

06

A bite size guide to:

# Improving deafblind patient and carer public voice in the NHS

Publications gateway reference: 05419

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

# Getting started

NHS England is committed to ensuring that patient, carer and public voices are at the centre of shaping our healthcare services and informing service development. Every level of our commissioning system needs to be informed by insightful methods of listening to those who use and care about our services. We need to ensure that patients, carers and the public, regardless of disability, are equally able to have their voices heard.

NHS England is committed to improving awareness and involvement of deafblind patient, carer and public voices.

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

# What is deafblindness?

A person is deafblind if they have a combined sight and hearing impairment that causes difficulties with communication, access to information and mobility. These difficulties can occur even when hearing loss and vision loss are mild, because the two senses usually work together, and one would usually help compensate for loss of the other.

Deafblindness (sometimes referred to as dual sensory loss or, in children, multisensory impairment) can have a significant impact on a person's life, even if they have some vision or hearing remaining. The combination of hearing and visual impairment causes communication and access needs that need to be addressed

specifically, and may require a different approach to that needed by a person with single sensory loss.

Deafblind people use many different methods of communication. The method, or methods used, will depend on the amount of residual sight and hearing, and any additional disabilities the individual has. It will also depend on whether the individual has learned formal language before becoming deafblind. Communication methods that may be used, amongst others, include British Sign Language (BSL) deafblind manual and block alphabet, and clear speech.

Getting started

What is deafblindness?

Core principles

Practical Steps

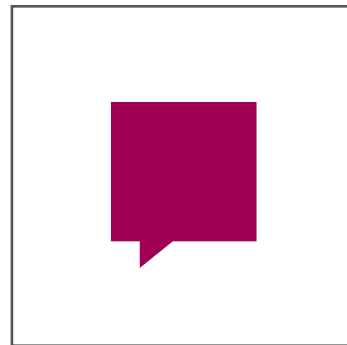
Challenges faced

Glossary

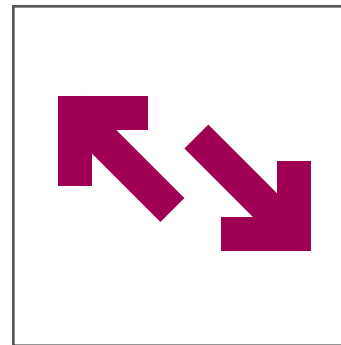
Want to learn more?

Other bite-size guides

# Core principles



The opportunity to participate and have your voice heard in the NHS should be equally available to everyone, regardless of disability.



A diverse range of approaches to engagement are needed to enable such equality of opportunity with regards to participation.



Deafblind patient, carer and public voice needs to be embedded in NHS services, and not seen as an “add-on” part of programmes.

Getting started

What is deafblindness?

Core principles

Practical Steps

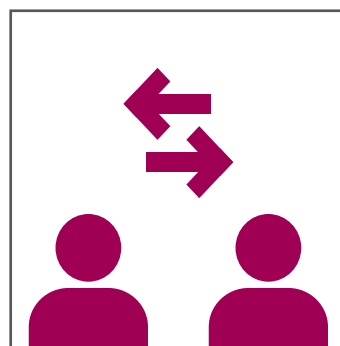
Challenges faced

Glossary

Want to learn more?

Other bite-size guides

## Core principles



Understanding the unique challenges of deafblindness and supporting deafblind people to participate will promote effective and inclusive patient involvement.



Having deafblind patient, carer and public representation and insight in the NHS will offer diverse perspectives, and improve services, quality, experiences and outcomes.



Supporting effective participation from deafblind patient, carers and the public requires knowledge, understanding, planning, support and resource.

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

# Practical Steps

- 1. Take responsibility.** It is everyone's role to ensure that diverse voices, including those of deafblind people, can be heard in all healthcare services.
- 2. When arranging engagement activities, be sure to ask people if they have any communication or other support needs which will enable them to participate.** Be proactive in offering support and adjustments, and be mindful that deafblind people will often require a combination of different mechanisms to support communication.
- 3. Plan ahead.** When engaging with deafblind people, consider that participants may need support from interpreters or communicator guides at events. They may also need information in alternative formats, for example, via email, on audio CD or in braille, Matakoto or Moon. They may also find 'sans serif' fonts, such as Arial point 16 to 26, easiest to read. These can take time to arrange, and as such, more notice may be required.

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

## Practical Steps

- 4. Speak to existing stakeholders and patient and public voice groups, especially those in the voluntary sector.** They are a great source of expertise and could offer guidance on ways to engage with deafblind people.
- 5. Reach out to deafblind patient and community groups to make sure they are aware of your programme and that you want to hear their views.**
- 6. Build the costs of supporting deafblind people to participate in your work into your programme budget.** Consider the cost of interpreters and communicator guides at events. They may also need support to communicate using a communication tool or aid, for example, Tadoma or a Voice Output Communication Aid (VOCA). A deafblind person may also use non-verbal communication including gestures, pointing or eye-pointing.

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

01 02 03 04 05 06 07 08 09 10  
11 12 13 14 15 16 17 18 19 20

## Challenges faced

*"We only have two deafblind patient representatives, why are we making adjustments?" "Booking an interpreter is too expensive"*

NHS England has a duty to involve, as expressed in the Equality Act 2010 public sector equality duty, and is committed to ensuring everyone has the same opportunities to have their voice heard, including people with different communication needs. Unless we take proactive steps to involve, and encourage involvement from people who are deafblind, and other people with disabilities, it is likely that people will feel excluded and their voices will not be heard.

As with many groups who face barriers to accessing and getting the most from NHS services, effective engagement with deafblind people is likely to mean that decisions and services improve for wider groups too.



Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

## Challenges faced

### Case study

Janice, who is herself deafblind, has spent many years campaigning to raise awareness of the needs of deafblind people. This has included delivering deafblind awareness training to a variety of health and social care settings, assisting the national deafblind charity Sense with campaigning, and much more. Recently, Janice was asked by her local Healthwatch to be a volunteer, and be their local champion for people using health and social care.

*“Being able to volunteer for Healthwatch makes me feel valued both in terms of me as a person and the knowledge that I have. I was delighted when they said they could cover the costs of my support worker – I wouldn’t have been able to take part otherwise.”* **Janice**

*“Janice has been a great addition to our growing Healthwatch Northamptonshire volunteer community. She brings personal experience of living as a deafblind person, and is able to provide advice and guidance to us on how to ensure we engage with people.”* **CEO, Healthwatch Northamptonshire**

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

# Glossary

**Braille:** a tactile reading format used by people who are blind, deafblind or who have some visual loss. Readers use their fingers to 'read' or identify raised dots representing letters and numbers. Although originally intended (and still used) for the purpose of information being documented on paper, braille can now be used as a digital aid to conversation, with some smartphones offering braille displays.

**British Sign Language (BSL):** BSL is a visual-gestural language that is the first or preferred language of many d/Deaf people and some deafblind people; it has its own grammar and principles, which differ from English.

**BSL interpreter:** a person skilled in interpreting between BSL and English. A type of communication support which may be needed by a person who is d/Deaf or deafblind.

**BSL interpreter - hands-on signing:** a BSL interpreter who is able to sign with the hands of the person they are interpreting for placed over their hands, so that they can feel the signs being used. A type of communication support which may be needed by a person who is deafblind.

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

## Glossary

**BSL interpreter - visual frame signing:** a BSL interpreter who is able to use BSL within the visual field of the person with restricted vision. A type of communication support which may be needed by a person who is deafblind.

**BSL interpreter - Sign-Supported English (SSE):** a BSL interpreter who is able to communicate using BSL signs but in the order that they would be used in spoken English. A type of communication support which may be needed by a person who is d/Deaf or deafblind.

**BSL translator:** a person able to translate written or printed English into British Sign Language (BSL), to support face-to-face consideration of a document, or for recording for use in a BSL video for example for publication on a website.

**BSL video:** a recording of a BSL interpreter signing information which may otherwise only be available in written or spoken English. A BSL video may be made available on DVD or via a website.

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

## Glossary

**BSL video remote interpreting (VRI) - also known as video interpreting, remote interpreting or virtual interpreting:** an online service in which a BSL interpreter interprets via video software. It works using a computer and webcam, a smartphone or tablet. Provided through contract or on demand by a range of organisations, it enables a direct connection to an interpreter so that the d/Deaf person can sign to them what they want to say. The interpreter then speaks this to the hearing person (via video link) and signs back their (spoken) reply.

**Communication tool or aid:** a tool, device or document used to support effective communication with a disabled person. They may be generic or specific / bespoke to an individual. They often use symbols and / or pictures. They range from a simple paper chart to complex computer-aided or electronic devices.

**Deafblind communicator-guide:** a professional who acts as the eyes and ears of the deafblind person including ensuring that communication is clear.

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

01 02 03 04 05 06 07 08 09 10  
11 12 13 14 15 16 17 18 19 20

## Glossary

**Deafblind intervenor:** a professional who provides one-to-one support to a child or adult who has been born with sight and hearing impairments (congenital deafblindness). The intervenor helps the individual to experience and join in the world around them.

**Deafblind manual interpreter - deafblind manual alphabet:** a person skilled in interpreting between the deafblind manual alphabet and English. The deafblind manual alphabet is a tactile form of communication in which words are spelled out onto a deafblind person's hand. Each letter is denoted by a particular sign or place on the hand.

**Deafblind manual interpreter - block:** a person skilled in interpreting between the deafblind block alphabet and English. The block alphabet is a tactile form of communication in which words are spelled out on to the palm of the deafblind person's hand.

**Deafblind manual interpreter - haptic communication:** a person skilled in using haptic communication and interpreting between this and English. Haptic communication is a tactile form of communication in which signs are used to describe information which would otherwise be provided by sight. The signs are given through touch, commonly to the back.

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

01 02 03 04 05 06 07 08 09 10  
11 12 13 14 15 16 17 18 19 20

## Glossary

**Hearing loop system:** a hearing loop or 'audio frequency induction loop system,' allows a hearing aid wearer to hear more clearly. The loop system allows the sound of interest, for example a conversation with a receptionist, to be transmitted directly to the person using the hearing aid clearly and free of other background noise.

**Large print:** printed information enlarged or otherwise reformatted to be provided in a larger font size. A form of accessible information or alternative format which may be needed by a person who is blind or has some visual loss. Different font sizes are needed by different people. Note it is the font or word size which needs to be larger and not the paper size.

**Lipreading:** a way of understanding or supporting understanding of speech by visually interpreting the lip and facial movements of the speaker. Lipreading is used by some people who are d/Deaf or have some hearing loss and by some deafblind people. A person can be supported to lipread by the speaker clearly addressing the person and facing them whilst speaking, avoiding touching or covering their mouth, and ensuring conversations are held in well-lit areas.

**Lipspeaker:** a person who repeats the words said without using their voice, so others can read their lips easily. A professional lipspeaker may be used to support someone who is d/Deaf to communicate.

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

01 02 03 04 05 06 07 08 09 10  
11 12 13 14 15 16 17 18 19 20

## Glossary

**Makaton:** a communication system using signs, symbols and speech. There are three levels of Makaton, used according to the individual's circumstances and abilities – functional, keyword and symbol reading. Makaton may be used by people with deafblindness or a learning disability.

**Moon:** a tactile reading format made up of raised characters, based on the printed alphabet. Moon is similar to braille in that it is based on touch. Instead of raised dots, letters are represented by 14 raised characters at various angles.

**Non-verbal communication:** communicating without using speech and instead using gestures, pointing or eye-pointing.

**Notetaker:** in the context of accessible information, a notetaker produces a set of notes for people who are able to read English but need communication support, for example because they are d/Deaf. Manual notetakers take handwritten notes and electronic notetakers type a summary of what is being said onto a laptop computer, which can then be read on screen. Notetakers are commonly used in combination with other communication support, for example people who are watching a sign language interpreter are unable to take notes at the same time.

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

## Glossary

**Sign language:** a visual-gestural language and way of communicating.

**Sign language interpreter – not BSL:** an interpreter of a non-British sign language, for example Irish or American Sign Language.

**Speech-to-text reporter (STTR):** a STTR types a verbatim (word for word) account of what is being said and the information appears on screen in real time for users to read. A transcript may be available and typed text can also be presented in alternative formats. This is a type of communication support which may be needed by a person who is d/Deaf and able to read English. A STTR may also be known as a Stenographer® or Palantypist®.

**Tadoma:** Tadoma involves a deafblind person placing their thumb on a speaker's lips and spreading their remaining fingers along the speaker's face and neck. Communication is transmitted through jaw movement, vibration and facial expressions of the speaker.

**Text Relay:** Text Relay is a national text to voice relay service run by British Telecom (BT). It allows people with hearing loss or speech impairment to use a textphone to communicate and access any services that are available on standard telephone systems.



Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

## Glossary

**Translator:** a person able to translate the written word into a different signed, spoken or written language. For example a sign language translator is able to translate written documents into sign language.

**Voice Output Communication Aid (VOCA):** also known as a speech-generating device (SGD). An electronic device used to supplement or replace speech or writing for individuals with severe speech impairments, enabling them to verbally communicate.

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

# Want to Learn More?

<http://www.sense.org.uk>

<http://deafblind.org.uk/>

<http://www.nhs.uk/Conditions/Deafblindness/Pages/Introduction.aspx>

<http://www.legislation.gov.uk/ukpga/2010/15/section/149>

<http://www.britishsignlanguage.com/>

## Need help?

Visit our intranet pages:  
<http://www.england.nhs.uk/ourwork/patients/public-voice/>  
or contact the Patient and Public Voice Team at [england.nhs.participation@nhs.net](mailto:england.nhs.participation@nhs.net)

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

## Other Bite-Size Guides

Click on the links below to download each of our '[bite-size guides](#)' to participation.  
Additional guides are in development.

[Bite-size guide 1 – Principles for Participation in Commissioning](#)

[Bite-size guide 2 – Governance for Participation](#)

[Bite-size guide 3 – Planning for Participation](#)

[Bite-size guide 4 – Budgeting for Participation](#)

Guides 5 -15 are also available via the following link:

<https://www.england.nhs.uk/participation/resources/>

Getting started

What is deafblindness?

Core principles

Practical Steps

Challenges faced

Glossary

Want to learn more?

Other bite-size guides

01 02 03 04 05 06 07 08 09 10  
11 12 13 14 15 16 17 18 19 20

 [www.england.nhs.uk](http://www.england.nhs.uk)

 [@NHSEngland](https://twitter.com/NHSEngland)

 0113 8250861

 [england.nhs.participation@nhs.net](mailto:england.nhs.participation@nhs.net)

Date: June 2016

Publications gateway reference: 05419



**This is an interactive PDF:** To navigate, use the arrow buttons at the bottom or the main menu on the left side of the page.

NHS England's series of 'Bite-size guides' aims to help colleagues plan and deliver the best possible patient and public participation, in line with Transforming Participation in Health and Care.

For further information, please contact  
[england.nhs.participation@nhs.net](mailto:england.nhs.participation@nhs.net)

***Produced by the Public Participation team at NHS England.***

The Disability Partnership

