



Accessibility:

Are health and social care services meeting information and communication needs?

March 2023

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Executive Summary

NHS health and social care services care are legally required to follow the [Accessible Information Standard 2016](#). This includes doctors, dentists, hospitals, pharmacies and social workers.

The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

[Healthwatch Sandwell](#) have explored with people with disabilities, sensory loss, or impairments whether health and social care services are meeting their information and communication needs as required under the [Accessible Information Standard 2016](#).

The findings within this report provide insight and detail to highlight that overall services are not sufficiently, or consistently, meeting the [Accessible Information Standard](#). Therefore Sandwell residents with disabilities, sensory loss, or impairments there is **inequity** in access and receipt of health and care services and **inequalities** in health and mental wellbeing.

The report findings are consistent with the national picture gathered by [Healthwatch England](#) and a coalition of user-led charities. Recommendations have been made to [NHS England](#) to incorporate into a proposed review and revision of the [Accessible Information Standard](#). Experiences of health and care services for Sandwell residents confirm the [Healthwatch England](#) report findings.

This [Healthwatch Sandwell](#) report complements the national picture by providing a practical “toolkit” resource based on the experiences, voices and views of local people to help inform and improve accessibility in health and social care services.

[Healthwatch Sandwell](#) have worked directly with residents with disabilities, impairments or sensory loss, families, carers, and local community support organisations to look at and identify the key issues where services are failing to meet people’s accessible information and communication needs and provides guidance and suggestions on what could work to better meet needs.

The report includes 10 recommendations for delivery and commissioning of services in Sandwell and the Black Country health and care services.

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Introduction

Healthwatch Sandwell are independent and champion the voice of Sandwell residents in their health and social care services. Experiences and insight gathered from engaging and listening to people is shared with health and social care providers and commissioners to help inform and improve services.

Based on public feedback the theme identified for the priority projects 2022/23 was to explore:

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Challenges and barriers in communication can present:

- inequity in accessing and receiving services
- inequalities in health and wellbeing outcomes
- risks to patients health and wellbeing.

Healthwatch Sandwell have grouped the project work into 3 areas where individuals may experience challenges and barriers with information and communication:

- communication needs due to a disability, sensory loss or impairment
- language barriers
- using or accessing digital technology

Communication needs due to a disability, sensory loss or impairment

This report is focused on exploring whether health and social care services are meeting the information and communication needs of people with a disability, sensory loss or impairment under the requirements of the [Accessible Information Standard 2016](#).

Project work on the other 2 focus areas is summarised below:

Using or accessing digital technology

The [Healthwatch Sandwell report - using digital technology in primary care services - March 2021](#) includes patient feedback on challenges and barriers that using digital technology as an information and communication tool can present for some people. Digital technology can be either a barrier or a useful tool for people with a disability or sensory loss. Some of the findings in the digital technology report complement this accessibility project report.

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Language barriers

The Sandwell population is ethnically diverse; for some people English is not their first written or spoken language. The [Accessible Information Standard 2016](#) does not cover other languages. Healthwatch Sandwell plan to explore the impacts of language barriers, and other cultural aspects, on patient experience of health and social care services in the [priority project programme 2023/24](#).

Overview of the accessibility project report

The [Accessible Information Standard 2016](#) states that NHS funded health and social care providers must meet the information and communication needs of people who access services. Meaning people with disabilities, impairments or sensory loss and their parents or carers have rights to reasonable adjustments.

The Healthwatch Sandwell project engaged with people with a disability, sensory loss or impairment and parents, families and carers to:

- explore the picture on whether health and social care services are meeting peoples information and communication needs
- hear about individuals health and social care service experiences to inform services
- explore the impacts of information and communication needs not being fully met
- listen to peoples voices and views on what works for them in meeting information and communication needs.

This report reflect the findings and outputs from participant voices including:

- sharing insights on how to achieve accessible information and communication
- providing a “toolkit” resource to help services deliver
- making recommendations based on Sandwell resident and patient voices and views.

Accessible Information Standard 2016

The next section provides a summary of the legal context and service delivery requirements of the [Accessible Information Standard](#) to support the project report.

Summary of Accessible Information Standard 2016 in accessible formats

The NHS has produced overview information on the [Accessible Information Standard](#) for patients, service users, carers and parents in a range of formats. The links follow:

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[Word document for screen reader – Accessible Information Standard 2016 overview](#)

[Audio recording – Accessible Information Standard 2016 overview](#)

[British Sign Language with sub-titles – Accessible Information Standard 2016 overview](#)

[Easy Read – Accessible Information Standard 2016 overview](#)

Overview and legal context

[The NHS England – Accessible Information Standard Specification](#) states:

From 1 August 2016 onwards, all organisations that provide NHS care and/or publicly funded adult social care are legally required to follow the Accessible Information Standard. This includes doctors, dentists, hospitals, pharmacies and social workers.

The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

Commissioners of NHS care and publicly funded adult social care must also have regard to this standard, in so much as they must ensure that contracts, frameworks and performance-management arrangements with provider bodies enable and promote the Standard's requirements.

The [Accessible Information Standard 2016](#) is in force by law ([section 250 of the Health and Social Care Act 2012](#)) and is also applicable in relation to the following laws:

[Equality Act 2010](#) – places a legal duty on all service providers to take steps or make “reasonable adjustments” to avoid putting a disabled person at a substantial disadvantage when compared to a person who is not disabled. The Act is explicit in including the provision of information in “an accessible format” as a ‘reasonable step’ to be taken.

[Care Act 2014](#) details specific duties for local authorities with regards to the provision of advice and information, this includes the requirement that, “Information and advice provided under this section must be accessible to, and proportionate to the needs of, those for whom it is being provided.”

[British Sign Language Act 2022](#) came into force on 28 June 2022. The Act legally recognises British Sign Language (BSL) as a language for England, Wales and Scotland and will guide public bodies on how to meet the needs of people who use BSL as their first or preferred language.

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Service delivery requirements

The [Accessible Information Standard](#) specifies that organisations that provide NHS health or adult social care must do five things. They must:

1. **Ask** people if they have any information or communication needs, and find out how to meet their needs
2. **Record** those needs clearly and in a set way
3. **Flag** or highlight the person's file or notes so it is clear they have information or communication needs and how to meet those needs
4. **Share** information about people's information and communication needs with other providers of NHS and adult social care (when they have consent or permission to do so)
5. **Meet** needs by taking steps to ensure that people receive information which they can access and understand and receive communication support if they need it.

The [Accessible Information Standard](#) also states that people with a disability, impairment or sensory loss and parents and carers should:

- Be able to contact, and be contacted by, services in accessible ways
- Receive information and correspondence in formats they can read and understand
- Be supported by a communication professional at appointments if this is needed to support conversation
- Get support from health and care staff and organisations to communicate

Are services meeting the Accessible Information Standard?

Healthwatch England – the National picture

In 2021 [Healthwatch England](#) and a coalition of user-led national organisations collaborated to look at how the NHS and social care are failing to support people's accessible communication needs. The findings are summarised in a report:

[Review of Accessible Information Standard - Healthwatch England and user-led organisations](#)

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Following on in 2022 Healthwatch England ran a national campaign “Your Care, Your Way” to gather more public experiences on getting accessible health and care information and communication support.

The overall findings highlighted widespread non-compliance with the [Accessible Information Standard](#) by NHS trusts. The findings have helped to inform a review of the Accessible Information Standard which had been commissioned by [NHS England](#), with a view to launching a revised version of the Standard.

Healthwatch England made five recommendations, calling for:

- 1. Health and care services to be made accountable for fully delivering the standard.**
- 2. Every health and care service to have an accessibility champion.**
- 3. Better IT systems so that patients can update services with their communication needs.**
- 4. Involving people with communication needs in designing better services.**
- 5. Mandatory training on accessible information for all health and care staff.**

Further detail on the recommendations:

[Healthwatch England – Accessible Information Standard recommendations](#)

[Easy Read – Healthwatch England – Accessible Information Standard recommendations](#)

Healthwatch Sandwell – the local picture

“Health services are not accessible to me!”

“Communication support tools are no longer the issue – system and professional attitudes is the barrier to equality in health and social care and it is a very serious issue!”

Healthwatch Sandwell have heard much from patients, families and carers replicating and endorsing the [Healthwatch England](#) findings that health and social care services are failing to meet people’s information and communication needs under the Accessible Information Standard 2106.

However, it would not be useful to create a project report that simply replicates the results.

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This Healthwatch Sandwell report aims to complement the Healthwatch England report findings by providing useful practical local insight through Sandwell residents voices to help inform and improve services, including:

- Inform understanding of challenges and impacts on local people relating to accessible information and communication and highlight considerations needed
- Profile and promote local representation for groups of people with Learning Disabilities, Blindness, Visual Impairment, Deafness and hard of hearing
- Share a “toolkit” of information links based on patients’ feedback of what works well for them
- Through recommendations help inform and guide Sandwell health and social care services towards improving delivery on the [Accessible Information Standard](#) requirements in a collaborative working approach.

Accessibility project key findings

Headline specific findings from project participant feedback useful to share includes:

- 1. High impacts on individuals with information and communication support needs from failure to meet needs, including breach of privacy and confidentiality, feelings of exclusion, isolation, frustration, stress, anxiety and depression.**
- 2. Low awareness of the Accessible Information Standard, patient, parents, and carers rights and complaint processes (which are not always accessible).**
- 3. Most patients do not perceive that they have been formally asked about their information or communication needs or preferences. It seems asking questions on a GP practice registration form may be an insufficient process; that patients are not recognising it as being asked, and it is not resulting in identification, recording, sharing, and meeting of individual needs.**
- 4. Individual’s information and communication needs not fully met during health or care service provision including insufficient time given for health consultations.**
- 5. Lack of provision or failure to show of British Sign Language (BSL) interpreters. Also lack of clarity on how BSL interpreter booking processes are supposed to work.**

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6. **Individual needs are not being fully considered – one size solution does not fit all – individual’s preferences should be verified.**
7. **A reliance on family, carers, or support workers to interpret information and communication to individuals, despite health and care services being responsible for provision, including costs.**
8. **Some patients feeling that they are not directly included in their health and care services – communication instead being directed to a third party.**

Accessibility project approach

Who we spoke to

To gather the picture on whether health and social care services are meeting people’s information and communication [Healthwatch Sandwell](#) have engaged directly in many conversations with local residents with disabilities, impairments or sensory loss, families, carers, and local community support organisations.

The project has also been informed by focused work [Healthwatch Sandwell](#) have undertaken over recent years looking at issues and challenges in health and social care services for people with disabilities and sensory loss. Relevant findings from these engagement project reports are referenced and incorporated in this report.

The findings in this report are informed by the experiences, voices and views of Sandwell residents who have:

- Blindness or virtually impairment
- Deafness or are hard of hearing
- a learning disability or are Autistic
- an acquired brain injury or other processing challenges
- also, family and carers.



Sandwell Voluntary and Community sector support organisations collaborated with [Healthwatch Sandwell](#) to deliver the project including helping facilitate group conversation events.

What we looked at

Conversations with individuals and groups explored patient experiences of the five main steps health and social care services need to take under the Accessible Information Standard, namely, to **Ask, Record, Flag, Share** and **Meet** individuals’ information and communication needs.

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Some patient's stories of experiences of services meeting, or failing to meet, information and communication needs are included for illustration to help inform services.

Additionally engaging with Deaf young people presented the opportunity to explore the challenges of transitioning from child with adult support to young adults able to access health and care services independently. The initial findings and recommendations are included within the report.

The project focus and Healthwatch Sandwell role is patient experience and voice, so health or social care service delivery has not been explored in depth. However, to help gain insight on accessibility of primary care services 8 GP practices in Sandwell kindly responded to requests for information. Oakeswell Health Centre provided a comprehensive response and added *"There is always room for improvement. Challenges could involve staffing, limited funding, and time."*

Supplementary useful information

Participants in the project provided useful insight on communication tools that work well for them. This report incorporates a "toolkit" of information links based on patients shared knowledge.

Creating an accessible project report

To ensure this report is accessible it has been produced using simple plain English language and produced in the following formats:

- a) Word version to suit screen reader and visual impairment.
- b) Audio report summary.
- c) Easy Read report summary.
- d) Video report summary in British Sign Language with sub-titles.

The report can be requested in a larger font, spacing, or other languages.

Accessible information and communication – why it matters, and impacts of not meeting needs

Barriers to communication can present risks to patient's health and wellbeing and **inequity** in access and receipt of services.

The quality and format of information and method of communication can directly impact an individuals' experience and outcomes in health, care, physical and mental wellbeing.

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Information communicated poorly presents risks such as:

- insufficient understanding of health issues by the patient
- mismanagement of medication
- impacts on self-care
- missed or misdiagnosis
- lack of treatment or improvement
- failing to identify support needs
- reduced physical wellbeing
- impacts on mental well-being.

Providing information and communicating in ways that meet an individuals' needs help ensure **equity** in access and receipt of health and care services and **equality** in treatment, services and outcomes.

Participants in the project also shared with Healthwatch Sandwell some psychological impacts of information and communication failing to be accessible to them – including:

- **challenges with accessing and using services independently**
- **enforced dependency on family, friends or carers**
- **lack of privacy and confidentiality regarding personal health and mental wellbeing**
- **cause of frustration, anxiety and depression**
- **lack of patient voice representation in services.**

Focus Groups

Reasonable adjustments to support information and communication required to meet those needs depend upon the individual requiring support. Some people may be efficient at accessing and receiving services, including using technology, despite a disability or sensory loss. Other people may experience a lot of barriers and challenges.

One size does not fit everyone – health and social care services need to **ask** the individual person about their information and communication needs and **identify, record, flag, share** and **meet** those needs. However, there may be in general information and communication solutions that might suit a specific disability or sensory loss, e.g. BSL for people who are Deaf.

Healthwatch Sandwell collaborated with local voluntary and community support organisations to explore detail for the following groups of people:

- Blind and Visually Impaired
- Deaf and hard of hearing
- Young people with Deafness or hard of hearing – including issues specific to young adults
- Learning disability and autism
- Other information processing challenges e.g. acquired brain injury

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The next section of the report shares experiences, voices and views from each group, indicating what works well and making suggestions for improvements to services.

The report recommendations are based on these findings.

1. Blind and visually impaired

The [RNIB key statistics](#) state that there are over 2 million people in the UK living with sight loss and 340,000 people are registered blind or partially sighted.

Sandwell Visually Impaired offer connection and support to local people with blindness or visual impairment. Sandwell Visually Impaired supported Healthwatch Sandwell enabling opportunities for engagement and conversations to support the project.

“I get fed up saying I’m visually impaired, don’t send me a letter!”



“Taking humans out of service provision is very limiting and raises great barriers for some people.”

Healthwatch Sandwell engaged through **6** events including park “Walk and Talk”, a “Tea and Toast” focused conversation with **21** attendees, the Annual General Meeting and a Women’s Group on-line meeting.

a) Audio extracts of the focus group conversation:

[Accessibility - conversation with people who are blind and visually impaired - You Tube](#)

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b) Key insights from focus group conversation

Blind and visually impaired people generally find **verbal** communication easier than written format; voice technology on smartphones or computers can aid communication for some people confident in using technology.

20 out of **21** people did not think that they had been asked about their information or communication needs by their health or care services.

1 person was able to share with the group the experience of their local hospital and GP practice making reasonable adjustments to meet their information and communication needs. The patient experience had been recently improved through support from **Healthwatch Sandwell**.

Patient experience – planning for a stay in hospital

Mr A is a Sandwell resident who developed blindness a few years ago, he uses a cane and has a guide dog. During a “Walk and Talk” event Mr A and Healthwatch Sandwell chatted about plans for his upcoming hip replacement operation.

The hospital had called Mr A to ask what support he might need, he had replied “a taxi home”. Healthwatch Sandwell helped Mr A to consider his communication and support needs a little more regarding the practicalities of staying in hospital for a few days.

Healthwatch Sandwell contacted Mr A’s GP practice and the local resolution team at Russells Hall Hospital and asked them to re contact Mr A to look in more detail at his needs. Both services made contact promptly, the GP practice switched Mr A’s services to on-line, Mr A fed back on the hospital response:

“A big Thank You for all you have done. Russells Hall Hospital phoned me today, we later visited the hospital and had a meeting with the nurses and physiotherapist. They were very helpful and showed me round a private room. I found the visit very useful and came away feeling much happier about my forthcoming operation.”

Healthwatch Sandwell explored with the focus group what information and communication methods work well, and what needs more consideration for blind and visually impaired people. The findings are shared in the next section.

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c) What can work well (for most people):

- Verbal communication – face-to-face or phone call
- Audio recording
- Text – particularly useful for appointment reminders
- Email communication can be good

To assist people reading with visual impairment or if using digital screen readers:

Left justified black text on a white background provides the best contrast.

Use a clear font (Arial is preferred), 16 point and good line spacing.

Avoid where possible but if using ensure – accessible hyperlinks, use alt text image descriptors and check that tables tab across.

“I am visually impaired, but I registered with patient online. The receptionist helped me by typing in the code to register. I have a screen reader tool that I can use with my smart phone – with ear plugs too, I can have privacy.”

Reasonable adjustments – positive patient experience

A patient, who is blind and has challenges with mobility, was recently unwell – she told Healthwatch Sandwell:

“Cape Hill Medical Centre have been good to me with phone consultations and home visits”

d) What needs more consideration:

Issues highlighted	Solutions suggested
Letters – Blind unable to read – breach of privacy and confidentiality	Email for screen reader Text to mobile phone
Letters – Visual Impairment difficult to read	Clear font, good line spacing and contrast, minimum 16 font
Braille readers	May be able to use email

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Issues highlighted	Solutions suggested
Using technology can be challenging or impossible for some	Identify individual communication preferences and meet needs
Embedded links or PDF's not readable	Create accessible hyperlinks and PDF documents
Links in texts to book appointments difficult to navigate or may not work	Develop service through involvement of patient reference group
Physical navigation of health and care environments	Staff recognition of sighted guide needs People to help guide Tactile and visible (to some) guides on floors, doors, walls (at eye level) Technology – navigation tools (e.g. Near Field Communication with fob/mobile)
Patient awareness of environment and support needed e.g. during hospital bed stay	Staff recognition of sighted guide needs Pre orientation visit and plan stay Verbal communication Physical instruction

2. Deaf and hard of hearing

The [Birmingham City Council – Deaf and hearing loss community profile information](#) includes that the Office for National Statistics (ONS) estimates that 1.2 million adults have a moderate hearing loss (65dB or greater), and 900,000 are severely or profoundly Deaf.

[British Deaf Association facts about the Deaf community in the UK](#) include that the annual GP practise survey consistently measures BSL users as 0.3% to 0.5% of adult patients.

[Sandwell Deaf Community Association \(SDCA\)](#) and [Deaf World](#) support and empower Deaf and hard of hearing people in Sandwell and surrounding areas. Both organisations supported Healthwatch Sandwell enabling opportunities for engagement and conversations to support the project.

SDCA and [Healthwatch Sandwell](#) have worked together over time to raise the profile of issues and challenges for Deaf and hard of hearing people with health and social care services.

3 reports have been published, some of the content has informed this project – report links:

[Healthwatch Sandwell – Deaf Focus Group – December 2019](#)

[Healthwatch Sandwell – Deaf Focus Group – September 2020](#)

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Healthwatch Sandwell - Listening to the needs of Deaf and hard of hearing people - September 2022

Healthwatch Sandwell engaged through **2** focus group events and individual conversations with **20** Deaf and hard of hearing people.



a) Key insights focus group conversations

“Deaf people learn differently, in a visual way – this is their culture.”

People with acquired deafness or who are hard of hearing may have English as their first or second language. However, for people born Deaf, British Sign Language may be their first language, English may be their second or third language. Deaf people may have a level of understanding of English language but may not be fluent, able to hear or speak it or have much reading skill.

Many Deaf people require the support of a BSL interpreter to be able to understand information conveyed and to communicate with a health or care service provider. Under the [Accessible Information Standard](#) health and care services have a responsibility to provide a BSL interpreter, when required, to meet an individual’s identified needs.

Overall participant feedback was that information and communication needs were not being met, especially regarding meeting BSL interpreter needs.

“Recognise that British Sign Language is a first language and don’t assume people can lip-read.”

Specific feedback from Deaf participants on BSL interpreter services included:

- 1. Failure to book or provide a BSL interpreter or the interpreter not turning up a common complaint.**

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2. **BSL interpreter not allocated for sufficient time and may leave to attend other bookings.**
3. **BSL interpreters without medical knowledge – risk of lack of communication of vital health information.**

[NHS England – guidance for commissioners: Interpreting and Translation Services in Primary Care](#) states BSL interpreters should be level 6 qualified and that those working in health and social care settings should have sufficient knowledge of medical terminology to communicate information effectively.

4. **Preferable to have the option to specify the gender of a BSL interpreter e.g. for gender specific health matters or for cultural reasons. Observation was made that there may be less male qualified BSL interpreters available.**

NHS England guidance states gender preference requests should be met whenever possible.

5. **Sometimes health and care service providers rely on family, carer or support workers accompanying a Deaf person to interpret.**

This is not considered best practice in [NHS England](#) guidance.

“My Mum can’t sign well, it’s not right!”

“Decisions are made without asking me!”

No interpreter – no service!

A Deaf young person shared a health care experience from October 2022 with Healthwatch Sandwell. He has been receiving eye clinic services to get contact lenses fitted and, as a young adult, attended the appointment independently. At the first appointment it was confirmed that a BSL interpreter had been booked for the contact lens fitting appointment. On the day of the appointment the interpreter was reconfirmed when booking in at reception. However, while in the waiting room the patient was approached by a consultant. The consultant showed the Deaf young person a piece of paper with the message **“No BSL interpreter”** written on it, they also made a signalled **“cancelled”** with their hands and left.

“I was disappointed and confused – no interpreter, no information!”

Healthwatch Sandwell supported the Deaf young adult by providing information on the complaint process and asking Deaf World to support them to resolve the situation. The Deaf young person has fed back that they have had a new consultation with a BSL interpreter present.

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“It’s important that Deaf voices are heard, opinions and views about the NHS.”

Healthwatch Sandwell explored with the focus group what information and communication methods work well, and what needs more consideration for blind and visually impaired people. The findings are shared in the next section.

b) What can work well (for some people):

- BSL interpreters
- Face-to-face
- Hearing loop for compatible hearing aids or cochlear implants
- Video – in BSL and sub-titled
- Written format in plain simple English language
- Text messaging
- Email
- Name on display board in reception when called for appointment
- Digital on-line technology and Apps such as:
 - Chat functions
 - NHS App
 - QR codes
 - 999 App
 - Speech to text
 - On-line BSL interpreting e.g. Sign Live (emergency use only)

“I have two cochlear implants, they connect by bluetooth to my mobile phone.”

“Social care services have provided me with a flashing doorbell, fire alarm bell, vibrating pillow and loop system in my flat.”

SDCA informed about a useful communication service – [Relay UK](#) is a free, regulated service, which is possible to use it for arranging GP and hospital appointments over the phone, at normal call rates.

“Many health staff still have no idea what [Relay UK](#) is or forget to use the prefix number **18002 to make the call, which means the Deaf person is unable to take the call.”**

It is operated via an App or a [TextNumber](#) allocated to the usual phone number. [Relay UK](#) connects callers to a relay assistant who can type speech to text for reading or read typed responses.

[How to use Relay UK for a phone call with a deaf or hard of hearing person](#)

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c) What needs more consideration:

“The psychological effects of being hard of hearing – I’ve felt very low and excluded.”

“Audiology - the one place you would expect all staff to be able to engage effectively.”

Issues highlighted	Solutions suggested
British Sign Language is a 1 st language for many Deaf people – English may be a 2 nd (or 3 rd) language	Communicate in BSL where needed Use simple plain English language – “cut the jargon” Verify understanding of information communicated
Health and care information not provided in accessible formats	SignHealth - a Deaf health charity offer the largest free BSL health library: SignHealth - Free health information BSL video library
Not everyone can lip-read	Ask individuals what works for them and make sure it is recorded If communicating with lip-reading face the Deaf person and speak clearly
Face masks – a problem for lip reading	Use a clear face mask if wearing one with Deaf patients
Phone calls to book or receive health appointments do not work	Ensure patients individual needs are met in supporting and enabling equal access to services
Language barrier with access to pharmacies	Commissioners to consider
Challenging for a Deaf person to make a complaint	Ensure complaint processes are accessible and that Deaf patients are aware of the process
Patient frustrations with audiology services, including failures to provide BSL interpreters	Service review
Deaf young adults raised that the Covid App was useful for Deaf people, but it has disappeared	Set up Patient Involvement Groups to explore and develop information and communication including the use of technology options.
NHS texts are no-reply to texts but could instead present a good communication opportunity for Deaf patients	Explore this issue and aim to develop text communication options for Deaf patients
NHS dental services some lack of awareness of NHS Trust funding for BSL interpreters and how to book	Commissioners to consider Should be part of Accessible information Standard review

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**“Emergency departments saying they can’t have BSL until they have been triaged.
How do you triage if the accessible information needs are absent?”**

Deaf communication support needs at Accident & Emergency

An example was cited when a person had a medical health emergency, so they text 999. When the paramedics arrived, the person had to lip read but they were wearing masks. They wrote down information, but the person does not read English as BSL their first language. The person repeatedly asked for an interpreter but was refused and had to wait 2 hours for an interpreter to be booked even though it was a medical emergency. The hospital tried to engage with a BSL level 1 signer, but this was not effective.

3. Specific issues and challenges for Deaf young adults

Deaf World enable and empower Deaf and hard of hearing young adults to acquire skills for independent living. Deaf World welcomed the opportunity to ensure Deaf young people’s voices were heard within the project. The Deaf World young people’s steering group organised a consultation event to look at health and care services and were supported by Healthwatch Sandwell.

12 Deaf young adults, **1** sibling and **9** parents, carers, support workers and interpreters attended the event.

“I gave my feedback – it was a very worthwhile experience!”



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a) BSL and sub-titled video summary of consultation event

“The experiences shared in the video clearly show that we need to set up a meeting between NHS leaders and Deaf people – so they can discuss the barriers, make services more accessible and improve equality for Deaf people.”

Some of the Deaf young people attending the consultation created a video of the event which can be viewed here:

[Accessibility consultation event with Deaf young adults - You Tube](#)

b) Key issues highlighted

“We discussed what needs Deaf people have, the struggles and difficulties they have to understand things.”

“The feedback made me realise what problems – the background that you would not be able to see.”

The Deaf young people’s consultation event was very engaging, a lot of experiences and views were shared. General feedback regarding accessible information and communication has been included within the main body of this report.

The consultation event involved workshops with focused conversations. This presented the opportunity to explore with participants experiences of health and care services as dependent children and the journey of transitioning to becoming an independent young adult.

Clear issues and challenges more specific to Deaf young adults were highlighted indicating that health and care service interventions are required and may need to be commissioned. More engagement and patient voice involvement would be required. The key issues raised have relevance for the accessibility information and communication project they are illustrated by case stories and briefly summarised below.

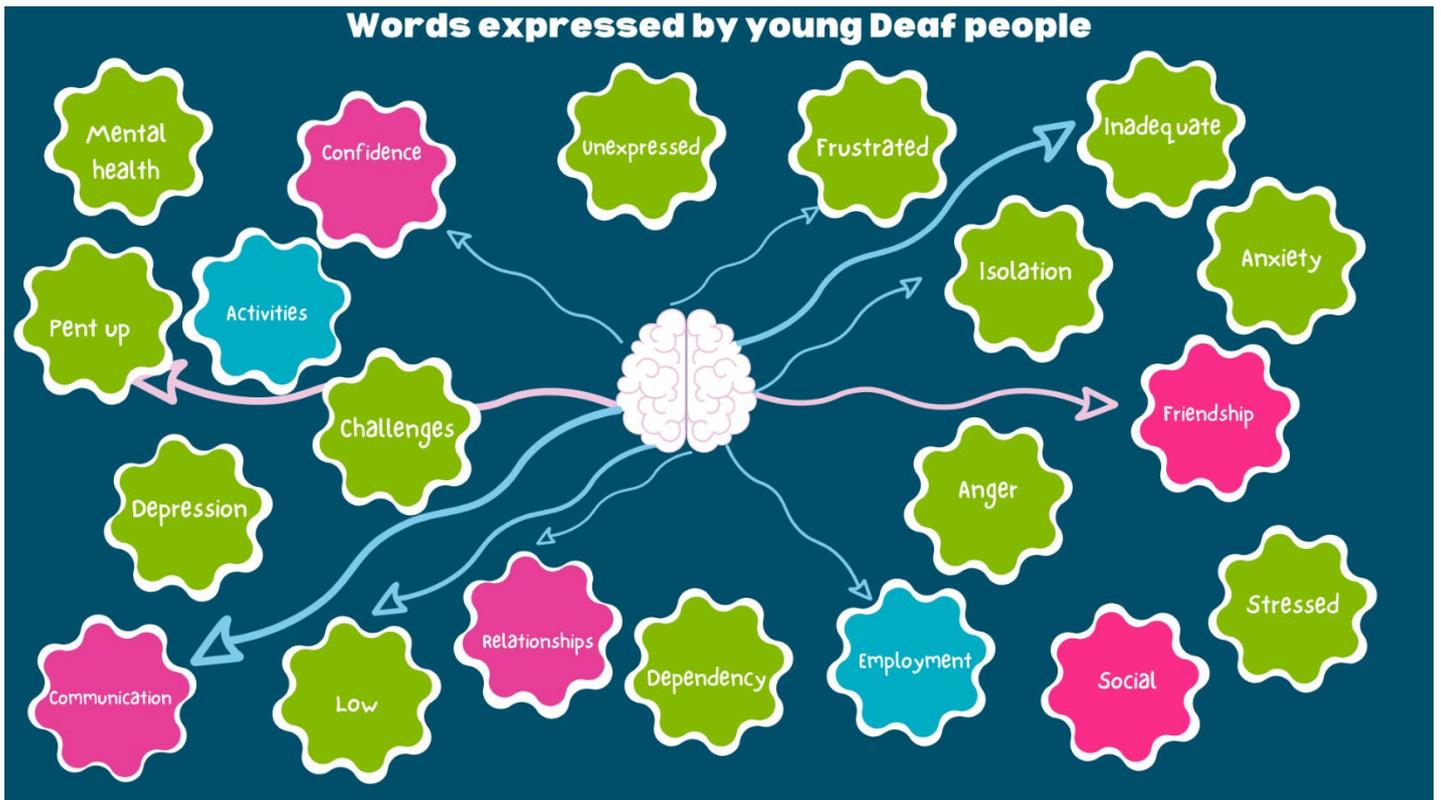
c) Mental health

Deaf health charity SignHealth research indicates that at least **40%** of Deaf young people experience mental health problems compared to **25%** of hearing young people. They also state that currently there is no primary care service that provides therapy or counselling for Deaf young people in British Sign Language.

Deaf World young people’s steering group fed back that Deaf young people’s mental health should be a top priority to consider in services for Deaf young people.

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Isolation of Deafness and impact on mental health

“B” is a Deaf young man who attended the consultation event with some of his family. The family having recently moved to the area, were not aware of local Deaf support services, including Deaf World. “B” had been diagnosed late with Deafness which had set back development of appropriate communication methods.

During workshop conversations the family shared insight on the traumatic experiences for “B” of receiving injections and stitches as a child. Healthwatch Sandwell asked “B” why he had felt so terrified – he replied **“I did not know what was going to happen to me when the needle went in.”** No one could explain the procedure and the likely outcome.

Funding for family BSL training had been inconsistent. This had emotionally and mentally impacted on “B” who with his family shared insight including feeling isolated, having very few friends, and struggling to be independent. This has hindered his confidence to communicate with others.

“B” met some new Deaf young people through the Deaf World consultation event and was encouraged to become more involved. Healthwatch Sandwell connected “B” and his Mother to signposting support in their area via Healthwatch Walsall.

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d) Achieving independence as a Deaf young adult

“My mother being involved in my health care is demeaning.”

“Confidentiality, personal, private – difficult with parents around.”

“Very rare GP reply to my email – reply very late. When my Father phones get immediate reply – it makes me feel inadequate!”

Engaging with Deaf young people presented an opportunity to explore transitioning from accessing health and care services as a child with adult support to being a young adult able to access and use services independently. Young adults over 16 years old have a right to consent to their own medical treatment and should begin a transition process from children to adult's social care services, if applicable.

“When turn 16 they throw us over to adult system, but no-one has prepared us from child to adult.”

Though some individual young people may have been helped to be well prepared for becoming independent adults Healthwatch Sandwell found that considering independence in using health and care services was too big a concept for many of the Deaf young people, especially considering that independence in life generally was a challenge.

Dependency through childhood, compounded by Deafness and support needs, possible impacts on mental wellbeing and personal lifestyle are all factors that could hamper a young person's natural progression towards independence. Overall health and care services are not structured or promoted in accessible ways for Deaf people to access or use creating more barriers for Deaf young people to be able to assume independence.

“How do I break away and be independent when I don't trust the system?”

Healthwatch Sandwell did not explore further on patient experience of transition from child to adult health or social care services as it was outside the scope of the project.

“System needs to be holistic. There is a lot of anxiety, and the Deaf person wants to be independent.”

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4. Learning disability and autism

[Mencap - research into health inequalities for people with learning disabilities](#) highlights:

National research findings state that people with a learning disability, compared to people without a learning disability, are more likely to have:

- worse physical and mental health
- a range of health conditions
- unidentified health needs
- a higher prevalence of deaths from an avoidable cause
- on average 18 years less life expectancy for females
- on average 14 years less life expectancy for males.

Ensuring quality accessible information and communication to support the health and wellbeing of people with a learning disability is clearly critical, as is the need for integrated health, social care, and support services.

“The doctor gave me two different tablets to take every day – I don’t know what they are for, and they do not make me feel better.”

a) Health and care experiences of people with a learning disability



Healthwatch Sandwell have, in the past few years, gathered significant insight on experiences of health and social care services for people with learning disabilities and autism. Findings include that quality and accessibility of communication and information is a key aspect affecting health and care outcomes.

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Healthwatch Sandwell have held conversations with over **30** people exploring health and wellbeing issues including with:

- people with learning disabilities
- young adults with learning disabilities
- people with autism
- parents and carers of people with learning disabilities or autism
- Voluntary Community organisations providing support services
- health and social care service providers.

Full information can be found in the published reports which include:

[Healthwatch Sandwell – learning disability and autism – Conversations about my GP appointment](#)

[Healthwatch Sandwell – Annual health checks for people with learning disabilities](#)

b) Key insights from focus group conversations

Among people with a learning disability, findings included:

- low awareness of the range of primary care service options or how to access services
- many aware of 999 emergency services but not NHS 111
- most appointment booking is undertaken by someone else
- frustrations of nothing to do in waiting rooms, some behavioural impacts

In relation to information and communication:

- consultation conversation directed at a person present, providing support, rather than the person with a learning disability, including during health consultations by phone
- issues with accessing information with low reading and processing skills
- difficulties understanding information communicated including verbally
- variation in quality of health and care professional interaction and communication skills with people with a learning disability or autism.

“My Doctor is very kind and asks me what is the matter. The Doctor listens to me and asks me some questions. My Mom helps me understand.”

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c) Communication support in hospital settings

Options for Life support people with learning disabilities and autism, they shared information with Healthwatch Sandwell of poor patient experiences in hospital settings including:

- Hospital Passports (a communication resource for people with a learning disability) are often not recognised or used in hospital settings [Mencap – NHS Hospital Passport template](#)
- lack of acknowledgement and communication with supporting carers
- lack of learning disability nursing support staff in hospital settings
- lack of clarity on learning disability community team services provision

The hospital patient experiences shared indicate a lack of hospital reference to GP patient records which should have identified, flagged and recorded how to meet patients' information and communication needs.

d) Annual health checks for people with learning disabilities

The [NHS Long Term Plan](#) set an ambition that by 2023/24, at least 75% of people aged 14 or over with a learning disability will have had an annual health check. Further information including on performance: [NHS England – learning disabilities – improving annual health checks](#)

“I would like to talk to the Doctor about losing weight, but I can only go and see the Doctor if I am poorly.”

Healthwatch Sandwell found that there was low awareness of annual health checks or entitlement to them by people with a learning disability or family or carers. The picture appeared to be that predominantly people with a learning disability in Sandwell have not been receiving annual health checks and there is general confusion about the service, as these carers voices illustrate:

“I had a phone appointment with the Doctor when my daughter was sick, they asked me about her weight and diet. Does that mean she had an annual health check?”

“I tried to book my son in for an annual health check but was told he would have to book himself as he was an adult. My son would not be able to do this himself so I was told he must write a letter to the practice manager saying that I could help him. But my son cannot write.”

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An example of good health and care services for learning disabilities

A parent carer of a child with learning disabilities told [Healthwatch Sandwell](#) about their experiences with their GP practice:

“My daughter has complex needs. She is totally dependent on us for caring for all her needs. She has lots of medical appointments as she has quite a few things wrong. Our Doctor is supportive. I have no problems getting an appointment and they always ask me if I am ok and can they help me in any way. My daughter has an annual health check. The surgery calls me up when this is due and have already made an appointment for us to attend. At the appointment they ask lots of questions including things about benefits and equipment we need for home to help us care for our daughter. They also check that medication is ok and have knowledge about all the other consultants that are involved in my daughter’s care. The only thing they cannot do is weight my daughter as she uses a wheelchair and is unable to stand up. They do arrange an appointment for me at the place where I can have this done. When I hear other parents talk about how difficult the find accessing their Doctor, I feel very lucky that I have this support. All Doctors should be offering the same standards of care.”

e) People with autism

People with autism may, or may not, have a learning disability. However, on the autism spectrum, some people may have information and communication needs to be [identified](#) and [met](#).

Outline scenarios below illustrate information and communication needs:

Person with autism – hospital operation planning

Mrs “C” is the Mother of an 18-year-old son “D” who has severe autism and associated learning difficulties. Mrs “C” shared the recent experiences of “D” needing an operation in hospital. “D” needed time spent on preparation for the hospital procedures. The parents advocated on behalf of “D” with the hospital, but they did not pay proper attention to them or to the information in the [Hospital Passport](#). Initially there were also barriers around the parents being able to be present in the hospital setting. As a result “D” became distressed and uncooperative prior to treatment in the hospital. Eventually a [learning disability nurse](#) became involved and spent time on relationship and trust building communications with “D”. The nurse prepared “D” as a patient, provided guidance to the hospital team and the operation was able to proceed.

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Information and support needs of parents with autism in perinatal services

Healthwatch Sandwell worked with the Perinatal Mental Health Community Service (Black Country Healthcare NHS Foundation Trust) exploring an increase in referrals for women with autism, a lack of suitable information available and a need for training within the multi-disciplinary team that support expectant and new parents through their pregnancy journey. Healthwatch Sandwell recommendations included the promotion and increase of use of Hospital Passports.

“I have two dependants with autism – they do not have learning disabilities but are quite complex and it impacts quite a lot on everyday life, including health and wellbeing. However, they are not entitled to an annual health check and, as far as I know, not on a register at GP regarding their autism. They have capacity but are unable to navigate through the GP access system. There is an inequality here that needs to be addressed.”

5. Other health conditions with communication challenges

Some health conditions may affect a person’s abilities with information processing and communication, in which case the Accessible Information Standard applies, and reasonable adjustments should be made to meet needs. A few examples of patient stories are shared below:

Lifelong condition

Healthwatch Sandwell heard about the experiences of a person with cerebral palsy. They require accompanying support to appointments, which need to be face-to-face. Healthwatch Sandwell were told that their GP practice, Lodge Road Surgery, Smethwick, has asked, identified, and made reasonable adjustments to meet their information and communication needs, including speaking their first language, which is not English.

Acquired brain injury

Mr “E” has a brain injury following a subarachnoid haemorrhage and operations. Mr “E” received information from his employer which helped him with ensuring reasonable adjustments in his health and care services.

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“When I was first diagnosed with this brain injury, I called my GP practice and requested an appointment to go over my condition and what support I would need. I have asked for appointments to be texted, a summary of what was discussed in appointments to also be texted. I usually write notes about my symptoms to discuss with the Doctor. This helps me with my memory issues. I have asked for face-to-face appointments. For continuity I try to request the same Doctor as much as possible. I have also explained my issues to the hospitals, and they are able to fill out forms on my behalf.”

“This is great for hidden disabilities. I know my rights, but not everyone would ask for the adjustments. It was very easy, and I am more than happy with the outcome.”

Degenerative neurological disease

[Healthwatch Sandwell - Case Study: A patient's journey of moving to a care home](#)

The report link above provides an in-depth report on the multiple issues and challenges faced by a person with a terminal degenerative neurological disease. The person was bedridden with very limited body movement and a hearing impairment. They were able to speak and used assistive technology and an iPad to access information and communicate.

Healthwatch Sandwell supported the person, including connecting them with [POhWER advocacy service](#), for support with health and social care complaint processes.

The Healthwatch Sandwell case study report challenged the failure of social care services to provide information to the patient in accessible formats asking “How can a person make an informed choice and also be at the centre of the decision making about their life when they do not have accessible information about the process of moving to a care home and the related issues?”

Healthwatch Sandwell also pointed out that the [NHS Constitution](#) also states that, “You have the right to be involved in planning and making decisions about your health and care with your care provider or providers, including your end-of-life care, and to be given information and support to enable you to do this. Where appropriate, this right includes your family and carers.”

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Conclusion

Though there are a few examples of positive patient or service user experience and good practise in the main [Healthwatch Sandwell](#) have found that the experiences shared, voices and views within this report have served to highlight that local services are overall not meeting the Accessible Information Standard. Therefore people with disabilities, sensory loss or other communication challenges are receiving an **inequitable** service, and experiencing **inequality** in receipt of health and care services, which is presenting unacceptable risks to health and mental wellbeing.

The recommendations from [Healthwatch England](#) and the [NHS England](#) review and planned revision of the [Accessible Information Standard](#) should bring improvements to services and patient and service user experience. However it will take time for national improvements to take effect.

The [Healthwatch Sandwell](#) report with an embedded “toolkit” of suggestions and information links provides local services with a resource to work with. Patients and service users have expressed the will to be involved and help inform development of the services that they need. If Sandwell health and care services, including as part of Black Country health and care, embrace the opportunities presented, and seek to work collaboratively, improvements to accessibility of services and outcomes for patients and service users can be addressed more immediately.

Recommendations

Based on the findings presented within this report Healthwatch Sandwell recommends:

Sandwell health and social care service providers:

- 1. Consider the [Healthwatch England](#) recommendations made to [NHS England](#) for improvements to the [Accessible Information Standard](#) – identify and plan for improvements to be made.**

Healthwatch England made five recommendations, calling for:

- Health and care services to be made accountable for fully delivering the standard
- Every health and care service to have an accessibility champion
- Better IT systems so that patients can update services with their communication needs
- Involving people with communication needs in designing better services
- Mandatory training on accessible information for all health and care staff.

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2. Revisit and review the information and communication support needs of individual patients, and those receiving social care. Ensure current needs are identified, recorded, shared, and will be met under the Accessible Information Standard requirements.

3. Review and ensure access to services and information is accessible to all patient and service users including awareness of the Accessible Information Standard and complaint processes.

4. Utilise the contents of this [Healthwatch Sandwell](#) report to inform and improve development and delivery of accessible information and communication services to any Sandwell residents who need it, ensuring reasonable adjustment policies, and investment in resources, needed for delivery are identified and included.

5. Be open to developing and improving services through involvement of patients and service users and collaborative working with [Healthwatch Sandwell](#).

Sandwell Health and Care Partnership:

6. Endorse the findings of this report and ensure recommendations are considered and implemented by the appropriate services.

7. Ensure patient voice and involvement is embedded in improvement and development of accessible information and communication services supporting patient reference groups or forums as appropriate.

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Black Country Integrated Care Partnership:

- 8. The Black Country Integrated Care Partnership consider the initial findings relating to Deaf young people's mental health and the transition from children to adult's services. Through direct involvement of Deaf young adults, review, identify and commission gaps in services to meet needs.**

Black Country Integrated Care Board:

- 9. Undertake a holistic review of health and care services for people who are Deaf or hard of hearing through direct service user involvement and including consultation with parents, carers, health, social care services and current providers.**

Include exploring the possibility of developing in-house British Sign Language (BSL) interpreter services (hospital and primary care networks) and addressing any gender imbalance in service provision.

- 10. Consider and review operation of hospital services for people with a learning disability or autism with information and communication support needs. Ensure the shared care record process is utilised to identify and meet needs, that there is awareness and use of Hospital Passports and recognition and respect for parent and carer support role inclusion.**

Review, identify and deliver sufficient provision of required learning disability support services within hospital and community settings.

Further information

To feedback your comments on this report or for more information please contact:

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“Thank You”





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