefer to maintain already adopted communication methods rather than learning alternative communication techniques (Jaiswal et al. 2020: 7).

It is very important that every older individual with deafblindness establishes what the right communication for him/her is and be proactive in asserting that everyone communicates with him/her in this way. However, older persons rarely achieve this level of assertiveness, thus it is their network(s) that should be educated on the preferred communication system (Schipper 1988: 86). As every person with deafblindness is different, the assistive device interventions should also be unique for each individual to be effective (Jaiswal et al. 2020: 7).

Some older persons with deafblindness consider functioning assistive devices and technology to be of the utmost importance for them in order to be able to remain independent, maintain social relationships, and participate and live an active life (Göransson 2007: 151; Jaiswal et al. 2020: 5).



Computer-based assistive technology has provided them with huge possibilities, especially when it comes to keeping in touch with other people and getting access to information (Göransson 2007: 151). That technology and new instant-messaging services have often become the only connection to the outside world for many older persons with deafblindness, especially during exceptional circumstance such as the COVID pandemic. These new telecommunication possibilities for the Deaf and Deafblind started with telefax machines in the 1980s. These devices provided individuals for the first time with the ability to communicate with someone who was not present. At the end of the 20<sup>th</sup> century, e-mail appeared, followed by SMS. With the advent of smartphones and video communication applications, the barrier to long-distance communication with others was diminished.

An example of how environmental barriers and lack of services result in a loss of autonomy is showcased by Alegría, a 74-year-old woman from the Canary Islands, Spain. 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 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 if she is taking a route not supported by the pedestrian device<sup>xxxii</sup>.

Unfortunately, many older people with deafblindness lose their fine motor ability, have the sense of feeling in the fingers reduced, which can present a problem with modern technology in general. Modern technology often requires handling small parts or pieces, particularly with handling modern hearing aids, which become smaller and smaller, with their controls following proportionately (Göransson 2007: 151; Simcock & Manthorpe 2021: 103). The other problem with modern assistive technology is the lack of information that is accessible for persons with deafblindness (Simcock & Manthorpe 2021: 103).

Some older persons with deafblindness deem themselves to be too old to learn new skills (Göransson 2007: 146). It might be that after so many disappointments caused by the limitations of their hearing and their vision, they stopped





believing in any possibility of improvement of their situation (Schipper 1988: 84). Although it might not be 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 to be taught about modern technology is by someone who understands the needs of a Deafblind individual and not by only a skilled IT expert, as it is often the case. An older person with deafblindness should learn only as much as he/she can use in his/her everyday life and in small steps (Schipper 1988: 84). Flooding him/her with superfluous information and jargon can make the person lose the will to learn and cause information overload. Learning even basic things on the computer for a person that can neither see well nor hear well is not only time consuming, but also energy consuming. Because of this, it would be best if his/her teacher is another Deafblind person, because he/she is well aware of the barriers often encountered in such a learning process.

Many older persons with deafblindness belong to a generation that has not had any previous contact with computers and are of the opinion that they need many hours of training. However, previous skills, such as typewriting skills come handy when having to use a computer with sight impairment, and can



be transferred over to learning new, modern technology (Göransson 2007: 144, 151).

There are other older persons with Deafblindness who engage actively with rehabilitation services and enjoy the opportunity to learn new skills and how to use new assistive and mainstream technologies. These individuals are directly challenging the negative construction of old age as a period of inevitable decline and withdrawal (Simcock 2016: 1732; Simcock & Wittich 2019: 9; Simcock & Manthorpe 2021: 101).

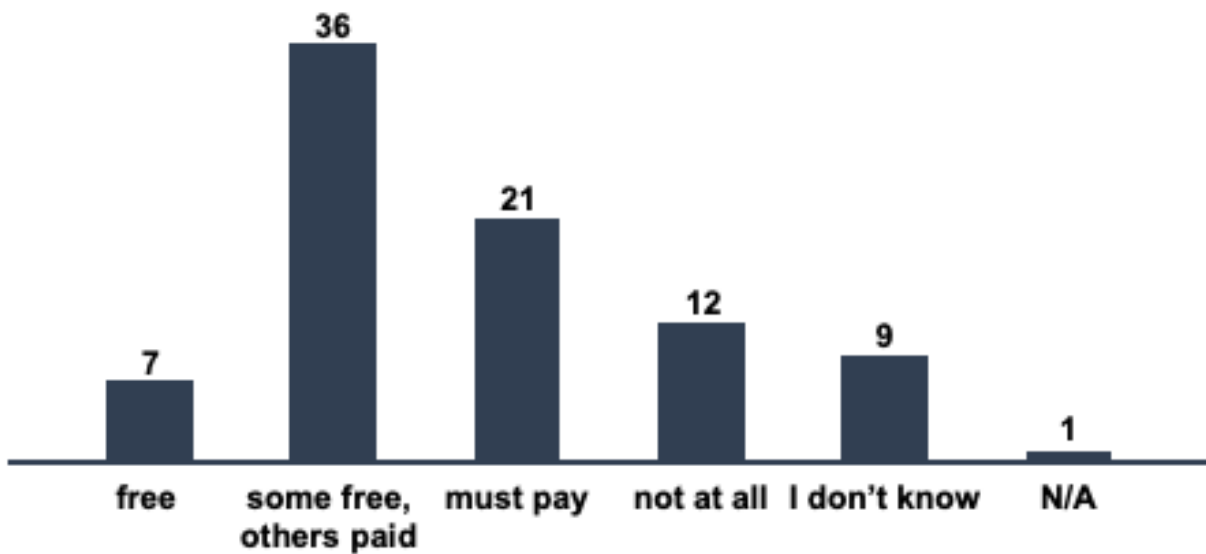
An older Deafblind person can learn, within his/her limits, not only day-to-day life activities, mobility activities, and recreational activities, but also Braille and how to use a computer. To accomplish this, it is very important that the older person with deafblindness becomes aware of what he/she still sees, hears, feels, and smells, which is useful for total rehabilitation (Schipper 1988: 86).

Other challenges with assistive technology that older persons with deafblindness meet are cost, training, maintenance, and adaptation of the device as per their individual specific need (Jaiswal et al. 2020: 5, 7).

There is another problem with technical aids: their availability. One of the questions in the survey was whether technology and assistive devices are



available to older persons with deafblindness in the region or country of the respondents. The answers painted an interesting picture (**Figure 7** and **Table 1**).



***Figure 7 - Availability of Technology and Assistive Devices.***



**Table 1 - Is Technology and Assistive Devices Available to Older Persons with Deafblindness in your Region or Country?**

Answers	By country		By continent	Total
Yes, they can get them for free.	Canada (1) India (1)	Spain (3) USA (2)	Asia (1) Europe (3) North America (3)	7
Yes, they can get some of them for free, others they must pay for.	Angola (1) Australia (1) Bulgaria (1) Canada (3) Denmark (3) Ethiopia (1) India (1) Italy (1)	Norway (4) Russia (4) Slovenia (4) Spain (9) Tanzania (1) UK (1) USA (2)	Africa (3) Asia (1) Europe (26) North America (5) Oceania (1)	36
Yes, they can get them, but must pay for them.	Bangladesh (1) Brazil (1) Hungary (2) India (1)	Kenya (2) Spain (11) Uganda (3)	Africa (5) Asia (2) Europe (13) South America (1)	21



<b>Answers</b>	<b>By country</b>		<b>By continent</b>	<b>Total</b>
No, they cannot get them at all.	Ethiopia (1) India (2) Indonesia (1) Palestine (1)	Rwanda (1) Spain (2) Uganda (2) USA (2)	Africa (4) Asia (4) Europe (2) North America (2)	12
I do not know.	Australia (1) Denmark (1) India (2)	Russia (1) Spain (3) USA (1)	Asia (2) Europe (5) North America (1) Oceania (1)	9
N/A	Malawi (1)		Africa (1)	1



Considering this question, the most interesting feature is how dispersed some national answers are. For instance, we can see that Spanish responses are distributed among all the available answers. Some of them answered that some of the aids can be obtained for free, while others must be paid for, some answered that all of them can be obtained only by paying for them, and some that aids cannot be obtained at all. Could it be that there are different policies concerning technology and assistive devices in different regions of the same country? Or, is it more likely that, the lack of information or lack of access to information that prompts different compatriots to give so different answers? Or is it the perpetually changing laws and regulations ruling the availability of technology and assistive devices, which impede persons with deafblindness and others around them to be up to date with the newest information? Spain is not the only example of this phenomenon, and the same can be seen for other countries. Respondents from India, for instance, gave four different answers to this question.

Also, the supposed difference between higher-income states and those middle- and lower-income ones does not seem to play a significant role in the distribution of nationalities among the answers.



A different problem presents in the form of receiving more means of assistance than necessary. Older Deafblind persons think that this might be because the professional in the field simply felt overpowered by their condition and had little knowledge of what exact service he/she must provide to the person. Because of this, he/she prescribes everything hoping that they had done something to ease the person's life (Göransson 2007: 151–152).

So how does one decide what type of support is needed and what is not? As the only evaluation criteria, Prickarts (1988a) posits the evaluation of the situation by the older Deafblind person him/herself by asking how much is *this* contributing to his/her quality of life (QOL) and to a pleasant, good, happy, safe existence? At Kalorama, the Dutch centre that provides support for Deafblind persons, quality of life is understood as a quality of the interaction between the individual and his environment. It is a subjective matter, it cannot be measured and expressed numerically. It is up to the older Deafblind person to determine whether something is contributing to his/her quality of life and to his/her feelings of wellbeing. For older persons with deafblindness, it is not easy to maintain an acceptable level of quality of life. Building an environment in which natural



psychological processes of coping, mourning, and acceptance happen in a natural manner for an older Deafblind person is a way of facilitating these processes without interference. When natural mechanisms fail to contribute to quality of life, professional intervention kicks in. However, rehabilitation should not be oriented solely on minimising limitations or learning new skills. It is the older person with deafblindness who should start this process of adapting to their challenges with a concrete demand, which soon can change to other demands. The rationality of the initial demand itself is never questioned, argued, no matter how unrealistic it seems to the rehabilitators. To improve the quality of life, rehabilitation oriented on functioning is more important than rehabilitation oriented on development or training. Rehabilitation oriented on the environment and directed by subjective standards of clients is more important than rehabilitation oriented on compensating for limitations and the development of specific behaviours (Prickarts 1988a: 88–90, 92).

Unlike those born Deafblind, older persons with acquired deafblindness have a wide knowledge of the world around them, based upon many years of experience and interaction. This means that what they need is appropriate information, advice, and





support to enable them to maintain two-way communications, and therefore, their quality of life. However, those who develop deafblindness later in life face these difficulties at a time when they are also dealing with the challenges of ageing. Many of them can count on little or no family or professional support, or the specialist expertise is only available to younger Deafblind persons (Duncan 1988: 66).

The life adjustment model acknowledges that adjustment is not just an individual response to impairment, but that persons with deafblindness also need the social environment and service providers to adjust as they age, which is not always acknowledged in the literature (Simcock 2016: 1735).

It is also important to note that, helping a person with disability can become a sensitive topic. Offering unsolicited help can more often be interpreted as “you are not able to do it, let me” than a noble intention. People who offer such help do mean well, but often end up being overambitious and overzealous, because a person with disability (deafblindness included) does not need help all the time (Göransson 2007: 144). Those around an individual with deafblindness should realize they will just ask for help when it is needed. Simcock *et al.* (2022a: 9) mentions two situations in which persons with deafblindness had



to deal with unasked-for help: “Caroline directly challenged a stranger who grabbed her arms to offer unrequested help, by telling him to ‘get out of my space.’ Rose recalled showing courage when challenging her parents about the support they offered, which was experienced as over-protection.”

On the other hand, there are situations when help does not need to be requested, but is provided intuitively, instinctively, and discreetly. Such situations are valued as instance of a good relationship between the person with deafblindness and the helper, as both the need for help and the way to provide it are mutually understood (Simcock 2022a: 19).

People willing to help might find themselves on a slippery slope. Offering unsolicited help might be understood as intrusive and diminishing the person’s capabilities. But not offering unsolicited help might be interpreted as selfish, demonstrating a lack of empathy and altruism to help one’s neighbour.

The important thing is for the person with deafblindness to make it clear to the service provider when he/she does need help and when he/she do not. Moreover, service providers should ask if and what kind of assistance is needed. As it



is not often the case that the same Deafblind person receives the same service provider on a regular basis, assertive communication is vital.

## **Health and Care Personnel**

Insufficient or lack of knowledge on deafblindness, persons with deafblindness, and their needs and methods of communication seem to be the greatest problem persons with deafblindness face when meeting professionals such as health care staff, social workers, etc.

Health and social care systems often seem to be designed around individual diseases rather than conditions involving multimodality (Simcock & Manthorpe 2021: 102). There are ophthalmologists for the field of sight and audiologists for the field of hearing, but the two areas remain separated. A Deafblind person must go to the former to have his eyes tested and to obtain a medical report on the status of his/her vision, and then must go to the latter to have his/her ears tested and to obtain a medical report on the status of his/her hearing. He/she acquires two medical reports for his/her unique condition, only reinforcing the “deafblindness is the mere sum of deafness and blindness” fallacy.



Simcock (2016: 1732–1733) states that persons ageing with Usher Syndrome Type I can lead a life of reduced access to information. Because of this, these individuals tend to be especially unaware of the ageing process and of the health and social care services provided for older people. Due to their impaired hearing and vision, most of these individuals rely on others to provide them with information, which was more often than not summarised and incomplete. Looking for and consequently finding useful information by themselves is not what some of them are used to do, which makes up to date information even harder to come by.

The following story extracted from a Croatian publication (*Starenje sa gluhošljepoćom* 2021: 19) can shed light on the situation that many older people with deafblindness experience. After her Deafblind mother, was hospitalised for two days in a row, her daughter, living abroad, realised that her mother couldn't live alone in the apartment any longer. She was also aware that placing her mother in a home would only further worsen her condition. Social services declined any possibility to help. Reluctantly, the daughter wanted to arrange for her mother to live in a nursing home, to which she received the following answer, "Unfortunately, we cannot accept your mother. She



is mobile, we do not know how to communicate in Sign Language. She has poor vision, we cannot take the responsibility. You know, we only have an inpatient ward, she is not for an inpatient facility. We won't be able to understand when she feels some pain, what she wants, and the like... Get in touch with us again when your mother becomes immobile, for the inpatient ward". The same happened to Viola, an 89-year-old Deafblind woman from Sweden: "The local authorities say that I am too well to live in a senior citizens home. It's not enough to be old and both Deaf and Blind" (Göransson 2007: 144). There are others who have also been denied a place in a residential home because their needs have not been considered severe enough to warrant help (Göransson 2007: 153).

These real-life stories illustrate the situation better among the professional care centres than much of the research conducted in the field.

Not many professionals with which persons with deafblindness come into contact know much, if anything, about deafblindness, let alone any communication method that can be used when they meet these individuals. Physicians burdened with a considerable number of patients seldom find time and patience to communicate with a person with deafblindness as they would with a hearing



and seeing one. More often, the physician says what he/she has to say to the interpreter-guide/Deafblind interpreter to be conveyed to the person with deafblindness only when they leave the consulting room. Hospitals sometimes refuse to include persons with deafblindness in therapy sessions because of “impossibility of communication” (Tarczay 2019: 5).

Access to information is usually not easily available for older persons with deafblindness. Thus, many of them are not even aware that there are healthcare services providing for older people. Unfortunately, if they have no idea of such existing services, they cannot apply for them and benefit from them (Simcock & Manthorpe 2021: 102). On the other hand, as 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, they 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. These individuals often fear medical mistreatment as a consequence of the impossibility of communication. Misunderstanding or not understanding medical information leads to worries and insecurity, as well as to severe medical consequences (Göransson 2007: 149).



It seems that both medical specialists and family doctors do not possess enough knowledge about the rehabilitation of older persons with deafblindness, the former because their specialisation is too narrow, the latter because theirs is too broad. Unfortunately, persons with deafblindness themselves do not know a lot about the opportunities they have for such rehabilitation (Schipper 1988: 83).

The general impression shared by the older Deafblind demographic is that the medical staff simply does not care. They assume that they are just there to do what they have to do, fill in the necessary papers, and call for the next patient (Matthews 1988a: 31–33). These individuals are concerned that health and social care services simply do not have the ability to meet their particular needs (Simcock & Manthorpe 2021: 97). Additionally, they fear that Deafblind services don't have the ability to meet their needs as older persons and that mainstream older persons' services don't have the ability to meet their needs as persons with deafblindness (Simcock 2016: 1732). They believe that the single sensory impairment services are inadequate when meeting the needs of those acquiring a second sensory impairment, in addition to a pre-existing one (Simcock & Manthorpe 2021: 102).



In short, the experiences of older persons with deafblindness in healthcare include inaccessible information, lack of awareness on deafblindness among staff, and limited communication support (Simcock & Wittich 2019: 8). This deeply affects the confidence of the older Deafblind person in his/her self-management of health conditions (Simcock & Wittich 2019: 8).

Article 25 of CRPD promotes the right of persons with disabilities to “the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.” A notable aspect of this article is the protection of “free and informed consent” in decision-making in health care, which includes raising awareness on human rights, dignity, autonomy, and needs of persons with disabilities through training and the promulgation of ethical standards for public and private healthcare. With respect to the notions of agency and decision-making, it is worth underlying that the CRPD Committee distinguishes legal capacity as “the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency)” (CRPD/C/GC/1, § 13). Additionally, they mention mental capacity, which “refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many





factors, including environmental and social factors”.

With respect to older people’s issues in navigating hospitals and other formal care systems, “medical language can be intimidating, and interventions and their risks are not always easy to understand”. As SHAPES deliverable Understanding older people: lives, communities and contexts highlights, “understandably, information is often parcelled, controlled, and exchanged in an asymmetric manner, especially before a diagnosis or a treatment plan is fully determined but it is also sometimes poorly articulated and impatiently delivered at a time of high stress” (SHAPES 2022). This is unfortunately often the case for an individual who participates in informed consents, whose understanding and accessibility hinder the genuine participation and involvement of the cared person. It must be underlined the importance of accessible and informed consent, especially for persons with deafblindness, with information being available in different accessible formats (braille, large font, sign language, etc.), and simple, easy to understand language, avoiding medical and administrative jargon. Also, medical information should be provided in a truthful and objective way, avoiding manipulation, harmful or unnecessary practices.



When a nursing home staff who is not familiar with the specifics of deafblindness, let alone with communication methods used by persons with deafblindness, a person with deafblindness remains alone, isolated, and without adequate support and care. This can lead to quick mental and general health deterioration, and a decline in the quality of life, caused by the denial of the fundamental rights to a dignified life, communication, and dignified ageing (Bojtor 2021: 10; Göransson 2007: 150–151, 154). In such an environment, even moving to and from one's own room can be difficult (Olesen 2012: 13), and an older person may react by staying in his/her room (Olesen 2012: 14).

However, life in a nursing home is often limited to meals, sleep, and idleness with no interaction with other humans. Alfredo, a 71-year-old male who is completely Blind and Deaf from Cordoba, Spain, shares his experience living in a nursing home for some months: “(My experience) is very bad, because I could not get used to the meals or anything. I could not move around the nursing home by myself, nor communicate with others. I could not communicate with other people. So, for me (it) was a very bad experience”<sup>xxxiii</sup>.

Older persons with deafblindness might also be increasingly exposed to neglect and mistreatment.



This goes directly against *Article 15* of CRPD (United Nations 2006), *Freedom from torture or cruel, inhuman or degrading treatment or punishment*, whose paragraph 1 states explicitly:

“

“No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.”

”

Lack of attention is even more enhanced by the hectic everyday life of the staff (or close family members, if the person stays at his/her home) who simply have not enough time to devote to the older person with deafblindness who needs more time than others to understand what is being said (Olesen 2012: 12). All this goes against article 9, paragraph 1, of the United Nations' *Convention on the Rights of Persons with Disabilities* (UN 2006), according to which, the State Parties assume the obligation to enable persons with disabilities to live independently and participate fully in all aspects of life.



The feeling of isolation of older persons with deafblindness living in residential homes where there are no peers with deafblindness, and the staff lacks awareness and training on how to communicate is only increasing. Older individuals with deafblindness are finding themselves unable to get answers to their questions and not being able to express their needs, with little to no influence over the service provided. 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. The results of such a situation often leads to misunderstandings, mistakes, and faults in the care provided, as well as insecurity and frustration. Oftentimes, all older persons with deafblindness want is to have a working communication with the staff in residential homes and within the home care service (Göransson 2007: 149). Another issue arises in home care service as these professionals can come and leave without the older Deafblind person even noticing it (Göransson 2007: 144).

A possible solution would be “a social care home (...) a public institution and this form, assuming proper execution, (that) offers the possibility of covering the specific needs of persons with deafblindness”, although, it is important to



emphasise, no such home that we know of exists in practice. Opinions on the best way these individuals can be cared for are divided, however; because, although many Deafblind older persons show a preference for living in a nursing and/or residential homes, surrounded by members of a similar population, such care can easily be considered institutionalisation.

The position of the European Union is that such institutions are unable to provide individual services or adequate support that is necessary for full inclusion in society” (Bojtor 2021: 8). This position is shared by Article 19 of the United Nations’ *Convention on the Rights of Persons with Disabilities* (UN 2006), dealing with independent living and being included in community, as well as by *General comment No.5 on Article 19 - Living independently and being included in the community* by UN’s Committee on the Rights of Persons with Disabilities (2017). This sentiment is also shared in the report *Thematic study on the right of persons with disabilities to live independently and be included in the community* by the Office of the United Nations High Commissioner for Human Rights (2014).

Residential homes adapted for Sign Language users where residents can meet other people with the same impairment, exchange experiences, have



a good time, and receive accessible older care (Göransson 2007: 155–156) seem to currently not exist.

In short, an older person with deafblindness should be able to freely choose how and where to live without compromising their rights. This is 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.

In their responses to the survey, two Deafblind persons, one from Spain and the other from Brazil, also urge for the creation of specialised inclusive residences for older persons with deafblindness with a multidisciplinary staff. It is a necessity for persons without a family not to feel alone and to have company with whom they can communicate and share everyday life. The survey questions show how the government could improve the lives of older persons with deafblindness. Several respondents saw a government-sponsored solution in homes for persons with deafblindness, in a kind of defiance towards international documents that label such establishments as unwelcome institutionalisation. A person with deafblindness from Bangladesh wrote,



“Government can (and should) establish care home for them (Deafblind persons) in special cases where they will be taken care of.” Two Spanish Deafblind persons wrote, “(There is a need for) residences in which the staff knows how to communicate and support these people” and “residences solely for older persons with deafblindness where they would have their peers, company, and their needs covered.” A respondent from Slovenia wrote about the need for “retirement homes adapted for persons with deafblindness.” A Russian volunteer of the foundation for the support of persons with deafblindness, conductor of scientific studies concerning Deafblind people and older people with deafblindness, and rehabilitator wrote about the necessity of “creating a chain of assisted living homes all over the country, mainly for single Deafblind persons. (And) Making sure that there are social workers, Sign Language interpreters, guides and other specialists working with Deafblind persons in all regions; (while) not imposing technical means of rehabilitation that are not suitable for those people.” This sentiment is far from being local. There are likely other older persons with deafblindness who share the same idea. Some respondents mention creating a safe space for persons with Deafblindness.



Another respondent, a professional service provider that directly supports persons with deafblindness from Spain also mentions residential centres for older persons with deafblindness should be created, along with day centres and other reference centres where *all* the professionals know the necessary communication systems and are adapted to the needs of this population.

The spread of this idea of Deafblind specific centres shows the diversity of opinions amongst persons with disabilities, some of which challenge the views of stakeholders such as the EU and UN, which oppose institutionalisation. However, paragraph (a) of the aforementioned Article 19 states that, “(p)ersons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.” Likewise, *Thematic study on the right of persons with disabilities to live independently and be included in the community* (Office of the United Nations High Commissioner for Human Rights 2014: 7) explicitly prohibits only *forced* institutionalisation.

Of course, medical and residential home staff are not the only professionals with whom older persons with deafblindness face many barriers. All individuals with biased behaviour are characterised





by the same problem: a wide-spread lack of knowledge, maybe even lack of interest, regarding the situation for older persons with deafblindness and their requirements, which has led to incorrect priorities and decisions (Göransson 2007: 164, 161; Westerholm 2012: 9).

The situation of older persons with deafblindness can be summarised as: lack of coordinated and systematic care for older persons with deafblindness, which severely affects their functioning and participation, lack of awareness, and sensitivity of healthcare providers, and other types of service providers toward the needs of older persons with deafblindness. It is also important to note that there is probably not enough effort being invested in research to develop assistive technologies catering to the unique needs of older persons with deafblindness. Additionally, the fact that older persons with deafblindness are generally not involved in decision making and consulting processes concerning their own life needs to change (Jaiswal et al. 2020: 6–7).

The situation is complicated by the fact that there are disability organisations that are not always able to respond to ageing issues, as well as services for older people that fail to respond to disability related matters. Even human rights campaigns for organisations for older people do not engage



explicitly with disability rights, which must change in order to be effective (Simcock & Manthorpe 2021: 101).

In contrast to the professionals who come in contact with older persons with deafblindness, a special mention should be made of carers, especially those 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. The aim of these programmes is 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**

The notion of empowerment is not solely restricted to an individual and personal dimension, but extended to the community and the environment in which a person lives. This means addressing the social, cultural, political, and economic determinants of people's lives, and



adopting a multi-disciplinary approach. Four themes shape the concept of empowerment at the individual level<sup>xxxiv</sup>:



Having a sense of personal identity



Having a sense of choice and control



Having a sense of usefulness and being needed



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 intersections, as well as individual characteristics such as personality and life experiences).

When looking into the realities of older persons, the process of empowerment necessarily addresses the social, cultural, political, and economic determinants. Based on literature and



consultations of older persons, the main challenge to empowerment is the impossibility of the outside world to communicate with persons with deafblindness and vice-versa, because many other challenges arise from this one.

One of the major challenges to empowerment is when there is no organisation of persons with deafblindness. While the voices of individual Deafblind persons are important, organisation speaking in the name of many Deafblind persons is more likely to have a bigger impact than individual efforts. Persons with deafblindness usually do not know other persons with their condition, so it is finding and uniting them that makes fighting for their rights even possible. Another challenge is lack of funds. A non-profit organisation with no steady income can only function haphazardly and by obtaining finances from projects and other temporary sources. Such an organisation can hardly engage a permanent staff, which is needed for its functioning. The same is valid for interpreter-guides/Deafblind interpreters. Volunteering is possible, but only if the person has some other steady income. Unpaid or poorly paid interpreter-guides/Deafblind interpreters do not remain long in the field, especially if financing them becomes the duty of somebody else and not the state.



The next challenge concerns the education background of the persons with deafblindness. Until recently, primarily Deaf persons attended schools for the Deaf, where they acquired inadequate education and were offered training in a limited range of jobs, some of them actually graduating from such schools totally illiterate in the majority spoken language. The salaries for the jobs they were allowed to do and available pensions were often barely sufficient. How can such a person fight for his/her rights? When Deaf, Blind and Deafblind children are integrated in regular schools and have assigned a teaching assistant, in line with the CRPD, the future for them looks brighter.

Another challenge are cultural perceptions of disabilities. In some cultures, a person with a disability is still an untouchable, discriminated against, humiliated, excluded, and fit to be exploited. The roots of such a behaviour reach very deep in the past, making this perception hard to eliminate. This perception also causes a deep distrust of persons with disabilities towards persons without disabilities. Even in societies that formally accept persons with disabilities as their peers, individuals may still retain some negative views and opinions on them.



It is evident how socio-economic and educational status, cultural backgrounds, and generational factors, as well as institutionalised ageism, matter when it comes to empowering people.

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. For example, older women with deafblindness face multiple challenges, prejudices, stereotypes, and discriminations due to such intersections. It is therefore key to adopt an intersectional approach when analysing the realities of older persons with deafblindness, as well as attitudinal barriers. Furthermore, a change in the perception or stigma surrounding older persons with disabilities is necessary, as they are often described as a vulnerable or weak group. This negative generalisation often leads to patronising behaviour and discrimination. This is not only inaccurate for many, but harmful as it removes the ownership and legitimisation of the decision-making and empowerment of older persons. Also, it ignores the fact that many older persons are caregivers themselves and can



provide different types of support to the community and society (financial, emotional, etc.).

With all these factors influencing participation, decision-making, and impact on empowerment, a balanced relationship between the various actors involved in each decision is essential. Therefore, approaches like person-centred care and shared decision-making shine through. These are both possible only if the communication flows correctly, in an accessible and inclusive way. Quality communication between all stakeholders involved in the ecosystem of older persons with deafblindness (interpreter-guides/Deafblind interpreters, healthcare professionals, caregivers and family, etc.) is one way of ensuring empowerment and respect.

Sustaining empowerment across the lifespan relates to four principles (4Ps) (Seidel et al, 2021):



## PARTICIPATION

Providing older adults with the capability to choose (and being inclusive)



## PROCESS



Raising awareness and engaging with change in all stages of life (life-course approach)

## PRACTICES

Recognising and enabling people's contributions (moving away from stigma and discriminations)

## PURPOSES

Providing the opportunity to live according to one's own intentions (person-centredness)

These general principles, coupled with the individual indicators for empowerment (having a sense of personal identity, having a sense of choice and control, having a sense of usefulness and being needed, and retaining a sense of worth) are key elements for empowerment.

Such empowerment indicators embrace the concept of agency.

It is not only important to provide the opportunity for older individuals to make a choice; it is important that they act on that opportunity and that they translate their choice into an intended outcome.





## Access to Information

The challenges persons with deafblindness face every day are usually reduced to communication and mobility problems. Very often, the third major problem, access to information, seems to be “forgotten”. It is true that this barrier is closely connected to communication barriers, because information is usually accessed by some means of communication, but the outcomes are different.

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 (Olesen 2012: 10–11). For a person with deafblindness to be able to live a life of his/her own, this access of information is of critical importance.

Keeping up in a society that is constantly changing and putting new demands on the individual can be very hard for an older person with dual sensory impairment. The constant stream of new information is difficult to deal with for an ageing person with his/her vision and hearing deteriorating (Göransson 2007: 152).



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. That includes the information flow, in particular, which may be difficult to handle for someone who is getting older and whose vision and hearing is deteriorating (Göransson 2007: 152).

Acquiring information about things that are going on, both in the close environment and in the world in general may be a problem for older persons with deafblindness (Göransson 2007: 150). Nowhere was this problem so emphasised as during the COVID pandemic, when several interviewed older Deafblind individuals were left clueless about what was happening. As if the lock-up itself was not damaging enough for persons with deafblindness because of restricted communication possibilities, it was hard to be informed in real time of what was occurring and what the momentary restrictions and instructions were. Older persons with deafblindness could browse the Internet, use some messaging programmes/applications, or who have someone living with them who could keep them up to date were in a better position.

The importance of accessibility to information in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms is



stressed in the *Preamble* of United Nations' *Convention on the Rights of Persons with Disabilities*, only to be further elaborated in the following articles: the obligation of States Parties to promote the availability and use of new information technologies, to provide accessible information about mobility aids, devices and assistive technologies (Article 4, paragraph 1), to ensure access, on an equal basis with others, to information (Article 9, paragraph 1). The whole of Article 21 is dedicated to freedom of expression and opinion, and access to information. (UN 2006)

Today, information is largely available.

Unfortunately, a lot of misinformation is available, as well. For older persons with deafblindness to have a better access to such information, several conditions must be met. The education of older persons with Deafblindness on how to use the digital technology must be simplified to be more efficient. Moreover, the contents must be delivered in a way that can be accessible to persons with deafblindness, and available in multiple formats. There is also a third factor: the technology itself should be affordable for persons with deafblindness user. There are cases where modern technology can be prescribed as any other aid or medicine, with the state covering part or all of the expenses. In other states, especially the



lower-income ones, covering such expenses are out of the question.

## Rights and Independence

Rights, especially human rights, belong equally to all people, those with disabilities and those without. So why did the UN feel the need to issue the *Convention on the Rights of Persons with Disabilities (CRPD)* in 2006, 58 years after adopting the *Universal Declaration of Human Rights (UDHR)* in 1948?

Both rights and independence are valued by older people and are of significant concern for persons ageing with impairments (Simcock 2016: 1734).

The independence of older persons with deafblindness in relation to both activities of daily living (ADL) and instrumental activities of daily living (IADL) are affected by their dual sensory impairment in a negative way. This challenge to a person's independence becomes more serious if deafblindness is acquired later in life and as the person gets older. Damen et al. (2005) and Simcock & Wittich (2019: 4) note that "people with Usher syndrome, a genetic condition causing hearing impairment and progressive sight loss, had increased difficulties maintaining their



independence as they aged,” but unfortunately, they do not provide additional arguments for this claim.

Independence might mean different things for different people. There are two views on the issue. 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 Deafblind persons 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 instead stands for being in control of how and when that assistance is provided, because remaining autonomous and in control is as important as being able to care for oneself (Simcock 2016: 1734).

But not all of the former desire to be independent. There are those who would reject independence in exchange for assistance or a “helping hand” (Simcock 2016: 1734).

No matter what the older Deafblind person’s view on independence is, most of them find it hard to accept the fact that as the loss of their sight and hearing increases with time, they will have to



become more and more dependent on others (Jaiswal et al. 2020: 4).

## **Abuse and Mistreatment**

Persons with disabilities are more likely to be exposed to abuse than their peers without disabilities, and this is of course the case for older persons with deafblindness. The sheer difficulty in communicating is often the reason individuals discriminate against them and for hearing and seeing members of family to take over the reins of the Deaf/Deafblind person's life. This history is the reason why today there are still Deaf and persons with deafblindness who mistrust hearing and seeing people, fearing that they want to exploit them. This is a gap that will take some time to bridge.

Unfortunately, it is still true that persons with deafblindness are deemed to be one of the most disadvantaged groups in society, which includes vulnerability to exploitation, abuse, and harm. These individuals are potentially at greater risk of all forms of abuse and those from minority ethnic groups face particular disadvantage (Simcock & Wittich 2019: 10). This showcases the importance of intersectional discrimination.



Increased vulnerability indicates loss of dignity, while equal treatment means that dignity is maintained (Simcock & Wittich 2019: 10). Within its *Principles for Older Persons*, the United Nations (1991) define dignity as associated with security and freedom from exploitation and abuse (§17) and fair treatment regardless of age, gender, racial or ethnic background, disability, or other status (§18).

Five articles, 13 to 17, of the CRPD (United Nations 2006) 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 of the integrity of the person. These are rights that all human being should enjoy but are often taken away from those in vulnerable positions. Most of all persons with disabilities, including older persons with deafblindness are the most disadvantaged.

The dignity of the person with deafblindness must be maintained. All the organisations and associations that work with persons with deafblindness maintain a *Code of Ethics* with a goal to preserve the dignity of the person with deafblindness.



Among the persons with deafblindness, older women with deafblindness are more likely to be subject to discrimination, 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.

Women with disabilities exposed to multiple discrimination are the subject of *Article 6* of CRPD (United Nations 2006), which obliges all State's Parties to "take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms" and to "take all appropriate measures to ensure the full development, advancement, and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention."

Vicky, a woman from Tenerife, Spain, who was born Deaf in a hearing family has multiple experiences with discrimination. She has two Deaf brothers, however; their life outcomes have turned out very differently. Her male siblings had access to higher education, married and had children, secured paid jobs, therefore; received a pension at retirement. However, Vicky received a basic education, struggled to find a paid job, and was





offered to be a volunteer, ironically, at the same company where her Deaf brother was employed. She was encouraged to stay at home, interacting very little with the outside world and became a primary carer for older family members. Today, Vicky, is a 66-year-old woman with deafblindness living alone in a rural area, who experiences financial struggles due to an insufficient pension. Additionally, she faces isolation and marginalisation due to a limited social support. Vicky experiences multiple and intersectional discrimination based on her disability, gender, and age<sup>xxxv</sup>.

A lack of adequate reporting mechanisms, access to justice, and appropriate support systems are the major barriers in this matter, which are vital to enforce accountability and avoid impunity. The underreporting of mistreatment and limited data on such a sensitive topic means that this issue remains invisibilised and rarely spoken about.

## **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 (Simcock and



Manthorpe 2021: 100). This is confirmed by Viola, an 89-year-old Deafblind person from Sweden, when after starting to lose her sight recalled that “(t)he foreman at work noticed that I was insecure and clumsy, and after a while I had to leave” (Göransson 2007: 144). Sometimes the person with deafblindness him/herself is the one giving up, as attested by (ZH), “Work, I can’t work, I’m Blind, Deaf, and cripple(d)... it’s very hard to participate. I used to but one by one I gave everything up... because of the loss of my hearing and the loss of my eyesight” (Jaiswal et al. 2020: 4).

Early retirement following the onset of deafblindness is common, especially for older individuals. Acquiring a second sensory impairment often means the termination of the employment of the person with deafblindness, which is especially expected for those over 55 years of age. 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 (World Federation of the Deafblind 2018: 21; Simcock & Wittich 2019: 6).

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. Because of this, within five years of retiring, one in four older persons “unretire”, that is, return to paid employment. This is mostly for financial reasons, but for some, the reason is enjoyment and job satisfaction that work provides. Unfortunately, staying in the workforce is virtually impossible for older persons with deafblindness (Simcock & Wittich 2019: 5).

Routine is sometimes a very important factor in a person’s life and losing that routine can lead into depression and mental deterioration. This is why many opt to re-enter the workforce after their initial retirement.

In the past, the vocation range for Deaf persons was rather restricted, mostly due to the then Deaf education system providing the Deaf with a limited, summary education. When such a person starts losing his/her vision, the easiest solution for the employer is to have him/her leave the job.

Inclusive schooling has enabled persons with disabilities to a greater variety of job opportunities, including jobs with university degrees. However, the problem for the employer now becomes adapting the workplace for a person with deafblindness, which means additional expenses.



Article 27 of CRPD (United Nations 2006), *Work and employment*, recognizes “the right of persons with disabilities to work on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive, and accessible to persons with disabilities.” It also prohibits “discrimination on the basis of disability with regard to all matters concerning all forms of employment” including “continuance of employment.” Thus, deafblindness (or any other disability) should not be a reason to let the employee off, as is often the case with persons with deafblindness.

## Poverty

Around the world, but especially in middle- and low-income countries, poverty is stressed as a major obstacle for persons with deafblindness. Respondents from Kenya flagged this matter and advocate for the importance of programmes which can enable Deafblind individuals to participate in the development of their society. This high need for social support is seen Uganda, too, as older individuals with deafblindness are neither benefiting from movement pensions nor from the National Social Security Fund (NSSF) which



supports older people after retirement. The reason is that due to traditional disability challenges, not many can participate in higher education and can therefore not enrol in formal employment and the social protection service available.

It should also be noted that in Uganda, most Deafblind persons are illiterate. Thus, a professional that indirectly supports persons with deafblindness, who completed the survey, stressed the need to prioritise the education needs, communication needs, and health care needs of persons with deafblindness for their meaningful participation in their society. A professional service provider that directly supports persons with deafblindness confirms a similar situation in Ethiopia. Persons with deafblindness don't receive required governmental services and the government doesn't get involved in the accessibility of education, medical service, and other service provisions for the Deafblind.

Two articles of CRPD (United Nations 2006) address this issue. Article 28 mention explicitly "the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing, and housing, and to the continuous improvement of living conditions." A key aspect is access to education, which has direct links to Article 24 since it



recognises “the right of persons with disabilities to education” and to “the full development of human potential”.

Moreover, some older persons with deafblindness engage in voluntary work, most often within local organisations of or for persons with deafblindness, although older persons with deafblindness are less likely to volunteer than their non-sensory impaired peers. But those who do have lower levels of depression compared to older persons with deafblindness are not engaged in such activity. This happens 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 (Simcock & Wittich 2019: 7).

## **Creativity and Leisure**

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, usually organised by associations of persons with deafblindness or by organisations for persons with deafblindness, attract some individuals who find



fulfilment in something they can do with their own hands. Enrolling in new activities, especially creative ones, can prevent passiveness and give the person new opportunities to fill his/her schedule.

Within the local associations of persons with deafblindness in Croatia, for instance, persons with deafblindness can engage in a painting, sculpture/ceramics, and applied arts workshop; a theatrical workshop; a tailoring workshop, creating costumes for theatrical representations; even a cooking workshop with a small contest for the best cook. These workshops provide them with a chance to travel, visit new cities and countries, and meet new people.

Momi, a 76-year-old man with deafblindness from Milan, Italy, is a talented craftsman who uses wicker and clothes pegs to build different objects such as a chess board, baskets and vases. He has been carrying out this hobby independently for many years and is self-taught. Keen on passing on his expertise, after his retirement, Momi completed training at a national association of persons with deafblindness to become a formal instructor. He teaches younger persons with disabilities to work with wicker in weekly workshops organised by *La Lega del Filo d'Oro*, the Italian organisation engaged in assistance, education, rehabilitation,



recovery, and enhancement of residual potential and support for the search for the greatest possible autonomy of Deafblind and multi-psycho-sensory impaired persons. Additionally, he taught Italian Sign Language (LSI) to a group of young volunteers. Today, he is a handicraft teacher for persons with disabilities and loves sharing his passion with others. This hobby has been a welcome diversion during the COVID pandemic and has made him feel active and useful<sup>xxxvi</sup>.

Depending on the residual vision and hearing, as well as personal affinities, individuals can choose whether to engage in workshops and which ones. Individuals who have never thought that they could act or paint or sculpt or model can find their hidden talents and, what is even more important, joy in what they are creating. Viola, an 89-year-old Deafblind person from Sweden, finds working with ceramics relaxing and calming (Göransson 2007: 144). Bengtsson & Lagerdahl (1988: 106) also mention how in Halmstad, a little town on the Swedish west coast, pottery groups are organised both for the Blind and persons with deafblindness. Unfortunately, for persons with deafblindness (and especially those who are older) living outside major urban centres such workshops are usually out of reach. The situation is even worse in lower-income states, where there is rarely 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 that their lives have a meaning.

Fifty-six respondents to the survey have answered the question whether their organisation organises regular creative workshops for persons with deafblindness and what kind of workshops are provided. Of all the answers, 21 were positive, 28 were negative, and 7 were unsure (**Figure 8**).



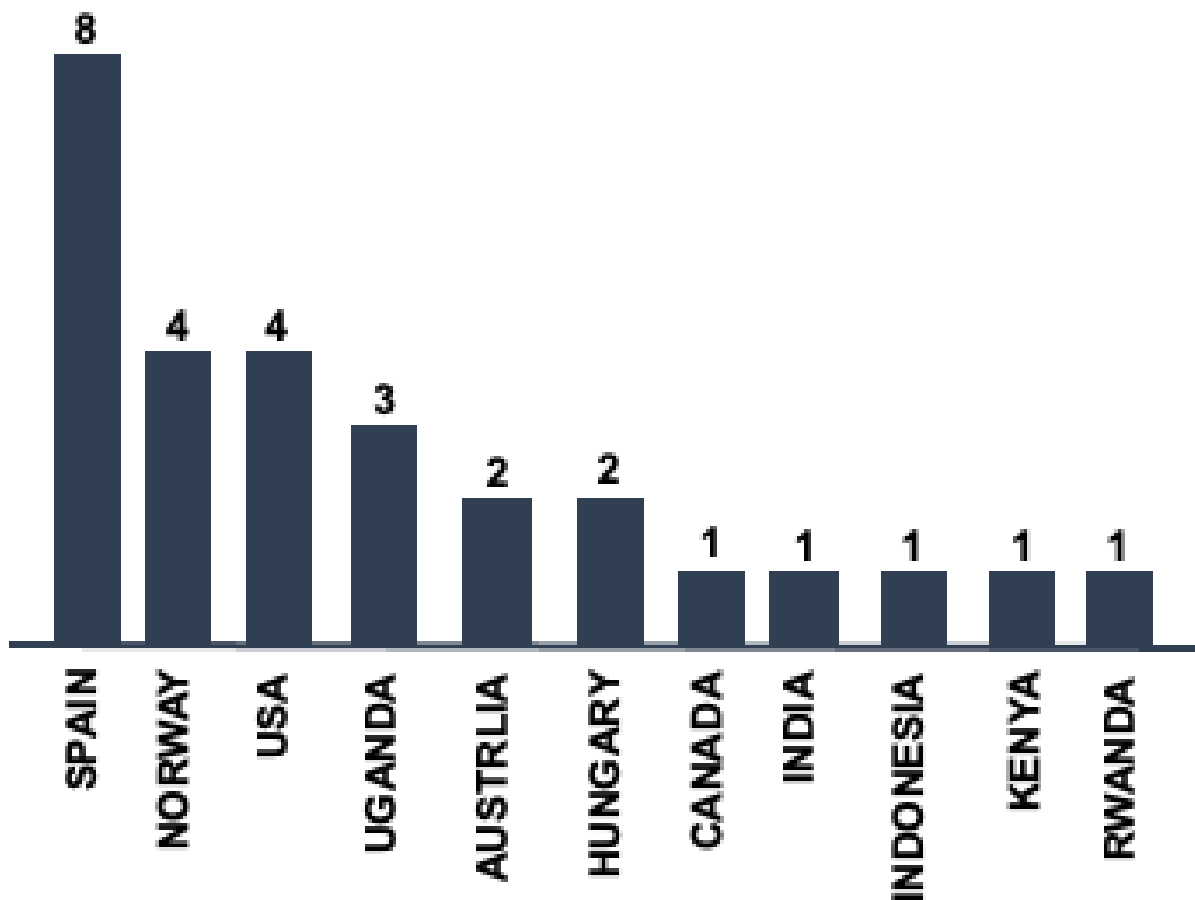
***Figure 8 - Regular Creative Workshops for Persons with Deafblindness.***

Again, there were contradictory answers coming from the same country. This time from Canada, India, Spain, Uganda, and the USA.

Respondents from India, Spain, and the USA answered that they don't know if there are regular creative workshops for persons with deafblindness organised.



The negative answers to this question came from Australia (2), Canada (1), Hungary (2), India (1), Indonesia (1), Kenya (1), Norway (4), Rwanda (1), Spain (8), Uganda (3), and the USA (4) (**Figure 9**).

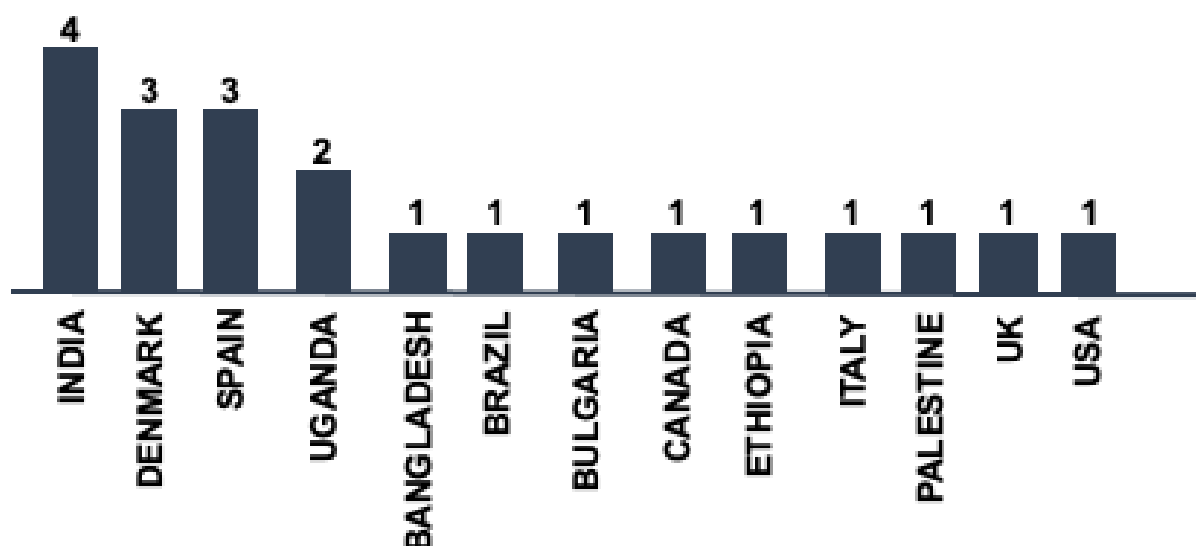


***Figure 9 - No Regular Creative Workshops for Persons with Deafblindness Organised by Country.***

Affirmative answers, a minority here, arrived from Bangladesh (1), Brazil (1), Bulgaria (1), Canada (1), Denmark (3), Ethiopia (1), India (4), Italy (1),



Palestine (1), Spain (3), Uganda (2), the UK (1), and the USA (1) (**Figure 10**).



***Figure 10 - Regular Creative Workshops for Persons with Deafblindness Organised by Country.***

Many creativity workshops are mentioned by respondents, including arts and crafts, painting, pencil drawing, colouring, theatre groups, choirs, singing, art therapy, making symbolic items typical of the country, applied art, folk and modern dances, pantomime, and virtual painting classes. Sports and motoric activities include sports competitions, different indoor games, gymnastics, and gentle gymnastics. Practical and occupational workshops include baking, wicker crafts, making objects with clothes pegs, vegetable gardening, cooking, and sewing. For example, in the case of

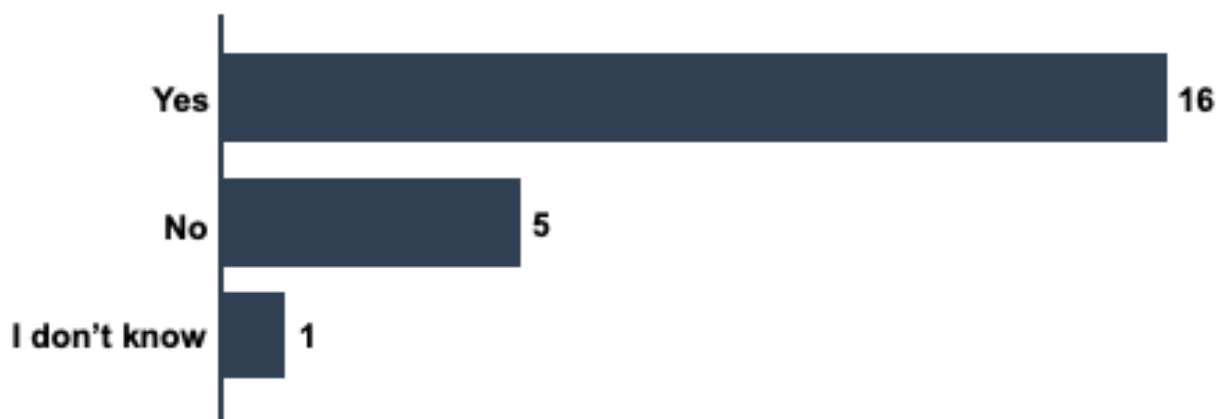


the organisation Sense, they run inclusive arts programmes<sup>xxxvii</sup>.

Other activities concern the autonomy of persons with deafblindness, like communication activities (Sign Language, Tactile Sign Language, Haptic Communication, etc.); SSP training; sensory workshops; recognition, awareness, and meeting programs in which the effects of deafblindness, levels, generalities, etc. are discussed; music therapy; and wellness and experience groups.

In the case of Denmark, workshops are organised only once a year.

As far as attendance to those workshops is concerned, 16 respondents to the survey answered positively, 5 answered negatively, and 1 answered “I don’t know” (**Figure 11**).



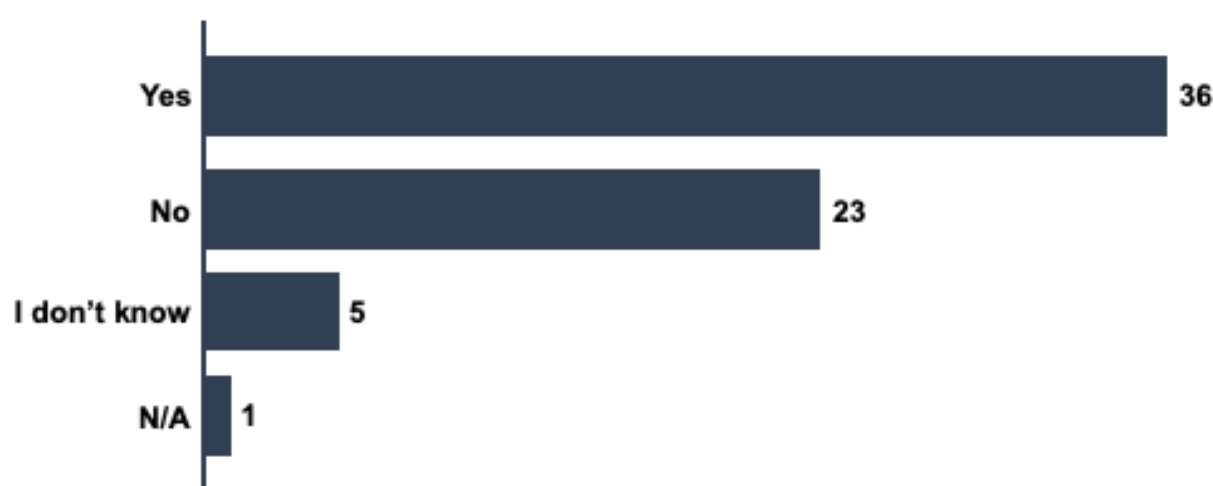
**Figure 11 - Older Persons with Deafblindness Attending Regular Creative Workshops.**



Negative answers came from India (3 respondents), Palestine (1 respondent), and Spain (1 respondent). One respondent from India answered that he/she does not know.

## Participation in Activities, Projects, and Programmes

Sixty-five respondents to the survey have answered to the question whether their organisation has done any work/project/programme focused on older persons with deafblindness. There were 36 positive answers, 23 negative ones, 5 answered “I don’t know,” and one person answered “N/A” (**Figure 12**).

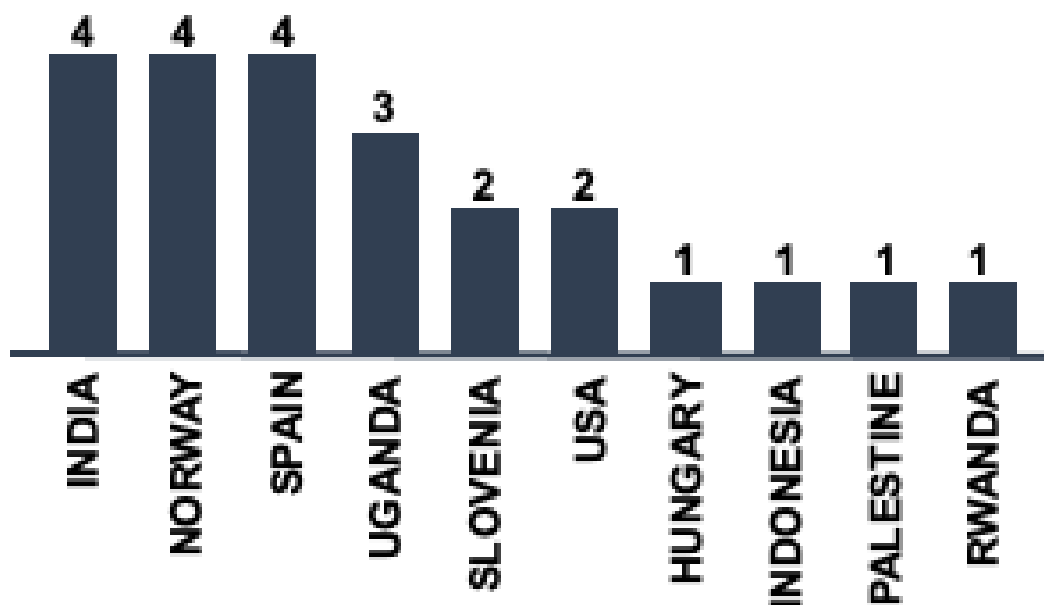


**Figure 12 - Organisations with Works/Projects/Programmes for Older Persons with Deafblindness.**



This is another question where different respondents from the same country gave opposite answers, probably as a result of difficulties in accessing information or, maybe, of individuals belonging to different organisations or regions. We can see such behaviour in answers from India, Spain, Uganda, and the USA.

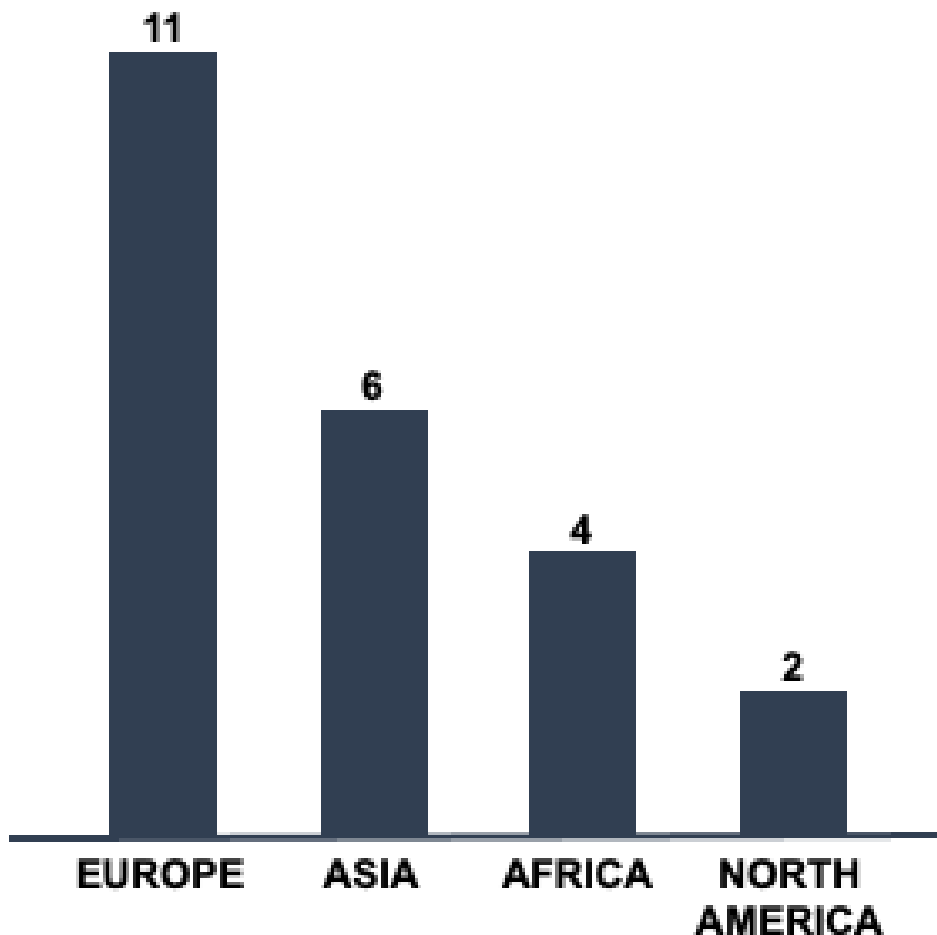
Negative answers have come from ten countries, Hungary (1), India (4), Indonesia (1), Norway (4), Palestine (1), Rwanda (1), Slovenia (2), Spain (4), Uganda (3) and USA (2) (**Figure 13**). However, when considering these numbers, take into consideration the information from the previous paragraph.



**Figure 13 - Organisations with no Works/Projects/Programmes for Older Persons with Deafblindness by Country.**



Negative answers came from all the continents apart from South America (which is represented by a single country, Brazil, answering, “I don’t know”). Negative responses included, 4 from Africa, 6 from Asia, 11 from Europe, and 2 from North America (Figure 14).



***Figure 14 - Organisations with no Works/Projects/Programmes for Older Persons with Deafblindness by Continent.***



Work, projects and programmes focused on older persons with deafblindness carried out by various organisations may roughly be divided in three groups: 1.) leisure, 2.) training, and 3.) political activity and material help.

In the leisure group, the most frequent activities are excursions and specialised Deafblind camps and retreats. The latter offer different training options for older persons with deafblindness. Some organisations also offer intergenerational programmes, in which persons with deafblindness of all ages can meet, socialise, and exchange experiences.

The types of training offered to older persons with deafblindness are of a different nature than those offered to younger persons with deafblindness. These trainings are more socially oriented, such as preparation 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 to older persons with deafblindness and to the society. Organisations assist persons with deafblindness in legal matters, campaign to improve remote communication for emergency and assistance calls and help them break isolation and loneliness (Deafblind





Information Australia. 2023a; 2023b). They carry out personalised projects aimed at promoting social participation; inclusion through creative, social, religious and cultural activities; educating older persons with deafblindness to be assertive in claiming their rights; and making them into active members of the Deafblind community.

Outwards political activities include spreading awareness; disseminating and communicating information related to deafblindness; government support for persons with deafblindness; and workshops on adapted environments, on sensory loss, and on communication possibilities.

The National Association of persons with deafblindness in Bulgaria (NADbBg) implemented a project (BG05M9OP001-2.011-0013-C02)<sup>xxxviii</sup>, which with the help of relevant activities, works to improve the conditions for active social inclusion of the members of the NADbBg. This is done through support for the existing and development of new services for persons with disabilities within the organisation.

Helping older Deafblind persons with money, goods and necessities is often an activity restricted to low-income countries.

Besides all those activities, these organisations are involved in somewhat more “regular” activities, like



advocating for better, cheaper, and free access to interpreter-guides/Deafblind interpreters and technical and other assistive devices. Many of these organizations are also involved in campaigning for volunteers to work with older persons with deafblindness.

### **Recreation and Participation in Social Life**

One question of the survey dealt with possible regular social events for persons with deafblindness organised by their organisation (i.e., gatherings, excursions, visits to museums, etc.). There were 54 positive responses and 7 negative ones (**Figure 15**).



***Figure 15 - Regular Social Events for Persons with Deafblindness.***

Negative responses came from Australia (1), Canada (1), India (1), Kenya (1), Spain (2) and the



USA (1). Respondents from all other countries (except for Kenya) had positive answers.

Answers to the survey question concerning regular social events partly overlap with those on works, projects, and programmes, as they both gather information on leisure activities. Recurrent answers include multi-day excursions, social retreats, picnics, summer trips and day trips.

Celebrations are also organised for days and weeks related to deafblindness, Sign Language and Helen Keller Commemoration Day, well as other holidays and local fundraising activities. Organisations also organise parties like foundation anniversaries and include Deafblind individuals in these events.

Simple gathering and socialising events, or club events with no specific programme, provide regular meetups for persons with deafblindness, and are also mentioned.

Respondents also mentioned workshops for those with deafblindness, theatrical and applied art workshops are explicitly cited, as well as thematic meetings. Amateur art activities and sport activities are also organised.

Visits are organised to different places including museums, galleries, cultural events, shopping



malls, sensory gardens, zoological gardens, and more.

Then there are more “serious” events, too, such as local experience groups, conferences or training events, but can still be considered a social outlet.

A Deafblind person from Spain has mentioned the impact of brotherhood meals (“*comidas de hermandad*”). During these meals, persons with deafblindness and their interpreter-guides/Deafblind interpreters come together towards the end of the year, coinciding with the Christmas period, to share a meal and enjoy a social gathering organised by their local Deafblind association.

A professional service provider from Canada who directly supports persons with deafblindness shared a suggestion in relation to social activities, “We encourage our clients to plan/organise these activities for themselves and their peers and provide intervention and literacy support in the planning process.” In this way, persons with deafblindness are empowered to take an active role in the planning and organising stages of socialising events by becoming subjects and not just mere objects of the event.

When it comes to older Deafblind persons attending those regular social events, 42



respondents answered “yes”, and 10 respondents answered “no” to regular attendance (**Figure 16**).



***Figure 16 - Older Persons with Deafblindness Attending Regular Social Events.***

Negative answers arrived from Uganda (5), India (4) and Spain (1).

## **Possible Solutions**

As previously mentioned, deafblindness and persons with deafblindness are a diverse group, and so are the barriers and challenges they must overcome in their everyday life. However, some possible solutions are discussed in the section below, which have been extracted from existing literature and from responses to the online survey.

A starting point for further discussion on solutions can include the following questions posed by Westerholm (2012: 8):



- How is Deafblind interpretation seen from the perspective of persons with deafblindness?
- How can persons with deafblindness achieve full participation, equality, independence, and empowerment in society?
- What do the authorities prioritise regarding the activities persons with deafblindness get the opportunity to participate in?

Matthews (1988a: 33) asks whether society is willing to do everything we can to enhance the life of Deafblind persons. This might include to try and maximise the use of remaining vision and hearing, improve the possibilities for communication, introduce new methods of communication, modify the environment, improve lighting, reduce noise, increase contrast, make adaptations, provide aids, teach orientation, introduce use of tactile clues, help with mobility, provide a guide, arrange self-help groups, provide transport, organise visitors, support a family with a Deafblind member, and train staff, amongst others.

We must never forget that every person with deafblindness is an individual with specific needs,



residual sight and hearing, skills, methods of communication, etc. This means that the support provided must be tailored to the individual in question, based on the individual's situation and condition. Because of this, it is important to identify where in the adjustment process he/she is, their current network (both the personal and the professional ones), and to chart progress in order to provide good support. This requires great flexibility and specific competence within the fields of communication and interaction (Göransson 2007: 156).

Göransson (2007: 158) posits four areas particularly important for the development of care for older persons with deafblindness who use Sign Language:





Establish  
specific  
housing

Develop the  
home care  
service

Establish a  
post for a  
regional  
seniors' guide

Develop the  
choice of  
activities and  
improving  
their  
accessibility

## Awareness and Education

Göransson (2007: 161–162) suggests that the specific needs of both persons who have a combined visual and hearing impairment as a consequence of ageing, and persons who have lived with deafblindness over time are probably best met in a specialised Deafblind Team. This team is a group of experts in the field who can look at deafblindness as a whole, not as separate blindness and deafness, and thus suggest or provide appropriate measures to be taken. This support needs to range from general public health information focused on what it means to live with a combined visual and hearing impairment when you get older, to more Deafblind specific support. A public health and care perspective about the impairment of deafblindness must be developed, with a person-centred approach which can help overcome challenges existing attitudinal, environmental, and institutional barriers.





The team's role in relation to older persons with deafblindness should primarily be consultative towards the individual's network, and above all, to spread specific CRPD-compliant and evidence-based knowledge about the impairment, in order to strengthen the networks around the individual. A valuable part of rehabilitation for older persons with deafblindness is to discuss the impairment in groups together with other people and to learn new strategies to manage their everyday life better. At the core of any solution for the status of older persons with deafblindness, and Deafblind persons in general, lies the dissemination of knowledge about deafblindness. This kind of education is needed for everybody, including Deafblind persons themselves (Olesen 2012: 15). After accepting one's condition as deafblindness, one should learn what it is exactly, what rights one is entitled to, and what options one has for leading a fulfilling life.

An important part of the education of a newly diagnosed Deafblind person is being able to discuss things with others who "know what it's like" or have the opportunity to meet with other Deafblind persons and have a good time with them (Göransson 2007: 159).

A second group that should be educated on deafblindness are those in the immediate environment of persons with deafblindness. As is



true for Deafblind persons themselves, family often denies or ignores the disability and looks for solutions outside of the Deafblind community. This is often the case with parents of young Deafblind persons. In the case of older persons with deafblindness, their entire ecosystem must accept that the person's difficulties are not just the consequence of ageing, but that there are other factors included, factors that can and must be acknowledged both by persons with deafblindness, his/her family and other key actors.

The third group that should be educated on deafblindness are the professionals, frontline workers, and service providers with whom persons with deafblindness often come into contact. These includes not only health personnel and social workers, but also lawyers, police constables, and others with whom Deafblind persons might regularly interact. "The primary goal is to educate experts and service providers about the specifics of deafblindness, access to persons with deafblindness, and standardise the attendance of training in specific forms of communication ... for all professions that potentially come into contact with persons with deafblindness at the national level" (Bojtor 2021: 9). The professionals' awareness and knowledge of deafblindness is of greatest importance to make them understand



persons with deafblindness (Göransson 2007: 155).

What would be even more important for this third group is to learn basic ways to communicate with a Deafblind person, including a new set of manners. For a Deafblind person, it is extremely important to be able to communicate with the professionals around them, including medical staff, carers, assistants, or staff at a residential home, because without that, there cannot be a proper quality of life and safe, dignified ageing (Göransson 2007: 155). Those professionals should learn to address the person in question, not the interpreter-guide/Deafblind interpreter and should accept the fact that Deafblind persons might need more time to process information than a hearing and seeing person. This means that those professionals must learn to have patience and resources when addressing a person with deafblindness.

Unfortunately, there are still situations where it is exactly that patience that is lacking. In many cases, the interpreter-guide/Deafblind interpreter might find themselves in the position to advocate for the rights of persons with deafblindness they are interpreting for if the proper care is not being provided.

As Göransson argues, rehabilitation staff must have the competence to communicate with a



Deafblind person using Sign Language and be able to use it both visually and tactually. This is essential to give a Deafblind person and Sign Language user emotional support in the form of a conversation partner, however; it is often unrealistic to demand of the local and regional authorities to have this competence (2007: 156).

Mortensen (1988: 109) perceives correctly that providing actual training and education in deafblindness is practically impossible for the larger part of professionals who come into direct contact with Deafblind persons, because the professionals are too many and too scattered geographically, and Deafblind persons constitute too small a part of their work. Therefore, a specific education would be too expensive for their employers.

As a solution, he proposes information with an aim to:

1. Raise awareness
2. Provide background information
3. Provide practical skills



4. Make changes in the approach to working with Deafblind persons
5. Show how to access specialists, and
6. Refrain from requiring the receiver of the education to be a specialist

This can be carried out in the form of information handouts containing simple tips and approaches, as well as information on where to turn with questions when working with individuals with deafblindness (Göransson 2007: 160).

In achieving the goal of providing older persons with deafblindness with a good quality of life, the co-operation between different actors, especially between the local and the regional authorities, and the co-ordination of the work they offer, is essential (Göransson 2007: 156, 161). There is a need to create a network of contact persons among the local authorities who know where to turn if an older Deafblind person needs visual or hearing aids (Göransson 2007: 160).

Finally, the public at large should also know about deafblindness and the Deafblind community. For instance, the red and white cane's colours, a universal symbol for deafblindness<sup>xxxix</sup>, loses this function if others do not know what it stands for. Some sporadic actions with limited reach may



inform several persons, but the lack of knowledge in general still prevails. It would be useful for education about those topics to start at a young age. Another suggestion is for Sign Language to become a compulsory subject so that every single person should learn the basics of the local Sign Language and even Braille, not only to communicate with persons with disabilities, but as a useful skill to have and an alternative mode of communication in case needed.

The need for education, learning, and training for professionals with whom Deafblind persons come into contact, but also of the general public on deafblindness, is mentioned in several papers, each one presenting its own method of approach to this topic, often in the author's national context. Balder (2008) wrote about an international awareness campaign, Bengtsson and Lagerdahl (2008) about the Home-Instructors programme in Sweden, Mortensen (2008) about training in Denmark, and Teurlings (2008a; 2008b) about trainings in the Netherlands.

One of the prerogatives to achieve this is moving away from a strictly medical, numerical definition of deafblindness, which is still present around the world. Instead, it is beneficial to move into functional definition that addresses and understands the sensory needs of these



individuals (Balder 1988: 101). Another option is to adopt the Nordic definition (quoted at the beginning of this report), and a human rights and CRPD-compliant approach. This will increase the importance of the needs of those with deafblindness and normalise the need of interpreter-guides/Deafblind interpreters and appropriate visual and hearing related rehabilitation. Older care must be made accessible to older persons with deafblindness, meaning that they should be able to participate in and influence the decisions that are made, but also that the other side maintains a respectful and professional attitude (Göransson 2007: 155).

Many respondents to the survey stress the need to raise awareness about deafblindness and the needs of persons with deafblindness, because “the community knows nothing about deafblindness,” and “the largest barrier is the behaviour and perceptions of persons WITHOUT disabilities, whose behaviour is often influenced by the presence of stigma and prejudice,” because what is needed is an understanding of the condition among the public at large. One respondent has found a succinct way of putting it, by suggesting we should focus on “normalising the presence of persons with deafblindness in society. Another proposed that education begins in schools and



institutions and “preparing society by explaining to them (what deafblindness is) and making them (see for themselves what it is like to be Deafblind, and) experiment (with) how they would act if they were in that place.” Similar campaigns in Croatia, titled »*Budi ja*« (“*Be me*”), tends to attract a large number of individuals who are curious and willing to test what it feels like to be a Deafblind person for several minutes. The public education on deafblindness should be held in medical and healthcare settings, but also among older persons with deafblindness, who should learn about their condition and their rights, as well as how to use the assistive devices and technology.

A professional that directly support persons with deafblindness from Spain responded, “There is a great need to sensitise and train families of Deafblind persons as a priority and to generate, at the governmental level, a network of services and adequate personal and technological support resources that are easily accessible for Deafblind persons and their family.”

A person with deafblindness from Kenya deemed that older persons with deafblindness need persons who can understand them emotionally.





## **Mobility**

Mobility, another barrier in the everyday life of persons with deafblindness, becomes even more challenging for older persons with deafblindness. For some, having an interpreter-guide/Deafblind interpreter is not enough, because their physical capabilities may impede walking or using public transportation. Here an accessible and adequate transport service should come into action, a service that can be accessed by persons with deafblindness that could help them get out of their homes, socialise, and participate in social life on equal basis to others. The person who is providing transport must be able to communicate with his/her passengers as well.

## **Activities**

Another matter mentioned in responses is organising various activities that should be free for persons with deafblindness (or at least only with a low, symbolic fee to be paid). These activities may include Deafblind camps, regular community get-togethers, activities in the environment. These activities should be available at the national level, adapted to socio-cultural and leisure activities, and engage persons with deafblindness in an active social life (culture, science, art, sports, etc.). This can be done through the help of volunteers, social



workers, family members of persons with deafblindness, cultural workers, and other persons. There is even a suggestion to organise activities that would include both persons with deafblindness with seeing and hearing persons. One respondent mentioned the possibility to engage with Deafblind persons through local organisations and programmes of specialised foundations, giving an example of local programmes for pensioners and older people. These programmes may include sports events, handicrafts, gardening, and excursion programs. It should be noted that currently, there is no such thing as specialised programmes for older Deafblind persons.

### **Human and Technology Facilitators**

A lot of respondents to the survey mention both human and technology facilitators, like interpreter-guides/Deafblind interpreters, intervenors, contact persons, co-navigators, mediators, personal and personalised assistance, and encourage extending the available interpreting hours per month to satisfy the needs of persons with deafblindness, who need an interpreter-guide/Deafblind interpreter every day. Additionally, there is a need for assistive devices, increased digital accessibility, technical resources, free access to technology, and products adapted to and designed for persons



with deafblindness that display information in multiple accessible formats.

## **Legal Recognition of Deafblindness**

A professional service provider that directly supports persons with deafblindness from India remarks that funding organisations should increase their support towards NGOs, including organisations of and for persons with deafblindness. However, for them to do so, NGOs must make their needs and goals clear to funding parties. Oftentimes, it starts with raising awareness about their existence.

Better education and employment opportunities, centres for older persons with deafblindness with staff knowledgeable of communication with Deafblind persons, fighting neglect and poverty among persons with deafblindness, and the improvement of integration and participation of older persons with deafblindness in society were also mentioned in some responses to the survey question.

Most of what has been mentioned is connected to government activities, with the inclusion of persons with deafblindness as a unique disability in national development programmes for better planning and budgeting. Many governments declaratively support the Deafblind community. However, as a



Deafblind person from Spain pointed out, “It is difficult since everything that is not fashionable and the difficult to sell politically speaking seems not to exist. We live in a country where laws are passed for illnesses like Amyotrophic Lateral Sclerosis (ALS), and then they are pushed aside and not enforced. I don’t feel that old (the respondent is between 50 and 65 years old), I am very bored as to how we move forward and progress.”

A respondent with deafblindness from Spain urges for the creation of the national organisation of older Deafblind persons.

### **Health and Other Professionals**

One of the answers to the survey included a proposition to have “a separate health care service unit for Deafblind persons as this may tailor to (a) good care services provision to persons with deafblindness.” However, considering the relatively small number of persons with deafblindness in any given country and their dispersion on the given country’s territory, organising such a service may present a problem. If there would be a single central Deafblind care system, some persons with deafblindness would have to travel a long way to reach it, and if there would be such care systems all over the country, many of them would service



only a couple of patients, and that would be financially demanding.

A professional that directly support persons with deafblindness from Spain responded, “In recent years, an increase in (the number of) older persons with deafblindness have been detected, so it is important to continue to have specialised professionals and technical means, as well, as to ensure that their communication needs are met.”

The answer of a Deafblind person from Bangladesh is worth quoting in its entirety:



“What we need the most to improve the integration and participation of older persons with deafblindness in society is respect, compassion, and determination of improving their living situation and their inclusion in every work in the society. Helping or taking care of a family member with deafblindness should be done out of love and respect not because of obligation or necessity. We need to help the persons other than the persons with deafblindness to feel the pain and problems of the persons with de(a)blindness. The persons without any disabilities cannot understand or will not face



problems of those with deafblindness and disabilities. They need to be grateful and help the persons with deafblindness out of that gratefulness and accept them as a human being and help them to ensure their rights. The inclusion of both persons with and without disabilities is the way of improving the integration and participation of older persons with deafblindness in society.”

After we have gone through proposed solutions to the barriers and obstacles older persons with deafblindness meet in their life, we can turn our attention to some solutions that have been carried out in practice.

### **Examples of Best Practices from Survey Respondents**

Simcock et al. (2022a) argues that focusing one’s research on vulnerability and unfavourable outcomes is the source of maintaining negative stereotypes of persons with deafblindness as a passive, dependent population. This gives rise to misunderstanding of the impairment, to perceptions of incapability and neglect of the agency, to downplaying the creativity and ability of



persons with deafblindness, and eventually results in overprotection and control. These types of discourses must be avoided. On the other hand, in a salutogenetic approach (or salutogenesis)<sup>xi</sup>, consideration is given to the coping and managing strategies of older persons with deafblindness, moving the focus from the causes of the condition to the factors that support and promote health, and adopting a positive perspective by focusing on factors that protect and promote wellbeing. The results obtained by the respondents can be grouped in three categories: 1.) Deafblind persons taking action to protect self, 1.) their psychological coping strategies, and 3.) accessing and using care and support.

The respondents protected themselves in several distinct ways. They did this by constantly and continually educating the persons surrounding them about deafblindness and the needs of Deafblind persons and doing so repeatedly. Moreover, the respondents managed risks by identifying the potential risks, the consideration of the likelihood of harm, and calculating whether taking the risk is worth it. They also maintained human connection, both directly and through mainstream technology, thus providing access to information about the world and reducing isolation and felt loneliness. Additionally, the respondents



protected themselves by using reserves, such as prior learning and experience, residual senses, and activities that develop physical strength, in order to withstand challenge and thus reduce felt vulnerability. Further responses to risk include self-care by keeping themselves busy, (e.g., engaging in hobbies and sporting activities, gardening, and by taking time out.) They also maintained control by taking things step-by-step, making and acting upon their own decisions, using care and support in their own way, engaging in preparation and planning, and by demonstrating themselves as capable in providing good services at work. These individuals furthered self-care by identifying as accomplished artists and musicians, travelling independently, being economically “savvy,” and chairing charitable groups, thus demonstrating that persons with deafblindness are not only recipients of care, but also care providers.

The psychological coping strategies of the participants include accepting things that cannot be changed, enabling these individuals to cope with different aspects of their lives as persons with deafblindness, and changing their own attitudes and way of thinking. This diminished their felt vulnerability in particular situations because of tenacity and resilience, not because they believe there to be no alternative or because of a felt





sense of obligation. Instead, these individuals represented an ability to withstand challenge.

Access to care and support can include accepting both formal and informal support. This may include aids, specialists, and mainstream equipment and technology that establishes the attributes of effective and valued support. Deafblind individuals accepted support as effective when the individual is understood, maintains control, and expresses what desired future support should look like.

Positive support is routinely relationship-based and flexible.

## **Best Practices by Geographical Location**

The following paragraphs include several best practices from literature and from survey respondents and serve as examples of best practices from around the world.



### **Sweden**

In Sweden, there is a service called Home-Instructors. One of their tasks is to train persons with deafblindness in activities of daily living, like mealtime, preparation of food, hygiene, how to clean up, dressing, how to take care of one's clothes, mobility, how to go to the nearby shop,



and communication. The aim of that service is that persons with deafblindness should be able to stay in their usual environment and maintain their social relations. Home-Instructors offer support and information to persons with deafblindness in their own homes. They help persons with deafblindness to become more active and thus break through the barriers of isolation. The service is a good investment for society, because Home-Instructors teach many persons with deafblindness to take care of themselves, in a more independent way (Bengtsson & Lagerdahl 1988). A similar service has been carried out as a project in Croatia with older persons with deafblindness becoming more active in their home life.

## **Denmark**

In Denmark, every person with deafblindness over 18 years of age has the right to a “contact person,” employed by the Municipality, whose purpose is to avoid the person with deafblindness from becoming isolated, by helping the person with deafblindness to live a fulfilling life in spite of the communication barriers and the need of support. This contact person visits and communicates with the person with deafblindness, provides company, and gives information about daily life to a person that might not be able to stay updated with the



news by reading books, newspapers, or magazines; watching television; or listening to the radio. This support person represents the link to the surroundings, helps with interpreting letters, information, bills, and other correspondence. These individuals also accompany the person with deafblindness in everyday outside activities, as well as accompanies and interpreters for him/her on official occasions, for example, medical appointments or court hearing. The contact persons are selected by a consultant with deafblindness, who ensures the contact person is a right fit for the person with deafblindness, and the person with deafblindness must approve of the contact person, so they are employed on a one-to-one basis. The same person with deafblindness is always paired with the same contact person. This one-to-one arrangement can contribute to the increase of trust between the person with deafblindness and the contact person, which is a very important thing when it comes to older persons with deafblindness. (Brøgger 1988).

Answers in the survey from persons with deafblindness from Denmark include, “In our experience group, we use “teleloops”<sup>xi</sup> and interpreters, but you have to speak one at a time, so that everyone can follow along.” Another respondent said, “The older (groups) like the



telephone or mailing friends. And exchange of experience (in) groups. Two clubs with different events and trips.” Another person from Denmark also mentions “experience groups.”



### Norway

All four persons with deafblindness from Norway refer to “social gatherings and tours.”



### UK

A list of resources was shared by respondents to the survey. For example, a professional that indirectly supports persons with deafblindness from UK directed us to the Sense blog that shares stories from Deafblind persons of all ages<sup>xlii</sup>.



### Italy

In Milan, Italy, the branch of the Association *Lega del Filo d’Oro*, serves as an organisation engaged in assistance, education, rehabilitation, recovery, and enhancement of the residual potentials and support. The goal is to achieve the greatest possible autonomy of Deafblind and multi-psycho-sensory impaired persons and offer the service of a residential unit located in the city centre. Founded in 1996, it is the first service of its kind for



older persons with deafblindness in Italy. It provides support and a social-education service within a community environment. The aim is to respond to persons with deafblindness needs by making it possible for him/her to express his/her character and respecting his/her way of life and background, and to guarantee a good quality of life, as well as quality assistance. This allows its clients to make significant experiences and be integrated in the social context (Acerbi et al. 1988: 39).

A professional service provider that directly supports persons with deafblindness from Italy responded to the survey by saying, “An emerging theme, also present in the *Lega del Filo d’Oro’s* Three-Year Improvement Plan, is that of persons with deafblindness or multisensory impairments entering old age: we are observing what needs they have, (and) how they would like to spend their day, but also how *Lega del Filo d’Oro* staff relate(s) to older users in order to offer services increasingly appropriate to their needs. In addition, through a user severity survey conducted every two years, we monitor how the health of older users, and their disability evolves in order to better respond to their needs and to design new services.” In Spain, for example, there is a committee on older persons in the associative movement of FASOCIDE



(Federation of Associations of Deafblind People of Spain), which is an example of a good practice on how Deafblind associations can integrate the priorities of older persons within their agenda.

A professional service provider that directly supports persons with deafblindness from Italy shares an example of a good practice as “individual programmes for older persons with deafblindness that are carried out on the territory.”



## Spain

As most respondents to the survey fell within the Spanish context, most answers came from that country. The mentioned organisations include ASOCIDE (the Spanish Association of Deafblind Persons), APASCIDE (the Spanish Association of Family Members of Deafblind Persons), and ONCE (the Spanish National Organisation of the Blind) as drivers of good practices. Respondents highlight the importance of encouraging relationships between people in similar situations as well as the organisation of lectures on deafblindness and volunteering opportunities.

A professional service provider that directly supports persons with deafblindness underlines the role of “communicative mediators” in Spain, who play a role in communication. One respondent



stated, “Support mechanisms both in-homes and at nursing homes, which is provided to Deafblind persons through communicative mediators alleviate situations of lack of communication, favouring contact and communicative relationship with the environment, access to their close environment, and transmission of information from the environment.”



## **Bulgaria**

A person with deafblindness, who at the same time is a professional service provider that directly supports persons with deafblindness from Bulgaria answered, “Communicating and living together with others in similar situations, makes persons with deafblindness feel safer, which leads to increased self-confidence of the individual.”



## **Russia**

A family member of a person with deafblindness in Russia shared other examples of organisations that provide support, “D.N. Mamin-Sibiryak Sverdlovsk Regional Special Library for the Blind and Visually Impaired in Yekaterinburg, Sverdlovsk Oblast ((an organisation that) work(s) with older



blind (individuals), visually impaired persons, and persons with deafblindness).” A respondent with deafblindness from Russia wrote, “There (are) already few assisted living homes for Deafblind persons (including older ones) in Russia. Older persons also willingly participate in festivals, creative and sport contests, excursions, and other activities and meetings offered by local communities or regional and federal organisations for persons with deafblindness. In addition, many of us maintain connections in the midst of our (organisational participation) through social networks and messengers.”

A volunteer of the foundation for the support of persons with deafblindness who also conducts scientific studies concerning Deafblind persons and older persons with deafblindness carries out rehabilitation activities that highlight the importance of publishing best practices and its wide dissemination to the public.

## **Hungary**

A relatively new initiative was shared by a 63-year-old person with deafblindness from Hungary who often uses a free service that produces text descriptions of videos for visually impaired and Deafblind persons, called Video for





Blind<sup>xliii</sup>. The system works so that the video stops at the end of each scene and then persons with deafblindness can read the descriptions of the scenes in the video using a Braille display. Many of the descriptions include transcriptions of the actors' speech. In this way, Deafblind persons can read what the actors are saying and what is shown in the pictures using a Braille display. Then, they can access the content of the videos without any barriers. The Foundation's website currently contains 400 video descriptions, 100 of which are available in English. In the future, the Foundation plans to make these descriptions available in even more languages. The importance of this initiative lies in the fact that nowadays, the most up-to-date information is often available through videos.



## Canada

From Canada, several different answers were received.

A person with deafblindness wrote, "Sadly, no small groups spring up (for) a person who is Deafblind. (Arranging an) event without ways to communicate with each other, that is rare. I would not know where an event was happening, (and), mostly by accident, I learn about it. Also, there should be more notice given of an event, because I



would have to try and arrange for help, transportation, and communication help.”

A service provider for persons who are Deafblind as well as persons who are Deaf, hard of hearing, and non-verbal with a developmental disability from Canada responded, “InterRAI Community Health Assessment Deafblind Supplement, a tool developed to assess persons with deafblindness or dual sensory loss, may be introduced in home care and long-term care homes. Terminology (for) older adults with dual sensory loss or older adults experiencing age-related dual sensory loss should be differentiated to be inclusive.”

Another respondent from a Canadian government funded organisation that provides services to persons who are Deafblind gave the following suggestions for improving the lives of Deafblind individuals, “Maintaining social networks and developing new social contacts with others also experiencing deafblindness, regularly scheduled staff visits to reduce confusion and anxiety about who and when they will receive assistance, adapting activities that they enjoyed so that they can continue to participate in them (gardening, cooking, games, crossword puzzles), (and) training staff about the unique needs of working with seniors (falls prevention, wheelchairs/walkers, mental health)”.



Yet another Canadian, a service provider for persons who are Deafblind as well as persons who are Deaf, hard of hearing, and non-verbal with a developmental disability, wrote the most extensive answer for solutions for individuals with deafblindness,

“Ensure there is communication support as required for people participating in group activities, or engage with people who cannot communicate with them (persons with deafblindness). Adapt environments for people’s vision and hearing needs, assessing and reassessing these environments as vision and hearing changes with age. Adapt activities so they are inclusive of people with DSL – such as modifying games to be tactile so someone with visual loss can participate. Always use names to identify people, think about where you are standing and lighting (not having your back to a window), use large print notes with black marker, use plain language.

DeafBlind Ontario Services organizes special training workshops for organisations supporting older adults in providing simple interventions as follows:

### **Adapted Environments – Virtual**



Increase awareness of accessibility needs and barriers in the home and community. Learn more about adapting environments to meet the unique needs of persons with sensory loss.

### **Communication 101: Bridging the Gap – Virtual**

This unique workshop provides virtual learning opportunities for organisations or individuals who are looking to expand their knowledge and understanding of individuals with a sensory loss and/or communication need.

### **Experience Tools: Expand your Communication Toolbox – In-Person**

*Recommended Prerequisite – Communication 101: Bridging the Gap*

Experience Tools are used to initiate conversation, enhance concepts, promote expressive and receptive language, encourage anticipation, reinforce choices, or reflect on memories.

### **Introduction to Sensory Loss – Virtual**

Understand the differing needs of individuals with sensory loss and how you can improve your work (and) practice to support and empower them. Learn about the eye and ear and maximizing residual vision and residual hearing.”



## USA

Several persons with deafblindness from the USA answered this question: “PLI (protactile language interpreting) in Oregon does a great job at this (including older persons with deafblindness in the community or have them participating in activities) and should be investigated further”.

One respondent stated, “We have volunteers who bring older adults with deafblindness to our events and help facilitate conversations/engagement in our activities. Another mentions “Picnics (and) socials bingo night” and “My local agency serving the Blind/VI (visually impaired) offers monthly lunch outings. Most of their services are done online. I myself do ok with technology but I think many struggle with it, especially if their vision/hearing is worse.” Finally, one respondent mentions that “Each individual has different needs, but the most common practice is how to get a Deafblind individual’s attention (is) to keep the(m) involved. Tap methods, haptics, protactile, (and) accessibility to any type of communication needs.”

A professional service provider that directly supports persons with deafblindness from USA also answered the question in this way, “SSP (Special Service Providers) and protactile



communicating tips should be taught within the Deafblind community (and) across the county in person and virtually, preferably the first. Deafblind (persons) should be the one(s) who dictates the terms as to how communication style and social cues should be done, not Deaf/hearing-sighted members.”



## Brazil

Respondents from outside of Europe and North America furnished some interesting answers, which could shed some light on the lives of older persons with deafblindness in those regions. For example, a person with deafblindness from Brazil wrote, “Yes, we have orientation and mobility and activities of daily living (*atividades de vida diária*) rehabilitation. I know there are countries with the social centres with many workshops and different activities for older people in general to include them. Even in Brazil. But it should be extended with accessibility for older persons with deafblindness.”



## Rwanda

A professional that indirectly supports persons with deafblindness from Rwanda shared some examples of best practices:



1. Create an inclusive resources centre to learn some skills
2. Empower people on tactile Sign Language for communication
3. Organize inclusive social gathering events where persons with deafblindness (can) participate
4. Avail accessible services in all domains.



## Uganda

Respondents from Uganda shared their views on the challenges Deafblind individuals experience, including “lack of awareness raising and campaigns. There is an overall lack of awareness and recognition of person with deafblindness as a distinct disability group. It is often wrongly assumed that people only required at best combination of the service that exist either for Blind or Deaf persons. This, however, ignores the specific barrier and communication requirement of each person with deafblindness at work because some employers feel like they can provide an interpreter or a personal assistant but (are) not looking into the specific ways of accommodating a youth employee with deafblindness.



These campaigns really start from the Deafblind employee, the government of Uganda, and other stakeholders because many of these youth are either employed by their organisations or their families who sometimes don't understand their uniqueness in being reasonably accommodated.”

Another respondent shares their views on solutions by saying, “One (solution) is home visit(s) by peers to control isolation, loneliness, and neglect which are key (factors) in the cause of health-related cases as stress, pressure etc. Regular access to information is also (critical, such as access to) health, mental, and emotional (resources to promote) stability. (This supports an individual) by knowing what happens around you and in the world beyond your reach.”

A professional that indirectly supports persons with deafblindness wrote, “Yes, families of persons with deafblindness do engage themselves in saving groups and do something small to provide (for) the direct needs of Deafblind children or parents. For example, group animal and bird rearing (for) Deafblind persons...are used to care of persons with deafblindness in community and involves their participation at lower levels.”



## Ethiopia





A professional service provider that directly supports persons with deafblindness from Ethiopia highlighted that “creating awareness is the basic thing.”



## Bangladesh

In that vein, a person with deafblindness from Bangladesh answered, “People were unaware of the existing problems of persons with deafblindness. But now they are learning about them, and some are willing to help them when necessary. This is helping the persons with deafblindness in their day-to-day life. People, government, OPDs, and also civil society were unaware of the persons with deafblindness (until now).”



## India

A person with deafblindness from India mentioned an implemented IGP Programme (Income Generation Programme) as an example of a best practice.

To summarise, multiple examples have been extracted from the survey respondents from around the world, some of them can be replicated



or simply been used to showcase existing best practices.

## Optimism for the Future

One of Helen Keller's writings, published in 1903 by T. Y. Crowell and company, is titled "Optimism: An Essay." As an homage to this essay, we end this report on a high note, statements of older persons with deafblindness which express their positive view on life are included below:

Hazel, from the UK adds:



... and another thing you've really got to have a sense of humour. It's no good if you haven't. You've really got to have that sense of humour and keep it. I've noticed that. When my hearing really went, I was withdrawn into myself and people noticed it. I must have looked a misery. Anyway, they noticed a change when I got this hearing aid and they started finger talking. But you need that sense of humour, not everybody's got it." (Matthews 1988a: 35)

However, I deal with all problems and difficulties optimistically! I don't let that slow me down in any way. I look optimistically at life and life's problems. It is never good to give into despair! You should always remain firm and deal with all the problems that, more

or less, other people have, just in a different way. One should be an optimist and live in faith in a better tomorrow! These kinds of thoughts kept me going and today I am, to some extent, satisfied, regardless of all the difficulties. I live in great wealth, and these are my children! It keeps me going!”

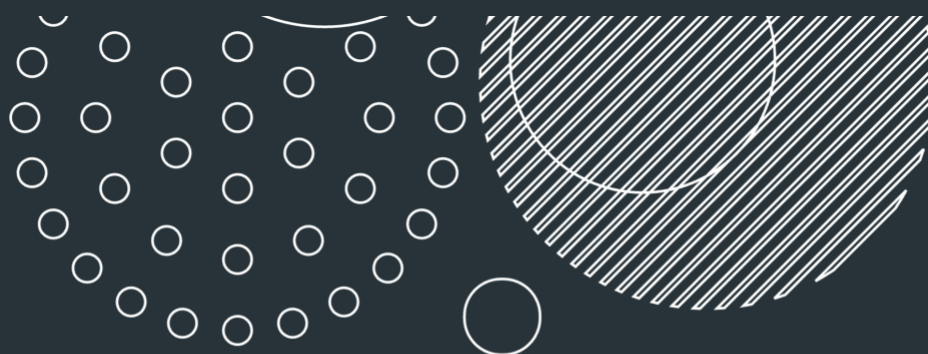
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## **CONCLUSION**





## CONCLUSION

Building on the first and second global report, WFDB has expanded its qualitative analysis of the situation of persons with deafblindness, focusing on older persons with deafblindness using data from available literature, interviews, and an online 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 firmer grasp of the concrete measures and interventions that work for persons with deafblindness. Although more robust research is required across all areas, this global report provides these stakeholders with best 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. However, they have additional obstacles to deal with, as well. In older persons with deafblindness, the effects of deafblindness and the effects of ageing interact with each other,



making both processes harder to cope with. The combination is enhanced by other disabilities and illnesses that can occur in old age, as well as intersectional discrimination.

Isolation and loneliness, one of the main problems of most persons with deafblindness, is manifesting more acutely when it comes to older persons with deafblindness. As they lose family members and friends, they are also exposed to increased barriers due to their disability and age. When these situations arise, it is not easy to maintain a social life. Mobility challenges also vary from those of younger persons with Deafblindness to older persons, due difficulties in walking, need of adequate transport services, etc.

If deafblindness arises in older age, it is often misdiagnosed as dementia or simply explained as a normal process in ageing, causing the older person with deafblindness not to get the appropriate treatment and the appropriate assistance. The same goes for those who refuse to accept that they are Deafblind, using the same erroneous arguments. This identity problem is typical for all persons who need to face the fact that they are Deafblind. This lack of acceptance is connected with the stigma of disability that still lingers in many societies today, while some superstitious beliefs elevate the plight of a person



with disabilities to the rank of supernatural calamities, meaning that in some contexts, some claim that they bring bad luck or misfortune to those who come in contact with them. As previously mentioned, to a person who cannot accept one's own deafblindness, many support services and mechanisms for persons with deafblindness are unattainable.

Deafblindness in old age can often be combined with other illnesses or disabilities, aggravating the person's situation, because the effect of the combined disabilities and illnesses is greater than the mere sum of their individual effects.

Older Deafblind persons often come in contact with health and care personnel that is unable to communicate with them. These miscommunications lead to some additional withdrawal into isolation: older persons with deafblindness hesitate to visit a doctor, even when the health situation becomes a serious one. Older Deafblind persons in nursing homes, where no one knows how to communicate with them, feel a profound sense of isolation; their lives confined to sleeping, meals, and waiting for time to pass. There were several propositions for special residential or nursing homes for older persons with deafblindness, as an alternative to breaking



communication barriers and of regaining meaning in their lives.

Deafblindness is not a static condition and permanent adaptation and learning new skills is a must. Many older persons are generally unwilling to learn something new, even if it would be beneficial for them, with the usual pretext that it's not worth doing considering the time they have left. However, others are rather receptive to learning new skills, under the condition that it might help them with their lives, hobbies, and interests, and that they are not inundated with superfluous information that they would never use. Older persons with deafblindness are not much different from the general average. It is essential to find the adequate and individual approach that meets their needs, interests and preferences.

Assistive devices and technology are developing at a fast pace, and for an older person with deafblindness, it is not always easy to follow these innovations. Decrease in size of those technical devices sometimes results in older persons with deafblindness not being able to use them because they do not have the motoric ability to fine tune them, in addition to the patience required for constant learning how to use newer and newer devices.



Persons who become Deafblind in older age are often not aware of their rights as persons with deafblindness, and without this information, their dignity and their independence is at stake, and they are more likely to be subjected to abuse.

Some older persons with deafblindness understand independence as something achieved with the support of an interpreter-guide/Deafblind interpreter. However, access to an interpreter-guide/Deafblind interpreter may present a problem as well, primarily depending on how the interpreting services are organised in a given country, and on how many hours of free interpreting a person is entitled to.

Some older persons with deafblindness find it hard to regain a meaning to their lives, often feeling useless. Organising and finding activities, works, projects, and programmes for them is a way out of isolation, because it is a way they can meet other persons with the same condition, socialise with them, and enjoy outings together. Creative activities are especially appreciated because they prove to older persons with deafblindness that they are still capable of doing something constructive. A step further in empowering their sense of being useful and needed is encouraging Deafblind individuals to teach other Deafblind persons the same skill they recently learned.





Furthermore, the legal recognition as a distinct and unique disability is absolutely essential for the diversity in communication methods for persons with deafblindness as legitimate languages. This is the primary goal for Deafblind associations worldwide, followed by the right to support and access to funded interpreter-guide/Deafblind interpreter services.

In the last part of the report, solutions to the challenges previously described with some examples of best practices are shared after being extracted from existing literature, research, and responses from the online survey.

Like all persons with deafblindness, older ones 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, 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 older 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 best 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 best practices of mainstream services for



persons with deafblindness are a good starting point.

The literature review revealed that there are many best 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 best practices across countries and regions, indicating that best 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 or other services that exclude or disempower persons with deafblindness, which is a major concern of the Deafblind community. In addition, this report left out 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.



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:

1. Establish 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. Establish 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. Establish **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. Provide **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

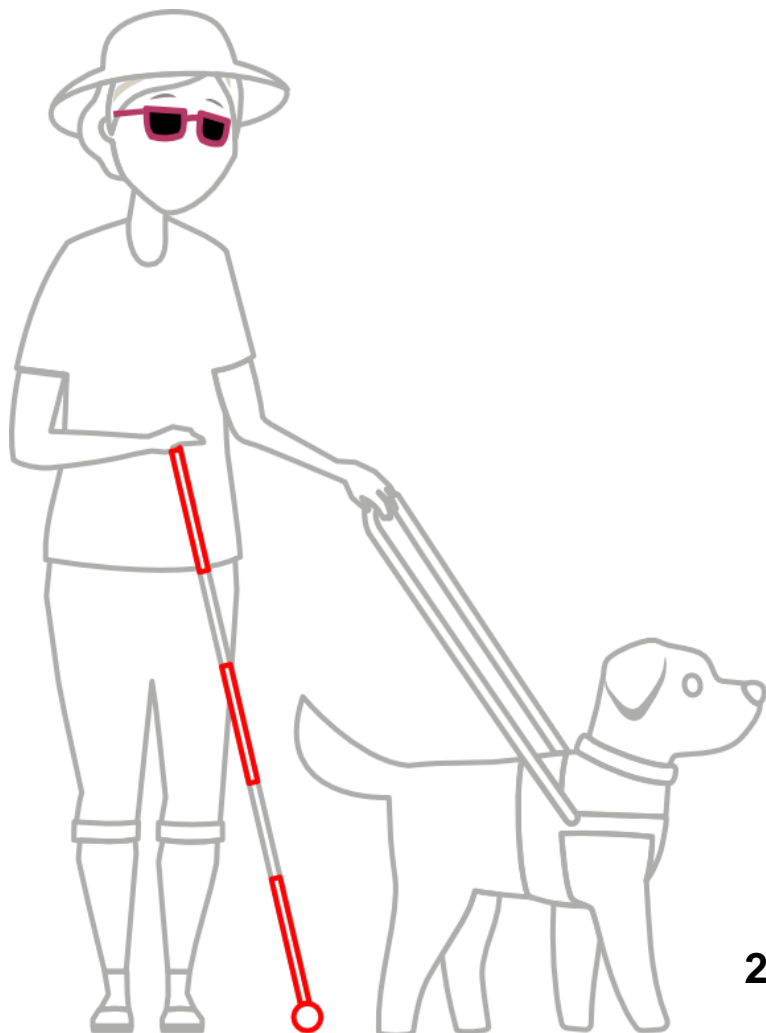
Some additional recommendations expressed by older persons with deafblindness have been listed below:

1. Establish centres and resources that provide specific and adequate services and support to older persons with deafblindness
2. Create 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. Fund accessible and public local transport and other specific services for older persons with deafblindness
4. Organise 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. Include the voices and perspective of older persons with deafblindness both within disability mainstream activities and in organisations of persons with deafblindness, involving them in decision making processes



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<sup>i</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/>.

<sup>ii</sup> *Ibid.*

<sup>iii</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.

<sup>iv</sup> We would like to express our gratitude to Mr. Peter Simcock, who shared with us several articles on this topic authored and co-authored by him.

<sup>v</sup> 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 underlines the



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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.

<sup>vi</sup> Interestingly enough, “in the United Kingdom (UK), services for disabled adults have often been targeted at those aged 18–65, whilst those over 65 are regularly transferred to mainstream older people’s services” (Simcock 2016: 1704).

<sup>vii</sup> A two-day workshop was conducted in Nairobi, Kenya on 27–28 November 2021, focusing on WFDB’s 2nd Global Report. The World Federation of the Deafblind (WFDB) organised the workshop in collaboration with the International Disability Alliance (IDA) and the African Disability Forum (ADF).

<sup>viii</sup> Data taken from the site

[https://en.wikipedia.org/wiki/Life\\_expectancy](https://en.wikipedia.org/wiki/Life_expectancy).



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<sup>ix</sup> The World Federation of the Deafblind (2018: 3) estimates the prevalence of persons with deafblindness to be between 0.2% to 2% of the global population.

<sup>x</sup> Balder (1988: 102) mentions the ratio as being 700/100,000.

<sup>xi</sup> SHAPES Official Website page:

<https://shapes2020.eu/>

<sup>xii</sup> Example of an accessibility report:

<https://wfdb.eu/wp-content/uploads/2023/05/Examples-of-accessibility-reports.pdf>

<sup>xiii</sup> Updated deliverable template used within

SHAPES: <https://wfdb.eu/wp-content/uploads/2023/05/Accessibility-checklist-deliverable.docx>

<sup>xiv</sup> Accessibility section on SHAPES' official

website: <https://shapes2020.eu/about-shapes/accessibility/>

<sup>xv</sup> Example of a useful accessibility resource:

<https://wfdb.eu/wp-content/uploads/2023/05/Accessibility-checklist-deliverable.docx>

<sup>xvi</sup> SHAPES section on WFDB's website:

<https://wfdb.eu/shapes-project/>



- <sup>xvii</sup> 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.
- <sup>xviii</sup> Dammeyer J. 2014. “Deafblindness: A review of the literature”. *Scandinavian Journal of Public Health*. 2014;42:554–62.
- <sup>xix</sup> Fletcher PC, Guthrie DM: 2013. “The lived experiences of individuals with acquired deafblindness: Challenges and the future”. *International Journal of Disability, Community and Rehabilitation* 2013, 12(1).
- <sup>xx</sup> Heine C, Browning CJ. 2004. “The communication and psychosocial perceptions of older adults with sensory loss: a qualitative study”. *Ageing Soc*. 2004; 24:113–30
- <sup>xxi</sup> Urqueta Alfaro A, Guthrie DM, McGraw C, Wittich W. 2020. “Older adults with dual sensory loss in rehabilitation show high functioning and may fare better than those with single sensory loss”. *PLoS One*. 2020 Aug 3;15(8):e0237152. doi: 10.1371/journal.pone.0237152. PMID: 32745118; PMCID: PMC7398548.
- <sup>xxii</sup> Continuum of Care for Older Adults With Concurrent Hearing and Vision Impairment: A Systematic Review Atul Jaiswal, PhD, MSW, BOT, 1,2,\* , Shikha Gupta, PhD, MHA, BOT, 1



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Abinethaa Paramasivam, BSc,<sup>1</sup> Sangeetha Santhakumaran, MSc,<sup>3</sup> Peter Holzhey, BPT,<sup>1</sup> Patrice Dupont, BSc, MLIS,<sup>1</sup>, and Walter Wittich, PhD, FAAO, CLVT<sup>1,2</sup>

<sup>xxiii</sup> Paul Thomas Mick, Anni Hämäläinen, Lebo Kolisang, M. Kathleen Pichora-Fuller, Natalie Phillips, Dawn Guthrie and Walter Wittich. 2020. The Prevalence of Hearing, Vision, and Dual Sensory Loss in Older Canadians: An Analysis of Data from the Canadian Longitudinal Study on Aging. Cambridge University Press. Available at: [https://www.cambridge.org/core/journals/canadian-journal-on--la-revue-canadienne-du-vieillessement/article/prevalence-of-hearing-vision-and-dual-sensory-loss-in-older-canadians-an-analysis-of-data-from-the-canadian-longitudinal-study-on-/EEAB27765E0BCA26AAD0C7AC56F048E0#ref9](https://www.cambridge.org/core/journals/canadian-journal-on--la-revue-canadienne-du-vieillessement/article/prevalence-of-hearing-vision-and-dual-sensory-loss-in-older-canadians-an-analysis-of-data-from-the-canadian-longitudinal-study-on-/EEAB27765E0BCA26AAD0C7AC56F048E0#ref96)

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<sup>xxiv</sup> The World Federation of Deafblind Global Report 2023

<sup>xxv</sup> The World Federation of Deafblind Global Report 2023

<sup>xxvi</sup> Sarah A Fraser et al Exploring Professionals' Experiences in the Rehabilitation of Older Clients with Dual-Sensory Impairment, Canadian Journal on Aging



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<sup>xxvii</sup> Atul Jaiswal CIHR Health System Impact Post-doctoral Fellow, University of Montreal – presentation entitled “Continuum of Care for Older adults with Dual sensory impairment (DSI) in Canada during the COVID-19 pandemic”

<sup>xxviii</sup> Example extracted from interviews conducted by WFDB in 2021, as part of SHAPES Work Package 2: Understanding the Lifeworld of ageing individuals and Improving Smart and Healthy living.

<sup>xxix</sup> Example extracted from interviews conducted by WFDB in 2021, as part of SHAPES Work Package 2: Understanding the Lifeworld of ageing individuals and Improving Smart and Healthy living.

<sup>xxx</sup> The motto of the Croatian Deafblind is “I can do anything, I just need three times more time.”

<sup>xxxi</sup> [https://wfdb.eu/wp-content/uploads/2023/06/Concept-Note-WFDBs-SHAPES-3rd-technical-workshop\\_June\\_23\\_Final.docx](https://wfdb.eu/wp-content/uploads/2023/06/Concept-Note-WFDBs-SHAPES-3rd-technical-workshop_June_23_Final.docx)

<sup>xxxii</sup> Section extracted from WFDB’s article “The red and white cane: obstacles and barriers” : <https://shapes2020.eu/shapes-stories/the-red-and-white-cane-obstacles-and-barriers/>





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<sup>xxxiii</sup> Example extracted from interviews conducted by WFDB in 2021, as part of SHAPES Work Package 2: Understanding the Lifeworld of ageing individuals and Improving Smart and Healthy living.

<sup>xxxiv</sup> 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>

<sup>xxxv</sup> Example extracted from interviews conducted by WFDB in 2021, as part of SHAPES Work Package 2: Understanding the Lifeworld of ageing individuals and Improving Smart and Healthy living.

<sup>xxxvi</sup> Section extracted from WFDB's publication "A Window to the World: Guide Interpreters and Tactile Communication" :  
<https://shapes2020.eu/shapes-stories/a-window-to-the-world-guide-interpreters-and-tactile-communication/>

<sup>xxxvii</sup> <https://www.sense.org.uk/information-and-advice/for-professionals/sense-arts-and-wellbeing-for-professionals/>



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<https://2020.eufunds.bg/en/7/0/Project/BasicData?contractId=c7ZH6c4W%2Bh39uvWC0Q0HzQ%3D%3D&isHistoric=False>

xxxix During the 6th WFDB General Assembly in Nairobi (Kenya) in November 2022, the red and white cane was recognized and approved as the universal symbol of deafblindness for WFDB.

xl This is a term applied in health sciences, and more recently in other fields, to refer to an approach to wellness focusing on health and not on disease (pathogenesis).

xli A hearing loop (sometimes called an audio induction loop) is a special type of sound system for use by people with hearing aids. The hearing loop provides a magnetic, wireless signal that is picked up by the hearing aid when it is set to 'T' (Telecoil) setting. It is the only assistive listening technology that can broadcast directly to a wide range of hearing aids, making them the most popular option for accessible audio in public spaces.

xlii <https://www.sense.org.uk/blog/>

xliii <https://videoforblind.com/>