The Big Conversation – BSL Users consultation

Wednesday 23rd August 2023, 10am-12pm at Redbridge Central Library

Facilitator: Cathy Turland, Chief Executive Officer, <u>Healthwatch Redbridge</u> (HWR)

Focus group support provided by:

Donna Young (HWR)

Sensory Specialists Daniels-Whittle - <u>Sensory Specialists</u>

Nicky Summers - Redbridge Council

BSL Interpreters:

Wendy Everingham (RSLI)

Cat Ward (RSLI)

Jess Cooke (TSLI)

Introduction

Healthwatch Redbridge was asked to support north east London Integrated Care System (NHS NEL) to listen to and involve diverse communities in responding to their 'Big Conversation'.

The 'Big Conversation' is about listening to the people in our local communities, hearing their thoughts about health, care and wellbeing in north east London and, most importantly, acting on them. It will help NHS NEL to focus on what matters to local people and to work with them and community partners, to improve quality address health inequalities.

The engagement will build on the recently published interim integrated care strategy that is turning their ambitions into actions and is an opportunity to focus on what matters to local people.

Based on what NHS NEL already know, they are currently focusing on four improvement priorities. These are:

•	Babies, children and young people	Local employment and workford	се
•	Long term conditions	 Mental health 	

Methodology

The 'Big Conversation' has been developed into an online survey and a series of public engagement events and specialised focus groups.

Healthwatch Redbridge agreed to support a focus group for Deaf participants, ensuring there was access to British Sign Language (BSL) interpreters throughout the session.

Deaf people are one of the most marginalised of our local communities with many facing a range of barriers and health inequalities mainly due to the lack of accessible information and communication support.

The focus group was created to provide an opportunity to those with lived experience to look at what is important for them.

The focus group was developed to be conversational, with notes being drafted from discussions had in small and large groups.

A simple presentation was created by Cathy from HWR. The design was developed using the specific survey questions, simplified to enable people to discuss the issues where English is not their first language.

Additional support

Healthwatch Redbridge worked with support from Sensory Specialists and Redbridge Council to promote the event within the Deaf community. Sensory Specialists also provided video promotion, contacting many of their members. Both organisations also helped to identify three BSL interpreters for the focus group to ensure information could be provided to participants. There was also an opportunity for individuals to participate in small group work and 1:1 session with support.

Two days before the event, we received a request for a palantypist (speech to text writer). Unfortunately, despite contacting several in and around London and the South East, we were unable to confirm a booking. Participants were made aware we were unable to accommodate the request, however they decided to attend the event.

Attendance information and known demographics

A total of 19 participants attended the focus group.

Gender

• Male 3

• Female 16

Ethnicity

- White/English/European 10
- Asian/Indian/Pakistani 6
- Black/Caribbean/African/Mixed 2
- Asian/Chinese 1

Age

- 25 49 years **5**
- 50 64 years **5**

• 65 – 79 years **9**

Session support



To understand what level of support individuals may need during the session, we asked participants if they were happy to share their level of understanding of written English.

The four options were "no written", "basic", "conversational", and "fluent".

When asked, all participants agreed they were mostly in the middle of "basic" and "conversational". They requested information was provided in basic, plain English and that photos would be useful.

Working with Sensory Specialists, HWR agreed they would support the development of short BSL and subtitled videos after the event, to identify and explain the findings of the consultation.

Participants also suggested, and HWR agreed, that another meeting should be held with BSL interpreters and a palantypist. This would ensure participants had an opportunity to understand the findings and ask more questions.

HWR agreed to take this recommendation back to NHS NEL to confirm a date for the event.

Activity 1:



Brainstorming – what do good Health & Care services look like to you?

As a large group, participants were asked to think about examples of good practice when accessing health and social care services.

Participants expressed how stressful hospitals can be when interpreters don't turn up on time, and the importance of them being present before the start of the appointment. One participant expressed they had requested an interpreter for an appointment (Whipps Cross) but has had to wait a very long time for reply.

A participant said they received two letters for a hospital appointment (Whipps Cross) that didn't explain the nature of the appointment. There were no instructions on how to make contact in an accessible way. Sensory Specialists had to make contact to find out what it was about, and the appointment date kept getting pushed back and no interpreter confirmed.

A participant experienced issues with interpreters in A&E (Whipps Cross). Sensory Specialists had to talk to triage about Deaf awareness. They eventually got a video BSL interpreter.

A GP practice (Gants Hill Medical Centre) told a participant there were no BSL interpreters or entitlement to them. There was also information for BSL access. The participant explained there was a poster in the practice about BSL, but the GP got defensive and said they didn't know. HWR offered to follow up directly on this.

There was agreement from the room that they don't want people to panic when they encounter a Deaf person, and this can be addressed through deaf awareness training.

Sometimes an interpreter doesn't turn up, but video BSL isn't always great with poor hospital Wi-Fi. One participant felt the NHS aren't focused on being able to see the interpreter for smooth communication (e.g., poor connection, disconnects, interpreter freezes, takes a lot of time).

The same participant recounted her experience of video BSL whilst giving birth and emphasised the need for the right support for the right services at right time.

"...They're not asking deaf people if they're getting what they need. It's frustrating accessing services. (Whipps Cross) is awful for pregnancy and childbirth (maternity services), specifically, there's an individual in that team who is horrible. She needs to be sacked because she is so discriminatory...

...Antenatal clinic is not accessible and will only offer appointments with interpreters during weekdays, but others can access evenings and weekends. I think it's because they don't want to pay more for interpreter out of hours...".

She went on to question the process of booking an interpreter, and emphasised how inappropriate remote BSL is when you are in labour. She felt the NHS were clueless to the Accessible Information Standard (AIS) and ended up booking her own interpreters for when she was scheduled to give birth and had to sign them up to an agency to ensure they were paid.

Another participant had a child recently. (King George and Queens hospitals) didn't have an interpreter for any maternity appointments. She kept telling them she needed an interpreter but was never given access to one. All communication had to happen on paper. She is currently expecting another child – (Queen's) have a video BSL interpreter on TV monitor through Newham Language Shop which has good connection.

One participant felt that hospitals should have BSL offices to offer 24 hour access.

Another participant brought up the use of flagging systems, stating that GP's and hospitals should know straight away that someone is deaf, and the flag should show they need an interpreter. She went on to suggest that needs could be colour coded, or a sticker used on paper forms.

The group questioned why this service wasn't available in A&E departments, and why it was only available in the maternity ward – although it was stipulated that face-to-face interpreting is always best. HWR said (Whipps Cross Hospital) are trialling the service with Newham Language Shop.

Although the aim of the session was to look for positive examples, it was very clear that most participants had difficulty seeing past the negative impact of inaccessible services.

Activity 2:

Activity Two: Storytelling

In pairs, one person to tell the story, one person to listen.

Think of a situation where you have used health or social care services.

- Did you feel you were seen, understood, and respected?
- If not, why not?
- What made you feel you received good care, or bad care?

5 mins then switch storyteller and listener

Storytelling

Participants were asked to asked to get into pairs and tell a story to the other person. They were prompted to think of an experience of using a service, and reflect on if they felt seen, understood, and/or respected. If not, why not? If they received good care, why?

Good experience:

The same participant who booked her own interpreters before had a good experience with a specific midwife, who listened and took on board that she was Deaf.

The midwife booked lots of appointments for her and they were proactive in making sure there was always an interpreter for appointments. She took it on responsibility for her care directly and gave the participant a direct text number. The result was the participant felt respected. This took place between 2017 and 2019 at Whipps Cross.

Another participant had positive experiences with maternity services. She has an 18-month-old son and is currently pregnant. The midwives always booked appointments with interpreters at **King George's and Queen's**. They had a new system on reception meaning it will flag access needs. The system ensures the access requirements are highlighted for every appointment. The participant felt reassured that an interpreter would be there. Last week, she met with her midwife at **King George's** - the midwife told off her colleagues for trying to ring the participant, and she made interpreter appointments for the participant. The participant trusts this midwife, and feels it is best to deal directly with her.

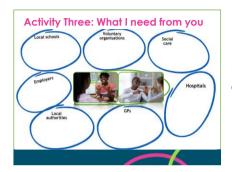
Poor experience:

A participant shared that she has 2 Deaf sisters. Their GP will text on the phone but as her sisters can't read English, they don't know if the message is real or a scam.

She felt lost as to where to go for information and support, and who to contact. She felt it would be best to have a direct face-to-face contact with someone.

She always had good service in Finsbury Park, where she lived for 20 years. She said Redbridge was not good.

Activity 3:



As a Deaf person, what do you need from these services to live well?

Using paper and markers, the group were asked to think about the following services and explain what they would need to live well:

- Local schools
- Voluntary organisations
- Social care
- Hospitals
- GPs
- Local Authority (Council)
- Employers

The group specified again the need for GP's to access interpreters.

When discussing social care, a group of participants agreed all staff should have Level 2 BSL and meetings should predominantly be face-to-face. They also stated the importance of staff being patient, engaging with good eye contact, and not to cover their mouth or turn away when speaking to a Deaf person (e.g., deaf awareness training)

A participant suggested voluntary organisations should have more drop ins where deaf people can go for deaf access support (e.g., help understanding letters, making phone calls etc) – similar service to a Citizen's Advice Bureau.

Participants were informed also of a new Deaf Club Wednesday afternoons Suvai Café.

Activity 4:



Imagine priorities

Prompt: How do we measure for good services? What does success look like?

HWR explained that if organisations had appropriate deaf awareness training and access to interpreters, it would probably mean Deaf people would receive a good service.

Deaf people needed to be included in evaluating all services, whether provided within health or social care. Inclusion would ensure Deaf people were seen as part of the general population and not as a 'problem' to be dealt with.

If a person presents with BSL or other access needs, the response should always be "no problem! Here's an interpreter". There is a need to break down barriers.

The consensus was that there needs to be more deaf awareness training for all front-line staff in health and care organisations immediately.

In the future, more training opportunities for staff to study basic BSL training where their role is customer facing. Participants saw their 'ideal' as a smooth service without having to worry how they would communicate.

Patient and user records should be clearly marked as BSL user and all interpreter services should be part of the appointment/contact process. This should also include parents or carer where they are Deaf (and not the patient); one parent mentioned they have had to request this every time her son has an appointment.

Services should never rely on family or friends as the main interpreter at appointments (however, participants understood the need when there is an emergency).

There should be text compatible numbers for Deaf patients. One patient received text instructions which were unclear and had no way of clarifying quickly. Equipment and connections should be tested regularly.

What happens next? Survey and consultation ends on Thursday 31st August. Responses will be entered into the consultation feedback. You can still complete the full survey online: Welcome to the Bia Conversation in north east London (alchemer.eu) To provide your feedback in an accessible way, email: nelondonicb.nelcommunications@nbs.net

What happens next?

HWR explained the consultation finishes at the end of August and provided the links to the online full survey for those that wished to complete it.

The report is expected to be presented to the NHS NEL Board in October 2023. Responses from today will be part of those findings.

Participants were invited to share their contact details with HWR if they wished to follow-up on any of the issues discussed within the meeting, or if they were concerned about anything they had heard.

HWR also confirmed that the report would remain anonymous and no person would be identified.

Additional issues brought up:

After the focus group, we were contacted by someone who had attended the meeting with further feedback:

 Local services e.g. plumbers, builders etc are not accessible for BSL users. I was recently overcharged and am being supported to challenge this.

Another person who was unable to attend the meeting emailed in with their experiences and suggestions:

- No checklist or guidelines across NHS to its service providers on what to do if they receive deaf or BSL user clients.
- Has wide ramifications where clients are overlooked:
 - o During covid GP clinics switch to telephone only services
 - Even now some hold telephone only services on certain days
 - o Phone bookings take too long because of 1-hour long queue on phone, so we often walk 10 mins to clinic to book. They would use computers to send text to us with appointment time. If problem with time we have to walk back to clinic to get different time cos can't text back to computer. This clinic (Roding Valley medical centre) is a difficult one when it comes to accessibility.

- Midwifery team also do not look at end to end process when they book in deaf patients. With no checklist, there is nothing to guide or prompt them.
- Antenatal midwives can book interpreters because they have info from booking appointments and can book interpreters ahead of times.
- But once a baby is born, no one knows what to do. I've had no
 interpreter for discharge process for my 1st child, my sister had to step
 in.
- With 2nd child I've had to instruct ward midwife to book interpreters for discharge process, instruct them to book for home visits. I had my 2nd child by c-section but was sent home after just 1 night and they were meant to follow up with a midwife next day. No one turned up because they didn't book an interpreter in advance and there was no one available.
- My daughter ended up having jaundice and I had to take her to triage in middle of covid lockdown.
- If they had a checklist in place the service providers like GPs, midwives etc would have known what to do.
- Barts Health Advocacy team is poorly trained in terms of Deaf Awareness.
- They tried to book me a video interpreter for the birth of my 2nd child. How was I meant to hold or look at a tablet, when having C-section or natural delivery? I also needed my hands free. They told me they asked doctors if video interpreting is ok, but these doctors have never dealt with deaf patients. Doctors said it was okay, but they should have known better not to. They should be asking us, the users, not the doctors.
- Part 6 of Health Act 2022 is meant to reduce inequality, but NHS is contributing to inequality by not providing interpreters on weekends.

- They refuse to pay interpreters weekend rates, but most people charge overtime rates for weekend or evening hours. NHS could set their own weekend rates and they would still be able to find interpreters.
- By not doing so, you are forcing deaf patients to go without interpreters when they need someone. Health issues don't operate within 9 to 5pm Mon to Fri.
- For my 1st child's discharge process, I tried looking for interpreters myself since midwives didn't think to book one ahead of time. But I couldn't get anyone to come because it was Saturday and NHS refused to pay weekend rates and had to ask my sister to step in.
- Same issue with NHS parent workshops, I had to beg interpreter friends to take the job at weekday rates. Otherwise, I would be forced to use annual leave for weekday workshops and I was trying to save my annual leave for my baby.
- No hearing people have to deal with this, so this is a systematic discrimination on deaf people by NHS.

Acknowledgements

Healthwatch Redbridge would like to thank the participants who attended the focus group session and engaged with the facilitator and other support staff.

Making our meetings accessible meetings is extremely important, and we would like to thank the BSL interpreters for their support and enthusiastic involvement, particularly with the additional 1:1 support provided at the end of the meeting.

We were also very grateful for the support from Nicky Summers (note taking), Marlene Daniels-Whittle (additional BSL support and advice), and Donna Young (admin, photographer, and Girl Friday!) who all helped support the event and ensure it delivered the required aim of ensuring everyone's voice was heard.