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Introduction

Communication needs due to a disability, sensory loss or an impairment are covered under the Equality Act 2020 and the NHS Accessible Information Standard (2016) which states that NHS funded health and social care providers must meet the information and communication needs of people who access services. Communication should be undertaken in ways that meet identified needs and information should be provided in formats that are clear and easy to understand. This means that people with disabilities, impairments or sensory loss, their parents or carers have rights to reasonable adjustments so that they can access information. Health and social care providers must ask and identify communication needs and preferences, recording the answers so needs can be met.

Background

Healthwatch Sandwell (HWS) are exploring whether health and care services in Sandwell are meeting the communication needs of individuals with a disability, impairment or sensory loss in their priority project 2 : **Accessibility – meeting information and communication needs**. The HWS work programme for 2022/23 has an overarching theme of health inequalities. This report will contribute to this priority project.

HWS engagement with the deaf community to date.

In partnership with Sandwell Deaf Community Association (SDCA), HWS have engaged with the deaf and hard of hearing community:

In December 2019 a focus group was held to discuss people's experiences of health and social care in Sandwell. The group gave feedback about their experiences which was divided into 3 headings:

1. Communication issues
2. Appointments with General Practitioners (GPs)
3. Experience at Accident and Emergency Department (Sandwell General Hospital)

This report made **14** recommendations.

<https://www.healthwatchsandwell.co.uk/wp-content/uploads/2020/06/Deaf-Focus-Group-Report-1.pdf>

During Covid-19 in September 2020, a second focus group was facilitated via zoom. The group gave feedback about their experiences during Covid-19, which was divided into 5 headings:

1. Feelings and emotional well-being/mental health
2. Coping mechanisms during COVID 19
3. Communication Issues
4. Care
5. Hearing Aids

This report made **2** recommendations.

<https://www.healthwatchsandwell.co.uk/wp-content/uploads/2021/01/Deaf-Focus-Group-Report-2.pdf>

In September 2020, the Sandwell and West Birmingham Clinical Commissioning Group (SWB CCG) approached Sandwell Deaf Community Association (SDCA) to engage with the deaf and hard of hearing community about their experiences accessing primary healthcare during Covid-19.

SDCA signposted them to HWS as the organisation that they engage with about health and social care in Sandwell. It was agreed to share the HWS focus group reports findings with the SWB CCG. As a result of sharing this report and the Chair of HWS having a place on Sandwell Place Commissioning Committee Meeting, HWS were invited to attend the above meeting on 18th March 2021.

A HWS representative and a deaf service user who uses BSL presented the findings of the 2 previous focus groups, we summed up the findings in the following 3 themes:

1. Affect on emotional well-being/mental health
2. Coping mechanisms during COVID-19
3. Communication Issues

This presentation was well received and assurances were given to address the recommendations to the reports.

Drivers for change

Equality Act (2010) sets out which service providers have a legal responsibility to provide reasonable adjustments to ensure safe, equal access to services for disabled people. For deaf people who use sign language this access would be a Qualified Registered BSL interpreter.

National Commissioning Framework for Hearing Loss Services July 2016

This is a guide to help organisations responsible for planning and commissioning local hearing services for deaf people and those with hearing loss launched by NHS England.

Accessible Information Standard April 2016

This aims to ensure that disabled people have access to information they can understand and the communication support they may need. The Standard applies to service providers across the NHS and adult social care system. As organisations that provide NHS services, GP practices are required by law to follow the Standard under Section 250 of the Health and Social Care Act.

5 Key requirements overview of the Standard

1. Ask patients and carers if they have any information or communication needs and find out how to meet their needs.
2. Record those needs in a universal way.
3. Highlight a patient's file, so it is clear that they have information or communication needs, and clearly explain how those needs should be met.

4. Share information about a person's needs with other NHS and adult social care providers, when they have consent or permission to do so.
5. Make sure that people get information in an accessible way and communication support if they need it.

Healthwatch England Project #your care, your way

HWE project is looking at accessible information which covers the needs of people who are deaf, blind, or deafblind, or who have a disability such as a learning disability. This includes interpretation or translation for people whose first language is British Sign Language. It aims to:

- Find out how well health and care services are delivering the accessible information standard.
- Make sure that, if the standard covers you, you know your rights.
- Find out who else has problems understanding information about their healthcare and needs to be covered by the standard.

British Sign Language Act 2022

The BSL Act 2022 came into force on 28 June 2022. The Act will create greater recognition and understanding of BSL, and inclusion and equality for BSL users by:

- Legally recognising BSL as a language for England, Wales, and Scotland.
- Requiring government departments to report on how they are promoting and facilitating the use of BSL.
- Providing guidance to government departments and public bodies on how to meet the needs of people who use BSL as their first or preferred language.

Purpose of this report

This report will give an overview of the findings of HWS third focus group, will inform Priority Project 2 and make recommendations to improve access to health and social care services for deaf and hard of hearing people.

Methodology

HWS facilitated a focus group, in partnership with SDCA, to gain an insight into the accessibility challenges regarding information and communication being experienced by deaf Sandwell residents.

SDCA supported the event by producing a poster and a BSL signed video that was used to promote the event on social media platforms. The focus group was held on 28th September 2022 at Gayton Road Community Centre, West Bromwich and was attended by **4** service users and **1** support worker, **2** BSL interpreters and **1** HWS volunteer.



Aim of focus group

The focus group aimed to answer the following questions:

1. Does the Equality Act 2010 and the NHS Accessible Information Standard (2016) meet the information and communication needs of people who access services?
2. Do Providers ask and identify communication needs and preferences, recording the answers so needs can be met ?
3. Is the information provided in formats that are clear and easy to understand?
4. What has been your experience of the fundamentals of care at Sandwell and West Birmingham NHS Trust?
5. What suggestions do you have to improve accessibility for Deaf and hard of hearing people?

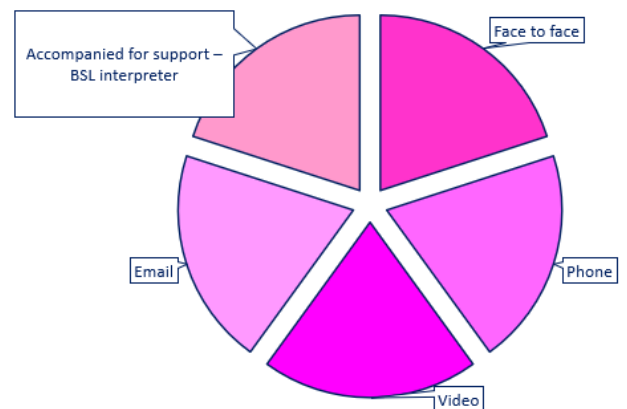
Findings

In order to answer the above questions participants were asked to share:

1. their experiences of the types of health and care appointments
2. rate their health and social care services
3. share their experiences of fundamentals of care
4. make recommendations to improve accessibility for Deaf and hard of hearing people

1. Experiences of the types of health and care appointments

People described their experiences accessing GPs, hospitals, dentists and pharmacies, and included contact with Sandwell MBC. This section will highlight the following methods of contact but the feedback, in part, is generalised across the above listed services as the issues raised were common to all services.



Face to face appointments

People had really struggled to get an appointment of any description due to Covid-19 restrictions since 2020, however recently they have been able to access appointments face to face.

Booking/accessing an appointment at local GP practices is a challenge for the general population however being deaf presents additional problems. The group described waiting for telephone calls to be answered as well as having to wait a month for a routine appointment. When people were unable to access an appointment they used alternative sources for health advice including the internet and 111. Unfortunately one participant described finding the

challenges so stressful that they stopped contacting the GP and stopped taking their medication.

Due to various barriers, the respondents stated they preferred face to face consultations with a health or social care practitioner. However, this group faced difficulties with this type of consultation, with the main issue being surrounding British Sign Language Interpreters.

Issues with BSL and interpreters

Not recognised as a language

There is a lack of understanding amongst health and social care professionals that British Sign Language is a language¹ in its own right. Examples were given of some professionals writing things down or subtitles being relied upon in video meetings, on the assumption that a person who uses BSL can read English and although some people can read some written English, English is their second language and BSL is their first. One of the participants described having 3 languages, BSL, Urdu and English.

Requires a qualified BSL interpreter

Some people rely on their families or support worker to interpret but they are not interpreters. Interpreters hold recognised qualifications². When family members do assist, it can cause embarrassment for the patient if the matter is personal.

At an appointment with Sandwell MBC, a person had been told that it was not appropriate to book interpreter because they had a support worker (see section Support at appointments on page 11)

Data protection issues

A respondent was told that it wasn't appropriate to book an interpreter due to 3rd party authorisation. This was described as '**excuses**'.

Booking of BSL interpreter

Respondents described that it was their or support worker or their families' responsibility to book the interpreter and also to check if one had been booked.

When healthcare staff did book the interpreter experiences were given of the interpreter not turning up or arriving at the wrong time and then leaving, although they receive their fee. This meant that another appointment had to be rescheduled even though the person had waited a month already for this appointment.

¹ British Sign Language Act 2022 <https://bills.parliament.uk/bills/2915>

² A postgraduate or master's degree in interpreting or translation or a Level 6 Diploma in Sign Language Interpreting. BSL Interpreter (Registered Sign Language Interpreter – Yellow Badge as recommended by National Registers of Communication Professionals working with Deaf and Deafblind People.

Sometimes when an interpreter was cancelled, the participants were told they weren't needed and to rely on their support worker.

When respondents had hospital appointments/admissions, the staff on wards did not sign or have access to an interpreter. The patient would have to wait sometime to access an interpreter. One occasion a paramedic rang ahead explaining the need for an interpreters but there was still no one available when they arrived at the hospital.

Respondents described that staff, in particular at GP surgeries and hospital (A & E), did not know how to book or access a qualified interpreter although there are various providers in the local area. There are 3 communication services that are used locally : SDCA communication service³, Communication plus⁴ and WORD 360⁵

The group spoke positively of WORD 360. Experiences of Communication plus were given which identified that bookings are accepted without having enough BSL interpreters to provide the service.

Coping without a BSL interpreter

When an interpreter isn't booked/available respondents have to make do and explained that they have things typed on their phone for staff to read. Some respondents manage to lip read but it's a struggle especially if they have poor eye sight or the wearing of masks. Some respondents do not lip read or write English. Due to hearing loss, respondents described missing announcements (transport) or being called for appointments, in both instances they were inconvenienced.

All of these issues with BSL interpreters had caused frustration, stress and exhaustion.

Participants believed that these issues could be rectified if their records indicated that a BSL interpreter was required for **EVERY** appointment. This would avoid all the waiting around, rebooking of appointments and they would have equal access to healthcare. Respondents stated that all healthcare professional should **record** that they are deaf and that they need a BSL interpreter for every appointment.

³ SDCA delivers specialist services to deaf and hard of hearing people on behalf of Sandwell Council. We provide a variety of services including Information, Advocacy, Volunteers, Training, Communication, Welfare Rights, Support Service, Consultation and Research and Community Groups.

⁴ CommPlus is a Sign Language Agency registered company in England and offers Registered Sign Language Interpreters, Communication Support Workers, Deaf Relay Interpreters and Interpreters for people who are Deafblind. They also offer notetakers and speech to text reporters. A private.

⁵ WORD 360, a private company, is a real-time interpreting delivered by experts who collectively specialise in over 350 different languages, either in person, over the phone or through remote video conferencing.

Although there are different departments in a hospital, I have one NHS number, why can't there be one record that everyone can access, this way requirements could be shared between services

The group were informed of NHS shared care record (ShCR)⁶ as a way of bringing together all separate records from the different organisations involved in health and care. This will let the professionals who are directly involved with a person's care see relevant information about the care and treatment you've had across all services. This should mean that a person will only have to tell their story once, and local health and care professionals have instant access to all the information they need to treat you in the fastest, safest and most effective way. This record **should** state that a BSL interpreter is required.

The respondents believed that the lack of access to a BSL interpreter is due to cuts in spending, however it was stated that it is their human right under Equality Act (2010) and Accessible information Standard (2016). They described feeling 'double disadvantaged' in that they can't get an appointment and then they don't have access to an interpreter.

They believed that some of the barriers they face are practical and some attitudinal i.e. staff don't want to be bothered. The group described being brushed under the carpet and that wheelchair users have access but not people who are deaf and that this form of discrimination should be fought together. Respondents also described attitudinal barriers including ignorance by Health and social care staff who were using outdated terms e.g. 'deaf and dumb' and deaf and mute, and how they had to challenge this and asked for the terms not be used and to be removed from their medical records. One respondent described 'feeling insulted'

All these issues can affect mental health and interpreters can solve these issues. The respondents concluded by saying that for a face to face consultation to be effective: an interpreter is essential.

Telephone

Booking/accessing an appointment at local practices is a challenge for the general population however being deaf has additional problems, especially when using a telephone. The group described waiting for telephone calls to be answered and that technical difficulties with the telephone created additional barriers.

Deaf people sometimes use Relay UK⁷ which uses a live relay assistant to help the person communicate. A participant described the difficulties with this system – a patient will phone the GP and the receptionist will say promise to get someone to call you back. But they don't

⁶ One Health and Care is a confidential shared care record which is being launched for people registered with a GP in the Black Country and West Birmingham during 2022.

⁷ Relay UK is a free service to help deaf people and those who have hearing loss or are speech impaired to communicate over the phone. It has replaced the Next Generation Text and the old Text Relay service.

forward the FULL number to the member of staff, so when they return the call without using the prefix the patient is unable to answer the call. The prefix number 18002 needs to be logged on the system. A respondent described being on hold/in queue for 45 minutes, the call is ended as staff don't know what Relay UK is and so therefore hang up. A person described a patient being discharged from the Practice because *'they didn't answer the phone'*. The majority of the group disliked using Relay UK especially as they can't read long English words and they questioned the security of the system and its confidentiality.

The group preferred Video Relay Service⁸ as they believe it's safer as personal information is not saved but it can be quite expensive. This VRS has a real BSL qualified interpreter and it feels safer. Only negative was that it uses English and his first language is BSL.

Text

Participants receive texts from their surgery or the NHS to remind them of appointments but unfortunately NHS texts are no-reply to texts. This was felt to be a missed opportunity as a way of communicating with their GP surgery and other healthcare providers.

Video Consultations

A respondent described that their GP practice struggle to provide video consultations with BSL interpretations due to the NHS software and how it is set up. It was described as too complicated for the patient to set up their end, and for this reason they feel that they have to 'pressurise' the GP service to provide a face to face appointments because not enough staff within the practice are IT competent.

It also needs to be remembered that some people do not have the internet (due to digital poverty) or may not be savvy with information technology. However, despite the barriers, it was suggested this could be a really good way to receive a consultation if people (staff and service users) know how to use it.

E mail

Respondents described how e mails were used but infrequently, which is good as written English is difficult for this group. Family members use them on behalf of respondents. People make assumptions that deaf people understand written English. This occurs when people hand write notes or use text to speech or subtitles on videos in English.

⁸ A video relay service, also sometimes known as a video interpreting service, is a video telecommunication service that allows deaf, hard-of-hearing, and speech-impaired individuals to communicate over video telephones and similar technologies with hearing people in real-time, via a sign language interpreter.

English is not my first language so I struggle. Writing needs to be simple – short words only

Support at appointments

Support workers are an excellent support, especially when they advocate for appointments, they also have good connections in the local community. They can take notes on the jargon used during the appointment and then find out what it means and explain to the deaf person.

Respondents described having to rely on their support worker to interpret but as raised on page 7 they are not qualified interpreters and it is not their role. Healthcare professionals assume that a support is an interpreter.

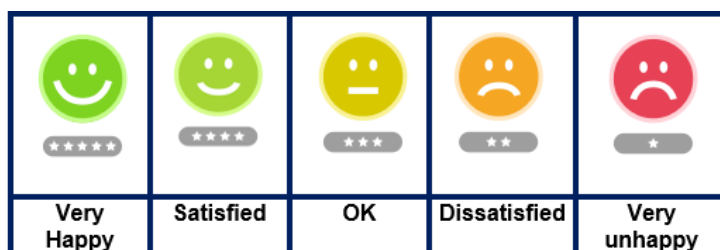
In a consultation everyone is needed and has a specific role: Patient, GP, BSL interpreter, Support worker etc, but there are times when the roles get blurred.

When there is a lack of support during a consultation, a person sometimes has to rely on lip reading but this is not effective for some and misinterpretation can occur. This is particularly worrying when trying to explain symptoms of poor health or receive information about treatment for poor health.

There was unanimous feedback that the support from SDCA is **excellent**, they were described as family and that they don't have to explain anything because they just get them.

2. Rate your services – meeting your communication needs.

The group were asked to rate the actual services, the participants rated GPs, Dentists, Pharmacies etc in various ways ranging from poor to average to good. The feedback varied for each person.



3. Fundamentals of care

Sandwell and West Birmingham NHS Trust (Hospitals) have developed a set of Care Standards, known as the 'fundamentals of care'. The standards are listed in the graph below. The respondents were asked to rate their experiences from the Trust, with a particular focus on :

- Informed and things are explained to me
- Listened to
- Involved

Overall the respondents rated their experience negatively. All agreed the standards are not being met based on their experiences.

Fundamentals of care		
Welcome	Informed and things are explained to me	Listened to
My point of view is valued	Involved	Service is polite, courteous and respectful
Service is caring and kind	Mistakes are admitted and put right	Services "go the extra mile"

Health services are not accessible to me!

4. Ideas for improvement to improve access

Respondents were asked for their ideas to improve access to health and social care services:

- Record a person's needs especially the need for a BSL interpreter
- Services should take responsibility for arranging a BSL interpreter
- Recognise that BSL is a first language
- Don't assume people can lip read
- Simplify writing, use small words
- Commit to Equality Act (2010) in action not just words
- VRS as a remote option and make the technology available for staff so that they can use it
- iPad as backups/multiple options available

Conclusion

This report has provided information to assess whether deaf people's communication needs have been met under the Equality Act 2020, the Accessible Information Standard (2016), National Commissioning Framework for Hearing Loss Services July 2016 and British Sign Language Act 2022. It also provided information about their experiences of the fundamentals of care at Sandwell and West Birmingham NHS Trust and suggestions to improve accessibility for Deaf and hard of hearing people

In partnership with SDCA, HWS facilitated a focus group and found that deaf people preferred face to face appointments with health and social care providers but they experience barriers due to a lack of BSL interpreter being provided and that BSL is not recognised as a language.

It was unclear who's responsibility it was to book a BSL and family and support workers were relied upon to interpret although they are not qualified interpreters and it was not their role. When an interpreter was not available people were expected to lip read or read written English

The respondents believe that the lack of access to a BSL interpreter were due to cuts in spending, and that their human rights under Equality Act (2010) and Accessible information standards (2016) were being denied.

They described feeling 'double disadvantaged' and that experienced poor attitudes towards booking an interpreter. The use of discriminatory language was described and that all these issues can affect mental health.

Respondents described their experiences of using telephone, Video Relay Service, text , video consultations, e mail and support at appointments which were all fraught with challenges.

The group were asked to rate the actual services, the participants rated GPs, Dentists, Pharmacies etc in various ways ranging from poor to average to good.

Overall the respondents rated their experience of Sandwell and West Birmingham NHS Trust (Hospitals) set of Care Standards, known as the 'fundamentals of care' as negative. All agreed the standards are not being met based on their experiences.

Participants made recommendations to improve accessibility for Deaf and hard of hearing people which included: Record a person's needs especially the need for a BSL interpreter and take responsibility for arranging a BSL interpreter, recognise that BSL is a first language and don't assume people can lip read.

This focus group identified many barriers and battles that they experience when accessing health and social care. It is disappointing for HWS when recommendations have not been implemented after reassurances were received from the Sandwell and West Birmingham Clinical Commissioning Group now known as the Black Country Integrated Care Board and that legislation has not been implemented since 2010 i.e. the Equality Act.

This focus group identified many barriers and battles when accessing health and social care and concluded that the Equality Act 2010 and the NHS Accessible Information Standard (2016) requirements are not being met.

Lack of inclusion for people who are deaf and those with hearing loss adds to further health inequalities, it fosters a sense of second class citizenship. Appropriate communication and information access will reduce the health inequalities, improve quality of life and ultimately save the NHS money.

Recommendations

From the findings, HWS would make the following recommendations:

- Commit to legislation and drivers for change including :
 - Record a person's need for a BSL interpreter
 - Services take responsibility for arranging a BSL interpreter for each appointment
 - Recognise that BSL is a first language and not English
- Don't assume people can lip read and simplify writing using small words
- Invest in information technology and train staff to use it

Acknowledgements

HWS would like to take this opportunity to thank our partners at the Sandwell Deaf Community Association.

Disclaimer

All data provided in this report was accurate at the time of the project.

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