



DEAFBLIND

• SCOTLAND •

**An Inclusive Communication Guide
for Engaging with Deafblind People**

This toolkit was created by Deafblind Scotland and funded by the Scottish Government in support of the implementation of the British Sign Language (BSL) National Plan: 2017-2023.

Within this plan the Scottish Government states that it wants ‘to make Scotland the best place in the world for BSL users to live, work and visit. This means that people whose first or preferred language is BSL will be fully involved in daily and public life in Scotland, as active, healthy citizens, and will be able to make informed choices about every aspect of their lives’. www.gov.scot/publications/british-sign-language-bsl-national-plan-2017-2023/

The BSL (Scotland) Act 2015 requires public bodies in Scotland to publish plans every six years, showing how they will promote and support BSL. This guidance aims to support the implementation of these plans through providing guidance to public sector bodies across the range of services where currently we are aware that BSL users are encountering communication barriers that reduce their opportunities to live ‘healthy’ and ‘active’ lives.

In support of the implementation of the British Sign Language (BSL) Plans, the central focus within this toolkit is on the communication support needs of deafblind people who are BSL or Tactile BSL users, however for completeness and in recognition of the range of barriers experienced by deafblind people, the toolkit will cover other significant elements of inclusive communication.

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Inclusive Communication Guide



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Foreword – Maree Todd

In 2015 Scotland took the important step of introducing new legislation to promote the usage and understanding of British Sign Language (BSL) - the British Sign Language (Scotland) Act 2015. When considering this legislation, the rights of all BSL users was highlighted, and the Act specifically references deafblind people who use BSL or modified versions of this such as Tactile BSL. Deafblind people can be amongst those least visible in society and they often face significant challenges in accessing information, making decisions, and - critically - in having that most important of needs met, to have a social connection with another human being.

These barriers can be due to a lack of understanding about the range of communication needs deafblind people have, and services continue to say that they are not confident in connecting with someone who is deafblind. Deafblind people also told us this during the development of the Act and the BSL National Plan that followed.

Deafblind Scotland has been a key partner for the Scottish Government over the years, ensuring that deafblindness is included when we consider BSL. In the 5 years since the inception of the BSL Act we have made progress in furthering society's understanding of BSL as a language, and there have been positive signs that we are beginning to see greater understanding of Tactile BSL and the communication rights of deafblind people. However, there is still more to do. As the Scottish Minister with responsibility for the Scottish Government's BSL National Plan, I am delighted to support the creation of this guide. My hope is that this will not only serve as a useful source of information but, most importantly, it will close that confidence gap that can get in the way of services engaging with deafblind people at times when they most need it.



Access to communication should not feel like a privilege, but rather a right we all share. I hope this guide will support and enable you to do what you can to ensure deafblind people are recognised and valued in our society.

Maree Todd MSP

Minister for Children and Young People

Foreword – Debra Wherrett

This toolkit is very welcome amongst the Tactile British Sign Language (BSL) community. I have fought for many years for Tactile BSL users right to access to Tactile BSL as our preferred method of communication. I hope this guide will continue to ensure deafblind people are recognised, valued and fully included in our society

BSL is my first and preferred language. When I started to lose my sight I feared I may also lose my language, and that I would not be able to fluently express myself in the way we all take for granted. Adapting to Tactile BSL has been vital for me. Tactile BSL ensures that I continue to receive information in my first language and that I maximise my ability to process information, participate and contribute to all aspects of life.

Deafblind BSL users have grown up learning and using BSL every day, therefore that language should not be taken away based on what society or others believe is the best approach. This is why it has been so important to have Tactile BSL included in every aspect of the BSL (Scotland) Act 2015. BSL users who lose their sight must have the right to access Tactile BSL and preserve our first language. If we are only offered English language information, we could not fully express ourselves. Having this access to accessible information through Tactile BSL has ensured I have full access to all the information available. This has been especially vital during the recent global pandemic. New terms and concepts are being used in our everyday life (i.e. restrictions, strategic frameworks, social distancing) by using Tactile BSL I am able to process the fullness of these concepts. Ensuring deafblind BSL users do not miss the opportunities to participate and contribute that everyone else in society has.

Deafblind people must be able to challenge the assumptions that individuals, organisations and communities make. Receiving the recognition that

deafblind people know what works best for them and therefore they should be the ones who are central to contributing ideas and solutions to society's challenges. This ensures deafblind people achieve solutions that work for them, rather than others deciding what is best for them.

I hope that this guidance will provide you with the awareness and practical help to ensure effective and meaningful inclusion of deafblind people in your work.

Debra Wherrett

Trustee, Deafblind Scotland

co-Chair - National Advisory Group

developing the BSL National Plan



Why this Toolkit is needed

Deafblind Scotland's vision is:

'a society in which deafblind people have the support and recognition necessary to be able to exercise their rights and fully participate in their communities as equal citizens'.

As signatories to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)ⁱ the Scottish Government have given a commitment to ensuring that the full rights of people with disabilities will be recognised.

People who are deafblind are amongst the most marginalised and invisible within society leading to profound isolation and a wide range of unequal life chances. The lack of awareness of the diverse needs of Deafblind people within the services that provide the support necessary to grow, develop and lead a fulfilled life has been described as 'both a cause and consequence' of this lack of visibility.

“Being deafblind is like living in a cupboard, the only time the light comes on, is when someone does Deafblind Manual on my hand, then they go away and the door closes.”

Dorrie Moore,
former Deafblind Scotland Member



Aims

This guide aims to address this issue of awareness and provide policy makers, service planners and providers with an insight into what it means to be deafblind alongside dispelling any myths that may hinder engagement.

Importantly the guide provides straightforward practical steps that can be taken to:

- reduce communication barriers through building an understanding of inclusive communication needs and how to put in place necessary support;
- improve access to information in preferred formats/language;
- ensure equitable access to public services that will help address health and social inequalities encountered by deafblind people; and
- open up participation opportunities within operational and strategic/ policy and legislative planning and development that will enable deafblind people to take up their place as equal citizens within civic and public life.



This guide has been written in partnership with Deafblind Scotland members and has been informed throughout by the real daily challenges and lived experiences of Deafblind people.

Part One: Introducing deafblindness

What is deafblindness?

Deafblindness is the combined loss of both vision and hearing. For some people this may be a complete sensory loss whilst for others there may be some residual sight or hearing that can be used. Deafblindness has been defined in a number of ways but in understanding the impact on people's lives it is important that it is not thought of in terms of two single sensory losses as this uniquely disabling condition is greater than the sum of its parts. When an individual experiences a single sensory loss or are Deaf from birth they often cope by making the best use of their other senses however, with a dual sensory loss this coping strategy becomes less effective.

Currently within Scotland there is no consensus on a clinical definition of deafblindness. In the absence of this a commonly adopted, helpful definition is that deafblindness is:

'The loss of functioning in one sense [that] cannot be compensated for with the other sense, resulting in a distinct disability'.ⁱⁱ

Deafblindness affects each person differently from some people being hard of hearing and having difficulty with vision that is assisted but not resolved by wearing glasses or contact lenses and therefore adopt coping strategies and communication methods that include a mixture of some residual sight and hearing through to a smaller group of those who are entirely D/deaf and/or visually impaired. Around three quarters of all deafblind people are older and have acquired deafblindness as they age.

KEY POINT: An important point of note is that deafblind people who are Deaf first may hold a Deaf cultural identity and be a part of the Deaf community. This is important as throughout this toolkit the term sensory impairment or loss is applied and for the Deaf community this disability focused terminology is not appropriate. Given the complex heterogeneous nature of an individual's journey to becoming deafblind with many acquiring sensory losses across life it is not possible to differentiate in every aspect of this toolkit. However, in adopting a person centred approach to planning and delivery of services these differences should be explored to ensure that the appropriate terminology is being used and that cultural identity is being taken into consideration. Other deafblind people who become deafened, hard of hearing or deafblind later in life may not adopt this cultural identity.

The impact of deafblindness

The combination of sensory losses can result in significant difficulties in areas of everyday life, including:-

- accessing information and learning;
- mobility and navigating the physical environment; and
- communicating and building and maintaining relationships (social connectedness).

Deafblindness can happen at different stages of life and the age of onset of a person's visual impairment and hearing loss (or Deafness) can have a profound impact on the consequences of deafblindness. This is particularly the case in relation to communication and language development. It therefore can be important to distinguish between:-

- **Congenital deafblindness** – where a child is born Deaf with a visual impairment or where a child acquires hearing loss and a visual impairment at an early stage in life before the development of

language. Occurring at a pre-lingual stage this form of deafblindness requires the child to develop language whilst deafblind.

- **Acquired deafblindness** – where vision and/or hearing loss is acquired during the course of life following language development, where language maintenance or adaption is the focus. An individual may already have one sensory loss and acquire a second during their life or both senses may deteriorate across life.
- **Usher Syndrome** – is a genetic condition which causes hearing loss from birth, and a later progressive loss of vision due to Retinitis Pigmentosa (RP). There are three types of Usher Syndrome (see **Part 3 Tools and Resources** for Key Terminology).
- **CHARGE** – is a genetic syndrome, each individual will have a varying degree of impairments and medical conditions, that can be linked to a recognised pattern. Most people with CHARGE will develop hearing impairment, vision impairment, and balance problems, along with life-limiting medical conditions from birth.

KEY POINT: Levels of acquired deafblindness have been increasing as they are more prevalent among older age groups and around **30% of over 80 year olds experienced deafblindness** to a degree (where their communication, mobility and access to information is significantly affected) creating challenges for language maintenance and adaption. Where deafblindness develops in childhood this can have other additional implications such as for family functioning, educational outcomes and life opportunities.

How Common is deafblindness?

As there is no agreed clinical criteria or thresholds for assessing when someone may be considered to be deafblind, the numbers of people affected are often underestimated and many people who experience severe difficulty with communication, information and mobility due

to a dual sensory loss are not identified. Historically figures as low as 5,000 people in Scotland have been cited. However, wider international researchⁱⁱⁱ would indicate that at least 0.2% of a global population will be deafblind and a developed nation such as Scotland should expect to see between 0.3% (based on Ireland) and 0.8% (USA) of the population with deafblindness to a degree that seriously impacts on their communication and social connectedness, ability to access information and orientation and mobility. In Scotland that would equate to between 16,000 and 43,000. Acknowledging the gap in measurement of prevalence rates, attempts have been made to apply Scottish population statistics to the deafblindness prevalence rates estimated by the Centre for Disability estimates that deafblindness levels in Scotland would sit somewhere between 12,800 by 2019 for those with the severest levels of dual sensory impairment and 34,000 for people who may still have difficulties with communication, mobility and information as previously set out. These estimates suggest a rise to between 17,500 and 37,500 in 2024^{iv} dependent. In the absence of agreed diagnostic or clinical thresholds this remains an estimate but based on international research^v this seems a realistic prevalence range. It is also of course a disability that will grow if the population continues to age with men experiencing higher rates of the most severe deafblindness.

KEY POINT: More research and consensus on definitions and thresholds for diagnosis is needed which would enable a greater accuracy of incidence and prevalence rates. A central point of note is that deafblindness is often described as a low incidence disability, however when compared to other more commonly understood conditions such as Parkinson's Disease or Multiple Sclerosis, even at the lower estimates it is at least as common.

^{vi} Smith A (2017) *'The incidence and prevalence of Parkinson's in the UK'*

^{vii} MS Society (2020) *'Incidence and Prevalence Report'*

Living with deafblindness

There is no one group or identity of deafblindness, with different levels of vision and hearing loss, different use of language modality, different kinds and severity of additional disabilities and different medical causes^{viii} making up some of the variables that mean that each individual's experience of living with deafblindness is unique. Furthermore, developmental factors such as when in life sensory losses first began to develop (pre- or post-lingual) and the family and service response to this play an important role. The support needs of someone who has been deafblind since birth will be very different to someone who develops a sensory loss later in life.



For example: a person who is Deaf from birth, may have learned British Sign Language as their first language and may have access to educational support to enable this process but when deafness occurs later in life a person may struggle to adjust to learn new communication skills and to find services that can support this.

KEY POINT: The impact on an individual is influenced by these many different variables, however how well an individual is able to respond or adapt to the losses associated with deafblindness (e.g. status, body integrity, valued roles, financial stability, independence and relationships) is influenced by factors across a range of levels, such as:

- Intrapersonal – self-efficacy, self-esteem, coping styles;
- Interpersonal– family structure, functioning and support, existing reliable and effective networks of support.
- Systemic - access to services - level of available and effective treatment, interventions and support, access to assistive, adaptive or rehabilitative technology;
- Structural - such as socio-economic circumstances, health status and whether living in an urban or rural setting.

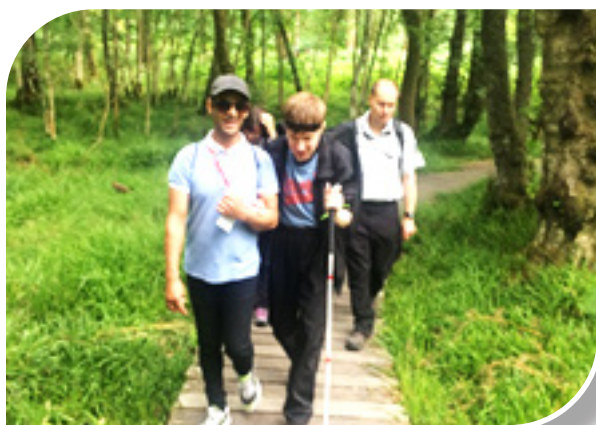
Persons living with deafblindness frequently require support with:

- **Communication and Social Connectedness** - Many people with sensory impairments or who are Deaf can become socially isolated due to factors such as:
 - lack of inclusive communication approaches and poor access to BSL or Tactile BSL communication support that would enable them to engage with others socially and intellectually or to gain information about social, learning, employment or other important life opportunities;
 - the stigma, discrimination and exclusion that can be daily experiences of people living with a sensory impairment;
and for those with a visual impairment
 - the added lack of access to support to navigate through the world to establish or retain social connections or learning and employment roles.

However, this can all be more complex for someone who is deafblind where the lack of access to the significant communication support required can prevent them remaining connected not just socially but also emotionally to others. Where full and meaningful communication is not enabled then a social distance can occur that leads to profound levels of isolation. For many the resulting loneliness will be pervasive and can bring with it self-stigma and a further tendency to withdraw. This cycle of exclusion, withdrawal and isolation not only impacts on people's life chances but also on their health, mental health and well-being.

KEY POINT: There is no standard way of communicating with someone who is deafblind, communication support needs will vary based on whether a person has pre-lingual or post-lingual deafblindness, which sensory loss developed first, and the level of residual hearing or sight.

- **Mobility** - The ability to get around freely is essential to achieving equal participation and full citizenship. Some people living with deafblindness may have a guide dog, others may use a guide cane or a red and white cane indicating that the person is living with deafblindness, and for those who have the funding support a Guide Communicator who can accompany them and paint the whole environmental picture – physical, social etc.



KEY POINT: For a deafblind person mobility support can be the key to having the confidence to engage with surroundings in a meaningful as well as safe way.

- **Access to information** - Some people living with deafblindness have the support of a Guide Communicator who can be the eyes and ears of the person and help them to increase their engagement with and connect to their environment. This not only includes support with understanding their physical surroundings, but also communication support to access and process information whether in written form such as with books, posters, and digital equipment or in face to face interactions with others.

KEY POINT: For a deafblind person having support to access information is vital in being aware of opportunities that can expand their lives and in knowing how to access these but also in understanding their rights and being able to enact these.
Information access is an essential human right

Communication with deafblind people

The key to ensuring the equal participation and inclusion of a deafblind person is understanding the diversity of communication support needs which if not accommodated will create barriers to engaging and interacting with people. There are a variety of techniques and methods of communication support, and there is no one single standard way of communicating with someone who is deafblind. Therefore, the communication support provided needs to be able to adapt to the individual and the specific setting.

Inclusive communication support needs will vary based on whether a person has pre-lingual or post-lingual deafblindness, which loss developed first, and the level of any residual hearing or sight. For example, a person who is Deaf from birth and later develops a visual impairment may still be able to communicate using British Sign Language if there is some residual vision or they may learn to adapt to use visual frame signing or Tactile BSL. Likewise, a person with a severe visual impairment since childhood and who learned braille, will still be able to use braille if they develop hearing loss later in life.

The type of support offered may also vary depending on the setting as discussed more fully in **Part 3 Tools and Resources – Inclusive Communication Support**. For example, what may be appropriate for one person in a one to one meeting could be very different to enabling inclusive communication when attending a conference or event where there may be lots of background noise and competing voices.

Many people who have acquired sensory loss across life will have found creative approaches to remaining connected with those around them and often use a blend of communication methods which may involve using a second person to help with communication, such as an interpreter or Guide Communicator. See **Part 3 Tools and Resources - Common Methods of Communication**



The Role of a Guide Communicator

Guide Communicators are specialist support workers who work to facilitate:

- equity of access to information;
- inclusive communication;

- safe mobility; and
- to open up opportunities for deafblind people to engage and connect with their community and society as a whole.

Guide Communicators have to be flexible and responsive to the diverse support needs of the range of people who live with deafblindness but also the interests and preferences of each individual – working in a person-centered way at all times. These services can significantly improve a person's ability to access opportunities that support growth and development and the realisation of a meaningful life such as education, employment, healthcare, and culture and recreational activities as well as democracy. A Guide Communicator will relay information without prior processing and will aim to paint a full picture of each and every situation and environment that a deafblind person finds themselves in. By being the eyes and ears of someone living with a dual sensory loss, they can be central in supporting that individual to have all the information that they need to be able to interact with the world in the manner of their choice. A Guide Communicator focuses on the full range of communication needs of each individual to enable them to have a quality connection with the outside world. This requires that this specialist workforce can adapt to and is proficient in a wide range of language modalities including Clear Speech, Lipspeaking, Sign Supported English, BSL, Tactile BSL and Deafblind Manual.

KEY POINT: The support as described above can be a critical lifeline for someone living alone or with little social networks but can also have a positive effect on entire families – partners, parents, children and extended family members through supporting a deafblind person to retain their role and status within the family.

Part Two: Engagement and Participation

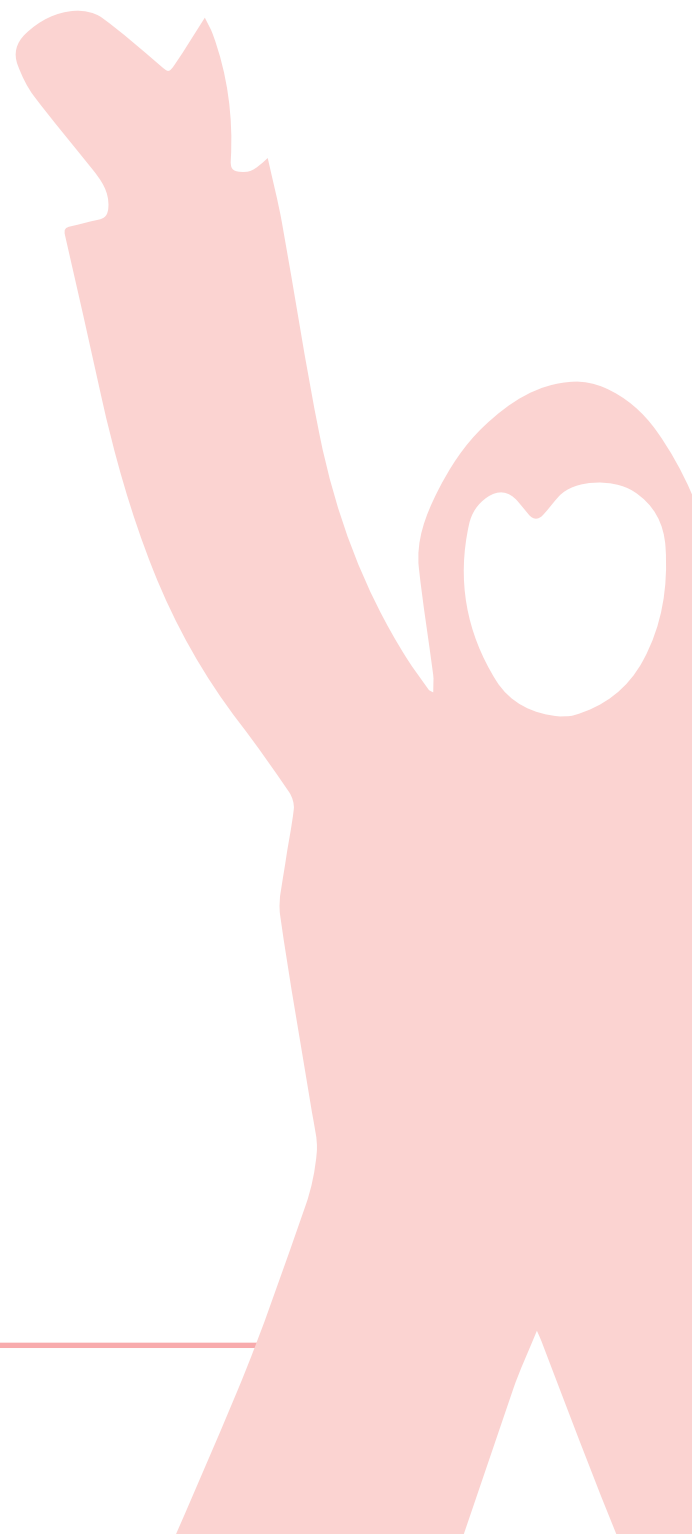
Making Introductions

Engaging effectively for the first time with someone who is deafblind is of course the same in many ways as reaching out to any member of the public, however, there are some additional considerations to take into account:

- As you approach try to convey your presence, letting the deafblind person know you are there
- Indicate where you are with a gentle tap, preferably on their hand
- Identify yourself, who you are, your name, your position using clear speech if the person has residual hearing
- Spell your name using Deafblind manual on their left palm if the person is a deafblind manual user (see Appendix 1).
- Be aware if the person is a BSL or Tactile BSL user before-hand if possible, to enable you to organise an interpreter. If you have only just met the person then learning to spell out on their hand 'are you a (Tactile) BSL user' will enable you to be aware whether you may need to enlist the support of an interpreter at an early stage.
- Make eye contact with the person you are talking to whether they have residual sight or not (not the Guide Communicator or Sign Language Interpreter).
- If the person hasn't understood your attempt to communicate - Repeat. Rephrase. Spell out again on their hand at a slower pace.
- Try another communication method if required, ask the person what will help. Other approaches may include, moving to an area with less background noise, writing things down in clear large print or using a mobile phone application.

When talking speak as clearly as possible, slowing down your speech if you normally speak quickly. Avoid talking over another person, it can become very hard to follow a conversation if there is more than one voice and be aware of background noise.

KEY POINT: Be prepared if possible and be aware if the deafblind person is a BSL user or if they use another form of communication. Some basic understanding of Deafblind Manual can often bridge the gap until you can enlist more specialist communication support.



MAKING INTRODUCTIONS

An Inclusive Communication Guide for
Engaging with Deafblind People



1. Introduce Yourself

- Make yourself know as you approach, using speech or a gentle tap on their hand.
- If no response try to make eye contact and fingerspell your name.
- If no response, spell your name on their palm using deafblind manual.



2. Repeat, Rephrase

If the person hasn't understood your attempt to communicate - Repeat. Rephrase. Spell out again on their hand at a slower pace.

BE PREPARED - FIND OUT THE PREFERRED
COMMUNICATION METHOD - BOOK LSP*



3. Ask the person what would help

Other approaches may include, moving to an area with less background noise, writing things down in clear large print or using a mobile phone application.



4. Further Information and Advice

Deafblind Scotland
1 Neasham Drive, Kirkintilloch,
G66 3FA
info@dbscotland.org.uk
0141 777 6111

For more detailed guidelines please refer to Deafblind Scotland's
"An Inclusive Communication Guide for Engaging with Deafblind People"

Organising a meeting

When organising a meeting involving people who are deafblind it is important to consider what you can reasonably do before, during and after a meeting to help the person prepare, engage and process discussions. This will depend on what type of meeting you are organising, a brief one to one meeting will have different considerations to a larger or longer meeting, or event. You may want to consider if virtual meetings are more suitable for an individual. If a virtual meeting is the best option and in particular is accessible for a deafblind person through using programmes such as Zoom, Skype or Teams then useful guidance is available from deafScotland website deafscotland.org.

When planning your meeting you will need to consider

- How you will invite deafblind participants
- Inclusive communication approaches and support needs
- Location and physical environment

Inviting Participants

Whether you are planning an event or a face-to-face meeting good communication, in advance of, during, and after the meeting or event is key to ensuring successful participation. Where possible, find out each person's preferred method of contact e.g. letter (check the format they require), email, friend or family member, telephone conversation via contactScotland and what time of day is best, e.g. on the phone out of office hours. When discussing communication support needs, people will know what works for them ask for detailed, specific information about their communication support needs both in terms of making contact and what will be required at a meeting or event.

Letter

Many people will still prefer to be contacted by letter. Ensure that letters are accessible, Deafblind Scotland defines **print sizes** as follow:

- Large Print (LP) 18
- Extra Large Print (XLP) 22
- XXL 36
- XXXLP 42
- XXXXLP 60

Some people may prefer a specific font style or colour or for letters to be sent in alternative formats such as braille or moon. Plain English should be used in all communications.

Best Practice for Plain English:-

- Avoid jargon and technical language, explaining complicated terms that must be included.
- Use shorter words and sentences, only communicate one point in each sentence (sentences should be around 15 – 20 words).
- Consider the points you want to make and present them in a common-sense manner.
- Plain English is not oversimplifying or change the meaning of your writing, it does help to convey your message in a concise accessible manner.
- Detailed information on Plain English can be found on the Plain English Campaign website www.plainenglish.co.uk

Email

Email is also an option for many people. For most people it is best to use plain black text on a white background, a minimum 18-point Arial font. Some people may have assistive technology that can translate

text to speech. Video or audio messages can be attached or embedded into emails if BSL or clear speech is preferable. It should be noted that applications that translate text to speech often can't read text from pictures or from pdf. If a picture is being sent (even if this has some form of description embedded such as with maps) it will need to be described in text format underneath the graphic. Likewise, if a pdf information sheet is being sent this will need to be described in a word document or copied to a word document.



Smart phones and tablets

Many people will use smart phones and tablets to support communication. This may include text, audio and video messaging services and such services can also be useful in providing meeting reminders.

Online BSL/English Interpreting Services

Including Video Relay Services (VRS) and Video Remote Interpreting (VRI).

Online services enable BSL users to communicate through a mobile device such as a smartphone or tablet or desktop computer, signing via the camera to the online BSL/English interpreter, who in turn calls (phones) the public, private or third sector organisation and relays the call between the two.

Organisations and Local Groups

People may attend local sensory impairment or Deaf community groups or be members of a range of health, social care or community organisations who can help with notifying people about local events, this can be a very good way of advertising and recruiting people to participate in focus groups or attend consultation events.

Additional considerations

Consider any reasonable adjustments that may help the process. Some examples may be:-

- Offering double length appointments for face to face meetings
- Ensuring meeting space and venue is appropriate if using BSL/English interpreters, or Tactile BSL/English interpreters and seating arrangements that ensure that the Tactile interpreter is able to sit alongside the deafblind person or a BSL Interpreter is able to sit opposite. Adjustable lighting is also important, not only in terms of a well-lit room but in ensuring that interpreters are not sitting in front of the glare of a window or computer screen. This is especially important for deafblind people with limited vision or field of vision.
- Consider building in break time if meetings are likely to be longer than 30 minutes.
- If meetings are longer, larger or more complex more than one language professional may be required. When booking a language professional such as an BSL/English interpreter or an electronic notetaker it is important to describe the length, size and scope of any meeting to enable them to provide the right level of support.

KEY POINT: When inviting people to a meeting ask them about their communication support needs beforehand. The individual will know best what works for them.

Maximising Participation during the Event/Meeting

Preparing for the event

You have a duty and responsibility to provide inclusive communication support for people attending meetings and events. Communication support requirements will vary depending on whether you are meeting one individual or a larger group of people, or are facilitating a focus group, or even a larger event where there may be multiple considerations. With a group of deafblind people there may be a number of different preferred or required communication methods.

When inviting people always ask about their communication support needs, this will help ensure you provide the appropriate and preferred support for people attending, this can include:-

- Electronic note takers
- BSL/English interpreters
- Deafblind Manual Interpreters
- Guide Communicators to support people to and from and during meetings
- Tactile BSL/English Interpreters
- Face-to-face spoken interpreters (lip readers, clear speech)
- or any other communication support methods that may be appropriate and people are happy to use.

Location and physical environment

Under the Equality Act 2010 you have a duty to ensure that the meeting venue, room or location is accessible to people with disabilities. There are many ways the meeting space and location can impact on how effectively people can access and participate in your planned meeting or event. For deafblind people this might include:

- how easy it is to move freely around the building;
- adjustable lighting;

- access to technological support such as a loop system;
- accessible toilets; and
- clear and accessible signposting.
- Good forward planning will help to ensure your venue is as accessible as possible. Accessibility is not just about being able to get into, or navigate around a building, it is important to consider the manner in which people will travel to the venue. See **Part 3 Tools and Resources** for an **Accessible Venue Checklist**.

Venue Facilities

As well as being able to find or navigate around a building, you have a duty to consider how appropriate and accessible facilities within the building are to meet the needs of people with disabilities, including people who are deafblind. Requirements will be dependent on purpose and people attending. A few questions to ask are outlined in **Part 4 Accessible Venue Checklist**.

During the event

Check in with people to ensure that any communication support or adjustments are working for them. If not, ask what could be done differently. At larger events have an easily identifiable person to raise issues with and who can help overcome difficulties on the day. Technology can fail so it is best to pre-test technical support such as loop systems and maintain these regularly. Equally there can be issues arising related to BSL/English interpreters such as seating arrangements where people may not be able to properly see BSL/English interpreters. Deafblind BSL users who have residual vision may be able to benefit from a BSL/English interpreter but only if they are within their visual frame. Ensuring that there are seats in the front row of an event set aside for deafblind attendees can minimise difficulties.

Good practice in meetings and events

Smooth and effective running of a meeting or event can make all the difference in effective participation. Ensure you have a confident chair facilitating the event and event support team who are deafblind aware. They should consider pace, language, access to written documents and audio-visual aids.

One speaker or BSL user signing at a time: Try to ensure only one person is speaking or signing at a time. This could be done by requesting people raise their hand if they want to contribute. You could risk important information being missed if everyone talks over each other or more than one person is signing. This is important for a deafblind person who may be trying to follow discussions with residual hearing or sight but also for BSL/English interpreters who are relaying the information.

Speed of communication: If speaking then use your usual tone, at your normal pace. The BSL/English interpreter will tell you if you need to pause or slow down. If you use a word that the interpreter is unfamiliar with, he or she may ask you to spell it.

Clear Speech: This may be used by a deafblind participant who has residual hearing or who is lip reading. Face the Deafblind participant in a well-lit area, get the distance right and use a firm, clear voice. Try and use plain straight forward language. Don't use jargon. Avoid distractions like chewing gum or hands gesticulating.

Reading time: If handouts or a power point presentation is being used it will be very challenging for a deafblind participant to read the handout and watch the BSL/English interpreter at the same time. Allow a few minutes reading time before you start explaining or discussing the document.

Explanations: Try to avoid acronyms, abbreviations, idioms and initials as this can be hard to interpret if the meaning is not clear, so explain them as you use them. This will prevent the deafblind person missing out on any important information.



KEY POINT: There are some specific resources available for settings such as GPs to enable them to support D/deaf patients, including those that are deafblind. This includes guidance such as placing an alert on patient's medical records to state whether the patient is a BSL user, outlining their communication preferences in GP consultations and additional support needs to ensure the experience of attending the GP practice is positive.

^{ix} Public Health Scotland (2020), 'Working with British Sign Language (BSL) users in primary care. Guidance to improve access and support effective communication'

Asking for feedback

Always ask for feedback and give people options of how they can provide feedback in accessible formats. Listen to any feedback particularly about what worked well, and any suggestions about what could improve communication support. Consider doing this during breaks at the event so that immediate improvements can be made as well as at the end of the event to improve for the future.

GOOD PRACTISE IN MEETINGS

An Inclusive Communication Guide for
Engaging with Deafblind People



1. Preperations

- Use a Deafblind aware Chair and Support Team.
- Consider - meeting length (include eye breaks), language, access to written documents and audio-visual aids.



2. Clear Speech

- Face the person.
- Position in a well lit area (no strong light behind you).
- Find the right distance.
- Speak clearly at a normal pace.
- Avoid distractions like chewing gum or unnecessary gestures.

BE PREPARED - FIND OUT THE PREFERED COMMUNICATION
METHOD AND FORMAT FOR ALL DOCUMENTS



3. Establish Communication Rules

- One Speaker or BSL user at a time
- Confirm that all loop system users can hear clearly
- Speed of Communication - if speaking use your usual tone, at your normal pace.
- Be mindful of the BSL/English interpreters, they will tell you if you need to pause or slow down.
- Allow reading time before discussing a document. Always provide documents to interpreters in advance.
- Explanations - avoid acronyms and abbreviations.

For more detailed guidelines please refer to Deafblind Scotland's
"An Inclusive Communication Guide for Engaging with Deafblind People"

Part 3: Tools and Resources

1 - Key Terminology

Deafblindness is the combined loss of both vision and hearing. For some people this may be a complete sensory loss whilst for others there may be some residual sight or hearing that can be used. Currently within Scotland there is no consensus on a clinical definition of deafblindness. In the absence of this a commonly adopted, helpful definition is that deafblindness is:

“The loss of functioning in one sense [that] cannot be compensated for with the other sense, resulting in a distinct disability.”

Congenital deafblindness – where a child is born Deaf with a visual impairment or where a child acquires hearing loss and a visual impairment at an early stage in life before the development of language. Occurring at a pre-lingual stage this form of deafblindness requires the child to develop language whilst deafblind.

Acquired deafblindness – where vision and/or hearing loss is acquired during the course of life following language development, where language maintenance or adaption is the focus. An individual may already have one sensory loss and acquire a second during their life or both senses may deteriorate across life.

Usher Syndrome – is a genetic condition which causes hearing loss from birth, and a later progressive loss of vision due to Retinitis Pigmentosa (RP). The condition was named after CH Usher, a British ophthalmologist. The first symptom to appear in RP is nightblindness, this may be coupled with difficulty in adapting to bright light or rapidly changing light conditions. Loss of visual field or ‘tunnel vision’, as it is commonly known, mean that the individual loses their ability to locate objects which are not

directly in front, so that for instance, they may still be able to read the bus timetable, but experience great difficulty locating the bus station without assistance.

There are three types of Usher Syndrome:-

Type 1

Usually, the person is born profoundly Deaf and may have British Sign Language as their first language. In their teens or early twenties night blindness may become a problem, as does adapting to changing lighting conditions. The visual impairment is due to Retinitis Pigmentosa.

Type 2

Usually, the person is born hard-of-hearing, often functioning in mainstream school with no use of sign language. As with type 1, Retinitis Pigmentosa visual impairment progresses.

Type 3

Least common type involves a progressive impairment of *both* sight (R.P.) and hearing.

CHARGE – is a genetic syndrome, each individual will have a varying degree of impairments and medical conditions, that can be linked to a recognised pattern. Most people with CHARGE will develop hearing impairment, vision impairment, and balance problems, along with life-limiting medical conditions from birth.

Charles Bonnet Syndrome (CBS) – “CBS causes people who have lost a lot of sight to see things that aren’t there. Medically, this is known as having hallucinations. CBS hallucinations are only caused by sight loss and aren’t a sign that you have a mental health problem.

The kinds of things people see with CBS seem to fall into two main types:

- simple repeated patterns or shapes, such as grids or brickwork patterns
- complex hallucinations of people, objects and landscapes.

Recent research suggests that about one in five people who experience sight loss develop CBS”

More information available from RNIB www.rnib.org.uk/eye-health/eye-conditions/charles-bonnet-syndrome-cbs

2 - Inclusive Communication Support

Guide Communicators

Deafblind Scotland can provide accredited Guide Communicators to support people attending meetings and events. Currently the service is available free for people living in Lanarkshire, Greater Glasgow or Lothian Health Board area and is funded by the NHS

To book a Guide Communicator contact: 0141 7776111

BSL/English Interpreters

BSL/English Interpreters can translate quickly and accurately between spoken English and British Sign Language (BSL). They will work in a variety of situations (medical, legal, meetings, workplace, conferences etc.) to ensure that all parties communicate effectively with each other.

To find a BSL/English Interpreter contact:

thescottishregister.co.uk

www.signlanguageinteractions.com

www.nrcpd.org.uk

www.deafaction.org

Electronic Note Takers:

Electronic note takers may provide a useful service for someone who has residual sight and can be used alone or to enhance the service provided by the BSL/English interpreter. Electronic note takers take notes on a laptop. This service can be used in large meetings or events to relay the information onto a large screen or as a one to one support through using two devices – one for the note taker and one for the deafblind person. The operator types a summary of what's being said into the computer and the text appears on the Deafblind person's screen. This allows the deafblind person to interact with the operator and add their own notes.

Electronic Note takers can be booked through:

www.signlanguageinteractions.com

www.deafaction.org

Online BSL/English Interpreting Services

Online services enable BSL users to communicate through a mobile device such as a smartphone or tablet or desktop computer, signing via the camera to the online BSL/English interpreter, who in turn calls (phones) the public, private or third sector organisation and relays the call between the two.

Video Relay Services and Video Remote Interpreting

contactScotland

Funded to facilitate BSL/English communication between public, private and voluntary sector bodies and the Deaf community, including deafblind people. They do not provide interpreting services but can provide a video relay appointment service to facilitate communication remotely to book and cancel appointments. The service is App based and the person must have the App to access the service

W: contactscotland-bsl.org

T: 0333 344 7712

E: admin@signlanguageinteractions.com

M/SMS: 07970 848868

SignVideo

Video Relay Services and Video Remote Interpreting provider across the UK. Providing British Sign Language (BSL) video interpreting services to enable communication between Deaf BSL users in the UK and hearing people.

W: www.signvideo.co.uk

T: 0208 463 1120

E: ask@signvideo.co.uk

Sign Live

Video Relay Services and Video Remote Interpreting connecting BSL users with businesses and organisations they use every day, to remove barriers to communication and improve choice for the Deaf Community.

W: signlive.co.uk

T: 0330 822 0288

E: hello@signlive.co.uk

3 - Common Methods of Communication

Face to Face Communication



British Sign Language (BSL): BSL is used as first and preferred language by the Deaf community. It has its own grammatical structure and syntax and is an officially recognised language in Scotland within the BSL Scotland Act (2015)^x. When communicating with others without proficiency in these skills an interpreter can be employed to translate information through visual signs.

Tactile British Sign Language: ‘Hands-on signing’ to another who understands BSL or by using an interpreter to translate one to one using hands on touch and movement.

Visual Frame Signing: A form of BSL adjusted for people with much-reduced peripheral vision, and signed directly in front of the face.



Deafblind Manual (Deafblind Alphabet): A tactile form of finger spelling where each word is spelled out on the person's palm using a specific manual alphabet derived from the BSL alphabet (see Appendix 1 Reference).

Block: Another form of manual communication in which English capital letters are drawn onto the palm of the deafblind person's hand.

Clear Speech: An effective and commonly used method of communication for people who have some degree of residual hearing involving ensuring that words are pronounced clearly and with adjustments to the surrounding environment if needed.

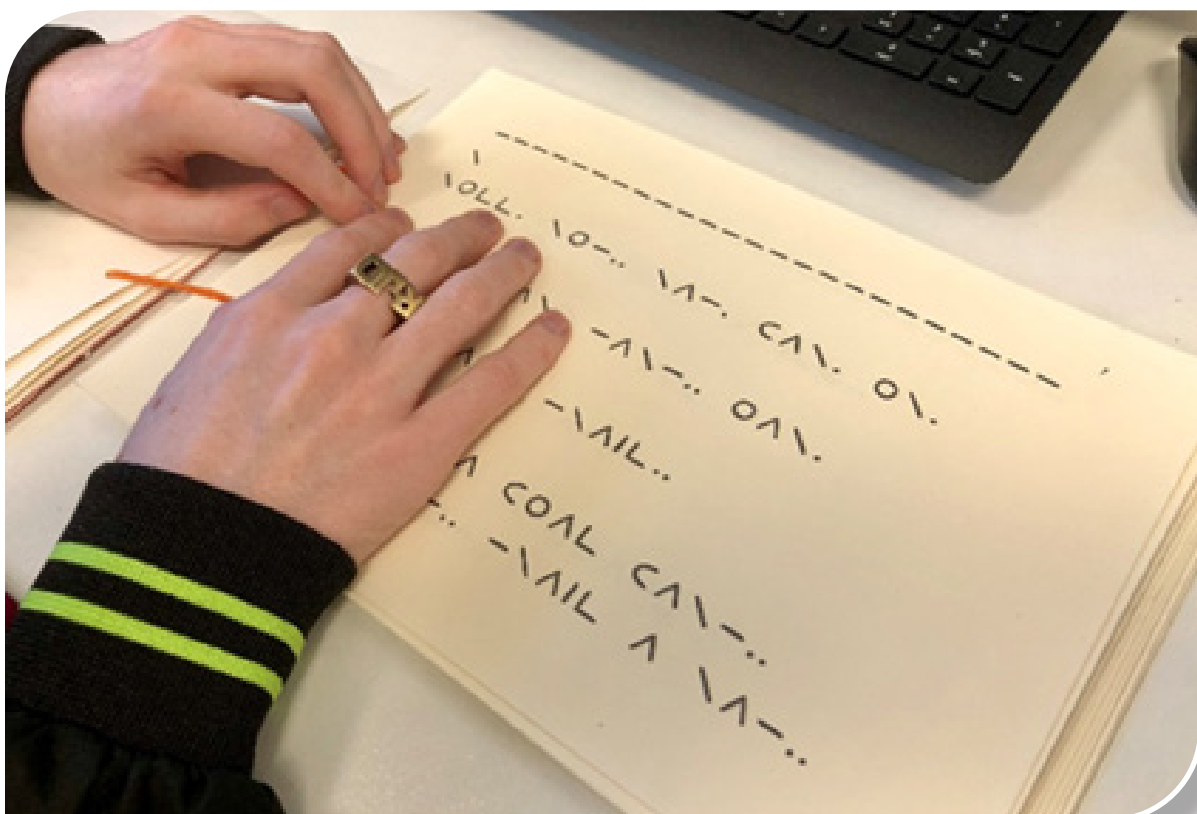
Lip-reading: Lip speakers repeat what is said in a way that can be lip-read easily.

Hearing Loop: a unique sound system used by people with hearing aids. The hearing loop provides a magnetic, wireless signal that is picked up by the hearing aid and/or cochlear implants.

Further information about types of communication support available at <http://www.deafblinduk.org.uk/typesofcommunication.html>

Printed communication: Letters and other written communication such as information leaflets and emails are a common way of providing information or communicating with people. Residual vision may make this possible if the size and font used is accessible. We recommend Arial 18 should be the minimum standard for writing to people with a sight impairment. If BSL is the first and preferred language then some BSL users may not be able to easily access communication written in the English language as BSL as described above is a specific language. Therefore, an interpreter or Guide Communicator may be needed to support the individual to access this.

Braille: Braille is a tactile reading and writing system using raised dots so that a person can read with their fingertips. As sensitivity can reduce through age this may for some people become less effective over time.



Moon: An alternative to Braille, Moon is an embossed written system, using raised curves, angles, and lines rather than dots. This can be easier

to learn for people who have not previously learned to use Braille as many of the symbols are similar shapes to written letters.

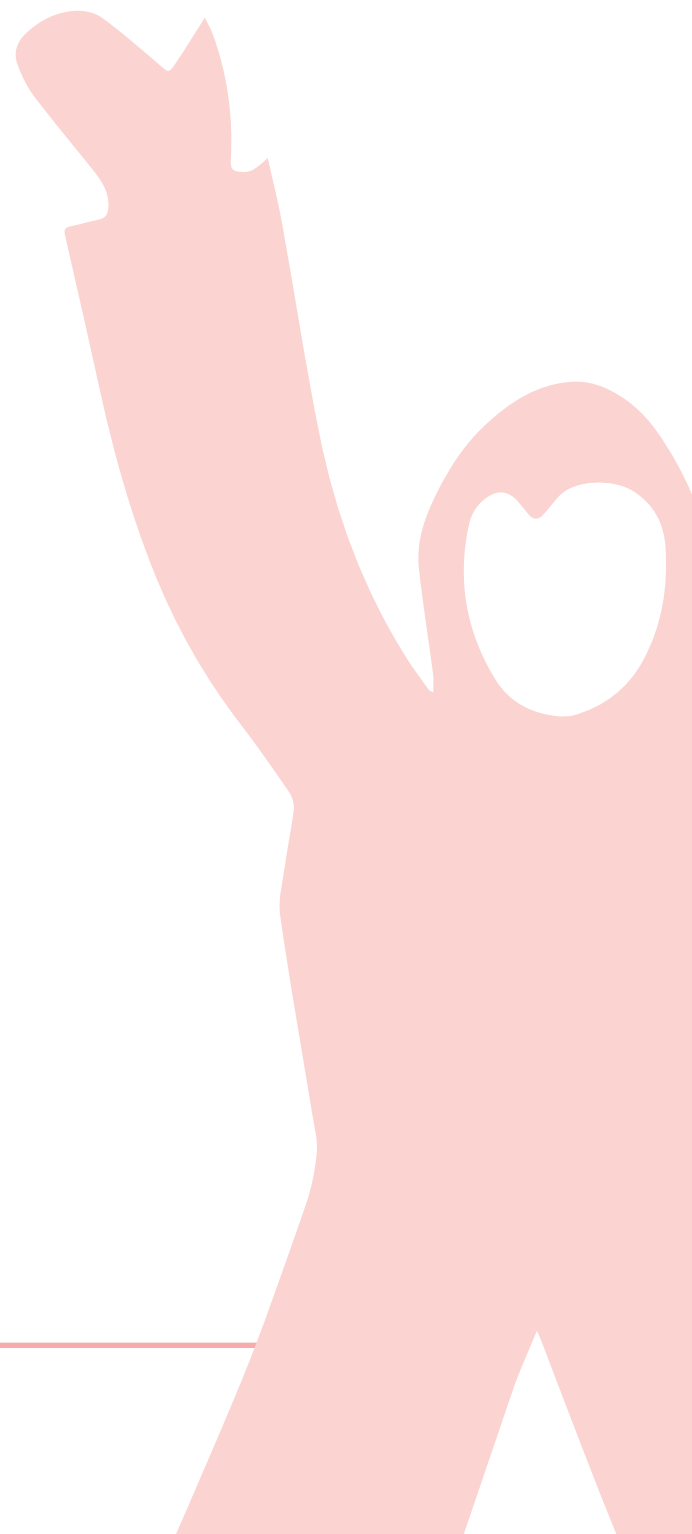


Assistive Technologies: Modern computers, tablets, and mobile phones open up the world of communication for everyone including deafblind people. Some devices have built in accessibility tools for people with sensory losses. For example, people with residual hearing can benefit from audio description services, or Video Relay Services can help people with a hearing loss communicate in real time with a BSL interpreter via live video links.

4 - Accessible Venue Checklist

- **Is an accessible toilet available?** Not every deafblind person will require an accessible toilet, however it will be good practice to arrange events in venues that can meet a broad spectrum of needs.
- **Does the fire alarm have a Visual (flashing) feature?** Features such as this can alert D/deaf or hard of hearing people of a fire. If not, consider what you need to do in case of a fire alarm.
- **Is there a loop system?** Is this available within in the meeting room or venue for hearing aid users? If so, is it working, and will someone be available to show you how it works? Avoid meeting rooms or venues that have unnecessary noise distractions as background noise and interference can make it harder to hear clearly. Room acoustics can also make a difference, so large rooms with high ceilings that echo are best to be avoided although this may not always be possible.
- **Is the lighting appropriate?** Good lighting can make a big difference for deafblind people. In large meeting rooms bright light sources shining directly towards people can make it difficult to see. Avoid glare, particularly on screens and displays. In face to face meetings avoid sitting in front of a bright window, the background light can make you difficult to see, and may affect a person's ability to lip read or see facial expressions. Blinds are useful on windows to reduce glare.
- **Does the room layout support inclusive communication?** The layout of a room is very important to ensure that people who are deafblind can participate safely and effectively. Ensure that the room is safe to move around and that there are no trip hazards. Placement of chairs will be important if using a BSL/English interpreter. For example, if using the services of a BSL/English interpreter, placing chairs in a position where both the speaker, and the interpreter are in the same field of vision will be easier for the participant, with a Tactile BSL/English interpreter it will be important for the interpreter and participant to be sat next to each other.

- **Are accommodations being made for Guide Dogs?** Some people who are deafblind use the support of a Guide Dog and it is important to take into account the needs of the dog as well as the deafblind person. Be aware that accommodation of Guide dogs is not a privilege but a right under the Equality Act 2010. It is important to ensure comfort breaks for the dog particularly during longer meetings and availability of water bowls. Meetings should be held in areas where there are nearby areas for dogs to be walked during breaks.



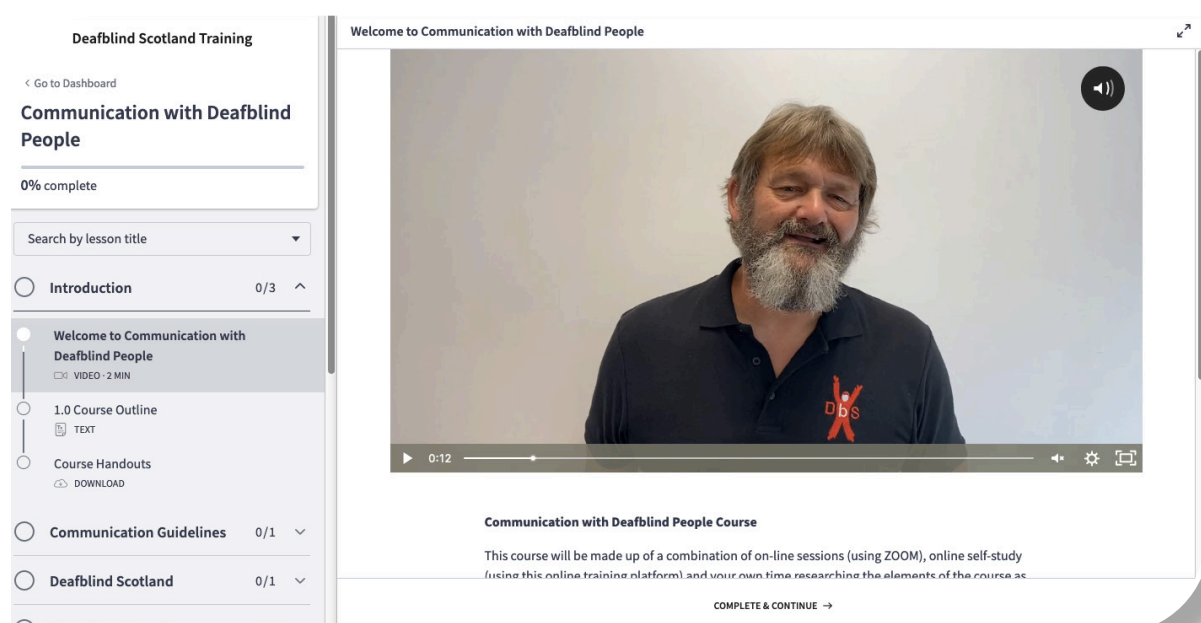
5 - Deafblind Awareness Training

Online and in person training available from Deafblind Scotland:-

Understanding Communication with Deafblind People

This course will be made up of a combination of on-line sessions (using ZOOM), online self-study (using an online training platform) and individual time researching and practising the taught communication tactics.

Training is delivered by resident Training Officer, John Whitfield, who is himself deafblind.



Visit the training webpage for more information: <https://dbscotland.org.uk/what-we-do/services/training-and-learning/online-training/>

6 - See Hear Highland Education & Learning Services

Free* – Deafblind Awareness E-Module available on TURAS (account registration required, open)

- How sight/hearing loss affects everyday life
- Help clients be independent
- Improve your communication skills
- Guiding a person with sight loss
- How technology can help
- Where to find support services

*Free access to health and social care staff in NHS, voluntary organisations and third sector organisations. To register visit here: turasdashboard.nes.nhs.scot/User/PersonalDetails/Create

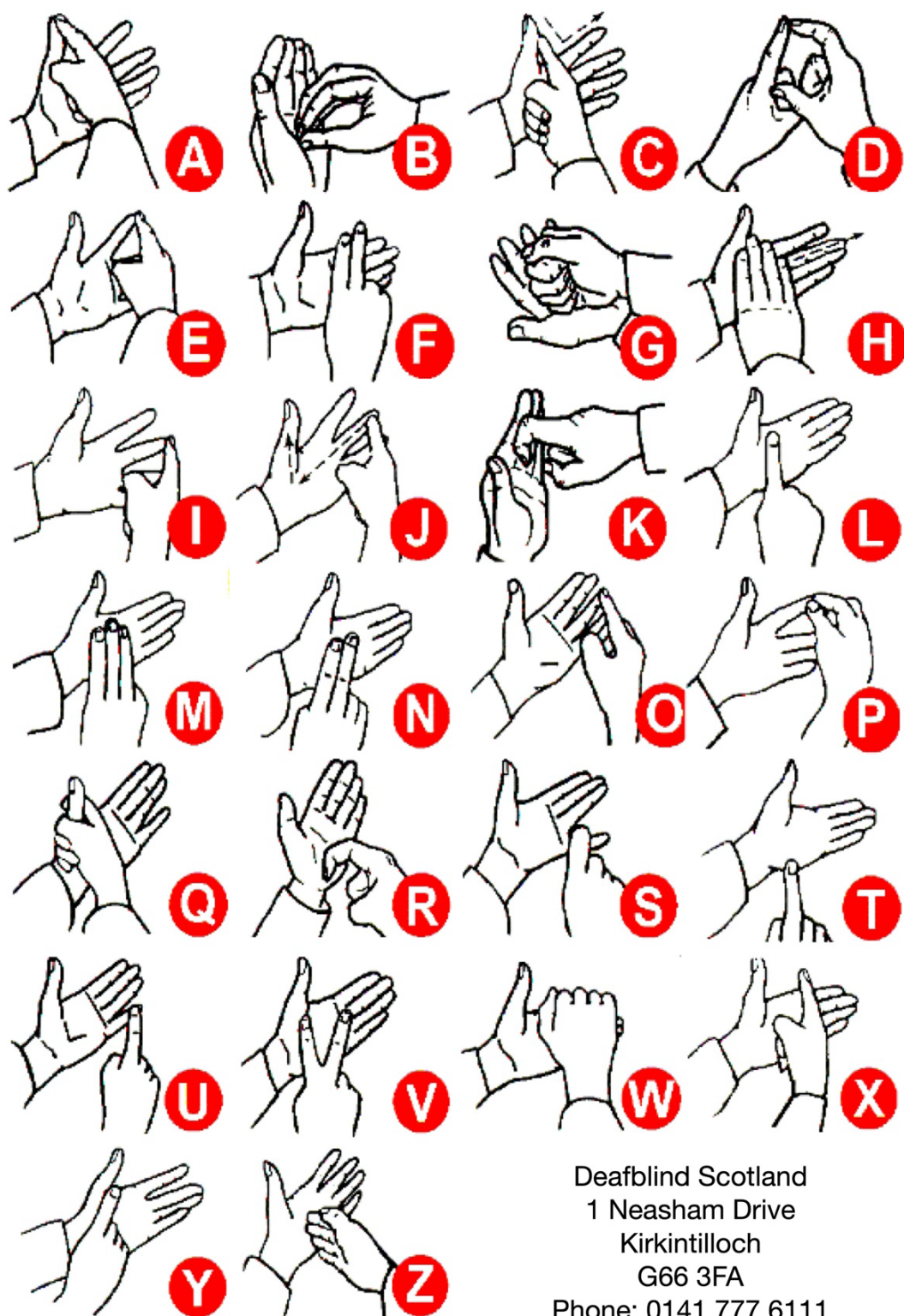
7 - NHS Inform Communications Toolkit

For intersecting inclusive communication and communication equality needs please see this toolkit for information.

<https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/communications-toolkits-and-leaflets/coronavirus-covid-19-communications-toolkit>



Appendix 1



Further information

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ⁱⁱⁱ World Federation of the Deafblind (2018), At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deafblindness, viewed 1 December 2020 <https://senseinternational.org.uk/sites/default/files/WFDB_complete_Final.pdf>

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^v Bezuijen J (2016) 'Deafness in Scotland' Deaf Action viewed 1 December 2020 <<http://www.deafaction.org.uk/wp-content/uploads/2016/10/Deafness-in-Scotland-A-recent-analysis.pdf>>

^{vi} Smith A (2017) 'The incidence and prevalence of Parkinson's in the UK Results from the Clinical Practice Research Datalink Reference Report' Parkinsons UK <https://www.parkinsons.org.uk/sites/default/files/2018-01/Prevalence%20%20Incidence%20Report%20Latest_Public_2.pdf>

^{vii} MS Society (2020) 'Incidence and Prevalence Report' <https://www.mssociety.org.uk/sites/default/files/2020-08/MS-in-the-UK_2020.pdf>

^{viii} Dammeyer J (2015), 'Deafblindness and dual sensory loss research: Current status and future directions', World J Otorhinolaryngology 5(2): 37-40, 10.5319/wjo.v5.i2.37, viewed 1 December 2020 <<https://www.wjgnet.com/2218-6247/abstract/v5/i2/37.htm>>

^{ix} Public Health Scotland (2020), 'Working with British Sign Language (BSL) users in primary care. Guidance to improve access and support effective communication' PHS, viewed 1 December 2020 <<http://www.healthscotland.scot/media/3305/working-with-bsl-users-in-primary-care.pdf>>

^x Scottish Government (2020), BSL (Scotland) Act 2015, Scottish Government, viewed 1 December 2020, <<http://bslscotlandact2015.scot>>



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