FOR HEALTH PROFESSIONALS AND FRONTLINE STAFF

BEST PRACTICE GUIDE

ACCESSIBLE HEALTH

2022

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Table of Contents

INTRODUCTION

Disabled people do not have equal access to health services and information in the UK. This is primarily due to the lack of coproduction that takes place with the disabled community in the design of these services. Furthermore, frontline staff and medical professionals lack training about how to support their disabled patients and don't understand their legal responsibilities to make reasonable adjustments in the workplace.

The content of this best practice guide has been created by members of 4 different coproduction groups. Approximately 20 disabled people from Real, DeafPLUS, ICM Foundation CIC and Beyond Sight Loss have shared their lived experiences of attending heath appointments at different medical establishments. They have worked together with us to coproduce recommendations that can improve access for different groups of disabled people.

We have also drawn upon the experiences of over 450 disabled people who took part in our research study looking at the experiences of disabled people during the pandemic in accessing health services and information.

What is coproduction?

The term Co-production refers to a way of working where service providers and users work together to reach a collective outcome (Involve).

Co-production understands how people, communities, citizens and different groups can contribute to care and support at all levels. It increases the scope for people to profoundly influence and shape the support they receive as an individual and as a community. It also enables strong working relationships built on direct, regular contact with senior managers and proximity to decision-making. The process of coproduction can lead to changes the relationship between people with complex health need and those experiencing health inequalities .

WHY THIS GUIDE IS IMPORTANT

The need for the best practice guide emerged after participants repeatedly reported that frontline staff and medical professionals lacked training in how to meet their access needs, make reasonable adjustments and adequately support them. Too often health services and information are designed without any consultation with disabled people, meaning the environment if often not accessible, and staff lack the knowledge and skills to communicate effectively.

This lack of coproduction with disabled people in shaping health services has resulted in them not receiving equal access to healthcare. It is a legal requirement to make reasonable adjustments for disabled people, and ensure health information is converted into accessible formats for all patients. These legal requirements can best be understood in relation to the following legislation:

Equality Act 2010:

"Under the Equality Act 2010, public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. Reasonable adjustments can mean alterations to buildings by providing lifts, wide doors, ramps and tactile signage, but may also mean changes to policies, procedures and staff training to ensure that services work equally well for people with... disabilities."
Source: www.gov.uk

Accessible Information Standard:

"The Accessible Information Standard says that all publicly funded adult social care and health providers, including GPs, hospitals, and care provided by social care services, must identify and meet the information and communication needs of those who use their services."
Source: www.sense.org.uk

HOW TO USE THIS GUIDE

This guide is divided into different chapters. These chapter themes were determined by our coproduction groups based on where they felt frontline staff and medical staff needed more training. You will also note that in each chapter, there is a section designated to each of the 4 coproduction groups we have worked with. The reasons we decided to break the guide into different impairment groups are:

- It's important to recognise that different groups of disabled people experience things very differently. Although this is also the case for people with the same disability, there are often many commonalities that can be drawn upon.
- To ensure the voices of our coproduction group are not lost, and that their individual experiences can be differentiated from others.
- To allow the reader to go to the chapters/sections they feel less confident in.

KEY THEMES FOR DIFFERENT IMPAIRMENT GROUPS (Page numbers)

THEME	Deaf and Hearing loss	Learning Disabilities	Mobility	Blind & visually impaired
Reasonable Adjustment and Access	17	25	29	33
Accessible Communications	49	55	63	64
Interpersonal Skills	68	70	71	
Preconceptions and Stereotypes	73	76	80	84
Recommendations	88	92	93	91

PARAMETERS OF THIS GUIDE

This guide focusses specifically on 4 impairment groups (blind and visually impaired, Deaf and hard of hearing, people with mobility issues and people with learning disabilities).

Other disabled people's views and experiences were captured in our initial research study, but they have not been involved in the co-production process to the same degree as our principal groups. This is due to staff capacity and funding limitations. It is important to note however, that many of the suggestions made in this guide are applicable to a wide range of disabled people and should not be viewed in isolation to one impairment type.

It is also important to remember that people have multiple impairments, so it is vital to treat everyone as an individual and not make blanket assumptions about their access or communication needs. The best thing to do if you are unsure how to best support a disabled person, is to.... JUST ASK !

How we collected data

We collected information for this guide in several different ways. Primarily, we ran workshops with our dedicated coproduction groups. In total, we ran over 35 workshops in 6 months. These workshops covered a range of topics from accessible vaccine clinics to disability training, and all provided us with insights into disabled people's experience of accessing health information and services. Prior to this, we gathered data from over 450 disabled people in Tower Hamlets about their experience during the pandemic. This information was gathered through a series of workshops, 1-1s, telephone interviews and surveys. We have also drawn on the knowledge of the staff working on our accessible health project from each of the partner organisations. Many of these staff are disabled themselves and have been able to share their own lived experiences of accessing health services.

A NOTE FOR THE READER

We hope this guide can help give you an insight into some of the challenges different groups of disabled people experience accessing healthcare and information.

We hope you come away feeling empowered to better support disabled people in your own workplace and the wider community.

We hope you gain some practical tips for how you and your staff can improve accessibility for all disabled people in your place of work.

We hope you will understand the enormous importance or providing equal access to healthcare and information, and your legal responsibility to ensure it happens.

We hope you will share your learnings with other staff members and recommend this guide, so the voices of disabled patients are placed at the heart of decision making.

We hope you will coproduce any future health services with your disabled patients.

RETHINKING YOUR UNDERSTANDING OF DISABILITY

CHAPTER 1

Models of disability Some explanations

There are several different models that help explain what is meant by disability.

The 2 principle models of disability are the 'medical model' and the 'social model'. We explain these more below. The other main models of the charity model and the human rights model.

Understanding what is meant by disability, and the causes of disability, is fundamental to understanding disabled people's lives and life experience. It can help you understand how conventional approaches to understanding disability can disempower people, even if it's unintentional

The social model of disability was developed by disabled people in the 1970s/80s in response to the medical model. Below we provide a brief overview of each model. Most medical professionals and frontline staff may have been taught to view disability through a medical lens. However, we encourage you, as you read through this guide to adopt the social model of disability to your work, and outlook on life.

Medical Model of Disability

The Medical Model of disability says...The problem is the disabled person!

The Medical model says..

- Something is 'wrong' with you
- You can't do things
- You are too different to fit in
- You are defective, deformed, abnormal etc

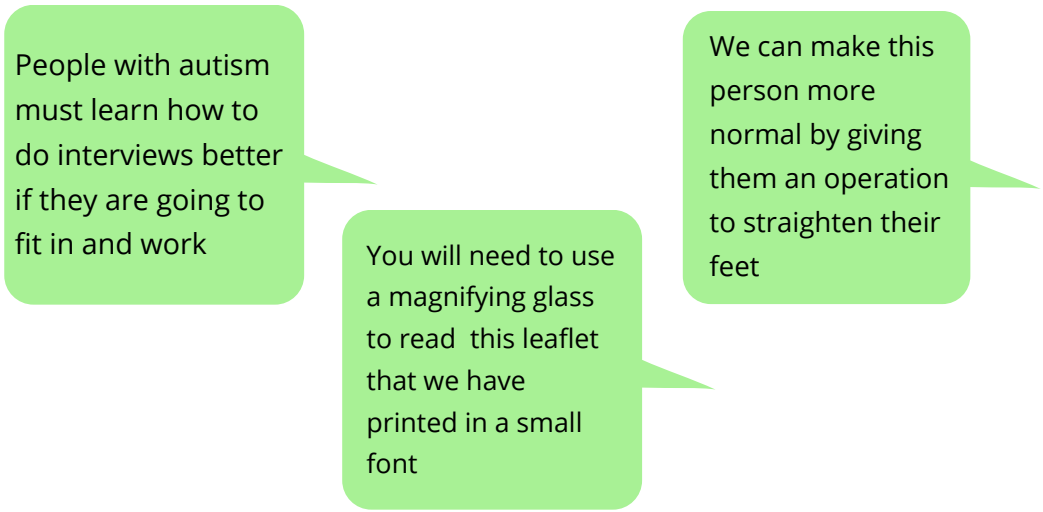
According to the medical model, illness or disability is the result of a physical condition and may reduce the individual's quality of life, and causes clear disadvantages to that individual.

Medical Model Solutions are...

- A cure
- Learn how to fit in
- Separate services
- Day centres, special schools, special mini-buses, segregated employment, charity, long term 'care' homes
- Specialist staff and medical advice

Because...the medical model stipulates that disability is the individual's problem!

Examples of the medical model of disability



Most people (and therefore organisations) still think in terms of on the medical model of disability – defining people by their impairment and using that impairment to explain the barriers that prevent equality - even if they don't know this language.

This attitude disempowers disabled people, because it doesn't recognise the societal barriers disabled people experience ,and therefore maintaining inequality

Models of disability - Definitions

Social Model of Disability

The social model of disability was developed by disabled people in the 1970s/80s in response to the medical model.

With the social model of disability, we believe people are disabled by unfair behaviours and practices in society, not by their impairment. We consider that our impairments are a natural part of human difference. We believe disability is a label placed on us by others. This is because of what they see as different from “normal”. We do not need to be “cured”. We should not be expected to adjust our lives to fit in with others’ expectations.

The barriers come from things such as the way other people choose to build things, the way transport is designed, the way other people communicate and, most importantly, other people’s attitudes and behaviors.

The social model stipulates that without barriers, people with impairments would not be disabled. Disability is caused by society. This can and should change!

Social Model Solutions are...

Assistive technology
Personal assistants
Sign language interpreters
Level access, ramps and lifts
Accessible information
Better attitudes

Because...disability is society's problem. Society is at fault not the individual.

Models of disability - Definitions

Social Model of Disability

Everything we do should be driven by the social model of disability. This means we believe it's the barriers created by society that cause inequality. By dismantling those barriers, disabled people will have fairer access to opportunities and improved life chances.

Embedding the social model of disability in our approach to work and life means we all need to think and take action to create an accessible environment, and challenge our own preconceptions and notions of disability. This guide is full of recommendation about how to do just this!

Below is some quick examples to help demonstrate what might disable a person and what can be done to remove this barrier.

What is the difference between impairment and disability?

Impairment	What disables people?	What can be done to remove disability?
Visual impairment	Streets full of obstacles and without adaptations	Tactile paving / crossings with audio
Wheelchair user	Medical centres with steps to get in or with high front desks or screens to check in.	Ramps that work. Training staff in their obligation to make reasonable adjustments (for example coming around to the front of a high desk)
Learning difficulty	Health information which is complicated and full of jargon	Easy read information or offering someone the support of an independent advocate
Hearing impairment	No induction loop, no alternative to telephoning No British sign language symbols. Face/lips not clearly visible	Specialist equipment. Email contact. Basic BSL training, and/or making it known you can provide access to an interpreter. Understanding how people lipread

WHY DOES A SOCIAL MODEL OF DISABILITY, MATTER ?

Many disabled people will not have heard of the social model of disability either. But when they get told about it, it is often life changing. Their life experience will be that they have been told that they are different, or need fixing, or they need to change. This can wear people down, and reduce their self-confidence and self-esteem. Approaching things from a social model of disability helps people understand that it is not “all their fault” and they don’t constantly need to fight for equal access

Adopting the social model perspective, non-disabled people can make a huge impact on how disabled people feel valued and accepted.

Actively recognising and removing the "disabling" barriers posed by services increases opportunities for access of people with disabilities compared to the rest of the population.

We think this makes sense because everyone working in health most probably chose this career path because they wanted to make things better for other people. Thinking in terms of the social model of disability means that you are more likely to do this. It also means that you are helping address the upsetting reality that many disabled people experience poorer health outcomes than non-disabled people. It should be a win-win situation.

Many disabled people will not have heard of the social model of disability either. Often, when they are told about it, it is life changing.

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REASONABLE ADJUSTMENTS AND ACCESS

CHAPTER 2

What do we mean by reasonable adjustment?

There a few definitions of reasonable adjustments, but the fundamental crux is that organisations and statutory bodies must make the necessary adaptions to ensure equal access to services, information, and opportunities for all disabled people. Reasonable adjustment is enshrined in law, and it's important that medical professionals/frontline staff talk to their patients to ascertain how they can create an equal service for them. In the coming chapter, we outline some priority areas that need to be addressed to ensure reasonable adjustments are made and recommendations for how you and your team can achieve it.

GOV.UK

Employers must make reasonable adjustments to make sure workers with disabilities, or physical or mental health conditions, are not substantially disadvantaged when doing their jobs.
Source: https://www.gov.uk

AbilityNet

The Equality Act 2010 requires employers and service providers to make reasonable adjustments that will allow disabled people to access the same opportunities and services as non-disabled people.
Source: https://abilitynet.org.uk

NHS

The NHS has to make it as easy for disabled people to use health services as it is for people who are not disabled. This is called making reasonable adjustments.
Source: https://www.england.nhs.uk

Examples of Reasonable Adjustments

Examples of Reasonable Adjustments

- Making sure there is wheelchair access in hospitals.
- Providing easy read appointment letters.
- Giving someone a priority appointment if they find it difficult waiting in their GP surgery or hospital.
- Longer appointments if someone needs more time with a Doctor or Nurse to make sure they understand the information they are given.
- Having information available in an audio format rather than expecting everyone to be able to access visual information, e.g. having a visual display board with the patient's name to alert them they are being called for their appointment that also audio transcribes the name, room number and Doctor out loud.
- Information videos should be subtitled and have an in-vision BSL interpreter.
- Assistance dogs are available for multiple disabilities and conditions such as Deafness, diabetes and neuro-diversities, as well as Guide dogs for the blind. It is important not to discriminate against any assistance dogs and they must be allowed into all premises by law.
- Being aware of the procedures for booking BSL interpreters. Many hospital staff are often unaware that the Clinical Commissioning Group is responsible for funding and providing interpreters to Deaf people for all NHS appointments. This lack of awareness can create barriers for Deaf people, potentially attending appointments without accessing communication support.

"There is a big gap in what people understand counts as Reasonable Adjustment. There is a perception that something that may take more time and effort is unreasonable, this is not the case. Also, something that may cost a bit more money. Just because investment in time / money occurs, this does not make it unreasonable. "

FOR DEAF AND HARD OF HEARING PEOPLE

REASONABLE ADJUSTMENTS AND ACCESS

Why are interpreters needed?

Why an interpreter is needed:

- To facilitate communication between hearing NHS staff and the Deaf service user.
- The interpreter should be fully qualified, registered with NRCPD, adhere to the Code of Conduct outlined by NRCPD and have the appropriate professional indemnity insurance.
- For some Deaf people, their first language is sign language. It is important that the Deaf person can communicate in their 'mother tongue' and have access arrangements to support this.
- To reduce the frustration and stress of miscommunication that occurs when staff members do not have the language skills to communicate in the Deaf persons language (BSL).
- An interpreter effectively reduces time by aiding communication between two parties by providing fluent interpretation.
- The presence of a qualified interpreter in medical settings ensures that the information shared by the medical professionals is correct and understood. It is imperative that a professional translation is provided, especially when discussing treatments and medications that may be life threatening if not followed correctly.
- To give the Deaf patient full accessibility to what is being discussed in the medical setting, including any passing conversation that any hearing person would be privy to.
- Providing interpretation, reduces the Deaf patients anxiety and provides a clear comprehension on the procedures and process regarding their health.
- An in-house BSL interpreter for medical settings would allow Deaf patients instant access to communication when they have an appointment.

How do interpreters work?

An interpreter will assess the setting to determine the type of interpretation required. They will usually work within 2 modes in a medical setting:

- **Simultaneous:** The interpreter will sign/speak the source language at the same time as the speaker, instantly with minimal delay. For example, in conferences, training and presentations. An example in a medical setting would be a health workshop where there is a trainer and an audience.
- **Consecutive:** An interpreter will relay information in a summarised format. The interpreter would listen to the speaker, pause and then relay in a chunked form. The conversation will not naturally flow and may have several pauses and delays. This is used in opticians when the view of the Deaf person is obstructed whilst they are undergoing assessments. The interpreter will summarise what will happen before the assessment and will wait for the next 'instruction'.

For an interpreter to work in a medical setting, they must be registered with NRCPD and hold a BSL/English interpreter qualification. Members of NRCPD are expected to adhere to the Code of Conduct and ethical principles that includes confidentiality in all assignments to protect the parties involved. (https://www.nrcpd.org.uk/code-of-conduct)

Working with communication professionals

- When working with communication professionals, Clinicians need to be aware of the expectations from both the Deaf patient and the interpreter themselves. Firstly, interpreters are highly skilled and qualified professionals. It cannot be assumed that the interpreter knows the Deaf patient or is a relative. The interpreter is not there to judge or assess the Clinician, but to work harmoniously to facilitate the communication taking place.

- When the Clinician questions the patient, it is fitting to look directly to the patient and not direct any questions to the interpreter. As the interpreter is looking at the hands, face and body of the patient, you will find little eye contact between the interpreter and the staff member. This is to show that even though they are a third party in the room, they are not part of the conversation, but are there to facilitate the conversation only.

- Depending on the setting, an interpreter will usually stand or sit opposite the Deaf person, sitting next to the Clinician side by side. The interpreter may need to halt the conversation to clarify something they have misunderstood themselves, or to clarify something for the Deaf patient

- Medical professionals need to allow additional time for the appointment and make provisions for that time. It is advised that the person responsible for booking interpreters, allocate double time for the appointment.

"A person arrived at a vaccine centre and there was no interpreter. They tried to explain they were Deaf and all staff did not know how to respond and kept talking to the person. They asked if information could be written down. Staff refused. They asked if masks could be removed to aid in communication. They refused. There was no Deaf awareness."

Appropriate interpretation

Don't ask family/friends

- It is highly inappropriate to expect a family member or friend to stand in as an interpreter for any medical scenarios. This practice is deeply problematic for several reasons. Only a fully qualified interpreter should conduct any translation between the two parties. A family member may know sign language but has not undergone years of specialist training to confidently work in the field. One has to be aware of any personal conflict of interests within family and friendships. It cannot be assured that the information is being translated truly without mistake. It is also inappropriate to burden the family member, such as a child to communicate complex and potentially sensitive information. For example, an appointment where the GP has some findings from a recent MRI, they have found a tumour on the brain. Expecting the child of the patient to relay such news is traumatic and potentially harmful to the mental health of the child.

- Another example of the inappropriateness of a non-qualified ‘helper’ is, if the person translating does not have the best interest of the Deaf person and wants to influence the course of action. An example of this could be at a sexual health clinic where an aunty or friend has strong beliefs over contraception and manipulates the conversation to not accept family planning, when in fact the Deaf person wishes to.

- Involving a family/friend, takes away the Deaf person's right to have a private and confidential conversation with the medical professional regarding their healthcare.

Adjustments when visiting a health provider

1 .Ensure the Deaf patient is seated in the front row or in full view, to allow them to see what is happening in the waiting room and who is walking in and out.

2. Staff should wear clear/transparent masks so Deaf people can lip read. This will make communicating easier. If this is not possible, removing their mask completely is advised.

3. Staff should always have an iPad or notepad available to type/write between themselves and the Deaf patient if this is an accessible means of communication for them.

4. The Nurse/Doctor/Receptionist should hold up the iPad/board showing the name of the person being called in the waiting room to allow Deaf people to see their names (if there is no LED display on the wall showing the name of the next patient).

5. Receptionists should allow extra time for all appointments with Deaf patients. Communicating may take longer than expected, therefore the front of house staff should be patient and respectful.

6. It would be a useful and a time saving resource for front of house staff to undergo basic BSL training, so initial enquiries are understood straight away. BSL Level 1 qualification can be learnt online/face to face, and offered nationwide. This would help both the Deaf patient and the staff who come into contact with Deaf people regularly.

Video Relay Service

Video Relay Service (VRS) is a telecommunications service that enables people who use British Sign Language to communicate with voice telephone users through video equipment, rather than through typed text.

- VRS allows a Deaf person to communicate via the telephone.
- There are several nationally recognised VRS services that hold contracts for public and private domains such as gov.uk, utility companies and the DWP.
- VRS access is a great resource for emergency appointments.
- For ambulances/paramedics, VRS software is incredibly important to aid communication with a Deaf person when attending the scene. Sign Video has just launched a 999 VRS (June 2022).

Other Access Needs

1. Deaf awareness amongst all staff.

2. Modernise current equipment in the waiting room, such as a digital flashing monitor to display names of patients and the room to go to.

3. Ensure the NHS website has an option to use an easy read version of information as well as a BSL version. This will help further people's education regarding current and trending medical news.

4. National Health advertisements/campaigns that are video streamed, should have a BSL interpreter included in the video, alongside captions (captions alone are not enough).

FOR PEOPLE WITH A LEARNING DISABILITY

REASONABLE ADJUSTMENTS AND ACCESS

Adjustments when visiting a health provider

- Provide opportunities to attend clinics when there are no other people there, or at quieter times to avoid anxiety.
- Reassure people if they are waiting and explain when their turn will be.
- Fast track access for those who struggle to wait.
- Provide home visits for those who are worried about going out.
- Offer the option of video or telephone appointments for those who are worried about traveling or being in a busy place and waiting for too long.
- Provide phone number of a named person and the address of where their appointment is beforehand so they can plan their journey accordingly.
- Explain clearly what is going to happen before the appointment so people know what to expect, for example:
    - who to see when they arrive, waiting their turn, what will happen in the appointment
    - any treatments and how they will feel, what to bring
    - send forms in advance or to be completed before arriving
- Staff should support patients to more clearly understand what to expect from their appointment.
- Staff should phone the individual to remind them they have an appointment (providing details of where to go, at what time, what will happen and what to bring).
- If staff are off sick or there is a change of appointment let people know in advance and clearly explain why there has been a change.

Other Access Needs

- Bigger space for waiting area
- Write up what has been spoken about at the appointment so patients can take this away.
- Allow people to have time to think about their treatment options – give information in easy read format and time to go away and think about what to do.
- Appointments need to be on time and not delayed as this can cause anxiety and have implications for care needs.
- Follow up phone calls to check in on the person and review any actions.
- Have someone who is dedicated to support people with learning difficulties when they arrive at the appointment to reassure them and explain what is going to happen.
- Pressing a buzzer to get into the building is confusing and frustrating - make this easier to do.
- Have information about the person available so that they do not have to keep answering the same questions.

Testimonies

"It is hard to hear the Receptionist and the Doctor because they talk too quietly and there is lots of noise. They need to talk louder and more clearly and slower so I can understand them better. I get headaches and feel dizzy when they don't communicate well with me and when I have to concentrate on what they are saying to me."

"People need to look at me when they are speaking to me. I use a hearing aid and people assume I can hear like everyone else. But it is hard to hear when there is so much noise. People need to speak up when talking to me."

"One person at the doctor's receptionist knows that I have a learning disability. She talks to me nicely and is very patient and understanding. Others don't know about me and I have to keep repeating myself."

"When I go to my doctors, I have to keep pressing the buzzer at the door before they let me in. Then the Receptionist is always on her phone and I have to keep repeating myself. I needed to do a repeat prescription, I asked the lady at the doctors to help me but they said I have to do it online. I said I find it hard to read and do things online but she said I have to do it online. I asked if she could help me do it online and she just said I have to do it myself. I got very angry and upset and shouted."

FOR PEOPLE WITH A MOBILITY ISSUE

REASONABLE ADJUSTMENTS AND ACCESS

Adjustments when visiting a health provider

- Step-free access to venue.
- "My GP surgery is supposedly step free but, in reality, it does have a very small step up. For me, as a wheelchair user, even this small step is not something I can circumvent easily. Step free should mean step free!"
- Disabled parking spaces are available.
- Ensure noticeboards are at a height that both wheelchair users and non-wheelchair users can access.
- Ensure that any equipment that patients need to access themselves, for example, auto check-in, is accessible to both wheelchair and non wheelchair users.
- "The computer check-in is accessible for me at my GP surgery but most the time it's not even working. I am not able to stand for long and sometimes there's a queue just to get checked in at the reception desk. If the computer based system was working I would be able to do it quicker and get sat down and out of pain quicker too."
- There should be a lower level desk at reception so that wheelchair users can communicate with staff and not be hidden because of the height of the desk.
- "I keep telling my GP about this problem, the desk is too high so when I am attempting to speak to them, they can't see me and I can't see them. It is not great."
- An accessible toilet is available on site.
- "My GP has a so-called accessible toilet but for a wheelchair user it is very difficult to get the door open and also to move around in the toilet, which is not really large enough."

Testimonies

"When in pain, I am not necessary the most articulate of people and so I'm not really able to advocate and communicate for myself very well. So having my Mum there who can do that on my behalf, who knows my medical history and who can accurately make Doctors and medical staff aware of what's happening, is really important."

"They did not have any seats, wheelchair or anything you could sit in. It just adds to the pain that you're standing in these queues. I was in it for like 3 hours with absolutely nowhere to sit down."

"I was going through a mental health crisis, she [Doctor] rang me late at night from her home. Her children were screaming in the background, she was obviously on loud speaker so all my relevant medical history was being discussed. People I don't even know could hear what was going on because she had friends and family over."

"They only have small fold away chairs. I found I could not get to sit on those chairs comfortably. So if I'm not happy, I do something. I actually took my giant mobility scooter into the cubicle with me and they never seemed to argue."

"One issue is that there is seating available or on hand or like some of the hospital wheelchairs are there on hand if somebody can't stand as long, even if they are not disabled you don't know why someone is in A&E."

Testimonies

"Because of the way they have changed everything for Covid you are largely standing. There is nowhere to sit so until you have gone through triage and until they have allocated whether you are in majors or minors or going to see the out of hours GP, there's no opportunity to sit down."

"I don't look like quite what they expect someone with a disability to look like because I don't always require you know aid to sit down or help with my sight and stuff, it's intermittent."

"I have to battle a receptionist who has not got any medical training to tell me that I have got to do an eConsult ? Which when I'm struggling mentally and physically I cannot do, with the hope of maybe a Doctor ringing me back in 3 months' time, it's ridiculous."

"The other problem with the GPs and the online thing is that they want you to take pictures and stuff. If you're not in a position to take pictures or you can't take pictures, you know what they say when you submit it? Oh, if you want medical treatment or medication or whatever you know we need a picture. I had to call my GP and say look I physically can't take pictures, so you have to physically tell them that, otherwise if you don't take a picture of whatever body part it is you don't get treated."

FOR BLIND AND VISUALLY IMPAIRED PEOPLE

REASONABLE ADJUSTMENTS AND ACCESS

Spectrum of sight Loss

It is important to remember that just like other disabilities, there is a spectrum of sight loss, and individuals experience different challenges depending on what type of vision they may or may not have.

There are 2 major groups: (1) Individuals who have some partial vision, and within this group there will be a variable degree of residual vision; and (2) Individuals with complete sight loss.

"The persons who have some sight have different kind of challenges than those who don't have any sight."

As you read through the following sections, remember not to make any assumptions about the access needs of individuals based on their impairment. The challenges and experience is different for each person, so the best thing to do is just ask what support someone needs, and how you can make reasonable adjustments for that specific individual. There are however common challenges for blind and visually impaired people, and there are many actions that can be taken within a medical setting to improve access for everyone. Below, we outline some suggestions.

In addition, there are blind people who have other impairments that need to be taken into consideration when meeting their access needs. For example, people who are Deaf and blind, may need additional adjustments such as an interpreter who specialises in 'Hands on' communication or visual frame. They may communicate using the manual alphabet – this is a tactile form of sign language which is carried out on the hands.

Adjustments when visiting a health provider

- If usual entrances/exits/routes are closed in the medical establishment:
  - Ensure somebody clearly explains and/or guides the person through the new route
- Provide tactile surfaces and signs for people to follow.
- Prioritise the booking of vaccines/injections at local sites (ideally the GPs) for all visually impaired people. It is difficult for blind and partially sighted people to travel new routes, especially when they are far away. They may need to organise additional support to do this.
- Requiring a visually impaired person to undertake a lateral flow test before a medical appointment is very challenging. Where possible, this should be carried out by trained medical staff when they arrive for their appointment.
- Visually impaired people may require support to fill out forms. Where possible, provide a dedicated member of staff to fill out the form for them.
- When a patient is called in for an appointment, ensure information is audio described/spoken verbally including:
  - The patient's name
  - The name of the Doctor they are visiting
  - The room number they are going to
- Reading the electronic screen is not accessible for visually impaired people so having audio description will ensure blind people don't miss their appointment times.
- Even with audio description, a person may need to be guided to the room.

Adjustments when visiting a health provider

"If I was sitting there whilst the appointment was flashing at me, I could have missed my appointment slot. I like the audio so when I hear I know when to get up. That has happened on many occasions. I don't like the fact that I don't have the control."

- When guiding a visually impaired person, describe the environment to them, especially any potential trip hazards. (Please see the section on how to guide someone p.37).
- Install tactile corduroy surfaces/paving at the top/bottom of stairwell, escalators and on the pavement outside to help alert visually impaired people to hazardous areas.
- Automatic doors should have a sound when opening and closing to help guide visually impaired people in and out of entrances/exits.
- Queueing is not accessible for visually impaired people as they are unable to see when somebody has moved up, what direction they should be facing, and/or if there is a line on the floor to stop you moving too far forward. Calling 'next' for each person would help, and/or provide the option for the blind person to sit down and wait until they are called.
- Ensure all rooms are well lit.
- Colour contrast can be useful for partially sighted people to see certain objects e.g. seating areas.

Testimonies

"Even today, if I have an appointment with a dentist, or in a hospital, I am required to go through the corona procedure, and they send a web address. This is very difficult for me, and I cannot manage. I have an appointment on the 19th with my dentist. I don't know the messages they have sent as I cannot access their website and I can't get things done the way they want. I don't know what they want exactly. I am going without following those instructions."

"A couple of weeks ago I had my surgery. In that time, they wanted some corona protocol to be followed. I was with my family but even then, it wasn't easy because they had to go to the pharmacist, tell them about the message from the hospital and then they gave the lateral flow test. It had to be done on the website. It was a procedure which I couldn't have done and would not be able to do it now also. This is the challenge now I am facing."

"Last week I was at Mile end hospital, which is one I am not familiar with, but I found my way, as obviously I can't see any of the signage to know where to go. I got to a reception, and they didn't understand my symbol cane or what I was asking them as it was a different department. When I made it clear I needed support to get there, they made me sit in a wheelchair and then 5 minutes later, they came and insisted on pushing me to an MRI. I then got to the reception and was told that it wasn't the right place and I needed to go to the new reception. I am sitting there in my wheelchair with my symbol cane out. She came up to me and handed me a form. I said look, can't you tell I am here with a symbol cane, I am blind, and I have broken an arm. She didn't have a clue and couldn't tell I wasn't in a fit state to fill in any forms."

Testimonies

"I had a PCR at a testing centre. I came in with my cane so they knew I needed guidance. But everyone wanted to keep their distance so I could not get the help I needed. I had to do the job myself when it came to putting the test together. It was challenging because I could not see and no one could describe it to me clearly."

"When I went to the GP they decided they didn't want people to go into the surgery and they had a notice on the door but I could not see it. So I rang the doorbell and no one responded. Then some lady started doing sign language and I signed back to her. She was screaming at me. How was I supposed to do any of the things that needed to be read."

"He (the Receptionist/Doctor) expected me to send photos, but I told him I was visually impaired. He made out that I refused to send photos. It was a personal place, how do I know who is seeing it, where it is going etc and with my visual impairment. I did go to the appointment and when I was in the room, the Doctor didn’t ask to look at the issue."

How to guide someone

You may notice someone who needs assistance to be guided somewhere, or perhaps a patient or member of the public might ask you for support. Here is how you can help to guide them in an appropriate way that makes them feel safe and does not put them at risk:

1. Before you start guiding someone, ask if they would like support

2. Ask them where they would like to go

3. Make sure you offer your elbow to them

4. Walk half a step ahead of them

"If I am holding your elbow and you are half a step ahead of me, most of the time, I will know what obstruction is coming up ahead of me by your own walk/ feet. I will know that there is a curb to get up or down. I may slip if I don't notice it, so if there is a curb, stair, or slope coming up, the person has to be very careful and tell me that it's a curb or stairs."

5. Walk at a normal speed. Ask the person if you are going to fast/slow. Everyone has different length legs, so what is normal for one person, may feel fast to another

"It is all about consideration for guiding the person, checking what the visually impaired person requires. Is this speed comfortable for you? Would you like me to go a little faster? "

6. Describe what is around them and what is coming up, particularly any potential trip hazards, steps or curbs.

"If there are stairs and the person guiding me to the staircase suddenly starts climbing up the stairs, they should tell me a staircase is coming. Also if it is going up or down. I can then follow the persons steps with their elbow and walk safe."

How to guide someone

7. If guiding to a chair or bench, place the person's hand on the back of the chair

"What happens when they take me to the chair and then leave me? Then I don't know if I am going to sit on the chair or on somebody's lap or on the floor. The best way would be to put my hand on the chair. Or, if it is a bench, put my hand on the bench where I am going to sit. I know my place to sit and manage myself."

8. If going up stairs, or over difficult terrain, you should offer to carry the person's bag so they have a hand free to hold the rail

"If psychologically, someone is carrying something and there is a proper flight of stairs ...they may have to say could you hold this bag so they have a hand free to have a hand on the stair rail."

9. Remember people can have multiple impairments so may have other access needs to be considered

"We are people so have other impairments. More complex than just sight loss. Others may also have difficulty with balance and walking for example, so care is also needed to support in broader ways."

10. A partially-sighted person may need some assistance too. Just ask if they need help getting somewhere

11. Be considerate

"They need to put into consideration walking speed. I have seen blind people getting dragged to reach a certain place on time and trying to make them walk faster. I have seen it on the underground when people are waiting for someone to guide them. They should be more caring when guiding blind people. It should be the speed they walk, also there is the cane to be aware about."

Frontline staff and medical professionals should receive professional training in how to guide a patient. This can be done either through a video, or by practicing with a Blind person through a practical training programme.

PA SUPPORT

CHAPTER 3

Why a PA/Carer is so important

In your workplace, you may hear a patient/client talk about their PA, [Personal Assistant], Carer and/or Support Worker. For all practical purposes, these terms are interchangeable and mean the same thing.

The support and help that a PA gives to their client can fall into a number of generic categories. Below is a list of some of the main groups along with some examples. You might want to think about other instances of support and how they fit into this structure. Some of these examples will cross over into other categories too.

Medical

- Helping with preparation and facilitation of a client's drug regime
- Changing dressings
- Supporting the client with toilet functions, stoma / catheter care
- Looking out for specific symptoms / conditions that may need medical attention

Physical / Practical

- Transfers between bed, chair, wheelchair, bath, shower, toilet etc
- Escort duties whilst out and about, driving
- Day-to-day living support
- Bathing and cleaning duties
- Supporting with walking, walking aids
- Meal preparation, help with eating
- Cleaning / domestic duties

Communications support

- Interpreting services - includes languages, signing support for Deaf people
- Comprehension issues - helping clients to understand and be understood when communicating with other people. For example, some people with a learning disability, cognitive disability and/or speech and hearing impairment may need support to better understand medical advice.

Emotional and social support

- Presence and coaching to help boost a client's confidence
- A buddy to support the client to undertake social activities e.g. going to the cinema

Advocacy type support

- Helping the client to perform specific tasks themselves [or in conjunction with a PA]
- Assisting with budgeting, financial management, benefits
- Supporting a client to get their views and thoughts understood in a particular situation when they are not able to advocate for themselves

Why a PA/Carer is so important

When you see a patient with a PA supporting them, do you have a preconceived idea as to what that support is?

Clearly, the support needs of a client can range from something quite complex and extensive to a simple single function. For this reason, it is important that you do not make assumptions about a client's support needs based on how they and their PA present to you. There's no one-size-fits-all and your perceptions may not reveal the full story.

Are there different types of PA?

As we have discussed above, there is an extensive range of support and services that a PA may provide for their client. The type of support that is provided is not what defines the type of PA they are.

Broadly speaking, there are two types of PA:

Most people who have a formal and funded [contracted and paid worker] arrangement with their PA, will have had their needs assessed and signed off. Usually through social care provision of the local authority and/or third sector organisations contracted to do this work

Whilst it is fair to say a large proportion of people with complex and severe health issues are likely to have a formal arrangement, many other disabled people choose to have a less formal approach for a PA to help them with their needs. This may be for example, a friend or family member providing support, and this work may be paid or unpaid. The nature of the relationship in this instance, between the client and their PA may appear less formal but the support and function of the PA, should not be seen as anything but formal.

It is important PAs of either type are recognised to be of equal value and importance to their client and clients' needs. The support they give should not be perceived as greater or lesser, irrespective of these PA type definitions.

Why a PA/Carer is so important

Assistance and Guide Dogs

It is already established in law how important the service is that these dogs provide to their clients. They should be accommodated as much as possible and only excluded if there is a very good and valid reason to do so.

It is beyond the remit of this guide to go into great detail on this topic but you might be surprised at the extensive range of possible support Assistance and Guide Dogs can give.

Please treat them with respect and accommodate your patient's access and support needs if they are provided in this manner. One of Real's members Jackie Kennedy shares her experience of having an assistance dog, and the vital role they play in her everyday life, but also in providing life saving care.

www.mirror.co.uk/news/uk-news/ex-policewoman-epilepsy-after-savage-20790030

A PA/Carer can be an important resource for many Deaf people. A PA/Carer can enhance their lives in different ways - such as helping them to become more independent and teaching them basic life skills. They can act as a buddy for the Deaf person which can help them to feel less isolated and reduce anxiety. Having a PA/Carer can also help Deaf people to feel more empowered. PA/Carers of Deaf BSL users are expected to have a good level of sign language fluency and can communicate with the client, being Deaf aware.

Testimonies

"When I went for my injection, [vaccine] I went with my PA and they did not allow my PA to be in the room with me. Therefore it was hard to steady my hand (because of my disability) so they could inject...I needed someone to help me, and I never had that help...I was anxious and scared...but at the end my PA came in and helped me. It would have been so much better if they came at the first time."

"Earlier this year I had to go to A&E because I experienced flare up of my condition and they would not allow my mum in with me. I don't have an allocated PA. The more I think about it the more I should probably get one, but I don't have one and so my mum largely serves as that role or my partner. I was in absolutely, excruciating pain and when I experience flare ups I am not necessary the most articulate of people and so I'm not really able to advocate and communicate for myself very well. So having my mum there who can do that on my behalf, who knows my medical history, who can accurately let Doctors and medical staff aware of what's happening, is really important....Not having that person there makes life extremely difficult for you and seven hours by yourself in A&E is not fun at the best of times, let alone when you require somebody to be with you."

"Not everybody who counts as a vulnerable person will have a carer whose dressed in like blues"

"Some carers and some PAs as well are just in normal clothes and so that is a thing, we are not lying to you because we want to have a bit of company."

"[We need] a bit more recognition and understanding when someone says they have someone who is there to [help with access], that they are believed and listened too."

ACCESSIBLE COMMUNICATIONS

CHAPTER 4

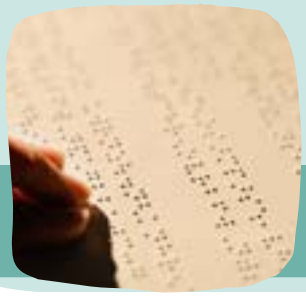
Overview - Accessibility of Covid Information

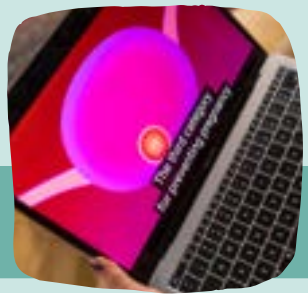
From January to July 2021, Real, ICM Foundation, DeafPLUS and Healthwatch undertook an outreach project to understand more about the experiences of disabled people accessing Covid health information throughout the pandemic. Although the findings below relate to a question asked about the accessibility of Covid health information specifically, many participants reported that their experience extended to all health communications.

Around 50% of the participants we spoke to found 'some' or 'all' Covid health information to be inaccessible and hard to understand. This rate was much higher amongst people with a learning disability. Some of the reasons sited were:

1. Language too complicated
2. Too much information is online
3. Low literacy levels amongst some groups
4. Communications were not targeted towards disabled people (e.g easy reads, images, BSL)
5. Lack of coordinated approach in Covid messaging across agencies
6. Contradictory information and advice
7. Not enough information in community languages
8. Some information was out of date (Helpline, Council website, NHS letter)

Overview - Accessibility of Covid Information





We asked the different groups of disabled people we spoke to, what accessible formats they would like their Covid health information to be in. The chart below provides a collective overview of their responses. However, as you will see in the following sections, each impairment group requires a tailored approach to communications - one size does not fit all!

The recommendations below can be extended to health information more generally.

Easy read format

Videos

Large font

BSL on videos

Braille

Subtitles on videos

More pictures, visual aids

Leaflets through post

Info in audio format

Shorter info in bullet points

Leaflets in Makaton

Posters

Tailored webinars for different impairment groups

Info in simple English

White backgrounds on websites

Picture booklets

Visually impaired Covid-19 radio programme

TVs in doctor's surgeries with BSL and subtitles

Phone calls (regular support from knowledgeable sources)

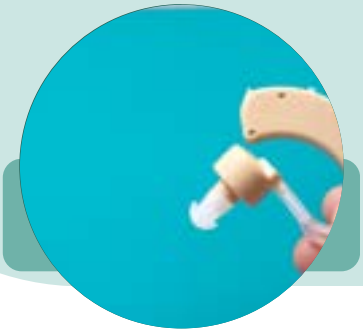
FOR DEAF AND HARD OF HEARING PEOPLE

"I wrote on a paper "I am deaf" in big letters and then stood in the waiting room and held it up, because my disability is not visible . It made me very uncomfortable , I should not have to do this."

ACCESSIBLE COMMUNICATIONS

See appendix 1 p97 for a case study on how Bart's Health made improvements to the experience of D/deaf and HOH patients

Not all Deaf people communicate the same way



- There are many different levels of Deafness. You may be Deaf but be able to speak. Alternatively, you may be Deaf and may not use your voice. Deafness does not have only one characteristic when communicating.
- Not all Deaf people wear hearing aids.
- Deafness can be caused by tinnitus.
- Some people are also Deaf-blind and use a different type of sign language to communicate called Hands-on.
- Not all Deaf people have the same experience. Every deaf person's experience is different. Some deaf people use BSL, some use lip-reading and some use both or neither e.g. if a person has become Deaf later in life, they are likely to be able to speak well.
- Some people may be Deaf for genetic reasons. E.g Being Deaf due to a recessive gene passed on from parents.
- Some Deaf people like wearing hearing aids but that does not mean they can hear everything. For some people, hearing aids provide information as to the background and environmental sounds. However, this does not mean that they can hear speech.
- Sometimes Deaf people may talk differently because they cannot hear what it sounds like to say the words they are saying. This is also reflected by the volume of their speech.
- If a person is Deaf from a young age, then BSL may be their first language. This means that English is a second language to them.
- There are some Deaf people who are very good at understanding written English. This can depend on the education they have received. However, even if a Deaf person understands written English, their preferred method of communication may still be BSL.
- BSL is not a universal language. British Sign Language is used within the UK. Other countries have their own sign languages.
- Around the UK there are regional accents that have developed within BSL. How you sign certain things, such as numbers or colours could differ depending on your locality.

Key Communication Considerations

- For BSL users, using your facial expressions is a key part of communicating with Deaf people.
- For Deaf people, their eyes are like their ears so they are looking for visual cues to help with understanding what a person is saying.
- Maintaining eye contact with the Deaf person is important.
- It is important to have a BSL interpreter present if a BSL user is trying to access information.
- If there is no BSL interpreter, and you are seeking alternative ways to communicate, the information needs to be written or typed in simple English to aid with the Deaf person's understanding.
- You could also use gestures, and use clear lip patterns to try and get your message across.
- Be prepared to repeat yourself.
- Ensure that you maintain a good amount of distance from the Deaf person so they can take in your body language, and can focus on your mouth (and facial expressions) if they are trying to lip-read what you are saying.
- It is important to empathise with BSL users. It can be frustrating trying to communicate with the ‘hearing world’. Please give Deaf people the time they need.
- Ultimately, you need patience.

Methods of Accessible Communications

TV Screens with information/subtitles

- In GP surgeries or hospitals it is important for there to be TV/information screens that alert people when the doctor or nurse is ready to see them.
- All monitors that display visual health information (e.g. videos) should be subtitled and have an in-vision interpreter.

Pen and paper

- When the Deaf person comes to the GP, the receptionist should be aware of how to communicate with pen and paper. The sentences should be straight to the point, refraining from using complex jargon or grammatical structures such as idioms or rhetorical questions.

Easyread posters

- Easy read posters should be available for Deaf people, using pictures, diagrams, and infographics as a visual aid.

Other methods

- QR codes that link to information videos with BSL.
- Having a flagging system under the patient's details on the intranet that alerts staff that the person is Deaf and has communication preferences.
- When a Deaf person approaches the desk, and supplies their information, a flag with the following should alert the member of staff: “Deaf – NEED TO BOOK AN INTERPRETER “ or “ HEARING LOSS – BOOK A LIPREADER.“

Best practice examples
-BSL health videos

https://signhealth.org.uk/videotags/alcohol/

https://signhealth.org.uk/videotags/bereavement/

For more examples of BSL videos on specific health topics, please visit SignHealth at www.signhealth.org.uk

FOR PEOPLE WITH A LEARNING DISABILITY

ACCESSIBLE COMMUNICATIONS

Methods of Accessible Communications

Easyread information

- Use pictures of people with learning disabilities/ people we know.
- Use easy to understand words.
- Clear contact information – e.g. name and phone number.
- Plain information and colourful – use contrasting colours of text and background.
- One side of A4 – format for web, email and posters.
- Send reminders of appointments in advance.
- Use a clear font and large text.
- Clear appointment date and time in font larger than other text.

Text/Email

- "Text is good and easy to get and reminds me of my appointments."
- "It is important to know who sent the text and how can I get in touch with them."

Letters

- "I need to know who sent the letter, how to contact them if I have a question or a worry and when my appointment is."
- "Letters need to be plain and easy to read."

Talking on the phone

- "Be friendly and ask how I am."
- "Wait for me to answer."
- "Ask me to repeat myself or say back to me what I say."
- "I do not like to wait ages to speak to someone on the phone."

Key Communication Considerations

Communicating effectively when we meet face to face:

- Body Language – smiling face and friendly.
- Talking – be polite and use easy to follow language.
- Find out about me – ask the right questions and show interest in me.
- Be patient – give me time to talk and answer questions.
- Do not make assumptions – I may prefer another language.
- Focus on me and do not become distracted.

Asking questions:

- Avoid yes/ no questions.
- Give me choices and check if I understand.
- Ask 1 question at a time and wait for me to reply.
- Look at me and not my carer/ support/ family/ friend.
- Give me time to answer questions or tell me in advance.

What information to include in communications to me

What to include:

My name
My address
Date of appointment
Time of appointment
Where to go
Forms and questions I need to answer before I come
Who sent the letter/ text/ email
How can I contact them? Phone number, email etc

Good questions/comments to use

- **Hello, my name is ……. I am a ……. How are you doing today?**

- **What have you been doing today?**
- **Have you had a good day?**
- **What help do you need while you are here?**
- **How can I help you?**
- **Do you need someone to help you?**
- **Take your time**
- **Can you please repeat that?**
- **What questions or worries do you have?**

Best practice examples
-EasyRead Posters

We asked our coproduction group to look at 4 easy read guides/posters and tell us which ones were the most accessible and why, here is what they said...

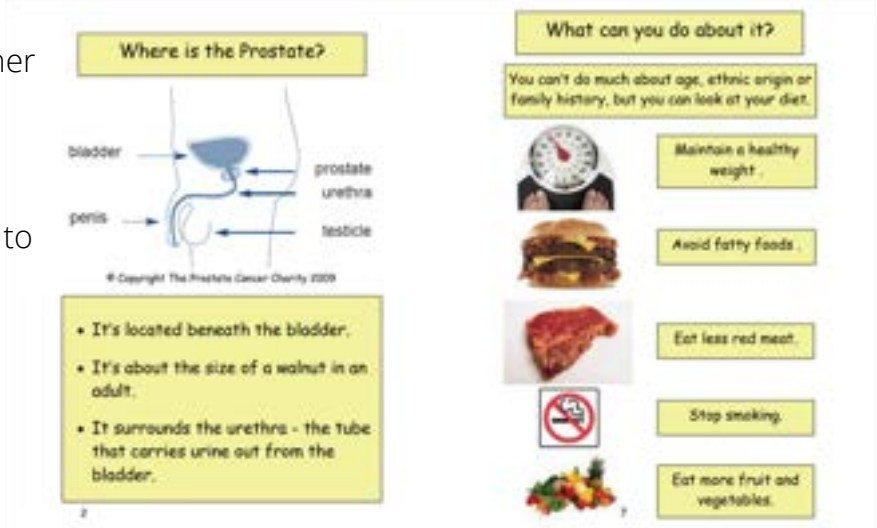
Source: MH-CoP-Detained-poster.pdf (assets.nhs.uk)

Mental Health Act CoP Detained

- It is good as it makes people aware of what to say
- The key image is good as it makes it feel as if you're locked up
- The pictures are clear and nice and easy to look at
- The colours are good to look at
- There is less text and more images and the balance between the text and images is good
- MH CoP Detained Mental Health Act Code of Practice – not clear what this means and why are the bubbles there? What do they mean?

Prostate cancer

- The pictures of food are good and explain healthy and unhealthy food
- Information is laid out better than the other posters/ leaflets
- The pictures and words are in line with each other
- Pictures are ok but some words are hard to understand
- It has more pictures
- There is important information
- The presentation and colours work well
- Pictures are good and it is easy to understand
- Prostrate Cancer leaflet was hard because it has all different pictures and words



Source: Prostate Cancer | Generate (easyhealth.org.uk)

Best practice examples
-EasyRead Posters

Source: Bipolar_Affective_Disorder2.pdf (southwest.nhs.uk))

Bipolar Affective Disorder

- The group feel the images do not represent what is being said in the text and they are confusing. They didn't understand the pictures and how they relate to the text
- Some difficult words that the group have not come across before and the text needed explaining to the group as well. Words such as antipsychotics and antidepressants needed to be read to the group and explained
- The title should be on top
- Don't like the front page and it is off putting
- Its not eye catching and looks boring
- Not much information about what to do next if you are diagnosed with bipolar disorder

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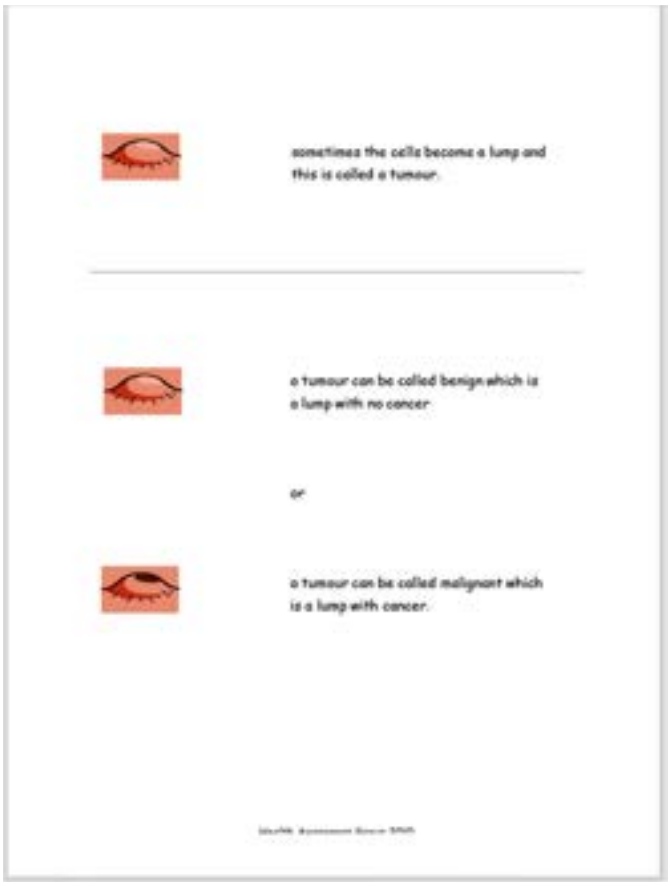
Telling you about stomach cancer

- Has an inviting cover – you want to open it to find out more
- Pictures are good and it is easy to understand
- The words and images are very small and there is lots of empty space on the pages



Source: www.easyhealth.org.uk/resources/76-telling-you-about-stomach-cancer

Best practice examples
-EasyRead Posters

What makes a good easy read poster and leaflet?

- Big pictures
- More pictures than words
- QR code to watch a video or hear audio
- Simple language
- Text and pictures not too small
- Light colour background but not bright – except white
- Yellow is also a nice colour for the background – good contrast
- Not too busy – some space between the words and images helps
- Large font and bold writing
- Contact numbers for more information

Below is an example of an easy read poster coproduced with members of ICM Foundation CIC. It was produced during the pandemic to provide guidance to people with learning disabilities about how to stay safe from Covid transmission. Looking at the layout, photos, structure and colours will help to provide good guidance to others creating an easy read poster for their own patients/members/community.

Best practice examples
-EasyRead Posters

FOR PEOPLE WITH MOBILITY ISSUES

ACCESSIBLE COMMUNICATIONS

Methods of Accessible Communications

In general terms, persons with mobility only impairment issues will not require a great deal of adjustments to be made with regards to most incoming communications. However, there are a range of issues that physical mobility may impact on with regards to replying to communication. You may need to consider this when communicating in the first instance.

Don't assume just because a particular method of communication is a person's preference, that they do not have access issues using that method. It may simply be the best method for them to use but by no means perfect!

Telephone

Incoming calls:

- Delays in picking up the phone. "Many times when the phone rings, I am not able to get to it in time before the person rings off. This is sometimes true when I get calls from the NHS but surely they should know from my records I've got a mobility impairment and know they should let it ring for longer?"
- Delays in speaking after picking up the phone.
- Difficulties holding the handset. "I can't always hold long conversations on the phone because it's difficult for me to hold the handset for any length of time."
- Dropping the telephone / handset during a conversation.

Outgoing calls:

- Difficulties dialling. "I wish they would call me, it's very difficult with my hands to make calls and I'm always getting the wrong number."
- Difficulties holding the handset.
- Dropping the telephone / handset during a conversation.

Emails

- Issues accessing interface devices, and standard devices like keyboards and mouses. It is important to be aware that replacement accessible interface devices may still be problematic. Typically, possible issues are:
  - Starting up the computer
  - Opening / closing specific programmes
  - File access and management
  - Text entry

"I make a lot of mistakes when writing emails because even the software gets things wrong and sometimes it's really difficult to correct these. I hate having to allow emails like this to go out but sometimes I have to in order to get them to where they need to go in time."

Letters

Computer generated letters:

- The same problems as listed above for email, plus the following
  - Usage and control of printers
  - Ability to post a letter

Handwritten letters:

- Difficulty writing
- Legibility of a handwritten document. "I try to avoid having to handwrite stuff but sometimes there's no other option. My handwriting is now really poor and most of the time I can't read it within an hour or two of writing it so what chance does anyone else have?"
- Ability to post the letter.

"It's so frustrating, having managed to put it together and print it, my mobility is too poor for me to go out that day to post it. Another delay."

FOR BLIND AND VISUALLY IMPAIRED

ACCESSIBLE COMMUNICATIONS

"There should be a system in place that should provide accessible modes of communication for blind people. When Covid came, everything fell apart. These organisations are breaking the law because the lives of people are being put in jeopardy because they are not getting special care from the health care workers."

Methods of Accessible Communications

Below are some of the challenges blind and visually impaired people experienced during the pandemic accessing Covid health information. Many of the challenges can be extended to healthcare more generally.

- Priority information received (e.g. letters through post) is not in large print or braille.
- A lot of information is online, which is not accessible to some blind people.
- People expressed difficulty in booking vaccines online – the system is not compatible with screen reading software.
- There is little or no accessible information to guide blind people as to how to carry out Covid-19 tests.
- Submitting forms online can be challenging for a visually impaired person.
- People who identify as Deaf blind/Usher's Syndrome struggle to access information in consultation rooms that are poorly lit. If the clinician is sitting or standing in front of a wall that's not plain or if the clinician is positioned outside their visual frame, due to Covid restrictions and social distancing, this can make communication more difficult.

Ensure people's communication preferences are recorded. Provide options for information/prescriptions to be in:

- Large font
- Braille
- Audio format

- Sending information via email or by phoning the individual can help to overcome some communication barriers.
- Ensure there are alternatives means to book an appointment e.g. by phone.
- Allow forms to be filled out on arrival with assistance from a staff member.

"My pharmacy does not produce large print font on medication when previously I have requested this. It should be permanently on record if large print, braille etc is requested. When people admit they need support there should be mechanisms within pharmacies and doctors' surgeries to draw on all available services."

MULTIPLE IMPAIRMENTS

CHAPTER 5

Supporting people with multiple impairments

Hopefully by this stage of reading this guide you will have a greater understanding of the nature of people's impairments and in a very general sense, how they affect their access ability. So far, we have looked at these issues mainly by looking at each impairment group in isolation and from testimonials from people who fall into that group.

Unfortunately, it isn't always quite so simple [not that it is simple in the first instance!]. In practice, you will find that many people have a combination of impairments that will fall across various impairment groups. Statistically, the amount of permutations that could generate is a very high number indeed!

So, how do I deal with this extra complication of a patient with multiple impairments and work out their access needs?

Sometimes, but not very often, a person may have access needs from different impairments that do not overlap. In this instance, you may be able to simply respond to these access needs together.

Here's a simple example:

- I have a mobility issue, I will need a chair to sit on while I'm waiting
- I also have a visual impairment, I will need someone to guide me to that chair

It's not generally that straight forward though. You are much more likely in practice to find that impairments frequently will have a cumulative effect on a patient access needs

Another simple example:

- I have a mobility issue, I will need a chair to sit on while I'm waiting
- My coordination is poor due to a separate neurological condition, it may take me a little while to get to the chair safely and there is a risk of me falling

If you combine these impairments, the hypothetical access needs become a little more complex

- I have a mobility issue, I will need a chair to sit on while I'm waiting
- My coordination is poor due to a separate neurological condition, I move very slowly
- I also have a visual impairment, I will need someone to guide me to that chair, sorry this may take a while for both of us

Clearly, it can be quite complicated. What can I do if I'm still not sure what support the patient needs?

Ask!

INTERPERSONAL SKILLS

CHAPTER 6

Interpersonal skills with Deaf people

Why are interpersonal skills important for accessible and positive communications with Deaf and hearing impaired people?

- Interpersonal communication is an intimate, human activity that can weigh heavily on a Deaf patient's overall psychological health and wellness, and therefore, warrants much discussion and attention. There are several strategies that can be adopted to improve communication in hospital and medical settings in regards to treating Deaf patients. This would start, especially at shift handovers, ensuring the staff are fully aware of the person's disability and the access that has been put in place. This would reduce the stress and anxiety of the patient, if they can physically see that clinicians are informed, confident and understanding of their needs.
- Strong awareness of the varied communication strategies are important for improving Deaf patients safety, but staff also need to be provided with the communication tools they need. Many hospitals do not provide disability or Deaf awareness training for the front of house staff.

What impact can it have on Deaf people when health professionals/frontline staff do not have good interpersonal skills?

- The main effects of poor communication in healthcare are a reduction in the quality of care, poor patient outcomes, wastage of resources, and high healthcare costs for the NHS. Communication failures often have a negative effect on Deaf patients and staff satisfaction.

- Poor communication between clinicians and Deaf patients can result in misunderstandings about medications and the miscommunication of follow up instructions, which can result in poor outcomes and readmissions. If a Deaf person has been denied access to an interpreter for an appointment, this could result in a patient coming to harm. Poor communication can also result in inadequately informed consent, which can lead to malpractice.

What interpersonal skills are often lacking when health professionals/frontline staff communicate with Deaf people?

- Reassurance
- Expressing appreciation
- Concern
- Empathy

Interpersonal skills with people with Learning Disabilities

Why are interpersonal skills important for accessible and positive communications with people with learning disabilities?

- "We need to explain how we are feeling or what we need or what is wrong."
- "When someone is patient, listens to us and asks us questions and talks to us nicely, we can feel comfortable and explain ourselves better."
- “When I am respected by staff I feel really good.”
- "We can feel better already when someone is nice to us."

What impact can it have on people with learning disabilities when health professionals/frontline staff do not have good interpersonal skills?

- “When I cannot hear the staff or have to concentrate hard to understand them I get bad headaches.”
- “I feel upset and disgusted with the staff.”
- “I feel uncomfortable trying to read something without help.”
- “When staff do not communicate well with me I feel worse.”

What interpersonal skills are often lacking when health professionals/frontline staff communicate with people with learning disabilities?

- Respect for us
- Active listening
- Being flexible
- Caring about other people and how they are feeling
- Being patient
- Communicating clearly and using simple language
- Working with us

Interpersonal skills with people with Mobility issues

Why are interpersonal skills important for accessible and positive communications with people with mobility issues?

- It is important to be able to adapt the way you communicate with a person with mobility issues.
- There are a range of impairments that may directly or indirectly, impact on that person's ability to communicate
- example - Some neurological conditions may present primarily as mobility issues but maybe impacting on that person's ability to communicate neurological issues
- Using empathic skills and active listening will help you to assess whether your attempts at communication are successful or you are running into difficulties
- If you think there is a problem, try to adapt how you communicate, try other methods
- If the person has a PA with them, they may be able to help facilitate communication. Be sure to ask the person first if this is OK and preferably in the presence of the PA

What impact can it have on people with mobility issues when health professionals/frontline staff do not have good interpersonal skills?

- Sadly, in many cases the person concerned may well have experienced this problem many times before. Because of this they may well be resolute, pragmatic, patient and determined to get a positive outcome.
- None of the above precludes, however, a series of negative outcomes too. These may include feelings of frustration, annoyance, sadness, fatigue, anger, isolation, reaffirming stereotypes and feeling less valued [See below].

What interpersonal skills are often lacking when health professionals/frontline staff communicate with people with mobility issues?

We appreciate that many busy healthcare professionals Have to balance and prioritise work on a daily basis and have unenviable heavy workloads. It's very easy for any of us in this situation to not always give as much attention to an individual patient, especially if the aspect of the interaction with the patient is not about the medical issue, that is, their access needs.

Skills that are less likely to be used under these circumstances, include:

- Concentration
- Empathy
- Establishing a good rapport
- Providing a safe space mentally and physically
- Listening

STEREOTYPES AND PRECONCEPTIONS

CHAPTER 7

FOR DEAF AND HARD OF HEARING PEOPLE

STEREOTYPES AND PRECONCEPTIONS

Common stereotypes

They can all lipread.

Some people assume that you are not disabled unless you look physically impaired.

They have communication support (family/friends) that can attend the appointments with them.

Medical professionals assume Deaf people want to be 'fixed' with invasive operations such as cochlear implants. These surgeries do not guarantee full hearing and do not make them 'hearing'.

Assume that some short appointments will not require booking communication support, such as a blood test or a smear.

What assumptions not to make:

- If you have a hearing aid, you can hear everything that a hearing person can
- Shouting will help the Deaf person hear better
- If a person presents themselves with clear speech, that indicates they can hear better
- Standing close to Deaf person's ear to talk will always work

What language not to use:

The following terms are offensive and should not be used at all:

- Deaf mute
- Deaf and dumb
- Stone deaf
- Don't say "the deaf" – use "Deaf people"

They are offensive because they assume the Deaf person cannot communicate well.

Also avoid judgemental phrases such as:
"suffering from deafness" or "afflicted by deafness" or "trapped in a world of silence".

What (appropriate) language to use:

- Hard of hearing
- Deafened
- Partially hearing/deaf
- Profoundly / severely deaf
- Deaf

What impact does this have?

Why are preconceptions harmful to Deaf people?

- Stops their ability to access information and advice.
- Places distrust towards staff/clinicians.
- Social withdrawal due to reduced access to services and difficulties communicating with others.
- Emotional problems caused by a drop in self-esteem and confidence.

" I used to attend medical centres (both hospitals and clinics). I would approach the desk and check in, then take a seat. The time for my appointment would pass so I would return to the reception to find out the cause of the delay."

"Several times the member of staff would say to me that the appointment has now finished and I missed my turn to be seen. I was waiting, on time and no one thought about the fact that I could not hear my name being called. I was disadvantaged, not able to access my right to healthcare."

"I now have to hold up a sign in the waiting room with my name on it and big capital letters, saying I AM DEAF!!! I shouldn't have to do this, It really angers me."

" I feel like a second class citizen, not worthy of patience and consideration. Just because I can't hear doesn't mean I cannot live my life as an adult and do normal things. People are in shock that I drive and have children. Outside of the Deaf community, I feel very isolated and lonely. People assume I am dumb and incompetent and they don't even know me. It really affects my mental health, it knocks my faith in humanity."

FOR PEOPLE WITH A LEARNING DISABILITY

STEREOTYPES AND PRECONCEPTIONS

Common stereotypes

What assumptions not to make:

- I can read and write
- I understand what you are saying
- I can follow instructions and directions
- I will tell you what I need
- I will answer a question straight away
- I do not get upset
- I don't have feelings
- I am stupid

What language not to use:

- Mental
- Mental head
- Stupid
- Idiot
- What's wrong with you?
- Dumb
- Annoying
- Different
- Lazy
- Frustrating
- Weird
- Twit
- Loud
- Strange
- Silly

What (appropriate) language to use:

- Use our names
- Person with learning difficulties and disabilities
- Someone who needs support to ... read/ write/ understand
- Person with additional support needs
- Patient with additional support needs

What impact does this have?

Why are preconceptions/stereotypes harmful to people with learning disabilities?

- It makes it seem that other people can treat us in the same way.
- We do not feel confident and think we have done something wrong.
- It makes me feel angry and frustrated a lot of the time.
- We feel that we are not good at anything.
- We lack confidence and become quiet .
- We feel that we cannot tell anyone what has happened to us.

"One receptionist knows I have a learning disability, but the others do not and I have to keep repeating myself."

"Staff need to look at me when they are talking so I can hear them properly. I have a hearing aid and people think I can hear everyone else. But, it is hard to hear when there is a lot of noise or if it is busy. So staff need to speak up a little when talking to me."

"It makes me feel upset when I am not treated nicely. I want to tell staff how I feel about how they treat me."

"I like it when people respect me and I can respect them back."

"Other people need to understand how I talk and react to what they say. Sometimes I speak slowly because I wear a mask. I just want to say it once and not to have to keep repeating it again.

How stereotypes make us feel

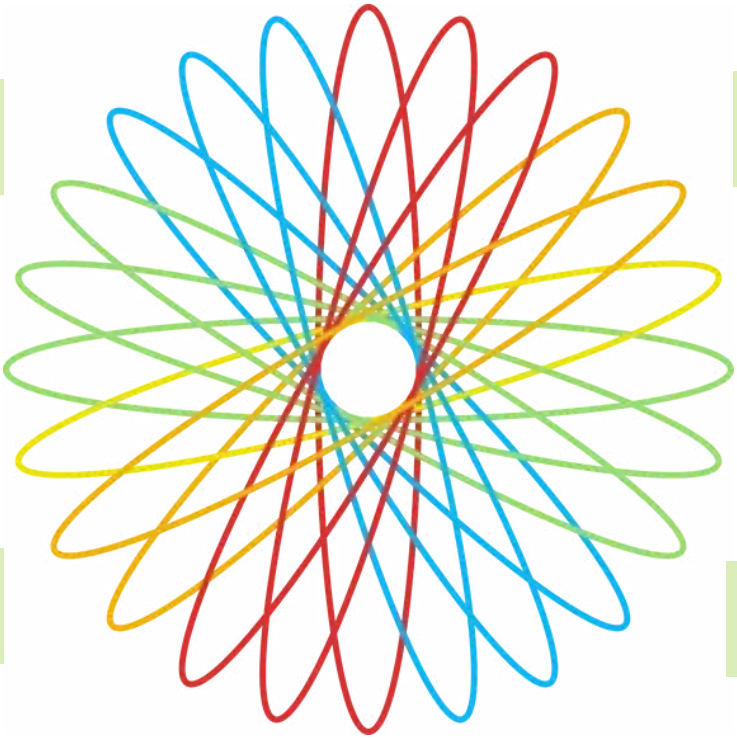
Quite

Awful

Upset

Annoyed

Unhappy



Sad

Worried

Suspicious

Scared

Angry

Confused

Bullied

Hurt

Frightened

Frustrated

Shy

FOR PEOPLE WITH MOBILITY ISSUES

STEREOTYPES AND PRECONCEPTIONS

Common stereotypes

All persons with cerebral palsy are unable to walk.

Not able to communicate effectively, so may ignore mobility impaired person and speak directly to support worker.

A walking mobility impaired person does not require seating.

A mobility impairment is always visible.

A person is not vulnerable because they are not wearing a mask.

What assumption not to make:

- I do need your help
- I don't need your help
- You know how to deal with my access / support needs because my presenting impairment makes that clear to you
- The access equipment that I have with me, provides all the help I need
- I am unable to discuss any of my issues, medical requirements [or absolutely anything else!] with you
- I have some sort of learning disability
- I can't communicate directly or that I need to be spoken to in a particular way

That's quite a list, what should I do if I'm unsure and want to avoid making assumptions?

Ask! It's that simple!

Common stereotypes

Language evolves constantly and frequently without our knowledge. By the same argument, appropriate language also evolves.

Just to complicate matters, there is also a subjective view in that some people are happy for certain terminology to be used to describe them which may be considered inappropriate and not generally used in that context!

Here is a short [but not definitive] list of current terminology / language to help to give you a better grounding with this especially tricky issue.

What language not to use:

- Cripple
- Handicapped
- Invalid
- Suffering from [condition]
- Afflicted with [condition]
- Wheelchair bound
- Confined to a wheelchair
- Spastic, spaz
- Able-bodied
- Dwarf; midget

What (appropriate) language to use:

- Disabled people
- Impaired / impairment
- Have [condition]
- Wheelchair user
- Person with cerebral palsy
- Someone with restricted growth or short stature
- Small person

What impact does this have?

Why are preconceptions/stereotypes harmful to people with mobility issues?

- " {I feel} Quite invalidated to be honest because I get that quite a lot because I don't look like quite what they expect someone with a disability to look like."
- "It is quite exhausting when stuff like that happens."

"There was no consideration of the fact that I am disabled. Just because I may not appear to be like your stereotype of what a disabled person might look like doesn't mean I don't have these access requirements."

"I wear a mask most of the time but sometimes if my coordination is poor it is actually more dangerous for me to be fiddling around my face and possibly poking myself in the eye and risking contamination that way. When challenged I have to explain this and I don't always feel believed - why would I make up a story like that!"

"They don't understand your mobility, they think because you're in a wheelchair you just get a wheelchair to go to A to B but what they don't understand is how difficult it is for you to go to A to B."

"Not all disabilities look the same and you can't see every disability and it's something I think I always assumed it would have been a given in the medical field."

Sometimes I have experienced quite a clinical approach to the things I experience in my disability, and I am largely not seen so it feels kind of quite dehumanising. something I feel like if there was a slightly more person-centred approach in training medical staff when it comes to disability ...there would be a lot more understanding and sympathy."

FOR BLIND AND VISUALLY IMPAIRED

STEREOTYPES AND PRECONCEPTIONS

Common stereotypes

All people that are blind can't see anything.

If a husband and wife are blind, it must mean there children are too.

People think that because a person is blind, they can't understand anything.

Not all blind people wear black glasses. Being partially sighted is different.

Some people speak loudly to the blind person. They feel that if the person cannot see, maybe they cannot pay attention to what they say.

People believe that if you are blind, you can't hear anything either.

The person will not speak to me directly, they will either speak to the person who is escorting me or even an unknown sitting next to me,

Testimonials

"When I say I'm blind, a lot of people say 'what you can't see anything?' But most of us that are blind can see, and there's a small number of people that can't see anything which is a special group within the blind category that are non-sighted and some of them have a long cane or a guide dog."

"Some people rather than talking to me will talk to my son as if I can't understand them. My son was with me, and I told them they can talk to me."

"Some people think that blind people can't hear properly."

"Some of my friends are registered as completely blind. I have taken myself to help them to GPs appointments etc. I will tell them I am partially sighted myself. They assume that I don't need help as it looks like I can guide someone. As I am supporting someone else they do not think I have my own impairments."

"Most of the public don't get what partially sighted means. For decades, I was telling people what partially sighted means, but I look normal. We don't wear black glasses. People make assumptions. If we were disfigured in other ways, they would automatically assume that disabled."

"People often assume that if a husband and wife are blind that their children will be blind also."

RECOMMENDATIONS

CHAPTER 8

Recommendations for Deaf and hard of hearing people

1 **Staff should learn basic BSL to help put patients at ease. Including:**
(1) The alphabet (so they can finger spell patient's names and confirm the time of appointment)
(2) Simple sentences such as:

- 'Welcome'; How can I help you'; 'What is your name'; What time is your appointment'; How are you?; Where pain?; Wait!; Please' Thank you; Numbers and alphabet.

2 **Check-in machines should have an option to pick BSL** (as there are often options for spoken languages). This would allow Deaf people to easily understand the questions being asked at check in.

3 **Staff should guide Deaf people with simple hand gestures to show them where their appointment room is.**

4 **Ensure the Deaf people are seated in the front row to allow them to see what is happening in the waiting room and make them feel welcome.**

5 **If an appointment is cancelled for a Deaf patient. The Deaf patient should not be contacted by phone but should be contacted via a method that is accessible for them** (e.g. text message).

Recommendations for Deaf and hard of hearing people

6 **Staff should wear clear/transparent masks so Deaf people can lip read.** This will help make communicating easier. If this is not possible, removing their mask will aid with communication.

7 **Ensure a BSL interpreter is present at all clinics:**

- NHS computers should have a flagging system/notification function in place an alert to staff when a Deaf person books an appointment, so a BSL interpreter can be booked.
- Have a contract with a video relay service. This means if a Deaf person turns up to an appointment and there is no BSL interpreter present, the service would be able to access an interpreter immediately.
- Staff should always have an iPad or notepad available to type/write any communications to people who are not BSL users.
- •Do not ask children, friends or family to interpret for patients

8 **The Nurse/Doctor/Receptionist should hold up the iPad/board showing the name of the person being called in the waiting room to allow Deaf people to see their names** (if there is no LED display on the wall showing the name of the next patient).

9 **Staff should have greater Deaf awareness**

Recommendations for Deaf and hard of hearing people

10 **Have visual materials to be able to ascertain the level of pain a person is in etc.** Such as a pain metre, pictures of emotions that express severity.

11 **Be aware that gestures can be used to aid communication, such as pointing to a watch, clock.**

12 **Understand the varied needs of the Deaf community. One size does not fit all.**

13 **Do not attempt to call the Deaf patient, unless you are certain they can hear on the phone.** Contacting them via appropriate methods such as text, letter or email should be easily accessed.

14 **Be aware that a Deaf person does not automatically get assigned an interpreter to accompany them 24/7. Interpreters are not carers, they usually work freelance and may not know the patient.**

15 **Medical staff should remember to address the Deaf person directly, not the interpreter when talking to them.**

Recommendations for blind and visually impaired people

1. **Disposable elbow bands available at health centres/clinics/hospitals to assist blind people to their seats, and in/out of appointment rooms. This will allow everyone to stay safe from Covid transmission**

2. **Ensure LED screen which displays a patient's name, also has audio description, including information about which doctor the patient is seeing and what room they must go to**

3. **Train staff in how to appropriately guide a blind person to seat/reception/appointment room etc.**

4. **Check in machines should have audio description.**

5. **Braille/Tactile numbers on doctor's room.**

6. **Provide priority seating for blind/visually impaired people, particularly in situations where there is queuing. Queuing is problematic for visually impaired as they can't tell when someone has moved up.**

Recommendations for people with a learning disability

1. **Provide individuals with the phone number and address of where their appointment is beforehand so they can plan their journey and know what to expect.**
2. **Provide opportunities to attend clinics (e.g. vaccine clinics) when there are no other people there, or at quieter times.**
3. **Be aware that pictures of needles can make people feel unsure about getting vaccines or blood tests.**
4. **Staff should phone the individual to remind them they have an appointment (and provide details of where to go, and at what time).**
5. **Staff should support patients to more clearly understand what to expect from their appointment.**
6. **Avoid long waiting times. This can cause anxiety.**
7. **Staff should have greater awareness about how to support people with learning disabilities/difficulties.**

Recommendations for people with a mobility issue

1. **Health clinics (e.g. vaccines) are planned where there is an accessible bus stop outside.**
2. **Step-free access to venue.**
3. **Disabled parking spaces are available.**
4. **An accessible toilet is available on site.**
5. **Some orthopaedic chairs are made available to people with mobility issues.**
6. **Doors are not heavy/automatic so people are able to enter the surgery/clinic.**

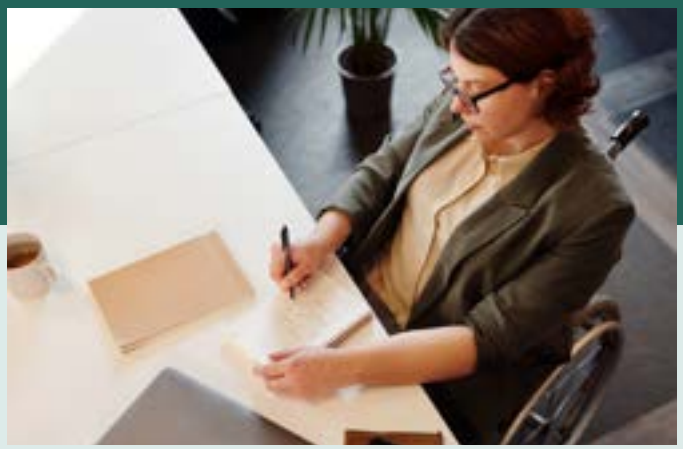
Recommendations for accessible communications

Make health information accessible to everyone in surgeries, hospitals, clinics etc., by providing:

1. **Easy read posters**
2. **TV with BSL interpreters and subtitles**
3. **Information in braille**
4. **Information in large font**
5. **Audio information (CDs/USBs)**
6. **Simple language**
7. **Bullet points**

Make sure you capture everyone's communication preferences and ensure you communicate with them using the methods they have selected.

Conclusion



Disabled people have been continually let down by individuals and institutions at all levels – from decision makers, and service planners to frontline staff and medical professionals. They repeatedly face the same barriers to inclusion. The way that we structure our built environment, the preconceptions and stereotypes that people hold, and the lack of awareness about people's communication needs means that many disabled people cannot participate equally in society. This is not acceptable, and we must all take responsibility for it.

Access to healthcare is a fundamental human right, and not being able to understand vital information can leave disabled people feeling scared, confused and disempowered. Furthermore, it can lead to them making an important decision without all the facts. You will have observed also in this guide the impact that preconceptions and stereotypes can have on an individual's wellbeing, and how inaccessible services can cause stress, anxiety and result in people feeling let down by the institutions that should be serving them.

Hopefully this guide has given you a snapshot of some disabled people's experience accessing health services and information, and demonstrated what you and your organisation can do to improve these services and create a more positive experience for every patient. Although there are lots of recommendations in this guide for how you can better support your disabled patients, and make reasonable adjustments, every disabled person is different, and it is important not to assume you know what they need. If you want to know what a disabled person needs, and how you can support them, just ask.

This best practice guide also accompanies a Deaf and disability training course aimed at frontline staff and medical professionals. If you would like to further your knowledge and undertake one of our training sessions, led by our fantastic coproduction groups, please do get in touch. So far, we have created modules on reasonable adjustments for Deaf people and people with mobility issues, and accessible communications with people with learning disabilities. We have more modules planned for the future including preconceptions and stereotypes and Deaf awareness training.

APPENDICES

CHAPTER 9

Appendix 1 -Bart's Health Case Study - Improving the experience of D/deaf and Hard of Hearing Patients

NHS Barts Health NHS Trust

Accessible Information Standard (AIS) Reminder

Making health and social care information accessible

AIS for people who are deaf or hard of hearing:

NHS Barts Health NHS Trust

Patients, service users, carers and parents with a disability, impairment or sensory loss should:

- Be able to contact, and be contacted by, services in accessible ways: email or text message.
- Receive information and correspondence in formats they can read and understand: ensuring simple language, have BSL versions of patient information leaflets, website materials and patient letters.
- Be supported by a communication professional at appointments: BSL interpreters.
- Get support from health and care staff and organisations to communicate, for example to lip-read or use a hearing aid.'

NHS England. Accessible Information Standard – Overview 2017/2018

Appendix 1 - Bart's Health Case Study

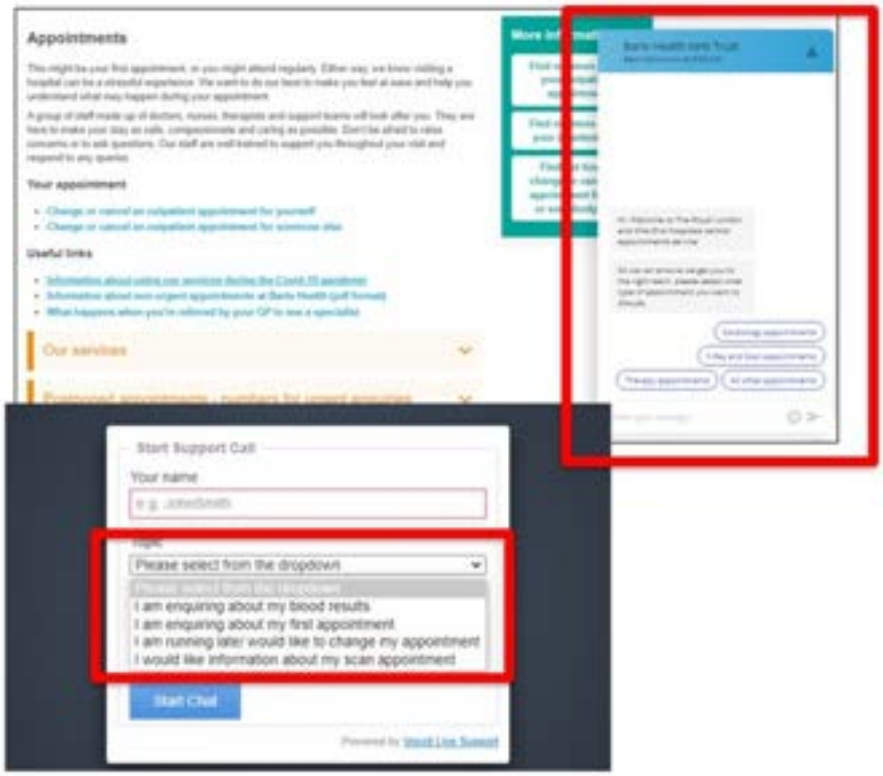
NHS Barts Health NHS Trust

1. 1/9/22 new inbox went live
bartshealth.helpfordeafandhoh@nhs.net

2. Added to the SignLive Community Directory so patients can communicate with us via BSL

3. Launched chatbots for the website – Appointments, Maternity

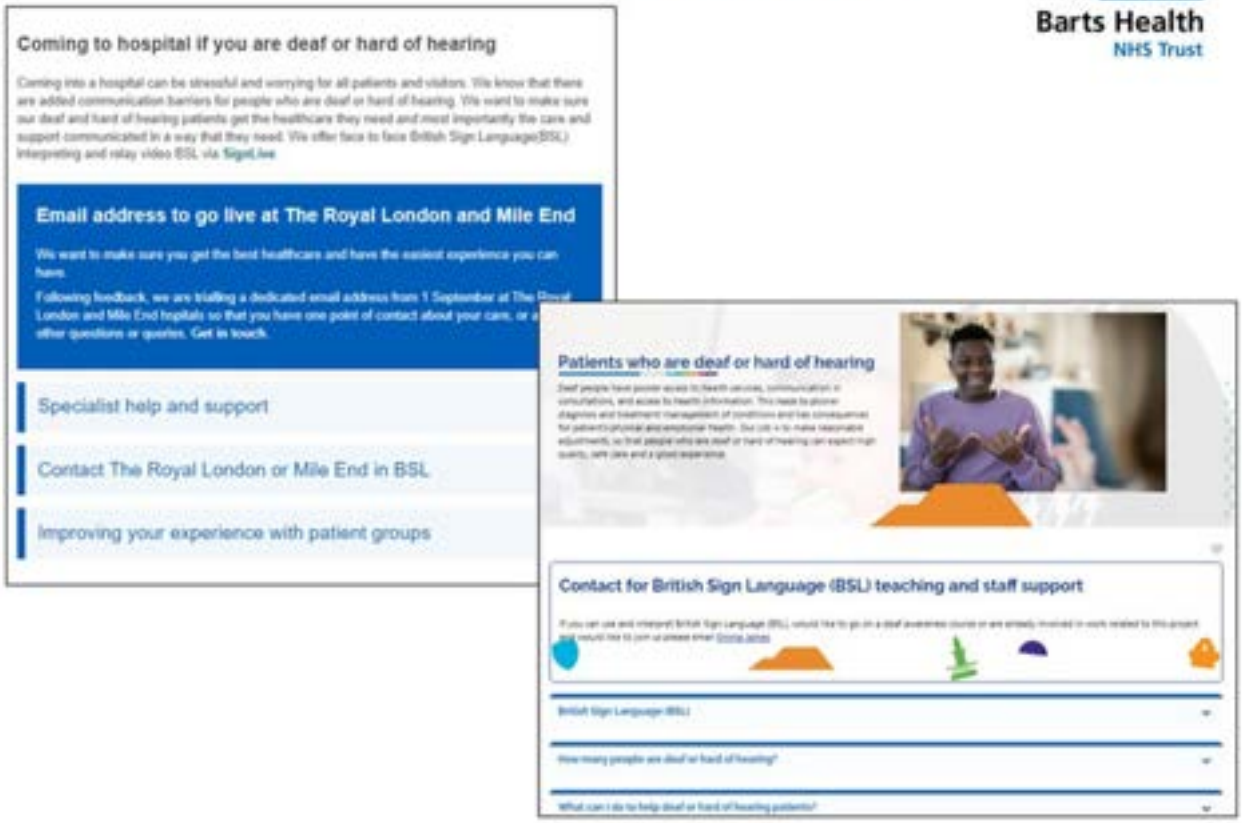
NHS Barts Health NHS Trust



Appendix 1 -Bart's Health Case Study

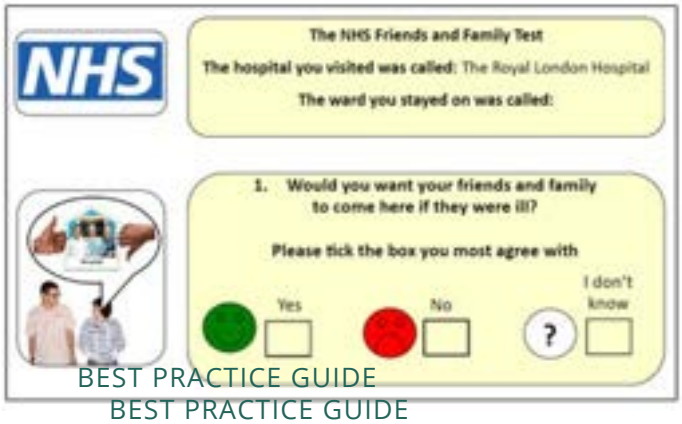
Body

7. Created internal Weshare page and external page



8. Delivered reminder posters on how to download and use SignLive

9. Easy read patient surveys

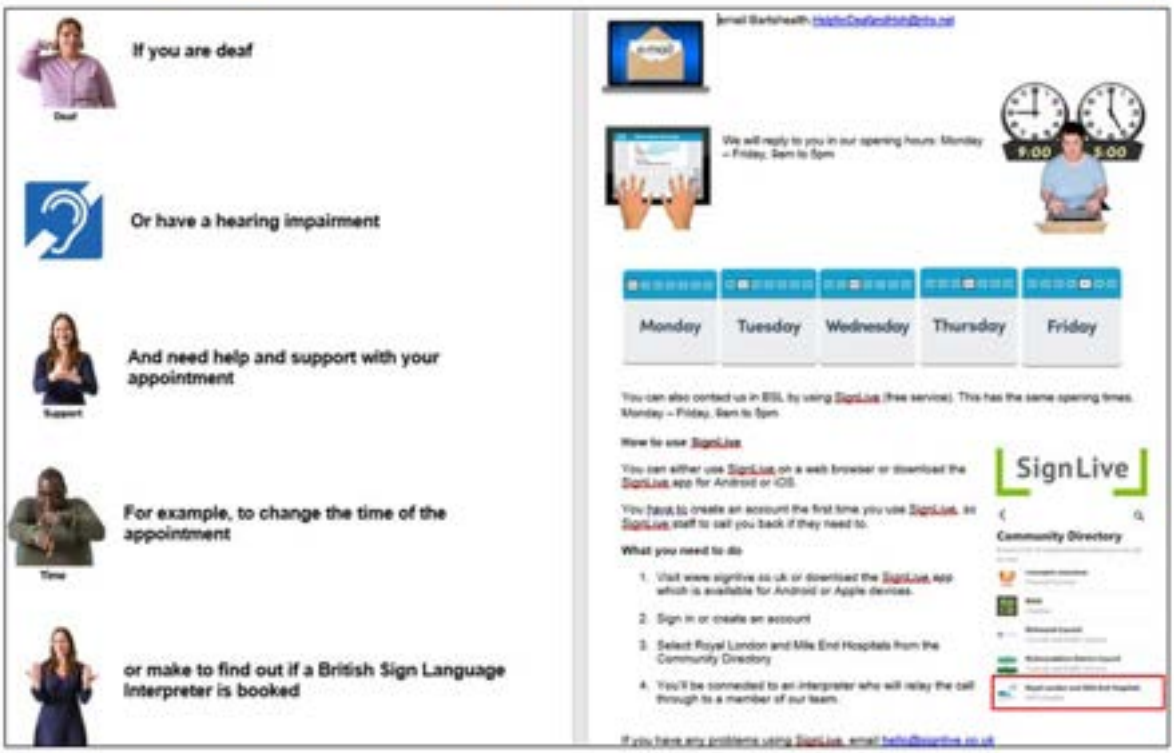


BEST PRACTICE GUIDE

Appendix 1 -Bart's Health Case Study

4. Investigating inserts to outpatient letters

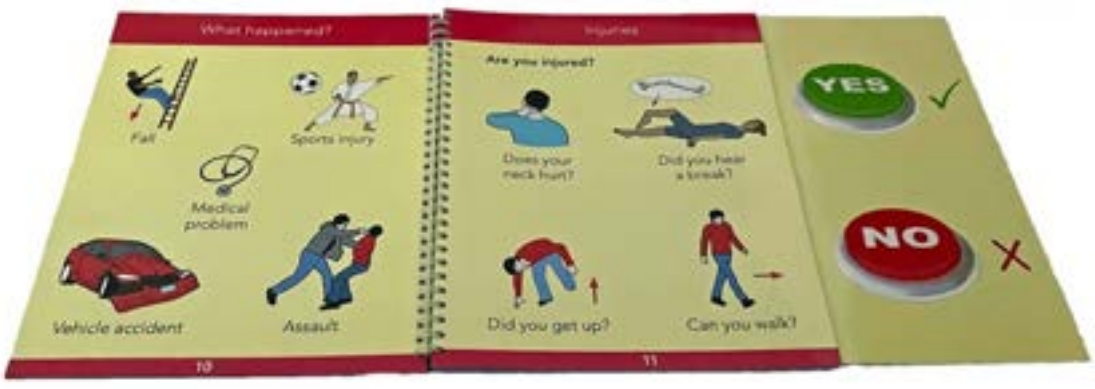
NHS Barts Health NHS Trust



5. Emergency ipad for relay interpreting

NHS Barts Health NHS Trust

6. Introduced communication (picture) books



Appendix 2 - Deaf Culture

BSL grammar structure and linguistics

BSL grammar and sentence structure is completely different to English:

- IN ENGLISH – What is your name?
- IN BSL – Your name what?

The question forms: what, where, how, when and why, are placed at the end of a sentence in BSL.

There is no written form of BSL, additionally, in BSL articles such as a/an do not exist in the language. Due to the vast differences between the two languages, some Deaf people have a lower standard of written English. Some Deaf people cannot access phonics or hear the word being spoken. They cannot hear the language that is encoded in print. The educational experience of learning to read for a Deaf person is not the same as a hearing person will experience.

Some Deaf people cannot hear words being spoken in its complete form. It can be difficult to pick up: ed, s, ies, 's, at the end of the word. The suffixes do not exist in BSL either.

BSL variations/regional differences

Deaf people who sign have 'accents' depending on where they live. Just like a Yorkshire accent is different from a Cornish accent, two Deaf individuals from opposite sides of the UK will be able to recognise the difference.

Two deaf signers can tell where a person is from by their use of signs or variations, similarly to two hearing people living in different parts of the UK. Nationally, there are regional signs that are unique to the location.

There is also an international influence in sign language, similarly to how other countries have influenced the English language.

Appendix 2 - Deaf Culture

Getting attention of a Deaf person

- Wave at them
- Standing in front of the Deaf person
- Gently tap the shoulders
- Stamp the floor
- Turning lights on and off
- Sometimes throw light objects at the Deaf person, if they cannot be reached.

Body language (facial expressions, gestures, tapping)

The uses of facial expressions are as important as the signs used by the hands. For example, one can show the severity of something, change the tone and attitude by a slight movement of the eyebrows or the cheeks. These micro movements are an integral part of the BSL language.

Differences in Deaf experience (lip reading. BSL, neither/both)

It is assumed that all Deaf people can sign. Some people lip read only or use paper and pen to communicate Some can only use BSL, as they cannot lip read.

Appendix 2 - Deaf Culture

Variety of hearing loss

- Deaf with speech or without speech
- Hard of hearing
- Deafened by accidents or old age
- Ushers
- Profoundly deaf

- Tinnitus

Tinnitus can cause hearing loss. It's a ringing in the ears, but it also can sound like roaring, clicking, hissing, or buzzing. It may be soft or loud, high pitched or low pitched.

Hearing aids are often helpful for people who have hearing loss along with tinnitus. Using a hearing aid adjusted to carefully control outside sound levels may make it easier for them to hear. The better they hear, the less they may notice their tinnitus.

- Hearing aids

Not all Deaf people wear hearing aids. Some Deaf people like wearing hearing aids but that does not mean they can hear everything. For some people hearing aids provide information as to the background and environmental sounds. However, this does not mean that they can hear speech.

- Deaf-Blind

Touching another person to get their attention is acceptable. For Deaf blind individuals, soft touching on the shoulder for example signifies an encounter for conversation. Deaf-blind people use a different type of sign language to communicate called Hands-on.

Appendix 2 - Understanding power relations with people with learning disabilities

How do power relations play out in a medical setting?

- Staff tell you what they think you need or what is wrong, but they don't listen to us and let us explain ourselves.
- We feel we cannot ask anything or tell someone what is wrong because staff are not willing to listen.
- We feel that if we do not agree with what staff say, we will not get any help.
- We think we cannot change appointments if they clash with our activities because we will not get another appointment.
- We feel we must do what the Doctor or Nurse tells us, or they will not like us.
- We find it hard to say if we are not happy with how we are being treated because then we won't get any help.

What impact can this have for people with a learning disabilities?

- It makes us feel sad, unhappy, powerless and worried about going to our appointments.
- We don't get the help we think we need.
- We prefer not to go to the appointment if we cannot speak for ourselves.
- We don't answer the phone because we are frightened about what the Doctor or Nurse will say to us.

How to avoid creating unhealthy power relations?

- We sometimes need another person to support us when we go to the doctors, hospital or appointment so we can explain ourselves.
- There needs to be someone there we can talk to who can help us.
- We need to be able to give feedback and complain about how we are treated.
- We need to be able to ask to see someone else if we are not happy with how someone is treating us.

Appendix 2 - Understanding power relations with people with learning disabilities

What does a positive, equal relationship look like with a health professional or frontline worker?

- Staff listen to us.
- They help us and work with us and make sure we are happy with what is happening or going to happen.
- Staff treat us with respect and talk nicely to us.
- Staff make sure we know what is going on and we can ask questions.
- Staff do not assume we are able to follow everything they say and keep stopping to make sure we understand what is being said to us.
- We feel in control of what is happening and what we talk about when we go to an appointment.

Appendix 3 Symbol Canes

A symbol cane or guide is used to alert people to an individual's sight and/or hearing loss. They cannot be used as a walking stick or a support aid. Symbol canes are held in front of a person and can come in different shapes and sizes.

A cane or guide dog means the person has a visual impairment and need guidance.

"A totally blind person will usually have a white long cane or a guide dog. A partially sighted person will usually be having a symbol cane or a guide dog. Once (a member of staff) see any person with these things, immediately they can see the person needs assistance and they should come and offer this assistance."

"If someone has a cane of any kind, talk to that person in a different way... if anyone is carrying a cane it is for a purpose to acquire extra support. A symbol cane is to alert of access issues. Staff should be coming to us and ask if we are aware where to go."

Appendix 4 - About partners

Real

Real is a user-led organisation run by disabled people who live, work, volunteer or study in Tower Hamlets. 100% of our board and a significant majority of our staff and volunteers are disabled. We are a registered charity.

Real primarily works with disabled people who live, work, study or volunteer in Tower Hamlets, but our constitution allows us to work beyond borough boundaries and to contribute to regional and national issues too. We support disabled people of all impairment types, all age groups, all ethnicities and all other protected characteristics.

We are deeply rooted in the history of the disability rights movement, whose slogan "Nothing about us, without us" led to disabled people taking control of their future. Being user-led is fundamental to who we are and what we do, which is why our tagline is "Disabled people working together for real choices".

Eight things you should know about Real:

- We're run by disabled people, for disabled people, and have been around in one form or another for over twenty years.
- We think disabled people should have the same choices and opportunities in their lives as non-disabled people, so we challenge inequality and discrimination.
- We support anyone in Tower Hamlets who is or has been disabled or who has a long-term health condition.
- We're driven by the social model of disability
- This means we believe it's the barriers created by society that cause inequality. By dismantling those barriers, disabled people will have fair access to opportunities and improved life chances.
- We support people with any type of impairment or disability, and of all ages, genders, gender identities, ethnicities, religions, beliefs, and sexual orientations.
- We also work with friends, families, carers, professionals and allies who support our goals.
- We're formed through a merger of Disability Coalition – Tower Hamlets and Disability Information Training Opportunity, bringing together lots of different skills and experience.
- We get most of our funding from Tower Hamlets Council and the local NHS, but we also get help from other organisations, businesses and donors.

Appendix 4 - About partners

ICM Foundation CIC

ICM Foundation CIC is a not-for-profit community interest company limited by guarantee established in 2010. We have over 30 years' experience of providing high quality educational and training services to a wide range of people within a diverse community setting in the field of learning difficulties and disabilities, including work with parents, carers and professionals.

We successfully co-deliver workshops to parents, carers and professionals on understanding challenging behaviour across the country. We deliver high quality training programmes to professionals in areas such as safeguarding, managing behaviour and establishing community projects for Greenwich University and University of East London and local colleges and local organisations and services. We provide vital support brokerage to families and individuals to help people with support needs lead a life they chose.

We are an established service provider in Tower Hamlets and we are well known for bringing the community together and working in partnership to provide exciting events and activities. We run CORE Projects for adults with learning difficulties and disabilities based in the Attlee Centre, Whitechapel and this includes CORE News - our newspaper project, CORE Sports which focuses on healthy lifestyles and CORE Training who develop easy read materials and run workshops to adults with learning difficulties and disabilities and for staff.
ICM Foundation aims to Inspire to excel, Challenge to achieve and Motivate to success to ensure that everyone we encounter benefits from our desire to meet the varied needs of the community.

Appendix 4 - About partners

DeafPLUS

DeafPLUS vision is an accessible world for deaf people, with barriers to participation and opportunity removed. Our mission is to empower deaf people – helping them develop the skills they need to take control of their lives.

We do this through:

- Information, advice and advocacy
- Skills training in support of personal empowerment (e.g. digital training, lipreading classes)
- Equipment and specialist assistance to aid independent living
- Delivery of personalised support services that recognise each client's unique set of needs
- Health and wellbeing services to support personal development, healthy living and overcoming social isolation.
- British Sign Language Advice Line

Contact Us

If you would like to discuss the content of the best practice guide in anymore detail, or arrange for your staff to take part in one of our training programmes, please get in touch.

CONTACT US

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