

See Hear Now

Access to health and wellbeing services for people with sensory impairments and learning disabilities

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What is Healthwatch Lewisham?

Healthwatch Lewisham is one of 152 local Healthwatch organisations that were established throughout England in 2013, under the provisions of the Health and Social Care Act 2012. The dual role of local Healthwatch is to champion the rights of users of health and social care services and to hold the system to account for how well it engages with the public. The remit of Healthwatch is as an independent health and social care organisation, representing the voice of local people and ensure that health and social care services are designed to meet the needs of patients, social care users and carers.

Healthwatch also supports children, young people and adults in Lewisham to have a stronger voice in order to influence how health and social care services are purchased, provided and reviewed within the borough.

Healthwatch Lewisham's core functions are:

1. Gathering the views and experiences of service users, carers, and the wider community,
2. Making people's views known,
3. Involving locals in the commissioning process for health and social care services, and process for their continual scrutiny,
4. Referring providers of concern to Healthwatch England, or the CQC, to investigate,
5. Providing information about which services are available to access and signposting,
6. Collecting views and experiences and communicating them to Healthwatch England,
7. Work with the Health and Wellbeing board in Lewisham on the Joint Strategic Needs Assessment and Joint Health and Wellbeing strategy (which will influence the commissioning process).



Strategic Drivers

This report is the result of a review carried out by Healthwatch Lewisham to provide an insight into the experience of deaf, blind, partially sighted and learning disabled residents when accessing health and wellbeing services.

Following intelligence from NHS England and Lewisham CCG it was evident that there is a lack of engagement with many 'seldom heard' groups, including people with sensory loss and those with learning difficulties.

The data from national research suggest that this is a wider issue, with the Department of Health in England stating that "disabled people, in general, often face unacceptable difficulties when they try to use NHS services" ¹. It is important to stress that disabled people are not a homogenous group and face different issues in relation to access.

Deaf people

According to research one in seven people in the UK are suffer from a learning impairment, most of whom are hard of hearing with approximately 70,000 of the total number being profoundly deaf. ² The latter group use the British Sign Language (BSL) as their preferred language. ³

Greater London Authority reported that deaf people in London experience poorer health than the rest of the population mainly due poor communication, lack of information and difficulties in access to services ^{4,5}.

Learning Disabilities

The 2013 research suggests that there are approximately 1.2 million people who have learning disabilities in England. It also states that people with learning difficulties have a generally shorter life expectancy and poorer health in comparison to the general public. To an extent, this is a result of barriers that people with learning disabilities face when accessing 'timely, appropriate and effective health care' ⁶.

Visual Impairment

We were able to identify very little research on health inequalities and sight loss, however, the Royal National Institute of Blind People (RNIB) argues that there is a strong link between visual impairment and social and economic inequalities including health ⁷.

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- 1 *"Doubly Disabled" Report, 1999 (NHS Executive)*
 - 2 *Middleton A, Niruban A, Girling G, Myint PK. Communicating in a healthcare setting with people who have a hearing loss. BMJ 2010; 341: 726-29*
 - 3 *Ladd P. Understanding Deaf culture—in search of Deafhood. Clevedon: Multilingual Matters, 2003.*
 - 4 https://www.london.gov.uk/sites/default/files/london_assembly_health_committee_-_access_to_health_services_for_deaf_people_-_june_2015_-_updated.pdf
 - 5 <http://www.cydraddoldebhawliaudynol.wales.nhs.uk/sitesplus/documents/1120/Sick%20of%20It%20Report1.pdf>
 - 6 <http://www.options-empowers.org/wp-content/uploads/2013/02/Improving-Health-and-Lives-health-inequalities-and-people-with-learning-disabilities-in-the-UK-annual-report.pdf>
 - 7 http://www.rnib.org.uk/sites/default/files/Health_Inequalities.pdf



Summary of Findings

This report provides a qualitative account of the stories and experiences of disabled people in Lewisham including deaf, people with visual impairments and those with learning difficulties. It explores issues of access to health and wellbeing services.

It was found that many disabled people experience inequalities, such as difficulties in booking a GP appointment, not knowing their eligibility to interpreters and difficulty in accessing health and social care information. It is worth noting however, that there are many shared positive comments and examples of good practice across the borough.

The majority of the participants felt that NHS staff would benefit from disability awareness training and said big improvements could be made by making small adjustments and having a sensitive approach. The communities suggested multiple improvements including making eye contact whilst talking to the deaf people, prompting a blind patient when it's their turn to go to surgery and guiding them to the appointment place.

Other comments related to system improvements: It was suggested to introduce a prompt to alert the staff that access files of any additional communication needs a person might require. Another suggestion was to use modern technology to improve access to interpretation services. Within each theme there were examples of good practice and excellent care which could potentially be used for learning and to drive improvement in services.

For participants from the deaf community, issues related to interpretation were the most critical, with eligibility, difficulties in booking interpreters and cancellation of appointments due to a lack of interpreters, being the other main concerns.

One significant issue raised by all participants was insufficient levels of advocacy services. Participants praised the current services provided, however the remit of current provision is limited and more is required to meet the need within the borough.

It is important to note that this research has been conducted before the formal deadline of 31 July 2016, by which all organisations that provide NHS or publicly funded adult social care, must have fully implemented and conform to the Accessible information Standard.



Methodology

The review focused on gathering qualitative data from a sample of population within three disability groups including deaf, blind, partially sighted and learning disabled people.

It was carried out throughout 2016 (and one engagement in the late 2015) in Lewisham. The evidence was gathered by conducting informal discussion in a group setting asking participants to share their experience of access to services. The groups were supported by appropriate translators and group facilitators.

Research participants

In total we spoke to 57 people from the different communities. The communities we engaged with were:

- Lewisham Deaf Community,
- Lewisham Support Group meeting at South East London Vision - SELVis
- Lewisham Speaking Up, a peer support and advocacy for people with learning disabilities

This report will be shared with the Lewisham Health and Wellbeing Board, participating groups, the Voluntary and Community Sector, the Lewisham Clinical Commissioning Group (CCG), the Care Quality Commission (CQC), NHS England, Healthwatch England, Lewisham Healthier Communities Select Committee, Public Health, Lewisham and Greenwich NHS Trust, Lewisham Council, local advocacy providers, and other relevant Healthwatch Lewisham stakeholders.



Themes: Common issues faced by the participants

Disability Awareness training for NHS staff

It has been found that many participants felt NHS staff need disability awareness training and that little adjustments in the way the staff act would mean patient access to, and journey through NHS services, would be much easier. Participants recognised the training would need to be offered on an ongoing basis due to staff turnaround.

Examples of issues raised from discussions:

- Some blind participants told Healthwatch they often don't know when it's their turn to go to a GP appointment as a result of receptionist forgetting to alert them.
- Another blind person told Healthwatch staff members call them when it's their turn for the appointment, however shortly after they walk away expecting the patients to follow.
- A blind male participant wanted to register at a GP practice and asked for help, however the receptionist refused to help him fill out the form.
- A deaf participant told Healthwatch about doctors who look at a computer during an appointment which means he cannot lip read.
- Another deaf participant said he told his doctor he was deaf, but he continued talking to him.
- A community nurse left a deaf patient a leaflet with information how to contact the service but it only had a phone number on it.

- Moorfields eye hospital operate a ticket system to access their pharmacy which creates a barrier for many blind people.
- A participant with a learning disability complained that doctors and nurses don't talk to him directly.

Some participants had very positive experiences of staff due to their awareness of disabilities, their sensitive approach and responsiveness toward the issues of disabled people. A few deaf participants praised The Jenner Practice and Lee Road Surgery for being very compassionate, deaf aware and a 'model of excellence'. Wells Park Practice was also praised for being supportive to patients and Queens Road Surgery was praised for a caring doctor at the practice who 'gives enough time to patients' and 'listens' to their concerns.

Lewisham Hospital's Dermatology and podiatry department is highly regarded for being helpful without being patronising and supportive towards visually impaired people.

The majority of participants with learning disabilities were happy with NHS staff. The details of the findings are outlined in a separate theme below.

Many participants felt that communicating information in a clear way and ensuring understanding are important aspects of disability awareness, especially in relation to deaf patients. Deaf focus group participants told Healthwatch medical test results were not always clear to deaf participants even with the help of an interpreter. Our findings echo a national study that suggests that 'one-third of deaf people left GP consultations uncertain about their condition and a third were unclear about how to take medication or had actually taken the wrong dosage.'⁸ It seems that the role of those who communicate the message



to a deaf person is not only to translate the medical vocabulary directly but also to explain what it means in a plain language and ensure that the patient clearly understands the message.

Staff communication and a caring approach

Staff communication, attitude and a caring approach are very important for participants with learning disabilities. The research however points out that people have various experiences with some participants praising staff for being nice and friendly and for explaining the procedures and examinations. Alternatively other people felt they weren't treated with dignity and respect.

Positive experiences from people with a learning disability and their carers.

- 'They provide more information to the patient.'
- 'Doctor talks to me and asks how I am.'
- 'Happy, because Doctor is friendly.'
- 'Good service in A&E. The staff introduce themselves to you and tell you what they will be doing.'
- 'It was alright; the information the GP gave me helped me relax.'
- 'My GP is a good listener.'
- 'Nurses are good at telling you about appointments.'

Negative experiences from people with a learning disability and their carers.

- 'They don't stick to what they say.'
- 'Sometimes the nurses are not cooperative or flexible.'
- 'Sometimes the nurses and doctors don't talk to you (the patient).'
- 'Sometimes the nurses are not sensitive.'
- 'They give you a time (for an appointment), then you have to wait longer, and they don't apologise.'

Booking system recognising patients' disability

Research participants felt frustrated when booking an appointment and when talking to receptionists. They wished the system acknowledged their disability and alerted the receptionists to their communication needs, including interpretation service's requirements. This would help to avoid many unnecessary frustrations and support patients to have easier access to services. Our findings align with the Accessible Information Standard recommendations that suggest that 'reasonable adjustments' can be made in areas of technology, systems and people's behaviour, in order to remove access barriers for those who have different communication needs.⁹

8 *Deafness might damage your health, The Lancet, 2012*

9 <https://www.england.nhs.uk/wp-content/uploads/2015/07/access-info-spec-fin.pdf>



Examples put forward by some of the participants:

- Some of the blind participants complained about not being recognised as blind despite using a white cane and being requested to do things that they cannot do such as self-register at a computer.
- Receptionists do not always remember to alert people who are blind and people need to enquire when their turn is.
- Deaf participants often need to book an interpreter when they book a GP appointment, however they are not always sure this has been arranged.

Accessibility Issues

Both deaf and blind participants expressed difficulties in accessing health and social care information in a suitable format. This reflects the national research that states deaf people have bad experiences of health and social care as a result of communication barriers.¹⁰

Deaf participants felt it is increasingly hard to find an email address to contact appropriate services, and partially sighted participants said services don't provide information in large print.

The issue of information accessibility extends to other areas including: test results such as HIV, medicine leaflets and even national news such as last year's global news about Zika virus. The lack of access to general information and difficulties in communication increase health inequalities for deaf people.

The research highlighted the fact that people with sensory disabilities and learning disabilities have different communication issues and often are from different countries. It was pointed out that not everyone understands BSL and speak or understands English which makes communication difficult.

Examples of what deaf people told us:

- An elderly deaf man with multiple health issues told Healthwatch a nurse who visits him at home left him a leaflet with contact details to the service in case he needed anything. The leaflet had only a phone number on it and there was no alternative contact details. He commented 'the nurses sometimes come and sometimes don't. How can I contact them if I need anything?'
- A deaf man expressed his concern that 'Deaf people say: 'I understand', but they don't always. They do understand, half understand, don't understand. You think you know, you half know, you don't know. It's vague. There is a danger of misdiagnosis.'
- Another participant said 'HIV results are not always clear. People don't understand.'

¹⁰ http://www.ruh.nhs.uk/documents/The_Lancet-Deafness_Might_Damage_Your_Health.pdf



Interpreters booking and eligibility

The research uncovered that deaf people in Lewisham face difficulties with interpreting services. There was a lack of clarity around whether accessing an interpreter was a patient's responsibility or if it should be arranged by a provider. We also found that when deaf people visit various services they simply don't know how to book interpreters. Our findings reflected a UK study stating that BSL/English interpreters were present at only 17% of GP appointments.¹¹

Examples of what deaf people said:

- A male deaf person told Healthwatch 'I go to the optician every two years without an interpreter. They say it's [providing an interpreter] nothing to do with me. I once went with an interpreter and realised that there was so much information that I have missed on the previous visits. As a result my eyes got worse.'
- A male participant told Healthwatch he doesn't know how to book interpreters at various NHS services: 'It doesn't say anywhere. We don't know.'

Waiting times for an interpreter

It was found that deaf participants are frustrated with waiting times when they book an interpreter as well as the amount of time it takes for interpreters to turn up at booked appointments. It has been reported that some participants experience long waiting times (approximately an hour) for an interpreter to turn up despite the appointment having been booked for a particular time in advance.

Examples of what deaf people said:

- 'When we're unwell we want to go and see a doctor just like anyone else. We need to wait so much longer.'
- '...What are we waiting for? This has been arranged in advance. It's very frustrating. It happens time and time again.'
- 'We go to the opticians and dentist. We wait for one month but there are no interpreters.'
- 'We are in the 21st century and the technology has advanced. Why it is still so difficult for deaf people to access services?'

¹¹ Reeves D, Kokoruwe B, Dobbins J, Newton V. Access to primary care and accident and emergency services for deaf people in the North West. 2004.



Risk of using family members as interpreters

Deaf people were concerned about using family members as interpreters and cited the potential risks associated with it such as confidentiality and translation accuracy. Some participants gave examples of instances where family members didn't correctly translate issues which resulted in treatment delay and risks to patients.

Discharge

The research found that blind and/or partially sighted people need some adjustment made in relation to discharge from hospital and access to aftercare. Participants who gave positive feedback praised their consultants for being supportive and making extra arrangements during their hospital stay which meant their treatment went smoothly. This also raised an issue for the need of advocacy if their care was not adequately arranged.

Case study:

A partially blind participant was admitted to hospital for a surgery on her eye. She was asked to go back home and come back the next day to the hospital as an outpatient. Being fully blind after the operation meant she was unable to travel home and come back to hospital the next day. As a former NHS staff she was assertive enough to insist she stayed in hospital longer to access the aftercare she needed. As a result, she was able to undergo the procedure and experience good results and care.

Advocacy

Participants of all three focus groups reiterated the importance of advocacy services and support groups and pointed out that the current services such as 'Contact Point' for deaf people, run by the Lewisham Council and Mental Health advocacy at SLAM, are useful however they provide a limited service. Current services are limited and participants feel there is a need for advocates who could help them navigate the system and support them when things don't go to plan.

The research identified that both family and paid carers play an important role providing advocacy support for people with learning disabilities and that they 'deal with the worries or concerns of people' in relation to their health and wellbeing. They also act as emotional support and coordinate the care to solve any issues that may arise.

Text alerts

Participants in all three groups valued text alerts about NHS appointments, however not all participants had access to this service. Those who did could translate the text into an accessible format. Participants commented that it was an excellent use of technology that helped to remind them about the upcoming appointments.



Fear of an emergency

Many deaf participants, especially those living independently, feared finding themselves in an emergency situation or needing to see a medical professional urgently. The research uncovered that almost half of the participants were not aware of what to do in case of an urgent need or an emergency. Some were not sure if they could access an interpreter in case they needed to book an urgent appointment. Equally, only half of the focus group participants were aware of the 111 and/or 999 service for deaf people. Participants shared their mixed experience of the 'on screen' translation service available at A&E departments at Lewisham, Kings and other local hospitals. Some deaf participants worried about a scenario where they need to be admitted into the A&E department but were unable to communicate with staff. A national study confirmed our findings, recording that only 7% of A&E consultations were conducted using English/BSL interpreters.¹²

Service location

Services being local was an important issue for participants with learning difficulties. This enabled a greater independence and increased accessibility. Home visits were also a valued service.

Participant with learning disabilities said:

'It's near, so I get to go on my own.'

Discrimination due to disability

Many carers of participants with learning difficulties worried that services discriminate against patients with learning disabilities. This was reflected in a comment by a participant who said: 'Sometimes the nurses in the hospital neglect the patient.'

However it is important to note that the majority of the comments from participants with learning disabilities were positive, praising NHS services and staff. A good example of caring staff and good quality care was when a participant was 'scared and anxious' during an MRI scan. The staff arranged it to be done at another date, helping the patient with the anxiety issue. Another participant shared a story of her phlebotomy test and confessed she is scared of needles. She confirmed that the staff were understanding and talked her through the procedure to help her overcome her fear.

¹² Reeves D, Kokoruwe B, Dobbins J, Newton V. Access to primary care and accident and emergency services for deaf people in the North West. Manchester: National Health Service Executive North West Research and Development Directorate, 2004.



Conclusion and Recommendations

As a result of our findings from our engagement with disabled people in Lewisham, Healthwatch sets out the following recommendations to help improve access to services for disabled people.

Providers and Commissioners

- Ensure disability awareness training for 'front-line' staff and implement simple measures to ensure that communication needs are met.
- Widen the availability of available technology such as video interpreting and text alerts.
- Clarify BSL interpretation eligibility and ensure patients have access to relevant information on how to book BSL interpreters.
- Increase availability of interpreters for deaf people.
- Install visual displays and voice alerts in reception areas to enable the deaf and people with visual impairments, to know when it is their turn for an appointment. Alternatively, train relevant staff to alert disabled patients of their appointment in an appropriate way.
- Enable 'reasonable adjustments' to ensure equality of access for disabled people.
- Ensure that all written communication directed to patients is written in accessible formats. Provide all possible contact details to ensure both deaf and blind people can contact your service. Ensure contact information (including emails) is easily found.
- Ensure the sustainability of the current advocacy services and increase the service provision to meet the demand and need.
- GPs and Consultants to make appropriate adjustments to treatment processes and procedures, including discharge, to ensure

disabled people have an equitable experience of services.

- Ensure there is a system in place that alerts health and social care staff of the patients' disability and their additional needs.
- Engage with disabled people in the development of the service to allow for the coproduction of an efficient and effective health service.

Accessible Information standard

Healthwatch Lewisham hopes that the information and recommendations in this report will help providers and commissioners in their implementation of the Accessible Information Standards locally.

Definition:

'Accessible Information Standard' – directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents, where those needs relate to a disability, impairment or sensory loss.

The Standard applies to service providers across the NHS and adult social care system, and effective implementation will require such organisations to make changes to policy, procedure, human behaviour and, where applicable, electronic systems.'

NHS England,

Accessible Information: Specification, 2015



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