

Hands that Speak: **Exploring the Lived Experiences** **of Deaf people.**



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About Healthwatch

STATUTORY REQUIREMENTS of a LOCAL HEALTHWATCH

1. To obtain the views of Luton residents on health and care service, to help shape the delivery and improve the quality of designing and commissioning services.
2. To make recommendations to service providers and commissioners in developing, designing, shaping, and improving the quality-of-service delivery
3. To support the involvement of Luton residents in the designing and commissioning of local services
4. Provide information and advice to inform Luton residents on choices available to them.
5. To escalate findings to local commissioners, providers and nationally to Healthwatch England along with recommendations for service change.

Healthwatch Luton is the local champion for people using health and social care services across Luton. We promote choice and influence the provision of high-quality health, social care, and wellbeing services for all in our community.

Healthwatch Luton (HWL) has significant statutory powers to ensure that the voices of local people are heard and acted upon by those who commission, deliver, and regulate health and care services. HWL engages with all parts of Luton's diverse population to ensure that a broad range of experiences and views are considered, understood, and reflected in decisions about care. Our work is rooted in strong community connections and grounded in the real-life experiences of the people we serve.

Healthwatch Luton is part of the wider Healthwatch network across England, one of three local Healthwatch organisations in Bedfordshire. We belong to a national network supported by Healthwatch England, which provides guidance and oversight to ensure local Healthwatch work consistently and effectively in each of the 152 local authority areas in England.

As the only independent body focused entirely on people's experiences of health and social care, our role is to make sure that these services—and the decisions surrounding them—are shaped by the people who use them. At Healthwatch Luton, we believe that everyone's voice matters and should be at the heart of care.

Healthwatch Luton Case Study

How do we capture insights?

Healthwatch Luton exists to listen to the voices of local people about health and social care. We gather these views in many ways: by speaking with residents at community events, hearing from them directly on our website (www.healthwatchluton.co.uk), and through conversations by telephone or in person.

This case study tells the story of Rosie, a Deaf resident of Luton, who spoke about her experiences – and those of her partner, Jacob, who is also Deaf – when using health and social care services. For confidentiality, their names have been changed. Rosie lives in Luton, while Jacob lived in London. Jacob was formally registered as Deaf/Deafened/Hard of Hearing with his local authority under Section 29 of the National Assistance Act 1948.

What is Deafness/ Hearing impaired?

People experience different levels of hearing ability. Some may have a hearing impairment or hearing loss, while others identify as Deaf. For instance, people with mild hearing loss may struggle to follow speech in certain situations, while those with moderate deafness may require a hearing aid. Individuals who are profoundly Deaf may rely on lipreading or use British Sign Language (BSL) as their primary means of communication. Many people also choose to use BSL to support or enhance their communication.

The environment can play a significant role in communication. Noisy spaces or poor lighting can make it harder to hear speech or see visual cues such as lip movements and signing.

The charity **Sense** explains: “Deafness or hearing loss is a difficulty hearing or recognising sounds. Hearing loss happens when a part of the ear or hearing system doesn’t work properly. This can be temporary or permanent. There are different levels of hearing loss depending on how loud sounds need to be for you to hear them. There may also be some sounds that you hear better or worse than others. For example, you can be partially deaf (able to hear some sounds), or profoundly deaf (very little or no hearing).”

How does being deaf impact your life?

Deafness can affect many areas of daily life, particularly communication, which may sometimes lead to isolation. Accessing health and social care services highlights the importance of providing the right support at the right time. In health or social care settings, a lack of accessible communication can result in social withdrawal, where a person feels excluded because they cannot engage with those around them. It is essential that professionals use an individual's preferred method of communication to ensure appropriate care and to reduce feelings of isolation.

The physical environment also plays a crucial role in communication. For example, someone who lipreads may struggle in dimly lit spaces, while those with partial hearing loss or who use hearing aids may find it difficult to follow conversations in noisy settings. Poor communication in care environments not only affects the quality of care provided but can also cause significant stress for the individual and their family. This stress may have wider consequences, influencing both emotional wellbeing and physical health.

What support do you have?

Jacob and Rosie both experience challenges with communication and use British Sign Language (BSL) as their primary language. Jacob has a communication support worker who understands BSL. However, in health and social care appointments, including hospital admissions, a qualified BSL interpreter should always be provided.

Rosie can lipread if a professional faces her and speaks slowly, but this becomes difficult when medical terms are used or when speech is too fast. Interpreters are available free of charge within the National Health Service (NHS) and can be requested for GP appointments, hospital visits, optician appointments, or inpatient care. To be fully supported, both Rosie and Jacob require BSL interpreters so that they can clearly explain their needs and fully understand diagnoses and treatment. Without this support, their health and wellbeing may be at risk.

Within Luton, the Deaf community currently has no formal social care support groups. However, members have created an online Facebook group where they connect with and support each other.

What have your experiences been like with health and social care services?

Both Rosie and Jacob described frequent difficulties when accessing health and social care. A common issue was the lack of preparation for appointments. Professionals often failed to review medical histories beforehand and, in some cases, did not arrange a British Sign Language (BSL) interpreter. On occasions, staff even decided unilaterally that an interpreter was not required.

Jacob also reported situations where unqualified individuals – such as his community support worker or Rosie herself – were expected to act as interpreters during medical appointments. This placed considerable stress on those involved, as they were not trained to accurately interpret complex medical information, including diagnoses. Such practices risk miscommunication and increase anxiety for everyone present.

Rosie expressed deep frustration and distress over Jacob's experiences in hospital, where staff often did not attempt to communicate with him directly. Instead, communication was channelled through her, leaving Jacob isolated and excluded. This not only undermined his independence but also left both Rosie and Jacob without the appropriate support they needed.

- The Equality Act requires health and care settings to make reasonable adjustments. However, health professionals often fail to do so, particularly by not arranging a British Sign Language (BSL) interpreter or providing suitable alternatives.

The **NHS Jack-in-a-Box campaign** was designed to encourage people to visit their GP if they had symptoms that worried them, particularly those linked to cancer. In the advert, a man carries a jack-in-a-box, symbolising the anxiety he feels about his health. For many Deaf people, this metaphor resonates strongly: living with constant uncertainty, barriers, and anxiety when seeking healthcare.

During the COVID-19 pandemic, the absence of a British Sign Language (BSL) interpreter at government health briefings left the Deaf community feeling abandoned, isolated, and unsupported.

Sadly, Jacob, who was Deaf, passed away due to a lack of appropriate care and failure by professionals to meet his individual needs. This loss

destroyed Rosie and Jacob's hopes of marrying and building a life together.

Where, then, were the **Accessible Information Standards** in these campaigns? This legal requirement ensures that all NHS and publicly funded adult social care providers meet the communication needs of patients, including Deaf people who use BSL. Under the Equality Act, information must be accessible to all. This includes providing BSL interpretation, subtitles, or other accessible formats to ensure that essential information is understood by everyone.

Jacob's hospital letters often stated that an interpreter could be provided, but this support never materialised. As a result, Jacob relied on friends to accompany him to hospital appointments, since without an interpreter he could neither communicate his needs nor fully understand his diagnosis or treatment.

What has worked well?

- When a qualified BSL interpreter is booked, communication is effective and individual needs are properly met.
- When health professionals review a patient's notes and make reasonable adjustments, care is more accessible and inclusive.

What hasn't worked well?

- Rosie and Jacob were told that BSL interpreters would be provided at vaccination centres. Rosie even travelled to London after being assured there would be an interpreter and information displayed on a screen. However, when she arrived, ***there was no interpreter***, and the only text shown was her name.
- At vaccination centres, ***no BSL interpreters were available*** even when Deaf patients were booked for appointments. As a result, Jacob was unable to ask questions about his medical history. ***The absence of interpretation created a language barrier***, as Jacob used BSL to communicate.
- After receiving his second vaccine, Jacob began to experience severe stomach pains. His GP did not arrange a BSL interpreter, nor did the hospital when he was admitted. Nobody listened to his distress or concerns. Jacob described stomach pain, pleuritic chest pain, and pain in his legs. Blood tests were taken, his medication was reviewed, and he was discharged. Without an interpreter, Jacob could not understand what was being communicated about his condition.
- Jacob's hospital discharge notes stated: "Jacob is aware that any new extreme chest pain with breathlessness or excessive bleeding from any source

requires urgent medical review. They recommend routine blood tests in 2–4 weeks to ensure patient safety. Appointment made for follow-up in 3 months with the respiratory team to check for any indication of heart strain and to review length of anticoagulation. GP to review.” However, how could Jacob have been aware of this when he was Deaf and ***no interpreter was provided to explain the instructions?***

- Jacob returned to hospital several times in December 2021 and January 2022. He was in constant pain in his legs, particularly when walking, and continued to complain of stomach pain. Each time, he was turned away and told to see his GP. Jacob tried to explain that he felt seriously unwell and feared heart problems, but this emergency situation was not taken seriously. ***Again, no BSL interpreter was provided.***

Why is there not a RED FLAG that states Jacob needs an interpreter!

In July 2022, Jacob collapsed. A neighbour tried to help him stand, but he was in too much pain. Rosie also attempted to assist, but Jacob’s pain was severe. The neighbour called an ambulance, and at Rosie’s request informed them that Jacob was Deaf and had a heart condition. Rosie does not know whether this information was recorded. Jacob was rushed to Accident and Emergency at the local hospital. On arrival, no staff initially came to check on him. Eventually, Rosie stopped a nurse to ask for pain relief. The nurse agreed and administered painkillers to Jacob through a cannula. After further waiting, Rosie and Jacob were told he would need to be transferred as an emergency to another hospital. At 19:00, an ambulance was finally found to take them there.

Where are 999 and 111 in relation to BSL?

At the hospital, Jacob waited 45 minutes in the ambulance while in severe pain and distress. The paramedic realised the supply of pain relief was empty, but explained she could not leave the ambulance to get more. Jacob became increasingly distressed, and Rosie was deeply worried for him.

When they were finally moved into the hospital, Jacob was again left alone without nurses or doctors present. Rosie tried to comfort him, but he was in considerable pain and began to withdraw. She wanted to find medical staff, but felt unable to leave Jacob for long, fearing he would be seen without her there.

When Jacob was eventually examined, ***Rosie had to act as his interpreter.***

Although Deaf herself, she was forced into this role while doctors and nurses surrounded Jacob’s bed, asking urgent questions. Jacob’s eyes filled with tears as

Rosie struggled to keep up with the rapid exchanges. A doctor then decided Jacob required a clot-busting drug for four hours and would need to be placed in a coma for four days. For Rosie, this was a traumatic experience. Most families would have been asked to leave the room at such a moment, but because she was used as a BSL interpreter, **Rosie was expected to interpret medical information** while simultaneously absorbing devastating news. No consideration was given to the impact on her emotional or mental health.

Rosie last saw Jacob in the hospital corridor, near the lift, as he was taken for surgery. They looked at one another and said, "I love you." With a nod of their heads, they silently agreed to be there for one another, whatever the outcome.

The consultant claimed Jacob understood the consent form he signed, with Rosie listed as next of kin. Rosie strongly disputes this, explaining that Jacob believed he was agreeing to a lifesaving operation. **Without a BSL interpreter, true informed consent was impossible.**

Jacob was placed in a coma and later his life support was withdrawn. Rosie recalls wanting to ask why he was sweating while unconscious, and why her and her daughter's requests for pain relief were ignored. She also questioned why staff in the Intensive Therapy Unit (ITU) **relied on hand gestures rather than providing a BSL interpreter.**

Rosie was eventually told that Jacob had massive blood clots in his stomach, liver and kidneys. He had received two doses of the AstraZeneca vaccine and had a medical history that included atrial fibrillation, hypertension, two stents following heart attacks at the age of 35, deep vein thrombosis, and ongoing leg pain.

Rosie asked: Did Jacob die because he was Deaf? He could not communicate how he was feeling, and professionals failed to build the full picture of his condition. **The Accessible Information Standard, which should have protected him as a Deaf patient, was not upheld.**

Medical notes recorded that Jacob should be referred to the Coroner because of how suddenly he deteriorated. Rosie disputes this, as Jacob had been unwell for some time, had visited four hospitals, called 999, and seen his GP during this period.

What could be improved?

Greater awareness and accessibility are essential when Deaf people access health and social care. Staff must be familiar with the Equality Act, which requires care settings to make reasonable adjustments. For Rosie and Jacob, this meant

the consistent provision of a qualified British Sign Language (BSL) interpreter for all appointments, conversations, and hospital consultations. Yet their experience shows that health professionals frequently failed to provide this, or even dismissed their need for an interpreter. Rosie recalls being told by her GP: *"You do not need an interpreter!"* This decision should never be made by professionals. There should be an **opt-out system**, where interpreters are arranged by default unless the patient chooses otherwise.

Decisions about communication must always rest with the patient, as only they know their own abilities. This information should be clearly documented in their medical records. Communication needs should be flagged prominently at the start of patient notes, and professionals should review these before consultations. A **red-flag system**, shared across health and social care services, could identify patients with communication needs and ensure that interpreters are automatically booked.

Professionals should also recognise the emotional impact of using family members as interpreters. Relatives are forced to hear difficult diagnoses and then convey them to their loved ones – an unfair and distressing responsibility.

Finally, all health and social care settings should ensure that **registered BSL interpreters** are used for communication and consultation. Communication support workers, however skilled, are not trained or qualified to interpret complex medical information safely and accurately.

NHS England's **Accessible Information Standard (AIS)** is a legal requirement for all organisations providing NHS or publicly funded adult social care services. Its purpose is to ensure that individuals with disabilities, impairments, or sensory loss receive information in a format they can understand.

Key aspects of the AIS include:

- **Identification:** Services must identify and record the information and communication needs of individuals.
- **Flagging and Sharing:** These needs should be flagged and shared across services to ensure continuity of care.
- **Meeting Needs:** Organizations must take steps to meet these needs effectively.
- **Reviewing:** [Regular reviews should be conducted to ensure that the information provided remains accessible and relevant.](#)

Healthwatch Luton spoke with a British Sign Language (BSL) interpreter who had worked with Rosie. She explained that Rosie's experiences are common across the Deaf community. While some hospitals employ BSL interpreters directly and others provide online translation or interpretation services, it remains far too common for family members or carers to be used instead.

Good practice would be to ensure that a BSL interpreter is automatically booked at the point when an appointment is made. Where possible, using the same interpreter consistently is also beneficial. In Rosie's case, the interpreter had supported her on several occasions, which meant she was already familiar with Rosie's history. This avoided the need for Rosie to repeatedly retell her story and allowed them to build a relationship, creating a deeper understanding of her communication needs and preferences.

In 2024, **Healthwatch Luton** carried out a survey of translation and interpretation services on behalf of the Integrated Care Board (ICB). The findings showed that while most General Practitioners were aware of the services available, awareness was much lower among other primary care providers such as opticians and pharmacists.

At the time of the survey, the translation and interpretation service available to primary care was DA Languages, a UK-based provider specialising in healthcare, education, legal, and local government sectors. Their services include face-to-face interpreters for patient consultations, telephone and video interpreting for urgent or remote needs, and document translation such as patient information, consent forms, and medical reports. They also provide British Sign Language (BSL) interpreting, with particular expertise in medical terminology.

For secondary care, services such as Bedfordshire Hospital and East London Foundation Trust were using The Language Shop, another UK-based provider specialising in healthcare, legal, and public sector interpretation. Their services include face-to-face interpreting for patient consultations, on-demand telephone interpreting, video interpreting for remote appointments, and both spoken language and BSL interpreting. They also offer translation services.

A number of themes emerged from the survey. Many practices were noted for using translation services effectively, and some offered advance booking of interpreters. However, availability – particularly of BSL interpreters – remained inconsistent. Practices also reported difficulties with last-minute bookings, especially when face-to-face interpreters were required. Coordination was

another significant challenge, with some settings struggling to arrange services in a timely way.

The physical environment of healthcare settings also played a role in accessibility. Good lighting and quiet spaces were observed to make a positive difference to the experience of Deaf patients, particularly those who rely on lipreading or BSL. Another issue raised was the visibility of services. Clearer signage and information about translation and interpretation provision would help ensure that patients are aware of their rights and feel confident in requesting support.

Overall, the survey findings highlight the importance of raising awareness among healthcare providers about the resources available, as well as ensuring that staff are trained and confident in using them. Improved coordination, greater consistency in BSL provision, and a stronger focus on accessibility are essential to meet the needs of patients.

From Rosie: Future Considerations and Areas for Improvement

- **Professional Development:** How can health professionals and BSL interpreters gain more knowledge to improve client care, particularly by developing greater awareness of Deaf community culture, enhancing communication skills, adhering to ethical standards, and actively seeking feedback from clients?
- **Regulation and Accountability:** The National Register of Communication Professionals working with Deaf and Deafblind People (NRCPD) primarily covers BSL interpreters but not all Community Support Workers (CSWs). How can this gap be addressed to ensure that all professionals providing interpretation support are held to the same standards of accountability and quality?
- **Reporting Concerns:** What measures can be introduced to enable BSL interpreters to raise concerns about colleagues – including other interpreters or CSWs acting as interpreters – in a safe, confidential, and constructive way?

Healthwatch Luton would like to thank Rosie for generously sharing her experiences. She feels very strongly that improvements must be made so that Deaf individuals and the wider Deaf community can access health and social care without facing the barriers she and Jacob encountered.

Through better communication and greater awareness, Rosie hopes that others will not have to endure the same struggles.

Redress

Rosie sought redress through the hospitals, making a complaint about the lack of BSL interpretation services, through the Integrated Care Board, raising the issues, concerns and experiences Jacob had, which the Deaf community experience regularly, and with the coroner, would Jacob's situation had been different if he could communicate with the professionals and they could communicate with him.

Recommendations

Based on the findings, the following recommendations are proposed to improve the effectiveness of translation and interpretation services (TIS) across healthcare settings for the Deaf community:

1. Reduce Reliance on Informal Translation Methods

Promote Awareness of Formal Services: Raise awareness among both staff and patients about the availability of formal translation and interpretation services, ensuring staff understand how to access them.

Encourage Use of Professional Services: While informal methods may sometimes be used, staff should be encouraged to rely on professional interpreters to guarantee accuracy, confidentiality, and quality of communication.

2. Improve Availability and Flexibility of Translation Services

Expand Language Options: Ensure translation services consistently include British Sign Language (BSL).

Improve Last-Minute Booking Processes: Develop a more flexible system to accommodate urgent or last-minute needs, especially for face-to-face BSL interpreters. A centralised booking system across departments could improve coordination and reduce delays.

3. Streamline the Interpreter Booking Process

Simplify Booking Systems: Introduce a user-friendly, centralised booking process to make it easier and quicker for staff to arrange interpreters.

Improve Cross-Department Communication: Establish clear systems to ensure interpreter requests are shared effectively between departments, including managing bookings, cancellations, and changes.

4. Improve Accessibility and Visibility of Services

Enhance Signage: Display clear signage in all healthcare settings — including GP practices, pharmacies, and hospitals — to make patients aware that translation and interpretation services are available, and explain how to access them.

Respect Patient Preferences: Offer multiple interpreter options, recognising that some patients may prefer face-to-face interpreters over online or remote services.

Conclusion

Rosie and Jacob's experiences reveal the profound consequences of inadequate communication support within health and social care. Their story illustrates how the absence of qualified British Sign Language (BSL) interpreters, poor preparation by professionals, and limited awareness of Deaf culture can create barriers that place both health outcomes and emotional wellbeing at risk.

The Equality Act and the Accessible Information Standard establish a clear legal duty to provide accessible communication, yet these requirements were not met in Rosie and Jim's case. This failure left Jacob isolated during critical moments of his care and placed an unfair burden on Rosie to interpret, despite her own communication needs. Such experiences are not isolated; they reflect systemic issues that continue to affect many Deaf people.

By implementing the recommendations set out in this report — including improved awareness among professionals, consistent use of registered BSL interpreters, and better coordination of translation and interpretation services — health and social care providers can begin to close these gaps.

This is not only a matter of compliance but of compassion and equity. Jacob's story reminds us of the human cost when services fail to meet communication needs. Rosie's determination to share her experience is a call to action: to ensure that no one else has to endure the same barriers, and that Deaf individuals receive the safe, respectful, and inclusive care they deserve.



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