

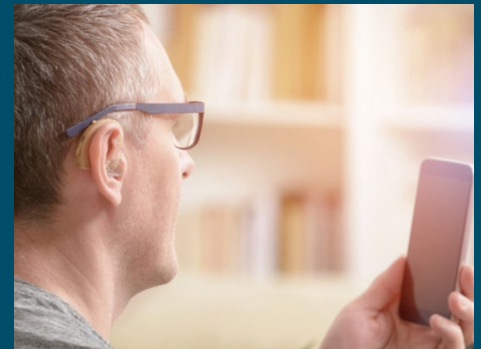
Healthcare Access without Barriers

I am D/Deaf - What does accessible mean to me?

Project Report March 2020



Content overview...



Introduction P3

What we did P6

What people said P8

What next? P14

Acknowledgements P15

**Appendix A -
References** P16

**Appendix B -
Online search
sample** P17

**Appendix C -
Survey results** P18

About HWCB P20



Introduction

Access to Healthcare is a right afforded to all citizens in the United Kingdom through the NHS. The first principle of the NHS Constitution for England is that 'The NHS provides a comprehensive service, available to all'¹.

Whilst no one would question this right, it is sometimes the case that people have difficulty accessing healthcare in a way that meets their individual needs.

Healthwatch Central Bedfordshire (HWCB) works to understand the experience of users and carers through a range of engagement activity. All local Healthwatch have a role in empowering people to get the most from the services they access, which can be a challenge for people from traditionally hard to reach groups, who may have additional needs, to ensure equality of access.

Legislation has worked toward equality for all for many years and in 2016 the Accessible Information Standard (AIS) was fully implemented in law through the Health and Social Care Act.








NHS commissioned video for the Accessible Information Standard
<https://www.youtube.com/watch?v=ZJngMo37WvA&feature=youtu.be>

The Accessible Information Standard (AIS)²

The Standard aims to ensure that people who have a 'disability, impairment or sensory loss' get the information they need in a way they can understand and applies to all publicly funded health and social care services.

There are five key principles that the Standard requires adherence to:

-  1. Ask individuals if they have any communication or information needs and how they would like these needs met
-  2. Record these needs clearly and consistently
-  3. Ensure file notes have the appropriate 'flags' for all professionals to be aware and follow
-  4. Share this information, with permission, with other providers of health and social care services
-  5. Take steps to ensure that information is provided in an accessible way and receive support if they need it.

¹ <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>

² <https://www.england.nhs.uk/publication/accessible-information-standard-specification/>



Since the introduction of the AIS there has been a post-implementation review conducted by the NHS, which worked to assess the impact of the Standard. The review also highlighted the inconsistent application of the principles and variable quality of support available for those who need it.

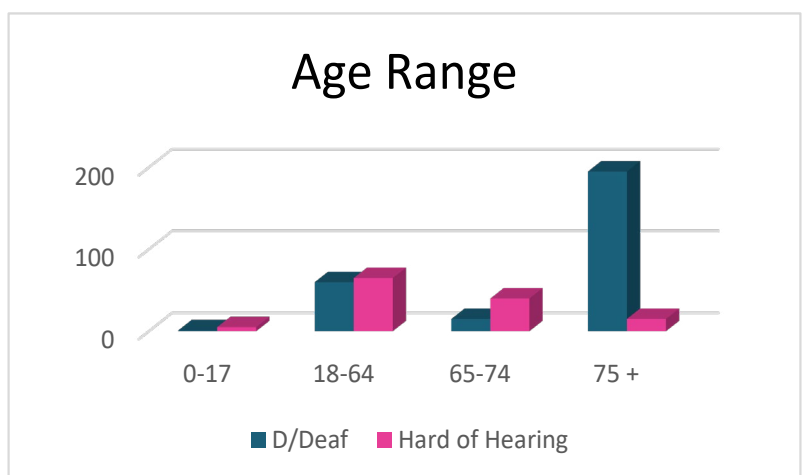
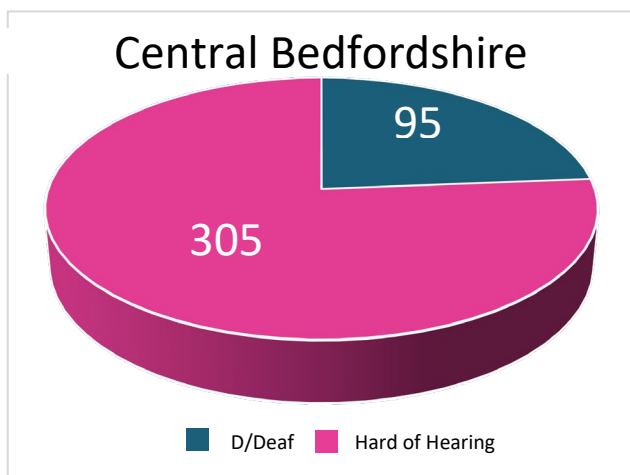
In 2018/19 HWCB were contacted by four users and/or their carers each with an experience of healthcare that had one common theme - the lack of appropriate communication support.

The needs in each individual case differed, as did some of the services accessed. However, the issue highlighted a concern for all - difficulty fully engaging with healthcare services due to being D/deaf or hard of hearing and HWCB decided to investigate further by engaging with people from the D/deaf community to find out more about their experiences.

Whilst this number was relatively low, there was still an identified trend that HWCB believed would benefit from further exploration.

The local picture

In Central Bedfordshire there are 400 people registered as Deaf or Hard of Hearing³, these numbers can be further broken down as follows:



³ <https://digital.nhs.uk/data-and-information/publications/statistical/people-registered-as-deaf-or-hard-of-hearing/people-registered-as-deaf-or-hard-of-hearing-england-year-ending-31-march-2010>



There are three distinct groups within this demographic:

People who are hard of hearing

Primarily, members of this group have acquired hearing loss that has worsened over time. Although some people accept hearing difficulties with maturing age, people who are hard of hearing have a measurable deficit.

As the loss happens over time these people will have already acquired a spoken language. They may utilise technology to manage, such as hearing aids and amplifying aid for telephone or television equipment.



People who are D/Deaf



The term D/Deaf has been adopted culturally to represent a shared identity for people with serious hearing loss, often from birth, who use communication methods including lip reading and British Sign Language (BSL).

Carers



Carers, who in general had a familial or friendship relationship with people from the two groups and provided support and care when interacting with health services.



What we did

Healthwatch Central Bedfordshire sought support from a range of organisations to develop a programme of engagement to speak with people within the D/deaf community and those who are hard of hearing. SignHealth and the British Deaf Association were included in initial preparations, for question development and advice on communication tools.

Given that the initial issues raised were within health settings, the project worked with the primary focus on health.

The key objectives for this project:

- To gather the views and experiences of adults who are D/deaf or hard of hearing and who have accessed health services
- To understand what challenges people face
- To understand what people find helpful when communicating with services throughout the health pathway
- To make recommendations to service providers based on the findings
- To publish a report and share with key stakeholders including those that participated in the project

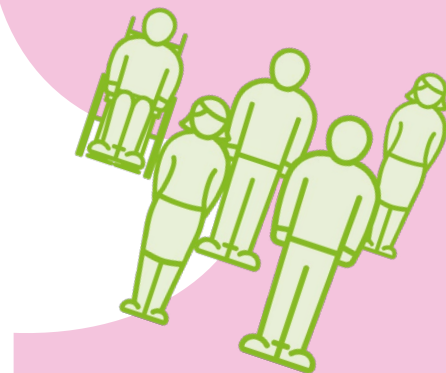


The programme of engagement included two forms of activity - a survey, designed with qualitative and quantitative format, and a focus group of service users/carers. The survey was available online and in paper form for ease of use. The focus group was planned to gather quantitative feedback about user and carer experience.

Initial recruitment for a focus group yielded low returns, with just two people asking to join. To enable an increased number to engage HWCB reached out to a community organisation for D/deaf people to host the focus group. This enabled more people to participate at one time.

The session was delivered during a regular meeting of the community group, with agreement from members and the group leader. The activity was facilitated by HWCB and communication was supported in full by a British Sign Language (BSL) interpreter.

Over thirty individuals participated in the focus group and a further eleven completed the survey.





Website review

During the period of this project, HWCB volunteers also undertook a review of local health services website information, specifically looking at content for D/deaf users and their carers. The purpose was to assess how services publicise their offer of support to people from the D/deaf community and if this information is easily identified and accessible.

The services included:

- Hospitals
- GP surgeries
- Dentists
- Opticians

The review looked at 15 websites and utilised page navigation and the open search function to locate the information.

The team used a range of criteria including:

- Alternative terms for D/Deaf
- Reference to accessibility
- Translation and interpretation
- NHS Accessible standard
- Reference to disability

The results varied significantly, a summary of the findings can be found at Appendix B.





Late running clinics can mean scheduled interpreting is not available

Having the information displayed on websites

What people said

“In our community there are many problems with getting interpreters for appointments. We do understand if its short notice, but the excuses keep coming and not much changes. I want more for my children”.



Eleven people participated in the survey, which was hosted online and provided in paper form on request. Ten were users of services, and one person was a carer for someone they described as ‘profoundly deaf’.



The age of respondents varied from 30 to 70+ years, with 70% female. All, but the carer, were Central Bedfordshire residents.

Please see Appendix C for a full breakdown of the information gathered from the survey. The survey highlights a number of themes:



All of the respondents had accessed a health care service and not unsurprisingly, the majority indicated GP surgeries (100%) with only one person who stated having visited a dentist.



Despite 63% saying they used sign, or sign and talking, to book healthcare appointments, overwhelming 90% said that they accessed health care services with the support of family or friends.



Only one respondent said that the service books an interpreter for their appointments. One person said, “I have found that services don’t book or can’t or say they can’t”.

It is perhaps unsurprising that there were common themes from both the survey responses and focus group feedback.

Focus group

Interpreters should be qualified to provide support in healthcare settings

Protocols for booking interpreters change from service to service



Over thirty people participated in the focus group activities, but not all in attendance were Central Bedfordshire residents. As we utilised a community group for the focus group activity, people attending were also from outside of the County, including; Cambridgeshire, London, Luton, Milton Keynes and Welwyn Garden City.

Many of the group had some knowledge of the Accessible Information Standard (IAS) and were able to identify the key principles and relate these practically to their experience of healthcare services.

People were keen to share their stories, both positive and negative, and common issues and themes were raised from many in the group.

A small number of issues required further exploration, which HWCB carried out post the event.



GP surgeries

A few people who were registered with a GP surgery and had long term relationships with the provider shared positive experiences. A family of four who are D/deaf felt their GP surgery was “fantastic” and a BSL interpreter was always made available when needed. They used text as a way of booking and some communication, which suited both the family and the service.



Hospitals

It was clear that communication support varied, not only between hospitals, but departments as well.

Positive experiences were described at both Milton Keynes and Bedford Hospitals, with the physio department at Bedford singled out for their support.

One lady, whose husband had to be admitted to a London hospital on GP advice, made a request on arrival for an interpreter as neither she nor her husband are hearing. She felt unable to leave and both were unable to fully communicate. It was not until the fourth day of his stay that an interpreter was provided. She felt that staff did not seem to know how to book an interpreter and they were left without the support that would have helped alleviate some of the anxiety at a very difficult time.

It was the understanding of many people in the group that when attendance at the hospital was necessary, the hospital PALs teams are responsible for booking interpreters. The guidance from the three hospitals identified by the group - taken from their websites, is noted in Appendix B. It is clear from the differences highlighted that there is not necessarily a standard for requesting interpretation. This has the potential to cause confusion for patients and their families and perhaps staff.



Finance

Use of text and email for booking appointments

Installing a hearing loop is not enough, staff need to know how to use it

Concerns were raised from some people within the group that provision of interpreters was reliant on budgets and if there were limited funds then the service would not be provided. One person said that they felt that *“There have been lots of cuts made locally, there isn’t the money”*.

Whilst we understand that all health care settings have budgets to manage and services to prioritise, it is unlawful to ignore the AIS. If there are constraints that affect delivery it would be advisable for management to escalate the issue to the relevant body to consider how to ensure that budgets are inclusive of AIS activity.



Provision

A general feeling amongst the majority of people within the group was that budgets for interpreters were spent more on other languages. It is difficult to ‘measure’ this without looking at each service spend in this area. This would then need to be balanced against population figures, ethnicity data etc. Whilst this is not within the remit of this work, it is important to understand that the group felt that their need was recognised less than those whose first language was not English.

Many people also highlighted the lack of availability of interpreters during bank holidays, the Christmas period and sometimes at weekends.

In addition, anecdotal evidence highlighted that people felt they had been ‘shifted’ to another service. The common experience shared was that when in attendance at a GP Practice, D/deaf people were often told to go to A&E. It was felt that in each case their illness did not necessitate a visit to A&E and that the surgeries were simply avoiding providing an interpreter.

Standardised appointment times (10 minute slots for GPs) clearly do not take into account the time needed for those with communication needs - *“More time at appointments is essential, you can’t have a quick visit, I need time to understand what is being said, for the interpreter to give me the information, for me to think and respond”*.

Timing is also important when securing interpreters. One person had experienced an over running clinic, the interpreter was booked for an allocated amount of time and had to leave before the appointment began, leaving the person without help. GP Practices need to recognise the need to prioritise appropriate appointment time slots for D/deaf patients, particularly when an interpreter is required.



Staff

Access to interpretation was considered to be reliant on staff knowledge, confidence with arranging, and sadly in some cases, attitude.

“When I walk into the surgery, I don’t like the attitude of the receptionist. They always say they need two-weeks’ notice. I do know it takes time, but they treat me like I’m a nuisance”.



No one should be made to feel like meeting their needs is too much trouble, even if there are difficulties. It is important to empower people to be able to fully participate in their care. One person was told *“You don’t need an interpreter; we can write it down. It was just a list of words, not really in my language”*. People felt that training might help people to understand the challenges that D/deaf people face - *“I’d like all NHS staff to have Deaf Awareness Training”*.



Interpretation services

In general, the group had praise for the interpretation support they had received in health care settings.

People told us they preferred to know the name of their interpreter before the appointment commences, specifically for those with long-term health issues, where multiple appointments were needed. People felt having a familiar/regular interpreter made it easier and less stressful.

Two people told us they had been let down by booked interpreters not turning up to appointments. It is therefore important that any service is reliable with both quality and reliability. This should be monitored closely and raised with the providers if issues recur.

Concerns were raised by a few people about the training levels of some BSL interpreters. Some interpreters were newly qualified and lacked experience, others were Level 2/3, which some people felt was not qualified enough to deliver interpreting in a health care setting. Leading training organisations in BSL interpreting support this belief and suggest that interpreters are at least Level 4 - 6 for medical appointments.

One person made a particularly interesting comment - *“I wish all hospitals had an in-house interpreter. Some people who speak different languages have staff that can speak with them, that’s something we’ve never had.”*



Follow-up

A few people had a card they were able to present to healthcare professionals that identified they were deaf and in need of an interpreter, however, the cards shown to HWCB representatives were generally limited to services in a geographical area such as a hospital trust and group of providers. A significant amount of interest was shown by others in the group about the potential for comparable cards in this area. Following HWCB’s research, we found that historically a similar card was developed for residents of Bedford accessing Bedford Hospital, however it was not clear if this was currently available.

Although SignHealth do not specifically offer a service of this type, they do recommend a card that can be downloaded and used by individuals, through this link <http://ohyh.org.uk/how-to/how-to-use-the-our-health-in-your-hands-card/>. This information was shared with the group.



Other feedback



During general HWCB engagement activity, people who are hard of hearing have shared their experiences to inform this report.

Many people told us that they considered it less problematic to access healthcare if there was no need for interpretation. However there were issues that prevented people from being fully engaged with their health journey.

Hearing loops were not standard in all settings and some people told us that they had been advised the hearing loops were not working, so could not be used at their appointments. At least five people had issues with staff not understanding how loops work, even with signs in place that suggest a loop - *“I was told by them, sorry I don’t know how it works, I can’t help you. What is the point of a loop if it is out of service or their own staff don’t know how to use it?”*

Carers expressed concerns that people may be exploited by companies selling hearing equipment. A wide marketplace is available to view online which can be confusing with many varied ranges of items and price points.

One person felt it was important to fully consider options and highlighted details of a showroom with demonstrations available and the opportunity to try before you buy and return if not suitable within twenty-eight days. The information was shared with friends and colleagues, though many were concerned that as this was not available locally, people would need to travel out of County to access the showroom which was not always easily managed.





In conclusion

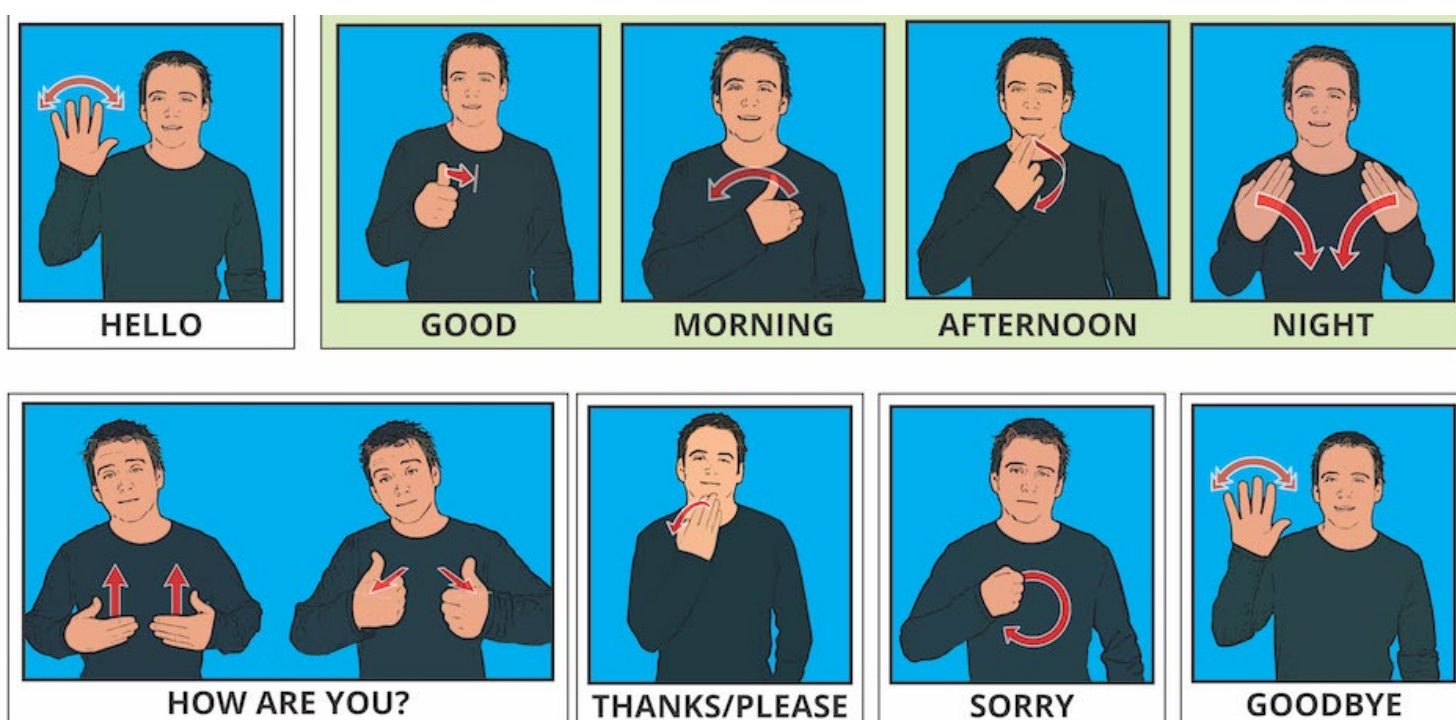
Despite the introduction of the Accessible Information Standard in 2016, clearly challenges remain for D/deaf people when accessing health care.

From the results of our engagement with D/deaf people, it would appear that the AIS is not applied consistently across health services and indeed geographically. People have raised concerns about the disparity that they feel between area provision - **“Different services do it different ways, there is no way of knowing what is on offer across the area, never mind if you have to go somewhere new, or to one of the hospitals further away like London. If they could make it the same, we’d know”**.

It is difficult to provide an accurate assessment of quality in each case as we received both positive and negative feedback relating to all services, though it is clear that good practise exists in certain areas.

The website review and feedback highlighted a lack of transparency with public facing information. If people with communication needs do not know what is on offer, it would be very challenging for them to make informed choices - **“When I moved from London I wanted to know if the GP surgery catered for my needs, I couldn’t tell from looking at the website. I couldn’t call to ask; how else would I know?”**. Individuals need to be empowered to choose services that can meet their needs, and this will only happen if providers arrange for the most up to date information and advice to be made available in various mediums.

From our recent engagement activities, we can see that more needs to be done to meet the needs of people from the D/deaf community in healthcare.





What next?

The experiences shared have clearly identified that D/deaf and hard of hearing people continue to face barriers when accessing health care.

Individual organisations have a responsibility to ensure they are compliant with the Accessible Information Standard. It is important to hold services accountable to confirm implementation and delivery, and given the findings of this report, this does not appear to be universally in place which indicates no firm evidence of good practice, or consistency across the health care sector.

Recommendations

- Documentation, including patient letters, to use plain English. It is important to avoid anacronyms and complex medical terms.
- Full implementation of the NHS Accessible Information Standard - all providers of healthcare should be aware of the AIS and put measures in place to ensure they are compliant, and staff are aware of the principles.
- Staff training and development - upskill all staff to understand their responsibilities and encourage confidence when supporting people with additional communication needs.
- Clearly written policy and supporting documentation to be made readily available, to ensure implementation is delivered at the frontline.
- The offer should be clearly communicated for public facing information including websites, and where appropriate, social media.
- Regular monitoring and review. This will enable services to assess take-up, manage budgets, evaluate quality and share best practice. This will also provide transparency to the D/deaf community.
- Use of the appropriate technology to enable effective communication and regular testing of the hearing loop and education of staff in its use.

Together we can make a difference



Acknowledgements

A huge thank you to the participants who shared their personal experiences, through surveys and focus group activity, which helped inform this report.

If you would like help to understand your rights the following organisations provide specialist information and support:

**THE DEAF HEALTH
CHARITY
SIGNHEALTH**

<https://signhealth.org.uk/>



<https://bda.org.uk/>

Appendix A

References

1. NHS Constitution

Retrieved from <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>

Accessed in June 2019

2. Accessible Information Standard, including review documents

Retrieved from <https://www.england.nhs.uk/publication/accessible-information-standard-specification/>

Accessed in June 2019

3. Local Joint Statistics Needs Assessment

Retrieved from <https://www.jsna.centralbedfordshire.gov.uk/>

Accessed in September 2019

4. Hearing Link

Retrieved from <https://www.hearinglink.org/>

Accessed in January 2020



Appendix B

Local public information search

To understand how health providers are communicating the support they offer to those with communication needs, in particular people from the D/deaf community, volunteers from Healthwatch Central Bedfordshire undertook an online information search.

Please note a number of search criteria were tested - Deaf, accessible, communication, British Sign Language, translation and NHS Accessible Standard. The most results came from use of the term 'translation'.

Service	Summary results	Link
Bedfordshire Hospitals NHS Foundation Trust	Full information through new portal (after merger) highlights what is on offer for patients at the Luton & Dunstable. There is very little information for the Bedford Hospital site. This was identified as the same prior to the merger when there were two fully separate sites.	https://www.bedfordshirehospitals.nhs.uk/patients-visitors/information-for-patients-visitors-luton-and-dunstable-university-hospital/support-and-assistance/translation-and-interpreting-service/
Milton Keynes University Hospital	There was no easily identifiable information on PALs pages.	Nothing found
Chiltern Vale: Toddington Medical Centre	Information found under search for 'Accessible'. Asks that the individual inform them of communication needs.	http://www.toddingtondoctors.co.uk/t147214.html?a=0
Ivel Valley: Greensands Medical Practice	There is no general search option on the website. In the new patients section there are links to leaflets in other languages.	Nothing found
Leighton Buzzard: Salisbury House Surgery	Information found under search for 'Accessibility'. There is no information on what the surgery offers. Mentions the NHS Accessible Information Standard. Asks that patients discuss their communication needs.	https://www.salisburyhousesurgery.co.uk/accessibility/
West Mid Beds: Houghton Close Surgery	Information found under search for 'Accessibility'. Mentions the NHS Accessible Information Standard. Asks that patients discuss their communication needs.	https://www.houghtonclosesurgery.co.uk/accessibility/
East London Foundation Trust (ELFT)	ELFT is the commissioned provider for Mental Health and Community Health Services. Their website has a public facing page about their commitment to the AIS.	https://www.elft.nhs.uk/About-Us/Publications/Accessible-Information-Standard
Opticians	No reference to AIS in Boots, Alders (a local service) or Specsavers. The promotion of hearing tests/aid service reference those who are hard of hearing.	
Dentist	Very limited information on any dentistry websites across Central Bedfordshire.	

Appendix C

Access to healthcare survey

Question 1: How would you describe yourself?

- 6 Deaf
- 3 Hard of hearing
- 1 Hearing Impaired
- 1 Other - Written responses: *I care for someone who wears hearing aids and is profoundly deaf.*

Question 2: How do you communicate with people?

- 4 Sign only
- 4 Talk only
- 0 Lip read
- 3 Both sign and talk
- 0 Other

Question 3: Have you visited these services?

- 3 Accident & Emergency (A&E)
- 1 Dentist
- 11 Doctors surgery
- 9 Hospital - for an appointment as an outpatient
- 3 Optician
- 11 Pharmacy / chemist
- 2 Walk-in / Urgent Treatment Centre

Question 4: How do you communicate with people at these services?

- 4 Interpreter
- 0 Skype / video call
- 1 Text message
- 4 Sign
- 1 Writing down
- 9 Help from family / friends
- 2 Other - Written responses: *I just talk to them. I help my mother at all of her appointments*

Question 5: If you need an interpreter, how do you arrange one?

- 7 Not applicable
- 1 Self-book
- 1 The service does it
- 1 Family does it
- 1 Other - Written responses: *I have found that services don't book or can't or say they can't*

Question 6: If you have had trouble accessing a health service what has been the problem?

- 2 Not able to communicate
- 2 No interpreter offered
- 2 Staff not understanding
- 1 Other - Written responses: *They said you can talk a bit, we can understand each other. I didn't know how to say no. I find they don't often have a hearing loop, or if they do no-one knows how to use it*

Question 7: Please tell us what would improve your experience of accessing health services

"Being offered an interpreter".

"Public buildings having hearing loops and staff knowing how to use it and advising people properly, that's what's needed".

"Different services do it different ways, there is no way of knowing what is on offer across the area, never mind if you have to go somewhere new, or to one of the hospitals further away like London. If they could make it the same we'd know".

"Clearer information on what is available and how to get an interpreter".

"For services to rely less on me as a family member and to provide Mum with the help she needs to know what is going on".

Question 8: About you

Are you?	Your age	What town/ village do you live in?
3 Male	0 Under 18	2 Dunstable
8 Female	0 19 - 30	2 Sandy
	2 31 - 50	0 Ampthill
	4 51 - 70	0 London
	5 70 +	0 Arlesey
		0 Biggleswade
		2 Flitwick
		0 Shefford

Question 9: Are there any other comments you would like to add?

"I feel if I didn't speak English I'd get an interpreter no problem, it seems if you are deaf there is less understanding of what you need, or what you should have the right to".

"I know I'm not the only one who has problems".

"Hearing loops should be standard in any service that is providing for the public. In this day and age we should be using technology to make lives better".

"In our community there are many problems with getting interpreters for appointments. We do understand if its short notice, but the excuses keep coming and not much changes. I want more for my children".



About Healthwatch Central Bedfordshire

Healthwatch Central Bedfordshire is the local consumer champion promoting choice and influencing the provision of high quality health, social care and wellbeing services for all across Central Bedfordshire.

Healthwatch Central Bedfordshire (HWCB) has significant statutory powers to ensure that the voice of the consumer is strengthened and heard by those who commission, deliver and regulate health and care services. HWCB engages and consults with all sections of the local population so that a wide cross-section of views are heard, understood and acted upon. Everything we say and do is informed by our connections to local people and our expertise is grounded in their experience.

Healthwatch Central Bedfordshire is one of three local Healthwatch in the County of Bedfordshire and belong to a network of local Healthwatch. Healthwatch England leads, supports and guides the Healthwatch network which is made up of the national body and local Healthwatch across each of the 152 local authority areas in England.

Healthwatch is the only body looking solely at people's experience across all health and social care. As a statutory watchdog our role is to ensure that local health and social care services, and the local decision-makers put the experiences of people at the heart of their care.

healthwatch
Central Bedfordshire



healthwatch

Central Bedfordshire

Healthwatch Central Bedfordshire
Capability House Wrest Park
Silsoe
Beds MK45 4HR

www.healthwatch-centralbedfordshire.org.uk

tel: 0300 303 8554

e: info@healthwatch-centralbedfordshire.org.uk
