

Deaf people & the Accessible Information Standard: how well are local organisations doing?

Introduction

Since August 2016, all organisations providing NHS care or publicly-funded adult social care are legally required to follow the Accessible Information Standard (AIS).

The Standard sets out a consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of people with a disability, impairment or sensory loss. This includes patients, service users, carers and parents.

The AIS was introduced to “make sure that people who have a disability, impairment or sensory loss are provided with **information that they can easily read or understand** and with **support so they can communicate effectively** with health and social care services.”

What we did

We wanted to find out how effectively this new legal requirement was being met in relation to Deaf service users. So Deaf Positives Action used a Community Research Fund award from Healthwatch Wokingham to conduct:

- 1) **A mystery shopping exercise** in which Deaf 'mystery shopper' volunteers visited a total of 34 different NHS and social care settings serving Wokingham Borough residents. Venues included a range of GP and dental practices, high street opticians, NHS walk-in centres, and the local Council.
- 2) **A small-scale survey using an online questionnaire** sent to 16 local Deaf people asking about their experiences of using health and care services over a six-month period (11 responses).
- 3) **A focus group** with three Deaf service users from their client base, to capture individual first-hand accounts of their experiences and specific examples.

Going to the dentist - Brodie

At the dentist, Brodie only understands them via lip reading... a little. Brodie just wishes that they would book an interpreter for appointments so then [s/he] would be able to understand more.

At one appointment they did root canal work. Brodie was not prepared for it, and had not taken enough time off work. It hurt a lot and Brodie could not tell them.

Thirty-four NHS and social services organisations in the Wokingham Borough were visited by independent Deaf, BSL users, Lipreaders, and Cochlear users, varying in age from 25 to 87. The organisations we visited were:

- Brookside Surgery
- Burma Hills Surgery
- Finchamstead Surgery
- New Wokingham Road Surgery
- Parkside Family Practice
- Swallow Medical Practice
- Wokingham Medical Centre
- Tywford Surgery
- Wargrave Surgery
- Wilderness Road Surgery
- Woodley Centre Surgery
- Woosehill Surgery
- Bracknell Urgent Care Centre
- Reading Walk-in Care Centre
- Minor injuries unit Thatcham
- Shinfield Dental Centre
- Loddon Vale Dental Practice
- Wokingham Dental Clinic
- Berkshire Dental Care
- Bean Oak Dental Care
- Puresmile
- Toothbooth
- Winnersh Dental Practice
- Crowthorne
- Peach Dental Care
- Boots
- Specsavers
- Leightons Opticians
- Stephen Aberly & Partners
- The Eye People
- Vision Express
- Optalis
- Wokingham Council
- Loddon Vale Practice

Our volunteers visited the venues on different times at the end of 2017. We handed them a questionnaire and asked them to answer the following questions. Responses were recorded using Survey Monkey.

Trying to book communication support at my GP - Alex's story (Part 1)

Several months before, Alex had handed in a letter requesting a lipspeaker for all appointments, yet still had to request one when it came to booking an appointment. He had to explain his requirements all over again.

The receptionist informed Alex that lipspeakers had to be booked ten days in advance, so the appointment was scheduled accordingly.

Ten days later Alex arrived at the surgery for his appointment, only to find the lipspeaker had not been booked.

What we learnt

The findings showed that **the extent to which local health and care organisations are complying with the Accessible Information Standard in relation to Deaf people is significantly limited.**

Most staff were friendly and welcoming towards our Deaf mystery shoppers. Yet organisations in general seemed ill-equipped to meet their information and communication needs.

The **mystery shopping exercise** revealed four key deficiencies:

- i) Most organisations offered **no communication support** (e.g. interpreter provision) for care appointments.
- ii) Many organisations and/or members of their staff showed **poor awareness** about communication support and their responsibilities under the AIS.
- iii) **None of the organisations used BSL** (British Sign Language) to communicate on their websites or TV screens - there was no 'in-vision' signing.
- iv) **More/better visual information was needed** (e.g. signs, subtitles and alerts) for Deaf and hard of hearing people at local health and care venues

My GP appointment without a lipspeaker - Alex's story (Part 2)

Alex took the decision to go ahead with the appointment, having already waited ten days for it. Alex described the feeling of having to "brace myself" to walk into an appointment without communication support.

During the appointment, Alex did not 100% understand what GP had said. Alex pretended to understand, and left unclear about what was wrong. Alex felt unable ask the receptionist what to do - "there was no point".

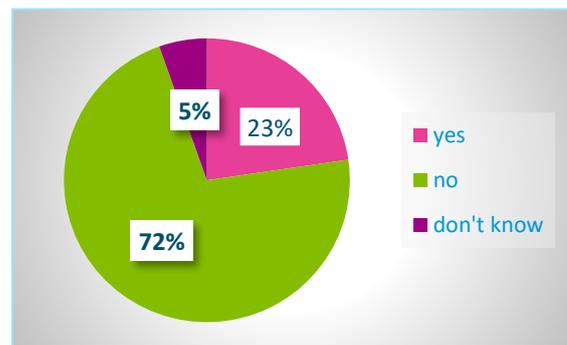
Do they provide communication support?

The figures show that 23% of the services we visited provided 'communication support'.

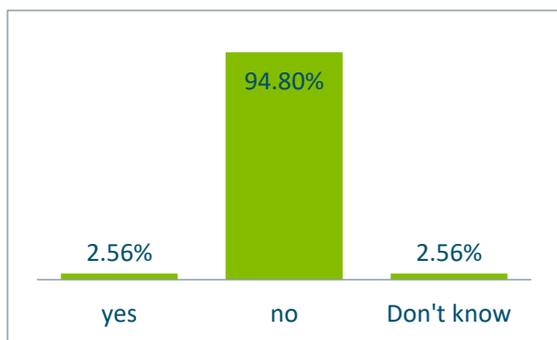
However, when we investigated further with our volunteers, they explained that the staff had handed leaflets about 'Community Navigators' which is not a provision of communication.

Two organisations suggested the 'hearing loop' was a method of 'communication'. One organisation refused to provide communication, and one organisation asked if they could 'bring a friend to communicate on the day'. The figure of 72% does reflect with our clients that we work with, who are not offered communication support at appointments.

On a positive note, one organisation contacted Deaf Positives Action after being visited by our volunteer. They asked us how to work with Deaf people, what the legal obligation was for a company providing NHS services and how they can improve their services.



Is their website accessible for Deaf people and include 'in-vision' signing?



Unfortunately, none of the websites include 'in-vision' signing, which was a suggestion in Deaf Positives' previous report for Healthwatch Wokingham about dentists.

The average reading age of a Deaf person who uses BSL is between eight and 12, so the content on the website can easily be misunderstood. This combined with lack of communication provision at the appointment can lead to misdiagnosis.

The opportunity to book an appointment online was available, but not to book communication support.

How did the staff communicate with you?

Overall the response was positive from our volunteers e.g. 'One person tried a little [BSL] sign, I felt welcome. I asked to write and then we managed to do well.'



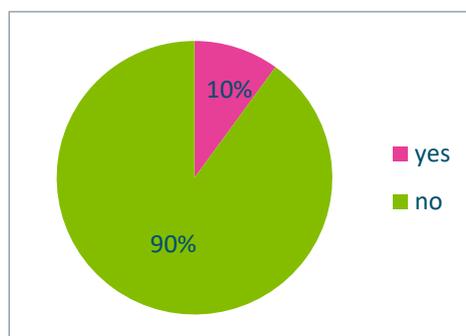
However, some reported communication difficulties.

- ✗ One receptionist just raised her hands to say 'I give up!'. I felt useless.
- ✗ Not offered a pen and paper to communicate.
- ✗ One lady just talked to me, but I couldn't understand and repeatedly said I was deaf - she kept talking and looking away.
- ✗ One person asked why I wasn't registered already.
- ✗ One person asked if I could bring someone in to talk for me or phone in later.
- ✗ I asked three people to help me. Everyone couldn't help, they just kept picking up the telephones and looking at me in an aggressive way.

Was there any information at the venue about accessibility for deaf people?

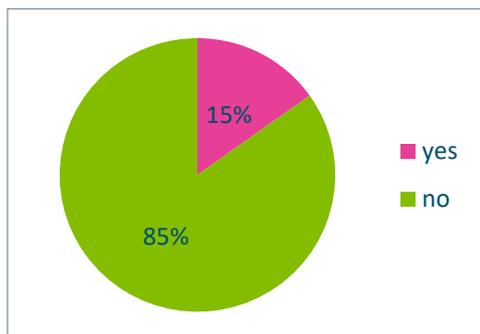
Of the 34 venues visited, the only information about Deaf accessibility was a Hearing loop sign with 'available on request'.

A hearing loop (sometimes called an audio induction loop) is a special type of sound system for use by people with hearing aids, commonly used for people that are deafened (hearing loss).



It is often mistakenly thought that Deaf people (people born deaf or profoundly deaf) can use hearing loops. Deaf people cannot use them, they wear hearing aids only to pick up sounds such as fire alarms or fire engines. Cochlear users cannot use Hearing Loops either.

**Did they have a TV screen explaining the services offered?
Was this accessible (e.g. signed, subtitled etc)?**



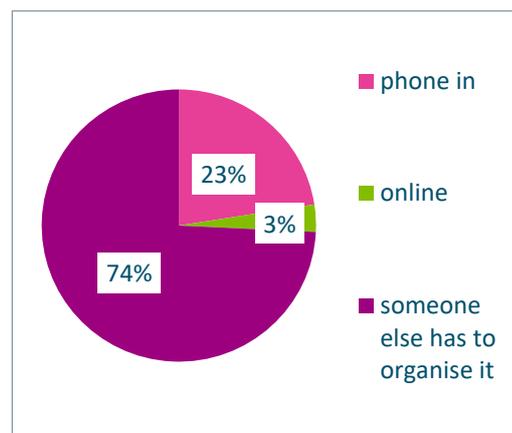
None of the screens gave any information in British Sign Language, although some of the venues did have subtitles. Some of the venues did not have any screens at all.

Only a few of the screens provided an alert to identify the next person to be seen. Not having the alert identifier on the screen would have been difficult for a Deaf person to know when they are being called for their appointment.

What was the process to book communication support?

When asked about who had to organise the communication support, it was said that the responsibility of the deaf person to organise the communication support.

Wokingham Borough Council suggested that they would bring 'Susan from Optalis' to interpret. However, after further investigation we have found out that she is not a Registered Interpreter.

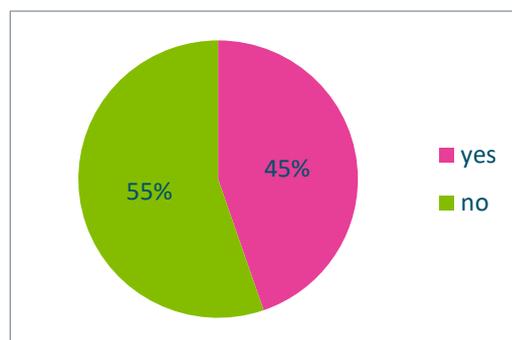


Three organisations suggested that it was too expensive to organise communication support. One asked if the volunteer could bring their own if they couldn't find one. One organisation said they don't normally but would try their best.

One asked why they don't have their mum or dad to help them interpret.

Were you given any information about the services they were offering?

55% of organisations provided information. 45% did not. These are some of the comments reported by our volunteers.



- Only a registration form. I requested on the paper that I needed an interpreter. They emailed me saying they could offer a hearing loop which they share in Datchet. I can't use a hearing loop.
- I was told that booking an interpreter is too expensive!
- "Susan from Optalis" [colleague who is not a qualified interpreter] can interpret
- I do not need to book a different communication support. I am a lipreader!
- Reception informed [me] that interpreters can be pre-planned. Same policies throughout all the practices; no emergency interpreters but can be booked in advance.
- Gave registration forms and advised that I should bring friend or family to interpret.
- Leaflets about community navigators that could assist with communication
- Wrote down what I needed to provide with my own communication support

Information provided by Deaf respondents to the **online questionnaire** indicated/confirmed:

- i) **Lack of communication support** - including at social worker appointments and for Deaf parents attending their children's appointments
- ii) Clear support for **deaf awareness training** across all services
- iii) **Quality and suitability** issues in relation to the communication support that is provided.

Participants in the **focus group** provided very evocative first-hand accounts of their health and care experiences. (Several are reproduced, anonymised, throughout this report - see boxes). Their stories clearly illustrated many of the problems identified above, and also some positive examples of good service.

At the opticians - Cameron

"I was greeted with a warm welcome. They said they normally rely on lip speaking themselves, and writing information down, but they did offer to find out about more support if I ever needed it. They said they would be willing to make a booking for future visits. This was a relief compared to some other services."

At the optician's - Alex

Alex went to Specsavers and approached reception to make an appointment.

The lady from reception lip-spoke very well. She showed Alex a calendar and asked which date Alex was able to attend. Alex found the conversation with reception a pleasant experience, but did not understand everything they said, so they wrote the information down.

Alex didn't request a [professional] lip speaker for the appointment. When Deaf Positives asked why, Alex replied that they knew that they wouldn't book a lip speaker so didn't bother to ask.

At the appointment, Alex didn't understand what was happening because it took place in a darkened room.

What we learnt - in summary

We were disappointed to conclude that **the extent to which local health and care organisations are complying with the Accessible Information Standard in relation to Deaf people is significantly limited.**

Most staff were friendly and welcoming towards our Deaf mystery shoppers yet organisations seemed, in general, ill-equipped to meet their information and communication needs.

The Accessible Information Standard gives Deaf people - like other service users - a legal right to (a) support so they can communicate effectively; and (b) information that they can easily read or understand. The mystery shopping exercise revealed four key deficiencies in this area:

- (1) Most organisations surveyed offered **no communication support** (e.g. providing interpreter at appointments) for Deaf people.
- (2) Many organisations/staff, even those who were friendly and well-intentioned, showed **poor awareness** of
 - appropriate ways to support communication between Deaf and hearing people
 - what is not appropriate
 - their legal responsibilities in relation to information & communication under the Accessible Information Standard.

Our Deaf mystery shoppers endured examples of **offputting obstacles** likely to deter Deaf people from trying to access care: being asked or expected to communicate by phone; delays and difficulty in getting served in person; and the impact of their basic requirements being labelled as 'too expensive' or exceptional.

- (3) None of the organisations used British Sign Language (BSL) on their websites or TV screens - there was **no 'in-vision' signing** for people whose first language is BSL.
- (4) There was **not enough visual information on display** in local health and care venues:
 - very few waiting areas provided a visual alert identifying the next person to be seen
 - no signs about communication support (e.g. interpreter booking)
 - not all venues had television screens
 - not all television screens had subtitles

Deaf Positives Action also used an online questionnaire to obtain feedback from Deaf patients and service users. Their feedback confirmed the lack of communication support and also highlighted issues about the quality/suitability of communication support where it had been provided. There was clear support for awareness training across all services.

What we recommend

It is clear that, more than a year after the Accessible Information Standard became law, the local health and care sector needs to improve its provision for Deaf people. Action is needed to ensure that every organisation complies with the law.

Healthwatch Wokingham joins with Deaf Positives in making six key recommendations under the following headings:

Training

- A. that staff at all levels across all NHS and adult social care providers receive **deaf awareness training**.

It should include, in particular:

- ✓ training about the Accessible Information Standard for reception staff
- ✓ training for social workers on communication support
- ✓ existing staff (e.g. refresher courses) and new staff (induction).

Identifying and recording/alerting

- B. that organisations adopt for recording people's communication requirements on their file/patient notes
- C. that they also red-flag the records of **children whose Deaf parents/carers require communication support** at the child's appointments

Eliminating inappropriate practice

- D. that health and social care professionals should **not allow the use of family or friends** to communicate on a Deaf person's behalf at appointments instead of arranging professional support.

Providing appropriate communication support

- E. that organisations **book an appropriate language service professional (LSP)*, registered with the NRCPD¹**, to provide communication support for Deaf people at appointments.

*e.g. a qualified sign language interpreter, lipspeaker or notetaker **in line with the Deaf person's stated communication preference**. The staff member/department who makes the booking should know (and tell the service user) the name of the LSP and their qualification, which should match the level of skill required for the task in question.

Empowering the service user

- F. that service users should be able to **book appointments online**. They should be able to indicate that an LSP should be booked, and what type. Deaf users should have the option to access the system using BSL.

¹ NRCPD regulates the communication and language professionals that work with Deaf and Deafblind people. Registrants have undertaken approved training, agreed to comply with the NRCPD Code of Conduct, are subject to a complaints process, maintain their professional development, have an enhanced disclosure from the Disclosure and Barring Service, and have valid professional indemnity insurance.

What next?

Healthwatch Wokingham is liaising with service providers and commissioners to discuss their responses to these recommendations. We want their suggestions as to how best to ensure that individual organisations across the sector take the necessary action to improve their services to better meet the needs of Deaf and hard of hearing people, and to promote good practice.

Ensuring that Wokingham Borough's health and social care services more fully engage with the Accessible Information Standard will ensure that Deaf people have the necessary information and support to use the publicly-funded services to which they - like the rest of the population - they are entitled and contribute. It represents a major opportunity for health and social care decision-makers to improve the health and wellbeing of the Deaf and Hard of Hearing community in Wokingham Borough.

Keep in touch! Help improve health & care services - tell us your experiences.



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