



December 2023

Older people with deafblindness



Easy
Read

Easy Read



This is an Easy Read version of some information. It may not include all of the information but it will tell you about the important parts.



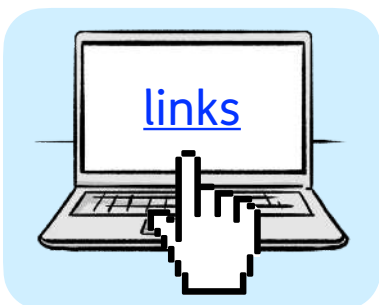
This Easy Read booklet uses easier words and pictures. You may still want help to read it.



Some words are in **bold** - this means the writing is thicker and darker. These are important words in the booklet.



Sometimes if a bold word is hard to understand, we will explain what it means.



Blue and underlined words show links to websites and email addresses. You can click on these links on a computer.

What is in this booklet

About this report.....	4
Deafblindness.....	5
Older people with deafblindness	6
What older people with deafblindness need.....	8
The SHAPES Project	9
What makes things hard for older people with deafblindness.....	13
What should happen next	36
Find out more.....	38

About this report



This report was written by the **World Federation of the Deafblind**.

The **World Federation of the Deafblind** works around the world to speak up for people with **deafblindness**.



Deafblindness is a disability where you have serious difficulty with both your hearing and your eyesight.



We want people with deafblindness to have the same chance to make the most of their lives as everyone else.



We have written this report to look at ways to support older people with deafblindness.

Deafblindness



Deafblindness is a disability that is different from other disabilities.

Deafblindness makes it hard to:



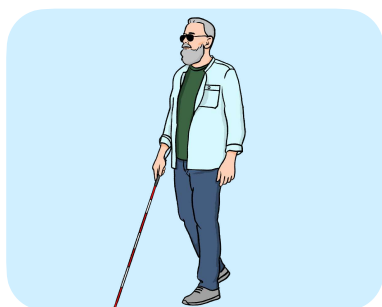
- Meet up with friends and family.



- Share information, ideas and feelings with people.



- Get the information you need.



- Move around safely.

Older people with deafblindness

Older people with deafblindness usually become deafblind in 4 ways:



1. They have had deafblindness for a long time, and it is not because they are getting older.



2. They have been deaf for a long time, but started losing their eyesight as they got older.



3. They have been blind for a long time, but started losing their hearing as they got older.



4. They could see and hear when they were younger, but started losing their hearing and eyesight as they got older.



Most older people with deafblindness are in the fourth group, and lose their hearing and eyesight as they get older.



These people often find it harder to share what they are thinking or feeling.



But all groups with deafblindness can find it difficult as they get older, and they usually need care and support.

What older people with deafblindness need

We found that older people with deafblindness often need help with:



- Everyday things, like shopping and chores around the house.



- Feeling happy. Many older people with deafblindness can feel worried, sad or lonely.



- Feeling good about their future.

Many older people with deafblindness need support to feel good about their future.

The SHAPES Project



The **SHAPES project** is making ways to share information about supporting people as they get older.



Different organisations from across Europe are working on this project.



The World Federation of the Deafblind has worked with the SHAPES project.



This report will help people learn more about supporting people with deafblindness.



We have included people with deafblindness in the SHAPES Project to learn more about them.



In July 2023, we asked people to take part in an online survey to help us learn about older people with deafblindness.

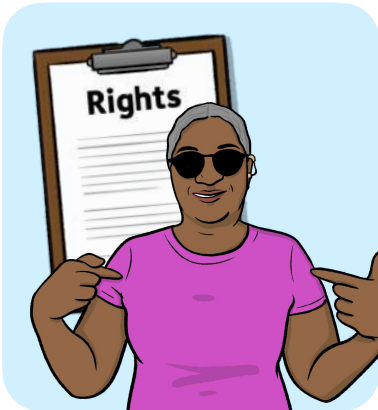


86 people from 24 countries took part in the survey.



We also met with people with deafblindness, to find out what they thought.

We learned that the SHAPES project should:



- Always respect the **rights** of people with deafblindness.

Rights are things that every person should be able to do or have, by law.



- Make changes to how they share information, so that people with deafblindness can:



- Understand the information they are given.



- Share their thoughts and feelings about the information.

We also learned that the SHAPES project should:



- Work with organisations that are run by people with deafblindness.

Projects should do this as early as possible, so that they do not need to make changes later on.



- Understand that people with deafblindness might need extra support.



- Support organisations that are run by people with deafblindness to speak up, by giving them time and money.



- Train the people working on projects to help them to understand deafblindness.



- Make sure that people can get information in ways that they are able to understand.

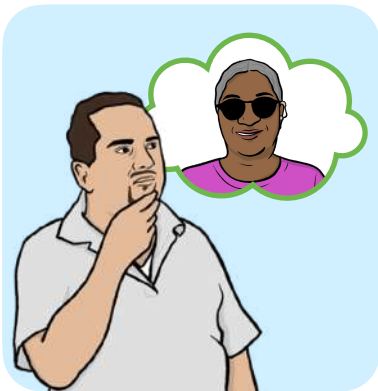
What makes things hard for older people with deafblindness



People told us about the things that can make life hard for them.

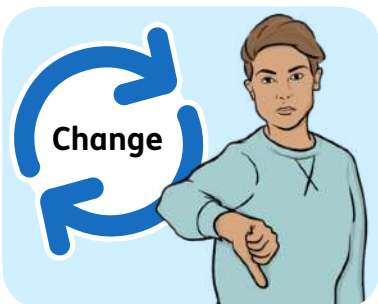
These are called **barriers**.

There were 2 main types of barriers:



1. How people think about older people with deafblindness.

Some people think that older people are unable to take part in daily activities.



2. Not enough changes to support people with deafblindness to take part in activities.



In this part of the report, we will explain more about the barriers that people with deafblindness face.

The law



It is important that the law in different countries mentions deafblindness.



This will help people with deafblindness to get the support they need.



But many countries and organisations around the world do not mention deafblindness in their laws and rules.



This means that people with deafblindness may not get the rights and support that they should have.

Emergency services



Emergency services help people who have a serious problem and need help quickly. These services include the police and ambulances.



Emergency services should provide support to people with deafblindness to make it easier for them to ask for help.

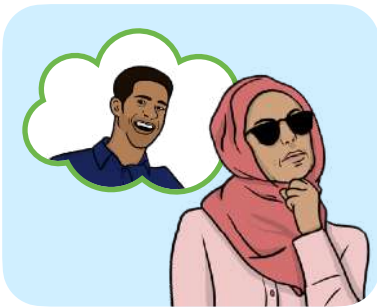


If they do not, people with deafblindness might not get the help they need when they are in danger.

Interpreters



Interpreters are people who help people with deafblindness to share what they are thinking and feeling with others.



It is not always easy for people with deafblindness to get an interpreter.



This can make all parts of their life harder.

Feeling lonely



Almost all people with deafblindness feel lonely sometimes.



It can be hard when others can not understand them, or when they can not understand others.



Other people, including friends, family and doctors, often do not know how to share information with them.



This is a serious problem, because it stops people with deafblindness from being healthy and happy.

Not speaking up



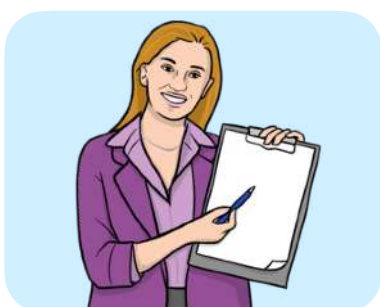
Many older people lose their hearing and eyesight when they get older.



They do not always realise that they need help and support.



These people do not always speak up about being deafblind, which means they do not get any help.



It is important that services know when someone has deafblindness.

Calling yourself 'deafblind'



I am deafblind

Many people do not want to call themselves 'deafblind', even if they have lost their hearing and eyesight.



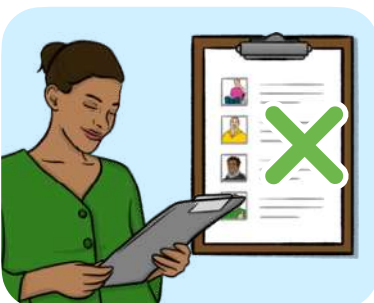
Just getting older

They might think it is just part of getting older.



Services

But this can mean that they do not get to use services for people with deafblindness.



It can also mean that countries think there are not as many people with deafblindness as there really are.

Meeting other people with deafblindness



It is important for people with deafblindness to meet each other.



It can help them to make new friends, and feel less lonely.

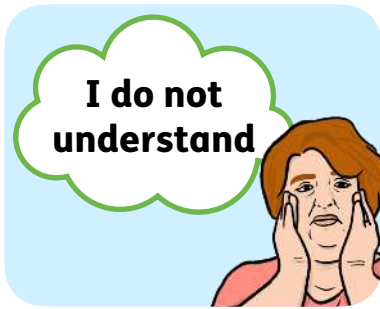
Dementia



Some doctors might think that an older person who has lost their eyesight and hearing has **dementia**.



Dementia is a disease in the brain. It affects your memory and behaviour.



This might be because the older person with deafblindness is finding it hard to understand things people say.



It is important for doctors to tell the difference between dementia and deafblindness.

Other disabilities and illnesses



People with deafblindness might have other disabilities and illnesses too.

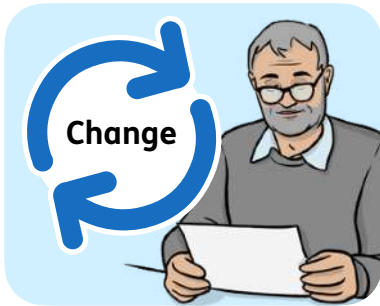


There are some disabilities and illnesses that are more common for people with deafblindness.

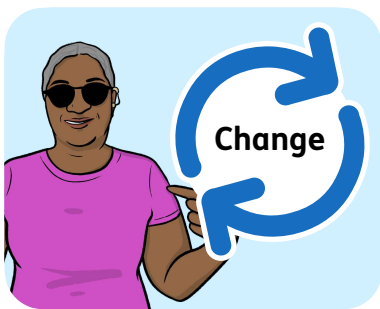


This can make their lives harder.

Getting used to changes



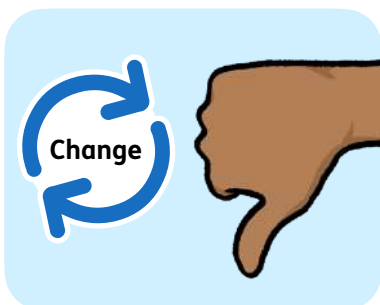
Older people with deafblindness often have to get used to changes in their hearing and eyesight.



These changes can mean their whole life changes.



They might need to change how they spend time with others, or how they take part in everyday activities.



Older people with deafblindness often do not want to change how they share their thoughts and feelings.



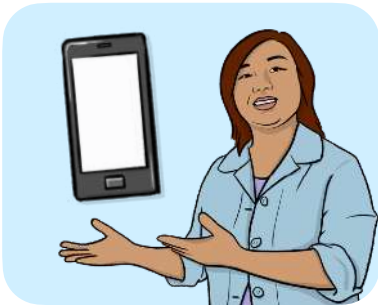
Some people with deafblindness use **technology** to share how they are thinking and feeling.

Technology is gadgets like phones and computers.



But some older people with deafblindness can find this technology difficult to use.

It is important to:



- Teach people with deafblindness to use technology in a way that is easy for them to understand.



- Give people help that is right for them.

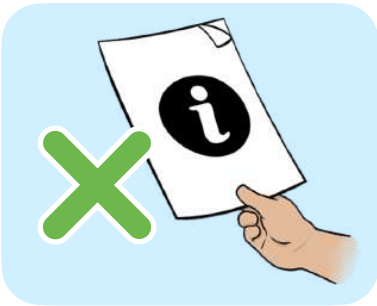


- Help people with deafblindness to speak up about the type of help that they need.

Health and care staff



Many people with deafblindness do not trust health and care staff to listen to them and give them the support they need.



They might not get information in ways they can understand.



Health and care systems do not always understand deafblindness or what people with deafblindness need.



This can mean that they are not as healthy as they should be.



Many older people with deafblindness live in care homes.



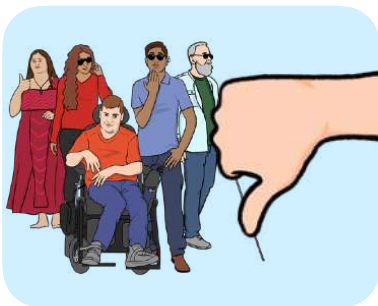
But care home staff do not always understand what older people with deafblindness need.



This can mean that older people with deafblindness are not treated well.



Many older people with deafblindness said that they want to live in care homes with other people with deafblindness.



But they do not usually get the chance to live this way.

Empowerment



Empowerment means having choice and control over your own life, and being proud of who you are.



There are many things that can stop empowerment for people with deafblindness.



The most important thing for people with deafblindness is that they should be able to share how they are thinking and feeling.

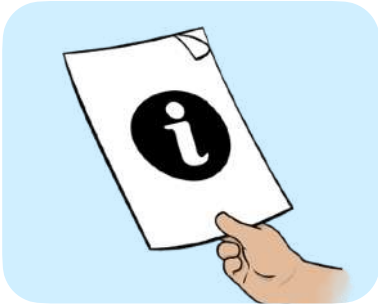


Older people are also not always given choice and control over their own lives.



It is important that services listen to older people with deafblindness.

Information



It is important for older people with deafblindness that they can get information that they can understand.



Most people get information from technology.

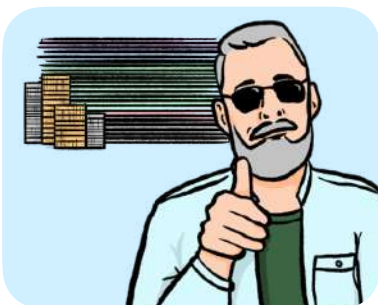
So, for people to get information, people with deafblindness should get:



- Support on using technology.



- Technology that is simple and easy to use.

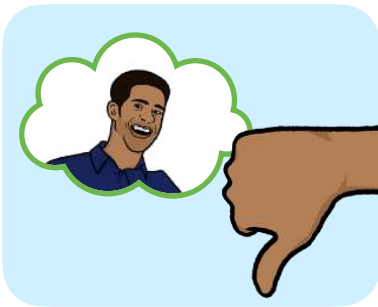


- Technology that does not cost too much.

Independence



Independence means doing things for yourself.



Some people feel that interpreters give them less independence, because they rely on them for help.



Others think that interpreters give them more independence, because they can do more.



It is important to give people choice and control, so they can choose the support they get.

Being treated badly



People with disabilities are more likely to be treated badly than people without disabilities.



Many older people with deafblindness are treated badly, including being hurt by others.



It is important that people can take the people that hurt them to court.

Work



Becoming deafblind can stop people from working.



This can make them feel more lonely.

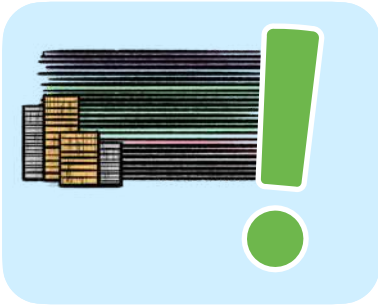


Older people with deafblindness often want to carry on working.



It is important for companies to think of ways of including people with deafblindness who want to work.

Money



Many people with deafblindness do not have enough money to afford the things they need to live.



Governments often do not do enough to help people with deafblindness to learn, stay healthy and get jobs.



This can make it harder for people with deafblindness to make more money.

Having fun



People with deafblindness have the right to have fun and take part in their local community.



Having fun can be a good way for people with deafblindness to share how they are feeling.



Activities for people with deafblindness can help them feel happier and less lonely.



But it can be hard for older people with deafblindness to take part in these activities.



Often, the activities are far away from where they live.



Some countries do not do these activities at all.

Taking part in projects

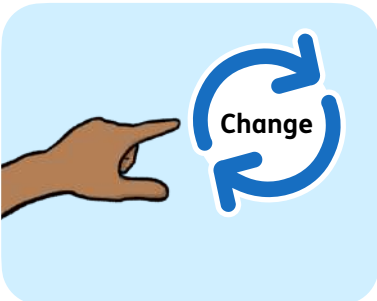
Projects for older people with deafblindness include:



- Fun activities.



- Training, like training on getting used to being deafblind, and daily activities like cooking.



- Making changes in their country, like speaking up about what older people with deafblindness need.



- Helping them to live better lives.



Some older people with deafblindness volunteer - this means they offer to help with projects and organisations without being paid.



This helps them to spend time with other people and make friends.

Spending time with others



Events can help older people with deafblindness to spend time with others. These can include:

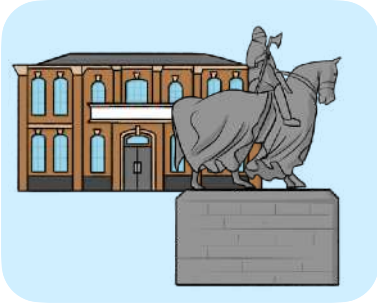


- Events that take place over 1 day, like a picnic.



- Chances to meet other people with deafblindness.

Events for people with deafblindness can also include:



- Trips, like to museums and shops.



- Training events.



People with deafblindness should organise these events for themselves, with support.

What should happen next



We can help get rid of some of the barriers that older people with deafblindness face.

We have some ideas for how to do this:



- Countries should mention deafblindness as a disability with its own barriers.



- Health and care staff should get training and information about how to support people with deafblindness.



- Countries should provide help for people with deafblindness, like interpreters, for anyone who needs it.

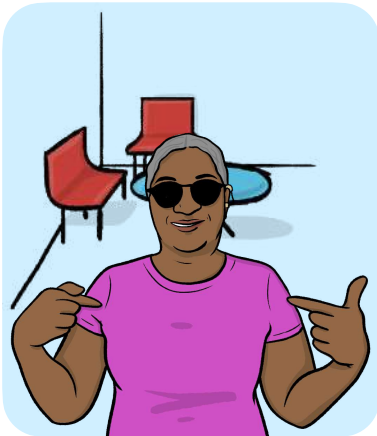


- Countries should find out more about how services can support older people with deafblindness in ways that respect their rights.

Older people with deafblindness also had ideas to get rid of barriers:



- Create places that provide services and information for older people with deafblindness.



- Create places where only older people with deafblindness can go, and spend time together.

The staff in these places would be trained on deafblindness.

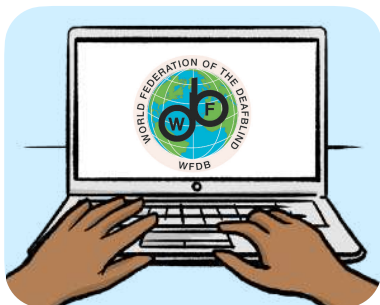


- Organise projects and activities for older people with deafblindness, to help them learn new skills and make friends.

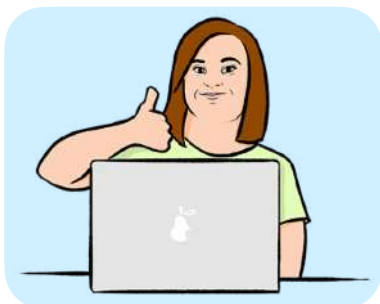


- Listen to older people with deafblindness and let them help with making choices about services.

Find out more



You can look at our website here:
www.wfdb.eu



You can find other versions of this report here:
<https://wfdb.eu/wfdb-global-report-on-older-people-with-deafblindness/>



You can also find out more by:

- Emailing us at:
communication@wfdb.eu

- Looking at our:

- Twitter:
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