

‘Our Voice in Health and Social Care’ British Sign Language Users

Summary report



Executive Summary

Healthwatch Lancashire ran an engagement project to explore the experiences of the Deaf community who use British Sign Language (BSL) when accessing health and social care services. Feedback was gathered from 149 people through focus groups, case studies and an online survey. A mystery shopping activity was also conducted. This report details our findings.

Two main themes were identified through engaging with individuals and carers:

- Barriers when trying to book a medical appointment due to the requirement to book an appointment by phone and only telephone appointments being available.
- Barriers during a medical appointment due to a lack of interpreters or unreliable video interpretation, resulting in distressing appointment experiences.

These barriers resulted in delayed appointments (leading to delayed treatment), a lack of privacy due to family and friends having to interpret for them, being treated inappropriately such as professionals shouting at individuals, and people not understanding diagnoses or results due to professionals writing information down which isn't accessible for the individual.

Feedback received from professionals who work within health and social care (or other related industries such as third sector) revealed that over half of professionals had received Deaf awareness training and the majority of respondents felt confident in supporting Deaf individuals who use BSL. The importance of an interpreter being available either in person or online was raised by respondents. Professionals suggested making written materials more accessible as well as a need for more funding to support the Deaf community's access.

Our mystery shopping activity revealed that there is a disparity in support provided between and within services, including whether services provide BSL interpreters or whether individuals must arrange their own.

Feedback collected from individuals, carers and professionals and intelligence received through the mystery shopping activity, highlighted that some NHS services are not fulfilling their legal requirements, under the Equality Act 2010, including providing an interpreter at appointments for people who are Deaf.

These findings have helped to formulate recommendations for the attention of Lancashire and South Cumbria Integrated Care Board (ICB) and Lancashire County Council (LCC) to help improve the accessibility and experience of health and social care services for the Deaf community.

Introduction

About Healthwatch Lancashire

Healthwatch was established in April 2013 as part of the implementation of the Health and Social Care Act 2012. Healthwatch uses people's feedback to better understand the challenges facing the NHS and other care providers and we make sure people's experiences improve health and care for everyone – locally and nationally. We also provide information and advice to support people to make decisions and access support they need.

Introduction

Healthwatch Lancashire established the project 'Our Voice in Health and Social Care' British Sign Language (BSL) users, in response to receiving feedback from the Deaf community about the barriers they face when accessing health and social care. Feedback included:

- Not being provided with an interpreter for a GP or hospital appointment
- Difficulties for people who are Deaf to communicate and interact with services, especially when making an appointment
- A lack of promotion of services that the Deaf community can access
- Patient records not being updated to explain that the patient is Deaf and would therefore require reasonable adjustments to be made to support access and understanding

The aim of the project was to gather rich feedback from individuals who are Deaf, carers and/or family members and professionals to learn about these barriers and formulate key recommendations to present to NHS and social care leaders to help improve access to health and social care services for the Deaf community.

Please note: in this report, when referring to people who are Deaf, we are discussing people who use BSL as their first language and are part of the Deaf community and culture.

Acknowledgements

Healthwatch Lancashire would like to thank all the people who took part in this project by sharing their views and experiences, the interpreters and members of the steering group including Lancashire County Council, N-compass and Lancashire and South Cumbria Integrated Care Board who provided us with guidance and assistance. We are particularly thankful to Lancashire and South Cumbria Integrated Care Board who provided additional resource to enable us to fulfil our goal for this project and Sue Gardam (Deaf Link worker) and Mark Heaton (person with lived experience) who volunteered their time to support us with the arrangement and participation of

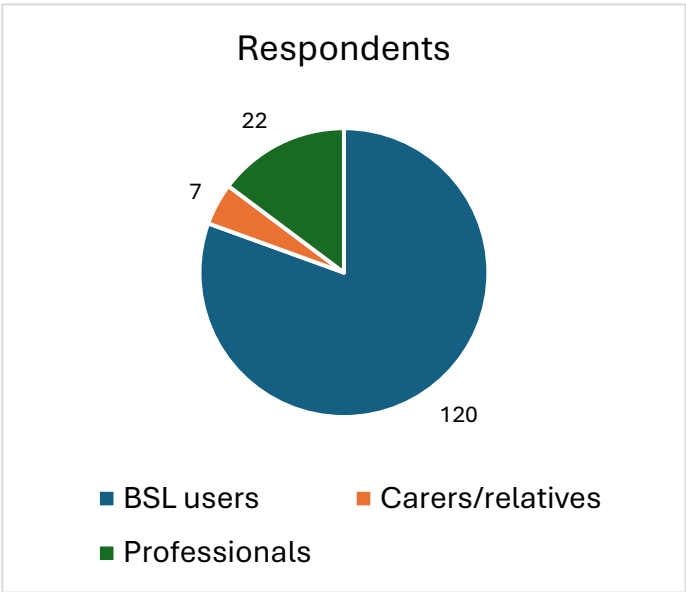
engagement sessions. It has been a privilege to work alongside so many amazing individuals.

Methodology

A steering group was formed in the early planning stages of the project to ensure the project was co-produced with the Deaf community and stakeholders who could enact change. The steering group met three times to monitor project progress and included stakeholders from N-compass, Lancashire and South Cumbria ICB, Lancashire County Council and a member of the Deaf community.

Engagement ran from 6th November 2023 to 1st February 2024. Feedback was captured through focus groups, case studies, online surveys and mystery shopping.

Feedback was collected from 150 people, consisting of 120 Deaf individuals who use BSL, 7 carers and 23 professionals. In addition, 39 health and social care services were contacted in a mystery shopping activity.



Please note: Some quotes refer to the organisation ‘CoSign’ who provide a BSL interpreting service. At the time of this report, CoSign was the commissioned service to provide BSL interpreting services across NHS services in Lancashire and South Cumbria.

Findings

Responses gathered during the focus groups have been analysed and revealed two main themes:

1. Barriers when trying to book a medical appointment
2. Barriers during medical appointments.

Individuals and carers were asked about their experiences of accessing social care services, but no experiences were shared.

Booking a medical appointment

Nineteen individuals shared their experiences of struggling to get a medical appointment, with most issues regarding GP services.

It was shared by eight people that they had experienced a delay in getting an appointment and therefore treatment as the service could not provide an interpreter.

One barrier experienced when trying to book an appointment was services relying on patients ringing them to make an appointment. This was shared by six respondents who said that they received written communication, either text message or email, from the service which stated, 'do not reply to this message' and respondents were instructed to call the service. Respondents shared their frustrations with this as they were unable to call the service without an interpreter.

"A hearing person can ring at 8am and get an appointment that day. How do Deaf people do that? We don't have that option...by the time we have emailed there are no appointments available"

"I got an email from my GP saying don't reply to this email, but I can't ring as I am Deaf. I had to go to the GP and explain and they hadn't even thought about it. How do they expect me to get through if I can't talk on the phone?"



Telephone consultations: Three people shared that their GP service only offer telephone appointments which is not appropriate for them.

"They [GP] said the only option was a phone call [consultation] and they said if I need an interpreter, I would have to find one myself."

There were also discrepancies between whether a service offers an interpreter or whether the patient must book one themselves.

During the medical appointment

Forty-nine people shared negative experiences during a medical appointment. 53% of these related to a hospital experience, 12% about the GP service, 12% about

opticians, 4% about dentistry and 18% did not state which service their negative experience referred to.

Thirty-nine people explained that they had a negative experience due to not being provided an interpreter, despite it being a legal requirement for services to provide an interpreter for people who are Deaf.

Of these, six people shared the distressing experience of having to use family members or friends to interpret for them which limited their privacy and impacted on their dignity.

A&E experience



I recently got blue lighted to A&E with a heart problem. The whole way there was silent, no one knew any sign language. I can lip read and the paramedic wouldn't take his mask off so I could lip read what he was saying. It was a scary time for me and I didn't not feel I was being supported.

I arrived at A&E and was told that there was no interpreter on shift and there should be one later. I faced-timed my husband as I was scared and no one would communicate with me. The doctor shouted down the phone at my husband "can you tell your wife something for me." This was highly inappropriate, my husband should not be translating for me when he was just as scared for me. He was stressed already with having the kids at home and me in hospital, but he was then translating for me.

There should have been 24/7 VRS available to me and there wasn't. I feel this could have been massively avoided, all staff were walking around with iPads and phones why can't there be an app on there to help translate for patients.



Four people shared that their distressing experiences of using emergency care and not having access to an interpreter, which exacerbated an already stressful time.



"I went to A&E at 3am, I asked for an interpreter and they said outright that there is no interpreters and that it was too early in the morning. The doctor wrote information down but it was in complicated language which I could not understand. I can't read this

language."

Four people shared their experiences of staying in hospital and not being provided an interpreter from the beginning, which meant they had to stay in hospital without fully understanding what was wrong with them or what was happening.

"My wife was in Royal Preston Hospital for six weeks, no interpreter was provided, the hospital staff tried to say that we didn't need one and that they could communicate with my wife. It was only in the last two weeks...that they finally decided that an interpreter was needed"

During focus groups, there was also discussion surrounding people's experiences of attending a hospital appointment and having medical staff with only Level 1 BSL training (with qualified BSL interpreters being trained to Level 6) being used to interpret. Individuals at the focus group (and interpreters) shared their views on how this is not acceptable and Deaf people do not know whether to trust what staff are saying to them.

Four people expressed the need for health services including GPs and hospitals, to change how people are called to their appointments. Respondents shared their experiences of not hearing when staff call their names to their appointment which sometimes means they miss their appointment. Respondents suggested having a tv displaying the patient's name and appointment room. However, this method is still limited as it relies on Deaf people constantly watching this screen. A flashing or vibrating pager was suggested, so Deaf people know when they are being called for their appointment.

"I went to Royal Preston Hospital for an X-ray and I noticed that everyone else was going in and out but I was still sat there. There was no display or monitors, they were only shouting names."

Other issues experienced as a result of not having access to an interpreter included medical professionals writing down information including medical terms which Deaf people cannot read or understand, professionals shouting in people's faces, refusing to take off medical masks so Deaf people can lip read, interpreters not being available as it is "too late in the day" or it is a weekend and interpreters not turning up to appointments.

Eight people had experience of using a video sign language interpretation service and experiencing poor connection due to Wi-Fi issues

"I used video sign and it kept failing and coming up with an error message. They eventually sent me a letter and it said please ring us."



Deaf Link workers

The importance of Deaf Link workers was highlighted, not only for supporting Deaf people in booking and accessing health appointments, but for other tasks such as helping with household bills and advocating for them. Individuals praised Deaf Link workers and their crucial role in supporting the Deaf community.

Feedback was also received regarding the need for more funding for Deaf Link workers to support more Deaf people, as at the time of this project there was only one Deaf Link worker covering the entire Lancashire area.

Professional survey

Utilising contacts from our Enter and View programme (recent services we had visited) and contacts we engaged with, throughout the project. An online survey was sent to them. We received 22 responses from people, on the back of this activity.

67% of professionals had received Deaf awareness training. 86% of professionals had experience of supporting someone who is Deaf and uses BSL. Respondents were asked how confident they felt in supporting people who use BSL. The majority of respondents felt confident.

85% of respondents shared that their organisation does offer support for people who are Deaf and use BSL. Over half of respondents shared that their organisation books an interpreter on behalf of a patient.

Respondents were asked what they think needs to be put in place to make their organisation/service more accessible for individuals who are Deaf and use BSL. The most common suggestion made was to make written information including information leaflets and letters more accessible for BSL users including the use of BSL videos, as well as more funding for supporting those who use BSL.

"It's not like being deaf is a temporary status, it's there for life, why should the service fluctuate on funding."

Finally, professionals were asked if they face any barriers at work in supporting individuals who are Deaf. Five shared not always having an interpreter is a barrier and medical professionals relying on 'writing things down'. Four professionals shared their lack of confidence and a need for training on Deaf awareness.

Mystery shopping

The mystery shopping activity on thirty-nine services including care homes, GP surgeries, opticians, dentists, hospitals and day services. It was clear that there are large discrepancies between and within services regarding what measures they have in place to support BSL users.



In regard to providing an interpreter, nine services (23%) said that they can book an interpreter for the patient, and six (15%) said that the patient needs to book their own interpreter. Only nine services (23%) shared that they have hearing loops in their setting and three services (8%) use VRS.

Six services (15%) shared that they were unsure what they have in place to support people and two services (5%), a care home and a day service, said that they do not provide anything.

Care Homes: When contacting care homes, four care homes stated that they were not accepting any new residents, so mystery shopping could not be completed for these services. Of those we spoke to, two (15%) shared that they could provide an interpreter for residents, and a further two (15%) shared that they would need the resident to arrange their own interpreter.

GP surgeries: 50% of GP surgeries contacted would provide an interpreter for a BSL user, and 17% would require the patient to book their own interpreter. 42% of GP surgeries contacted provide hearing loops. 17% provide VRS.

"It would depend on the practitioner they see, some might be able to do some sign language"

Opticians: Two (29%) opticians contacted would provide an interpreter for the patient, and two opticians shared that the patient would need to arrange this themselves. Two opticians shared that they would provide a longer appointment time for BSL users, two services provided hearing loops and one would offer a home visit if preferred. Two opticians were unsure on what support they had in place.

Overall, the mystery shopping activity produced mixed findings within and between services. It appears that some services provide an interpreter for people who are Deaf and others require the patient/resident to arrange their own. Only 23% of services provided hearing loops and only 8% had VRS.

Conclusion

Our project gathered feedback from people who are Deaf and their carers/relatives about their experiences of accessing health and social care services. Feedback was also received from professionals. Analysis of findings highlighted inequalities faced by the Deaf community and these findings have helped to formulate recommendations to improve services and experiences.

In conclusion, feedback from individuals and carers/relatives revealed significant barriers faced by the Deaf community when accessing health care services. Barriers related to trying to book a medical appointment and multiple issues experienced and exasperated during an appointment due to not having a BSL interpreter.

Some NHS services are not fulfilling their legal requirements, as stated in the Equality Act 2010, including their requirement to arrange an interpreter for a patient who is Deaf, as a high proportion of people were required to book their own interpreter.

These barriers resulted in delayed appointments (leading to delayed treatment), a lack of privacy and dignity due to family and friends having to interpret for them, being treated inappropriately such as professionals shouting at individuals, and not understanding diagnoses or results due to professionals writing information down which individuals cannot understand. Some individuals had also experienced medical staff who only have Level 1 BSL training interpreting for them which is not sufficient as a fully qualified interpreter is needed. All these barriers have resulted in individuals feeling frustrated, stressed, isolated and often confused.

The important role of Deaf Link workers was highlighted as well as a need for more Deaf Link workers, to support Deaf people and help them to overcome the barriers they are facing. At the time of this report, there was only funding available for one Deaf Link worker across Lancashire. This is a single point of failure; if this worker was to be off work or leave the post, there is risk that the Deaf community would not be able to access the same level of support.

Feedback revealed that although a large proportion of professionals felt confident in supporting someone who uses BSL, there is a clear need for information to be more accessible and more funding to support people who are Deaf.

The mystery shopping activity highlighted a disparity in the procedures that are used by service providers to support Deaf people, particularly regarding whether services provide BSL interpreters or whether individuals must arrange their own.

These findings have revealed that there is a clear need for healthcare providers to improve their knowledge and understanding of their duties under the Equality Act 2010. Recommendations have been formulated as a result of these findings to aim to improve experiences for the Deaf community when accessing health services.

Recommendations

The following recommendations have been formulated in response to feedback gathered for the attention of health and social care providers and commissioners.

1. Ensure that Health and Care services are clear about their legal duties under the Equality Act 2010 and audit services to ensure compliance.
2. Ensure that robust systems are in place to allow rapid access to appropriately trained (level 6) BSL interpreters
3. Ensure all services, including primary care, are clear that it is their legal duty to provide BSL interpreters, and that there is rapid access to this service
4. Ensure/ continue any current mandatory BSL/ Deaf Awareness training for all members of staff, is delivered by a Deaf person from an accredited company. o ensure that all staff are aware of Deaf culture, legal rights and responsibilities, BSL as a first language and etiquette.
5. Ensure that the Health and Care workforce are clear about a person's legal right to have reasonable adjustments made to support access.
6. Ensure there is a wide range of reasonable adjustments are available and tailored to an individual's needs.
7. Ensure that patient records highlight the person is Deaf and uses BSL, and staff are trained to understand how best to support a person who is Deaf and uses BSL.
8. Carry out an accessibility review to ensure that communications and appointment making procedures within NHS services are in line with Accessibility Information Standard (AIS).
9. Ensure that the Deaf community are listened and responded to following this report
10. Ensure that the Deaf community are involved and included in shaping and designing of services.
11. Ensure there is a quick and easy, standardised process in place so that Health and Care staff understand how to book interpreters
12. Add an option for patients to request reasonable adjustments online, including booking interpreters.
13. Utilise haptic feedback technologies such as a vibrating paging system to alert patients when it is their appointment in addition to visual displays and staff interaction.
14. Ensure that communications about health information are available in an accessible format including BSL in line with the Accessibility Information

Standard (AIS). Include QR codes to BSL videos on printed materials including leaflets and posters.

15. Ensure that information regarding patient experience, complaints and feedback are accessible to BSL users in line with the Accessible Information Standard (AIS).
16. Explore current funding allocations to determine whether the recruitment of more Deaf Link workers is feasible.
17. Consider the sustainability of the service and implement a contingency plan should the one Deaf Link worker go on long-term leave or leave their post.

Response from Providers

We have received responses from Lancashire County Council and the Lancashire and South Cumbria Integrated Care board (ICB) to our recommendations. A selection are listed below but can be found in the main report.

Lancashire County Council

- Lancashire County Council currently holds a contract with Co.Sign which provides access to appropriately trained interpreters. In most circumstances the Authority will provide at least three working days' notice for an interpreter. In some circumstance bookings will need to be made at very short notice. A response and confirmation of the ability to meet the requirement must be made within 1 working hour. If this is not feasible then we have the option of commissioning freelance interpreters.
- Lancashire County Council will continue to have representation at the BSL Forum and will use this opportunity to ensure that the Deaf community are involved in shaping and designing services.

Lancashire and South Cumbria Integrated Care Board

- Lancashire and South Cumbria Integrated Care Board (ICB) has been working with BSL users since our establishment. We have welcomed BSL users to various community engagement events and have been keen to understand the health service experience of BSL users.
- As such, we welcome this report. We have made some improvements to our services (BSL interpreters in Social care and streamlining contracts for BSL interpreters in primary care) but we recognise we have more to do. We will continue to contribute to more raised awareness of the legal duties and needs of BSL users, and we will work with our colleagues in social care, healthcare providers and with BSL users to ensure that they experience improvements in their use of health services in Lancashire and South Cumbria.

- We regularly receive feedback around accessibility of services and interpretation and BSL interpretation. Accessibility and availability of interpretation and BSL interpretation in particular are common themes. We aim to work with local GP practices and NHS services through our place-based partnerships to look at how access is improved to further improve health equity. This is a key consideration for any future commissioning of services.



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