**Executive Summary of 1st Global Report on the Situation of Older Persons with Deafblindness, November 2023**

**Transcript:**

**Acknowledgements and Disclaimers**

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by WFDB.

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All information and views

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are those of the author(s) and

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**Introduction**

In 2018, WFDB launched

its first global report

on the situation of persons

with deafblindness,

"At Risk of Exclusion from CRPD

and SDG Implementation:

Inequality of Persons

with Deafblindness".

This report sought to open a

necessary dialogue between

PWD's rights and SDG

stakeholders at domestical

and international levels,

and aimed to drew

attention to one of

the most marginalised

and underrepresented

groups in the world.

Representing 0.2% to 2%

of the population,

persons with deafblindness

are very diverse

yet hidden group, and are

more likely to be poor,

unemployed,

and have low education

outcomes.

Because deafblindness is

less well-known

and often misunderstood,

people struggle to obtain

the right support,

and are often excluded

from both

development and disability

 programmes.

The UN Convention

on the Rights of

Persons with Disabilities

(CRPD), the Agenda 2030

and the Sustainable

Development Goals (SDGs),

have triggered a greater

attention towards

the issues faced by

persons with disabilities.

Underscoring the

importance of

the ‘leave no one behind’

motto,

the momentum for higher

levels of equity

for PWD is building up.

However, as the first Global

Report highlighted,

persons with

deafblindness

are often not legally

recognised

as a distinct disability

group, hence

the persistent statistical

invisibility,

even where disability

data is collected.

The lack of reputable data

contributes to significant

breaches

in services supporting

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

advocates and SDG's.

This ecosystem does not

even begin to understand

the extent and diversity

of their issues

or their specific needs

for inclusion.

The first Global Report

outlined its findings

and recommendations

across a broad range

of policy areas and

flagged three initial steps

to bridge the gaps:

1. Establishing a universal

acknowledgement

and recognition of

deafblindness as

a unique and distinct

disability,

with its own specific

challenges, barriers,

support and inclusion

requirements.

2. Establishing publicly

funded deafblind

interpreting services,

in particular,

interpreter-guides/

Deafblind interpreters.

3. Ensuring the necessary

funding for

further research,

and strengthening of

the advocacy work,

including resources

for the tools and

technical support

needed.

Since the launch of the

first Global Report in 2018,

disability inclusion has

gained visibility

at the global stage

with events such as

the Global Disability

Summit (GDS) of 2018

in the United Kingdom,

and the subsequent 2022

GDS hosted remotely,

as well as networks

and mechanisms,

such as the Global

Action on Disability

GLAD Network,

and Assistive Technology

AT, 2030.

These events and

mechanisms

have provided

valuable space

to raise awareness

of disability inclusion

and have served to

advance

the global dialogue

on the practical ways

to implement

the CRPD and

the SDGs.

However, cuts to

bilateral funding,

the COVID-19 pandemic

lockdowns and restrictions,

and increased insecurity

in certain regions

have affected

this progress.

In 2023, the World Federation

of the Deafblind (WFDB),

published 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 gather data

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 essential elements,

measures that increase

and enhance

the inclusion of persons

with deafblindness,

case studies to

illustrate and inspire

good practices, and

programmatic approaches,

and recommendations

across thematic areas.

The aim of the report

is to serve as

an advocacy tool,

for WFDB members

and their allies

to stimulate collaboration

and partnerships,

to advance the rights of

persons with deafblindness

and to inform

stakeholders

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 UN entities

and country teams),

and others.

This report is the

first one issued by

the World Federation of

the Deafblind (WFDB)

that focuses on older

persons with deafblindness,

an underrepresented group,

also, when it comes

to research and

literature on them.

Within the group of older

persons with deafblindness

four subgroups are

usually identified:

1. Those who have

acquired deafblindness

earlier in life and not

due to ageing

2. Those who were

primarily deaf and started

losing their vision

due to ageing.

3. Those who were

primarily blind and started

losing their hearing

due to ageing.

4. Those who were both

sighted and hearing until

they started losing both

senses due to ageing.

The fourth group is

the largest one,

and its members are

usually unfamiliar

with the experience

of being deafblind

and with alternative means

of communication,

and therefore experience

more difficulties

to communicate, read,

access information,

and move independently,

amongst others.

This group is less

equipped to bridge the

gradually wider

communication gap

that is opening

between them

and their surroundings.

At the same time this

group is the one that is

covered by the majority

of the existing literature

on older people with

deafblindness.

The support and assistance

needed by the members

of the fourth group are more

general than those needed

by the members of the

first three groups.

However, all those persons

ageing with deafblindness

share the same experiences:

ongoing both impairment-

and ageing-related changes,

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

maintain their independence,

to name a few.

Regarding the incidence of

deafblindness among older people,

the numbers vary and are

likely to be outdated

or inaccurate.

In European countries, it is

estimated that in every

100,000 older people, there are

150 older people with deafblindness.

In Finland, for example, the

estimates range between

700 and 718 per 100,000.

In Norway, it is between

130 and 188 per 100,000.

In the Netherlands,

125 per 100,000.

In the Århus district of Denmark,

130 per 100,000

in Leicestershire, England,

970 per 100,000.

However, what all

researchers can agree on,

is that prevalence of

dual sensory impairment

 (hearing and vision loss)

increases substantially

with age.

**Context: The SHAPES Project**

The Smart and Healthy Ageing

through People Engaging in

Supportive Systems,

or SHAPES project,

is a four-year project (2019-2023)

that intends to build, pilot,

and deploy a large-scale,

standardised open platform

for the European Union (EU)

integrating a broad range

of technological, organisational,

clinical, educational, and

societal solutions

for long-term, health,

and active ageing.

More specifically, this project

looks at technology

in the home and in

local communities

to reduce health and

social care costs,

hospitalisations, and institutional

care of older persons.

WFDB is one of 36 consortium

partners,

composed of researchers,

technology companies,

and civil and public organisations

aimed at helping older persons,

across 14 EU countries and

engaging with over 2,000

older persons, caregivers,

and service providers.

The main objective is to improve

the long-term sustainability

of health and social care

systems in Europe

and improve the independence

and autonomy

of older persons.

This report has been

developed within the

context of the SHAPES

Project,

where WFDB’s participation

has provided an excellent

platform to collect data,

feedback, findings on

the situation of older

persons with deafblindness,

as well as identify key

challenges, gaps and barriers.

WFDB has decided to

assemble the information

produced during the project,

combined with existing

research and literature,

with the intention of

producing a living document

that will outlive the project

and can be used for

multiple purposes by

different stakeholders.

In a nutshell, the report

attempts to paint a picture

on the situation of older

persons with deafblindness

and its most recurrent

themes,

using the SHAPES Project

as a starting point

to raise awareness and

encourage future research

and documentation on

this very specific and

often neglected group.

This report must be seen

as a living document

that should be updated

and modified in time.

**Case Study: SHAPES**

**project as an example**

**of how to include older**

**persons with deafblindness**

The SHAPES Project

can be referred to as

an example of a good

practice on how to

ensure the participation

of older persons with

deafblindness in

mainstream programmes.

Persons with deafblindness

of varying ages have been

involved in activities to

collect data, such as

interviews, focus groups,

and workshops, on the

following areas 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 the testing the digital

tools and solutions being

developed for the project

have provided valuable insights.

A number of measures were

adopted to ensure the

inclusion of persons with

deafblindness in this project.

WFDB advocated for a

budget line for interpreter-

guides/Deafblind interpreters

for meetings and travel to

ensure that the participation

of persons with deafblindness

was meaningful and equal

to project participants

without deafblindness.

Persons with deafblindness

worked with interpreter-

guides/Deafblind interpreters

to participate in the data

collection activities, and

some of these activities

worked with smaller cohorts

to adapt to the communication

requirements of the group.

For example, focus groups

usually involved 2-3 participants

with deafblindness, and

workshops comprised

of 7-10 participants

with deafblindness.

Many of the project

events were integrated

so that WFDB could

connect with other

project partners and to

raise the profile of persons

with deafblindness among

mainstream partners.

For example, at one of

the online meetings, a

person with deafblindness

presented on a panel

while another person

with deafblindness

moderated the panel.

The good practices and

lessons learnt from

WFDB’s participation in the

SHAPES Project include:

Ensuring a rights-based

perspective with a CRPD-

compliant approach both

within SHAPES as a

project and its outputs,

to advance the rights of

persons with disabilities,

including those with

deafblindness

The central importance

of adopting accessibility

and inclusion as a cross

cutting requirement,

ensuring accessibility

standards and reasonable

accommodations amongst

others, including a budget

for interpreter-guides/

Deafblind interpreters

and information in

accessible formats

Involve a wide range of

OPDs, including those of

persons with deafblindness,

in the early planning stages,

including the proposal

development, to avoid

making changes to the

project at later stages

Persons with deafblindness

may require additional

support, such as a project

coordinator, to manage daily

activities and communication,

but they should maintain

ownership and decision-

making of the project

OPDs play a key role

as right-holders to guide

priorities and validate

projects result, as well

as in building awareness

and technical support

on accessibility and

inclusion measures in

mainstream projects.

They should be allocated

a budget and explicit

responsibilities, so they

are able to perform their

role adequately and make

meaningful contributions

Training for project partners

at the beginning of a project

on accessibility and

inclusion encourages

shared responsibility

between OPD partners

and mainstream partners

Ensure that all documents

and materials (including

overall approach, findings,

lessons learnt, etc.)

are available in multiple

accessible formats and

languages in all

dissemination efforts

to maximise reach

The SHAPES project

has provided a platform

for persons with

deafblindness to come

together on health and

technology issues,

resulting in a positive

exchange with mainstream

organisations, new

connections and partnerships

with mainstream organisations,

and peer-to-peer learning

between persons with

deafblindness.

WFDB plans to consolidate

learning from the SHAPES

project and produce a

final report highlighting

learning on project

participation of persons

with deafblindness as well

as insights on health and

technology for older

persons with deafblindness.

**Methodology**

This report is based on

existing literature on older

persons with deafblindness,

interviews with older persons

with deafblindness and the

answers sent by respondents

to an online survey

launched in July 2023.

Information from all three

sources have been grouped

together and presented as

different chapters, gathered

around the same or similar

problems, barriers, good

practices and possible solutions.

Sometimes a chapter was

based on just one of

the three sources.

A statistical approach was

implemented where relevant.

**Qualitative Research**

The qualitative research

focuses on data gathered

from the literature review,

which was analysed and

categorised according to

the topic they covered.

Each topic was then

structured in a different

paragraph representing

all the views, sometimes

supporting and sometimes

opposing each other,

in an attempt to portray

a wide a range of opinions

on the situation of older

persons with deafblindness

and professionals who

work with them.

The open answers to the

questions in the online

survey were examined in

a similar manner, grouping

together those that referred

to the same topic and

presenting the most frequent

as well as the most elaborated

ones for each question.

**Quantitative Research**

The quantitative research

was extracted from the

survey questions which

was completed by individuals,

and was analysed statistically,

often represented in a

graphical form.

The same is valid for some

other answers in which

numerically and statistically

representable data were contained.

A detailed summary of

the results can be found

in the full version of the

report, as well as findings

from literature.

**2023 WFDB survey on older**

**persons with deafblindness**

WFDB launched in July 2023

an online survey with the

purpose of gathering

information on older persons

with deafblindness

for this report.

The survey was intended

for WFDB members,

persons with deafblindness,

organisations by and for

persons with deafblindness

and other organisations and

professionals in the field

of deafblindness.

It was made available online

for a month and shared

widely with WFDB’s network.

This survey was organised

as part of the SHAPES Project

and counted on the collaboration

of the International Disability Alliance

(IDA).

Eighty-six persons from 24

countries responded to the survey:

Angola, Australia (2 respondents),

Austria, Bangladesh, Brazil,

Bulgaria, Canada (4 respondents),

Denmark (4 respondents),

Ethiopia (2 respondents),

Hungary (2 respondents),

India (7 respondents),

Indonesia, Italy,

Kenya (2 respondents),

Malawi, Norway (4 respondents),

Palestine, Russia (5 respondents),

Rwanda, Slovenia (3 respondents),

Spain (28 respondents),

Tanzania, Uganda (5 respondents),

UK and USA (7 respondents);

that is: 49 from Europe,

13 from Africa,

11 from North America,

10 from Asia, 2 from Oceania

and 1 from South America.

**WFDB SHAPES**

**Technical Workshops**

WFDB, in collaboration with

the International Disability

Alliance (IDA), has held

three technical workshops

within the context of SHAPES.

Participants include WFDB

Executive Council members

and Regional Representatives,

as well as well as European

Deafblind Union (EDbU)

representatives and respective

guide-interpreters/Deafblind

interpreters.

The main outcomes of

the workshops include:

Ensure proper knowledge

of, and ownership of the

ongoing work of SHAPES

Consultation and feedback

gathering on the current

situation, challenges and

barriers faced by older persons

with deafblindness,

good practices and

recommendations,

physical accessibility of public

areas and services,

digital accessibility and the

use of technology to

improve quality of life, etc.

Strengthen ties between

deafblind representative

organisations and

SHAPES partners.

Test digital solutions

being developed or

improved in the project

Engage in events or

meetings to promote the

SHAPES Project and

raise awareness on WFDB’s

participation in the project

These workshops have

provided an opportunity

to validate the findings

from the SHAPES Project

and generated insights

on older persons with

deafblindness, which has

fed into this report.

**Definition of deafblindness**

Deafblindness is a distinct

disability, as stated in the

Nordic definition from 1980,

revised in 2007.

 “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.”

**Needs of older persons**

**with deafblindness**

The findings of a study on

the needs of older people

from their own perspective

and how those needs were met

or why they were not met,

might be equally, if not even

more, be applicable on older

persons with deafblindness.

They can be categorised as:

1. Practical needs

 (includes everyday needs

such as grocery shopping,

home chores, etc).

2. Emotional needs, grouped as:

a) Feelings of anxiety

and insecurity

b) Feelings of insignificance

and of being neglected

c) Feelings of sorrow

and grief

3. Existential needs, listed as:

a) To find a meaning in life

from now until death

b) To find a meaning with life as a

whole and to be able to contribute

with one’s own knowledge

and experiences

c) To prepare for one’s

own death.

**Challenges or barriers for**

**older persons with deafblindness**

The following section

focuses on the most

recurrent topics or themes

that were identified in

the research and where

relevant links have been

drawn with CRPD articles.

One respondent to the

survey classified the barriers

into two groups:

1. Attitudinal barriers:

The ones due to perceptions

from persons with deafblindness

themselves and society

around them.

Some of them are perceived

as persons with deafblindness

being unable to involve

in their daily activities.

2. Environmental barriers:

The environment is not

supported for or adapted

to persons with deafblindness.

**Legal recognition of deafblindness**

**as a distinct disability**

Political and legislative

decisions influence the

everyday life of persons

with disabilities, including

those of older persons

with deafblindness.

The legal recognition of

deafblindness as a unique

disability, of deafblind

persons and, their needs

and communication systems

is the primary goal of every

association of persons

with deafblindness.

However, recognising just

one of the four categories

mentioned above does not

imply that all the others are

automatically recognised

as well.

Countries that officially

recognise deafblindness as

a distinct disability and/or

have adopted an official

definition of deafblindness

are more likely to provide

specific support services.

This is particularly the case

in low and middle-income

countries.

In 2004, The Parliament

of the European Union

adopted a Declaration on the

Rights of Deafblind People.

The UN Principles for Older

Persons from 2019

cover both political and

social participation.

Article 29 of CRPD

promulgates the effective

and full participation in

political and public life of

persons with disabilities.

Unfortunately, the World

Health Organisation still

does not recognise deafblindness

as a distinct disability in its

International Classification of

Functioning, Disability and Health

 (ICF) (2001).

In 2021, Slovenia was the

first country to include the

language of the Deafblind

into its Constitution.

Italy has also recognised

deafblindness by passing

the Law n. 107

from 24 June 2010, subtitled

Measures for the Recognition of

the Rights of Deafblind People.

Both lingua dei segni

italiana (LIS)

and lingua dei segni

italiana tattile (LIST)

Italian Sign Language and

Italian Tactile Sign Language

respectively, are also recognised.

The United Convention on

the Rights of Persons with

Disabilities (UN CRPD),

ratified by 186 states worldwide,

offers only limited references

to deafblindness, and those

concern the education of

children with deafblindness.

The recognition of the impairment

and of the language is a

significant step but is far

from the end of the struggle.

Alas, there is little evidence of

older persons with deafblindness

participating in the co-production

of policies and services that

promote their well-being.

The right to interpreter-guides/

Deafblind interpreters should

be one of the basic rights of

persons with deafblindness,

but it is hard to imagine that

anyone would provide

interpreter services until

compelled to do so,

only straightforward political

action by the government

can ensure that such a

service be available to all

the persons with deafblindness

who need it.

One important thing connected

to legislation is that as

deafblindness cannot be

described as a simple sum

of deafness and blindness,

older persons with deafblindness

cannot be described as a

simple sum of older persons

and persons with deafblindness.

Again, we have a sum that

is greater than the parts.

The respondents to the

survey suggested that the

governments should increase

their funding towards services

for the Deafblind, that the

numbers of hours per month

that a person with deafblindness

would be assigned an interpreter-

guide/Deafblind interpreter

should be increased,

that the government should

collect disaggregated data

on how many persons with

deafblindness live in the

country and their needs,

that educating and training

persons with deafblindness

should be organised, enabling

them to have a job, and

consequently, some financial

security,

with a promise of a pension

one can live on when retired,

and that access to urgent

and emergency care services

should be adapted for

persons with deafblindness

to use at all times.

**Response to Emergencies**

Respondents to the survey

tackled the question of

contacting emergency

services.

Access to urgent and

emergency care services

should be adapted for

persons with deafblindness

to use at all times.

It is suggested that

appropriate application (app)

and technology should be

developed for this purpose,

in collaboration with persons

with deafblindness and their

representative organisations.

This issue became extremely

important during the recent

COVID pandemic that has

particularly struck

older persons.

In the Second Global Report,

 (The 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,

remote working, health

appointments, or education

Lack of community outreach

to check on individuals

with high support needs

Those key concerns can

be applied to any of the

abovementioned emergency

situations.

Article 11 of the CRPD

mentions how all necessary

measures to ensure the

protection and safety of

persons with disabilities

in situations of risk.

**Interpreter-Guides/**

**Deafblind Interpreters**

**and other forms of**

**live assistance**

Interpreter-guides/Deafblind

interpreters are a crucial service

which enables the person

with deafblindness to reach

the level of independence

needed to fully participate

in society.

However, those interpreter-

guides/Deafblind interpreters

may be not always available.

The reasons for this are many,

from the most banal (an

insufficient number of interpreter-

guides/Deafblind interpreters)

to the mostly administrative

ones.

According to the World

Federation of the Deafblind,

many states, especially those

low- and middle-income ones,

do not possess a system of

interpreter-guides/Deafblind

interpreters,

but this is also valid for

those states that do

not recognise deafblindness

as a distinct disability

and/or in which Sign

Language is not recognised

as a minority language.

The usual obstructions in

environments where an

interpreting service does

exist are:

the assignment to every

single person a specific

and limited number of

interpreting hours per month

based on the severity of the

person’s impairment,

usually calculated on the

strictly medical, numeric

basis and has no relation

to the actual needs of

each individual and by

a local official who simply

does not understand the

situation and needs of the

older person with

deafblindness,

often being uneducated on

deafblindness and for whom

a person might just represent

an entry in the spreadsheet

to follow;

requiring a considerably

advanced booking, which is

not always possible, particularly

in emergency situations;

and providing a salary for

the interpreter-guide/

Deafblind interpreter

by the deafblind person.

The lack of appropriate live

assistance can affect almost

all aspects of a person with

deafblindness, which can

have a direct impact on

their quality of life.

**Isolation and Loneliness**

Isolation is a problem

mentioned by virtually all

the interviewed persons

with deafblindness,

authors and texts.

Isolation proved to be an

especially grave burden

during the COVID pandemic

because touching and

closeness, methods used

by most persons with

deafblindness to communicate

and access information,

were not allowed.

Loneliness could be defined

as not having anyone to

communicate with in one’s

own language and as not

having any or only very

few relationships in life.

Isolation is one of those

difficulties that persons

with deafblindness

experience that can be

caused by several instances

at the same time:

the person with deafblindness

withdraws from public life,

frustrated by his/her

inability to communicate

or be understood successfully,

by mishearing, by responding

inappropriately, and by

consequently appearing

foolish, even in a well-known

environment;

the person’s immediate

surroundings, family and

friends, begin avoiding him/her

because of difficulties in

communication,

perceiving the older

person with deafblindness

as an outcast.

Professionals and specialists

rarely know anything about

deafblindness or how to

communicate with them,

so, they reduce their own

activities to the necessary

minimum, not having time

or patience to communicate

with their patient/client.

Moreover, the community

at large rarely notices

persons with “invisible”

disabilities and ostracize

those identified as such.

The severity of the problem

of isolation lies in it being

the slippery slope that

leads to loneliness, which

often leads to depression,

leading to a person being

forcibly placed in an

institution where he/she

are given pharmacotherapy

to induce a vegetative state.

Older persons with

deafblindness in general,

seem not to fear

so much isolation itself,

but rather, the inability

to cope with it.

In any case, social isolation

experienced by older adults,

experiencing deafblindness

or not,

is a public health concern.

**Sight and Hearing Loss**

**due to Ageing**

Many older persons

with deafblindness

remain “hidden” because

they simply accept that

having visual and hearing

problems is a normal

consequence of aging,

affecting all individuals

and something that simply

must be dealt with.

Consequently, they will

not identify as persons

with deafblindness,

therefore, not seek

appropriate Deafblind

specific services, institutions,

and associations for

assistance, and will

remain undetected and

deprived of appropriate

support and help.

However, it is unimportant

whether the dual sensory

loss is the result of

ageing or a disease,

what is important is to

recognize it and realize

that action can and

should be taken.

**Identity**

As mentioned,

many individuals with a

dual sensory loss,

not only older ones,

refute to be labelled

“Deafblind”

for multiple reasons, even

when aware of mobility,

communication, and

information accessing problems.

When it comes to older

persons with dual sensory

impairment,

not perceiving themselves

as persons with deafblindness,

key players such as

health care workers,

social workers and other

professionals

can be a part of the problem.

This is because many

oversimplify and blame

it on aging,

refusing to recognize

deafblindness as a unique

and distinct disability, with

its own specific challenges,

barriers, support, and

inclusion requirements.

Not identifying oneself as

a person with deafblindness

can have serious

consequences, for example,

limited or no access to

exclusive services for

persons with deafblindness,

in a condition where

separate services for the

deaf and for the blind are

not sufficient or adequate,

i.e.: interpreters for the

Deaf and guides for the

blind, cannot replace

interpreter-guides/Deafblind

interpreters.

Also, peer-to-peer

counselling is not an

option when one does

not accept a peer as such.

This will also mean

that they will not be

accounted for in statistical

and data research practices,

which can affect the

Deafblind community in

general by representing

them as less frequent than

is the actual situation,

and therefore, their specific

needs and preferences

are less likely to be

accounted for.

**Socialising with Other**

**Persons with Deafblindness**

Meeting other persons

with the same condition

is of extreme importance

for any person with

deafblindness,

but especially

for an older one,

it may be crucial to

accept more easily,

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.

Such encounters and

gatherings within the

Deafblind community often

replace the friendships and

relationships lost over the

communication problems

of the older person with

deafblindness.

The presence of other

persons with the same

condition is beneficial in

rehabilitation as well.

**Deafblindness Misdiagnosed**

**as Dementia**

While people around older

persons with deafblindness

may interpret his/her

misunderstanding in

communication as a sign

of reduced mental abilities

due to aging,

they can also jump to

the conclusion that he/she

is experiencing cognitive

debilitation,

that he/she is senile,

demented or having

cognitive difficulties in

keeping up.

Unfortunately, misdiagnosed

dementia may lead to it

becoming true, ironically,

because deafblindness in

older persons can be

related to cognitive decline,

as well as depression,

functional decline, and

participation challenges.

Of course, an older person

with deafblindness can also

actually, experience dementia.

What is important here

is to be able to tell the

the two apart

since the problem

of diagnosing dementia

is extremely pronounced in

persons with deafblindness.

Namely, it may be difficult

to determine whether

a person is dealing with

the consequences of

deafblindness or signs of

dementia without

appropriate testing

and knowledge.

**Deafblindness Combined**

**with Other Disabilities**

**and Illnesses**

The term used in

psychological literature

for a combination of

disabilities and illnesses

is “multiple vulnerability”.

Psychiatric or psycho-

geriatric symptoms are

likely to develop with older

persons with deafblindness

when faced with their

own condition and the

consequences of isolation,

especially if the condition

was acquired at older age.

Sometimes, deafblindness

can incur for other

disabilities or illnesses,

while in other cases

multiple disabilities have

no mutual causal relationship

but can influence each

other negatively.

This situation is often

experienced by older

persons with deafblindness,

which can impact their

quality of life and

general wellbeing.

**Adapting to New**

**Circumstances**

Deafblindness is not

a static condition as

the level of hearing

and sight can vary

during a person’s lifetime

with no fixed pattern.

Within the older Deafblind

population, changes in

impairment occur concurrently

with changes associated

with ageing as a

“second disability”.

Moreover, persons with

deafblindness may

experience changes

associated with ageing

sooner than those

without impairments,

a phenomenon named

accelerated ageing.

Older persons with

deafblindness might

feel forced have to

make multiple, repeated,

ongoing, permanent,

and constant adjustments

all the time.

The range of adjustments

for older person with

deafblindness includes

psycho-social adaptation

and emotional acceptance

of deteriorating senses,

changes in relationships,

including personal relationships

and relationships with

social care services,

having to learn new ways

to complete everyday activities,

the use of modern assistive

technologies and access

to information, etc.

There are two main

types of adaptations

that are ongoing when

talking about older

person with deafblindness:

learning new communication

methods or adapting

existing ones

and learning new skills with

new assistive technology.

Communication becomes

more difficult with constant

changes in hearing and

vision, making existing

communication methods

unsatisfactory.

However, many older

persons with deafblindness

prefer to maintain already

adopted communication

methods rather than learning

alternative communication

techniques, being more

interested to retain or

regain use of their hearing

and vision to the greatest

extent possible.

As far as functioning assistive

technology is concerned,

such as hearing aids,

many older persons with

deafblindness consider it

to be of the utmost

importance to be able to

remain independent,

maintain social relationships

and to participate

and live an active life.

Unfortunately, one of

the problems with

developing technology

in general, is that it

strives towards diminution.

This can be a major

challenge for older persons

with deafblindness, since

many lose their fine motor

ability, have the sense of

feeling in the fingers reduced,

which can present a

particularly hard problem,

for example, when it comes

to handling ever smaller

and smaller modern

hearing aids controls.

Lack of accessible

information about available

technology is another

major problem.

Further problems related

to assistive technology

are its cost, training to

use it, maintenance, and

adaptation of the device

as per individual,

specific needs.

Some older persons with

deafblindness deem

themselves to be too old

to learn new skills.

However, if it is not easy

for an older person to

learn how to use new

technologies, it does not

mean that it is impossible.

One of the best ways

identified is to be taught

by someone who understands

his/her needs and not

by only a skilled IT expert,

as it is often the case.

An older person with

deafblindness should

learn in small steps, at

a slow pace and avoid

information overload.

On the other hand,

there are other older

persons with deafblindness

who engage actively

in rehabilitation services

and enjoy the opportunity

to learn new skills and

how to use new assistive

and mainstream technologies,

even in a much later life,

directly challenging the

negative and stereotypical

construction of old age

as a period of inevitable

decline and withdrawal.

A different problem

presents in the form

of receiving more means

of assistance than necessary,

when the professional in

the field simply ignores what

exact service is needed.

The only evaluation

criterion in deciding this

should be the evaluation

of the situation by the older

person with deafblindness

him/herself:

how much is this is

contributing to his/her

Quality of Life (QOL),

to a pleasant, positive,

happy, and safe existence.

The life adjustment

model acknowledges that

adjustments are not just

an individual response to

impairment, but that people

with deafblindness also

need the social environment

and service providers to

adjust as they age,

which is not always

acknowledged in the

literature.

Moreover, another issue

is providing unsolicited

for help to older persons

with deafblindness,

which can be a

double-edged sword.

On one hand, it can be

interpreted not as a

noble intention, but as

a patronizing.

On the other hand, some older

persons with deafblindness

are grateful for such help

because it demonstrates

the helper’s intuitive

knowledge what is he/she

supposed to do.

So, people willing to help

might find themselves on

a slippery slope.

Thus, it is important for the

person with deafblindness

to make it clear to the

service provider when

does he/she need help

and when not and for

service providers to ask

if and what kind of

assistance is needed.

**Health and Care Personnel**

Article 25 of CRPD is all

about the right of persons

with disabilities to equal

treatment when dealing

with health issues.

Unfortunately, insufficient

or lack of knowledge on

deafblindness, persons

with deafblindness, and

their needs and methods

of communication seems

to be the greatest problem

persons with deafblindness

face when meeting

professionals who should

provide services for them

such as health care staff,

social workers, etc.

Health and social care

systems often seem to

be designed around

individual medical conditions

rather than conditions

involving multimodality,

for example, ophthalmology

is separated from audiology

and not treated in

conjunction.

The person with deafblindness

acquires two medical reports

for his/her unique condition,

only reinforcing the

 “deafblindness is the

mere sum

of deafness and blindness”

fallacy.

Even hospitals sometimes

refuse to include people with

deafblindness in therapy

sessions because of

 “impossibility of communication”.

Many older persons with

deafblindness do not feel

that they can express their

own needs and wishes

without being misunderstood

or not understood at all

by others and often wait

as long as possible before

contacting the healthcare

system,

because they mistrust it

and do not feel safe

in a doctor’s office,

infirmary, or hospital.

In most cases, neither

medical specialists nor

family doctors possess

enough knowledge about

how to assist older persons

with deafblindness,

the former possibly

because their specialisation

is too narrow, the latter

because theirs is too broad.

On the other hand,

Deafblind services often

do not meet the needs of

older person with deafblindness

just like mainstream older

people’s services do not

have the ability to meet

their needs as persons

with deafblindness.

Furthermore, single sensory

impairment services are

inadequate when

meeting the needs of

those acquiring a second

sensory impairment.

In short, the experiences

of older persons with

deafblindness in healthcare

include

inaccessible information,

lack of awareness on

deafblindness among

frontline staff,

and limited communication

support,

which deeply affects the

confidence of the older

person with deafblindness

in his/her self-management

of health conditions.

With a nursing home

staff not familiar with the

specifics of deafblindness

or multiple existing

communication methods

used by the Deafblind,

a person with deafblindness

remains alone, isolated,

without adequate support

and care, which leads to

a rapid mental and general

health deterioration,

and a decline in the

quality of life, caused

by the denial of the

guaranteed fundamental

rights to a dignified life,

communication, and aging.

The life in such a nursing

home is often limited to

meals, sleep, and idleness

with no interaction

with other humans.

They might also be

increasingly exposed to

neglect and mistreatment

patronizing and condescension,

that is treatment contrary

to CRPD Article 15 –

Freedom from torture or

cruel, inhuman, or degrading

treatment or punishment.

It has been reported

that older persons with

deafblindness are often

expected to be grateful

for whichever level of

assistance they receive and

accept it without question.

Many older persons with

deafblindness show a

preference for living in

a nursing and/or residential

homes adapted for person

with deafblindness where

they could meet other

people with the same

impairment, exchange

experiences, have a good

time, and receive

accessible older care.

However, this option is

rarely available and can

be easily labelled as

institutionalization, something

both the EU and UN are

strongly opposed to.

In short, an older person

with deafblindness should

be able to freely choose

how and where to live if

their rights are not

compromised, in accordance

with existing legislation,

including CRPD Article 14 –

Liberty and security of

person,

Article 17 – Protecting the

integrity of the person,

Article 19 – living independently

and being included in the

community and

Article 25 – Health,

amongst others.

Last, but not least, in

contrast to the professionals

who come in contact with

older persons with deafblindness,

a special mention should

be made of carers,

especially those unpaid

workers, volunteers, since

they play a key role in

the ecosystem of older

persons with deafblindness.

More programmes and

research needed to address

unpaid care work within

households and communities

where older persons with

disabilities live with the aim

to support quality, affordable

and accessible care services

across sectors and improve

the situation for both care

receivers and the people

caring for them.

It is important to

acknowledge the gendered

distribution of unpaid care

work, identify trends and

patterns and provide

recommendations on how

to reduce and redistribute

unpaid work.

**Empowerment**

Four main themes

may shape the concept

of empowerment at

the individual level:

1. Having a sense of

personal identity

2. Having a sense of

choice and control

3. Having a sense of usefulness

 and being needed

4. Retaining a sense of worth.

There are multiple barriers

 and challenges to

empowerment in decision

-making at the individual

level (e.g., level of literacy

and confidence on the

domain when a decision

is requested;

psychological barriers;

age, disability, gender,

sexual orientation, ethnicity,

and their intersections;

as well as individual

characteristics such as

personality and life

experiences).

The process of

empowerment necessarily

addresses the social,

cultural, political, and

economic determinants.

The main challenge to

empowerment is the

impossibility of the outside

world to communicate

with the person with

deafblindness and

vice-versa.

When it comes to

empowering people,

socio-economic and

educational status,

cultural backgrounds,

and generational factors,

as well as institutionalized

ageism, highly matter.

When focusing on

older persons with

deafblindness, the dynamics

of empowerment in

decision-making are

heavily affected by ageist

and ableist attitudes,

environments, and structures,

leading to discrimination,

exclusion, and denying

rights of people

as they age.

Moreover, age intersects

with gender and disability,

as well as other

characteristics.

Person-cantered care

and shared decision-

making are both

possible only if the

communication flows

correctly,

in an accessible

and inclusive way.

Sustaining empowerment

across the lifespan relates

to four principles:

1. Participation

2. Process

3. Practices

4. Purpose

In order to empower

persons with deafblindness,

Article 3 of CRPD prohibits

all discrimination on the

basis of disability, while

Article 21 states that

persons with disabilities

can exercise the right to

freedom of expression

and opinion.

**Access to Information**

Access to information in

our modern society is

important for three reasons:

to be able to build the

basis to make one’s

own decisions and to

maintain independent

living,

to be able to maintain

communication with others,

and to be able to

participate in discussions

and conversations.

The constant stream of

new information might

be difficult to deal with

for an aging person

whose his/her vision

and hearing is deteriorating.

Problems with vision

and hearing make it

hard to keep up in

with a society that is

constantly changing

and putting new

demands on the individual.

Acquiring information

about things that are

occurring, both in the

close environment and

in the world in general

may be a problem

for older persons with

deafblindness.

Today, both information

and even more

misinformation are

available by moving

one’s fingertips over a

keyboard and moving

and clicking a computer

mouse.

Several conditions must

be met for older persons

with deafblindness to

have a better access

to information:

the education of older

persons with deafblindness

on how to use the

digital technology must

be simplified to be

more efficient;

the contents must be

delivered in a way that

can be accessible to

persons with deafblindness;

and technology itself

should be affordable for

the Deafblind user.

This must all be in line

with CRPD Article 4,

Article 9 – Accessibility

and 21 – Freedom of

expression and opinion,

and access to information,

amongst others.

**Rights and Independence**

Independence might

mean different things

for different people.

For some persons with

deafblindness, there can

be no independence if a

person is dependent on

interpreter-guides/

Deafblind interpreters and

other assistive personnel,

but other persons with

deafblindness are of the

opinion that it is exactly

the interpreter-guides/

Deafblind interpreters

and other assistive

personnel who enable

the person with

deafblindness to

be independent.

For the latter being

independent does

not mean to refuse

assistance or to have

no need for it, but stands

for being in control of

how and when that

assistance is provided,

because remaining

autonomous and in

control for them is as

important as being able

to care for oneself,

in line with the CRPD.

**Abuse and**

**mistreatment**

Persons with disabilities

are more likely to be

subject to abuse than

their peers without

disabilities,

and this is of course,

the case for persons

with deafblindness as well,

especially older ones.

Unfortunately, it is still

true that persons with

deafblindness are deemed

to be one of the most

vulnerable groups in

society,

including vulnerability

to exploitation, abuse

and harm that they are

potentially at greater risk

of all forms of abuse.

Increased vulnerability

indicates loss of dignity,

while equal treatment

means that dignity is

maintained,

and the dignity of the

person with deafblindness

simply must be

maintained.

Among the persons

with deafblindness,

older women with

deafblindness are more

likely to be subject to

abuse, and violence.

Due to their intersecting

and multiple sources of

discrimination, amongst

others, they may be

subjected to discrimination

based on their gender,

on their disability,

specifically, on

their deafblindness,

and on their age.

Access to justice is a

key matter, in order to

ensure accountability

and avoid impunity.

Relevant CRPD articles

include Article 6,

focusing on the rights of

women with disabilities,

obliging the signatories

to take measures to

ensure the full and equal

enjoyment by them of

all human rights and

fundamental freedoms,

while five articles,

13 to 17,

speak explicitly about

access to justice,

liberty and security

of person, freedom

from torture or cruel,

inhuman or degrading

treatment or punishment,

freedom from exploitation,

violence and abuse

and the protection the

integrity of the person.

**Work, employment**

**and retirement**

The sense of isolation

and loneliness may be

enhanced by the change

in the employment status

of the person with

deafblindness.

Such a person is usually

forced into an early

retirement due to his/her

low vision and hearing.

Older persons with

deafblindness belong to

two stigmatized and

marginalized groups with

high levels of exclusion

from the labour market.

Thus, persons with

deafblindness are more

likely to be unemployed

than those with other

impairments.

Although older persons,

those with deafblindness

in particular, experience

discrimination

in the workplace and

multiple barriers to

engage in paid employment,

many older persons

either work or have a

desire to work.

Within five years of retiring,

one in four older persons

“unretire”,

return to work.

Routine is sometimes a

very important factor in a

person’s life and losing

that routine can lead into

depression and mental

deterioration.

Inclusive schooling has

enabled persons with

disabilities to a greater

variety of job opportunities,

including jobs with

university degrees.

Now the problem for

the employer becomes

adapting the workplace

for a person with

deafblindness, which

means additional expenses.

Article 27 of CRPD,

Work and employment,

recognizes the right of

persons with disabilities

to work, on an equal basis

with others and prohibits

 “discrimination on the

basis of disability with

regard to all matters

concerning all forms

of employment “.

**Poverty**

Specially in middle-

and low-income countries

(but not only),

poverty is stressed as

the major obstacle for

persons with deafblindness.

Older persons with

deafblindness rarely

benefit from retirement

pensions nor from the

national funds which

support older persons

after retirement.

Due to the barriers

faced due to their disability,

fewer people can access

high education levels

which would give them

access to formal

employment and social

protection services available.

Most persons with

deafblindness in such

countries are illiterate,

thus, education needs,

communication needs

and health care needs

of the Deafblind should

be prioritized for their

meaningful participation

in their society.

Governments often don’t

give any attention

concerning accessibility

of education,

medical service,

and service provision

for them.

Two articles of CRPD

address this issue.

Article 28 mention

explicitly “the right of

persons with disabilities

to an adequate standard

of living for themselves

and their families”,

while Article 24 recognizes

the right of persons with

disabilities to education

and to the full development

of human potential.

**Creativity and leisure**

The right of persons

with disabilities to take

part on an equal basis

with others in cultural life,

the right of persons with

disabilities to have the

opportunity to develop

and utilize their creative,

artistic and intellectual

potential,

not only for their own

benefit, but also for the

enrichment of society,

and the right of persons

with disabilities to participate

on an equal basis with

others in recreational,

leisure and sporting

activities are all included

in Article 30 of CRPD.

Creative activities have

been proven to be one

of the most efficient outlets

for persons with

deafblindness in general

and older persons with

deafblindness in particular

to express themselves.

Creative workshops,

usually organized by

associations of the

Deafblind or by

organizations for the

Deafblind attract some

individuals,

who find fulfilment

in something

they can do with

their own hands.

Enrolling in new

activities, especially

creative ones, can

prevent that passiveness

and give the person

new opportunities to fill

his/her schedule.

Unfortunately, for

persons with deafblindness

 (and especially those

who are older)

living outside major urban

centres,

such workshops are

usually out of reach.

The situation is even

worse in lower-income

states,

where usually there is

no organized activity

for persons with

deafblindness at all.

This limits their chances

to learn something new,

meet others, and most

of all ‒ to feel useful,

to feel that their lives

have a meaning.

**Participation in activities,**

**projects and programmes**

The work/projects/

programmes focused on

older persons with

deafblindness done by

various organizations

may be roughly divided

in four groups:

leisure,

training,

political activity and

material help.

In the leisure department,

the most frequent

activities are excursions

and specialized Deafblind

camps and retreats,

offering different training

options for older persons

with deafblindness,

as well as intergenerational

programmes,

in which persons with

deafblindness of all ages

can meet, socialize and

exchange experiences.

Types of training offered

to older person with

deafblindness are of

two-fold nature:

involving them into cooking,

handicraft workshops

and other skills needed

in everyday life

on one hand,

and include them in

more socially oriented

trainings preparing them

for jobs,

education on

rehabilitation services,

personal autonomy and

mobility,

access to technology,

adjustment to deafblindness

and optimization of

communication on the other.

Political activity is aimed

both at older persons

with deafblindness and

society at large.

Organizations assist the

Deafblind in legal matters,

campaign to improve

remote communication

for emergency and

assistance calls,

help them break

isolation and loneliness,

carry out personalized

projects aimed at promoting

social participation,

respect and inclusion.

Outwards political

activities include

spreading awareness,

disseminating

and communicating

information related to

deafblindness,

government support for

persons with deafblindness,

workshops on adapted

environments,

on sensory loss and on

communication possibilities.

Helping older deafblind

persons materially is an

activity restricted to

low-income countries.

Moreover, some older

persons with deafblindness

engage in voluntary work,

most often within local

organisations of or for

the Deafblind,

and they demonstrate

lower levels of depression

compared to both

non-sensory impaired

older persons who

volunteer and

older persons with

deafblindness not

engaged in such activity,

because volunteering is

done in contact with

other persons,

so, it increases control

over one’s life,

and gives a person with

deafblindness

a sense of being needed,

resulting in reduced social

isolation and loneliness.

**Recreation and participation**

**in social life**

These events partly

overlap with those

concerning leisure activities

from previous section,

especially when it comes

to one- and multi-day

excursions, social retreats,

picnics, visiting recreation

and other places,

summer holidays.

Celebrations are also

organized for days and

weeks related to

deafblindness.

Simple gathering and

socializing events,

or club events, with

no specific programme,

but regular meetups for

persons with deafblindness

are also organized.

Visits are organized to

different places:

museums, galleries,

cultural events, shopping

malls,

sensory gardens,

zoological gardens.

More “formal”

events include

local experience

groups,

conferences or

training events.

The Deafblind should

be encouraged to plan

and organize these

activities for themselves

and their peers and

provide intervention

and literacy support in

the planning process.

**Possible solutions**

Possible solutions for

the barriers and challenges

met by older persons

with deafblindness

encompass

several topics.

The first and most

important is raising

awareness and education

on deafblindness.

Education should be

provided for the person

with deafblindness

him/herself,

those in his/her

immediate environment,

and professionals, frontline

workers and

service providers with

whom he/she often

comes into contact.

The second are solution

for mobility problems,

cause both by

deafblindness and age,

as mentioned in

Article 10 of CRPD.

Then, there are also

organized activities for

older persons with

deafblindness,

human and technology

facilitators,

social and political activity

by both organizations of

persons with deafblindness

and branches of the

government,

as well as several solutions

to the problems

with health and other

professionals.

**Recommendations**

Some initial steps

to bridge the gaps

outlined in WFDB’s

first and second global

report

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 good

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 organizations.

Additional recommendations

expressed by older persons

with deafblindness

are the following:

1. Establishing centers

and resources that provide

specific and adequate

services and support to

older persons with

deafblindness

2. Creation of sites for

older persons with

deafblindness only,

where they could socialize

and communicate with

their peers and where

the staff would be educated

in deafblindness and

Deafblind methods of

communication

3. Funding of accessible

and public local transport

and other specific

services for older

persons with deafblindness

4. Organizing workshops,

projects, activities and

programmes for older

persons with deafblindness,

counting on their

involvement and

collaboration, to enable

them to learn new skills,

socialize with their peers,

participate in leisure

activities and strengthen

community building.

5. Including the voices

and perspective of

older persons with

deafblindness both

within disability mainstream

activities and in

organizations of persons

with deafblindness,

involving them in decision

making processes.

**Conclusion**

Building on the first

and second global report,

WFDB has expanded

quantitative and qualitative

analysis of the situation of

persons with deafblindness,

focusing on older persons

with deafblindness using

data from available

literature, interviews

and a survey.

There has been progress

in raising awareness

on the situation of persons

with deafblindness with

the first and second

global report.

However, governments,

funders, NGOs, OPDs,

and other development

stakeholders must develop

a firm grasp of the concrete

measures and interventions

to address the situation

of persons with

deafblindness, concretely,

of older groups.

Although more robust

research is required

across all areas,

this third global report

provides these

stakeholders with good

practices and inspiration

for improved services that

are inclusive of persons

with deafblindness.

Older persons with

deafblindness must

cope with the same

barriers as all the other

Deafblind persons:

mobility, communication

and access to information,

amongst others.

However, they face

additional obstacles

related to age.

For older persons with

deafblindness the

effects of disability and

ageing interact with

each other,

often multiplying the

discrimination,

disadvantage and inequality.

This combination can

be enhanced by other

disabilities and illnesses

that can occur in old age,

as well as ableism,

ageism, other attitudinal

barriers and intersecting

sources of identity.

This Global Report

described some of those

barriers, obstacles

and gaps,

as well as some

suggested solutions,

recommendations and

some examples of

good practice.

This document is an

executive summary of

a full report.

You can access the

report in different formats

and languages here.