



# **Accessible Information as Standard Background Information: Peterborough**

Improving access to health and care for people with a learning or sensory disability in Peterborough 2017

# **About Us**

Healthwatch Cambridgeshire and Peterborough\* is an independent champion for health and care. Our job is to make sure that those who run local health and care services understand and act on what really matters to people.

We listen to what people like about services and what could be improved.

We share what people tell us with those with the power to make change happen. We encourage services to involve people in decisions that affect them. We also help people find the information they need about services in their area.

\*This started as a project of Healthwatch Peterborough in October 2016, in parallel with a similar project run by Healthwatch Cambridgeshire. Healthwatch Cambridgeshire and Healthwatch Peterborough combined to work together as one organisation on 1 April 2017.



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# **Key findings**

- There are low levels of public awareness of the NHS Accessible Information Standard and the benefits it provides to people with a sensory or learning disability.
- Most people are getting some accessible information support; however, this is variable. Even those getting some support are not getting all the support they need.
- The lowest level of provision we identified was within GP practices.
- The two most popular resources needed were an advocate and a qualified British Sign Language (BSL) interpreter. However, our findings show these are mostly provided by family members or support workers, rather than a professional advocate\* or BSL interpreter.
- People told us they highly value accessible information services when they are in place.
- Telephone calls and email have improved communication about appointments. This could be further supported by commissioning an on-call service for qualified BSL interpreters.
- Staff attitudes are mostly positive towards providing accessible information. However, frontline NHS and care staff would benefit from training in disability awareness and their responsibilities under the Accessible Information Standard. This would improve the patient experience, increase public awareness and take up of this service.
- Communication between NHS and social care providers could be better to make sure people's needs are recorded and shared as they should be.

\* We use the term 'professional advocate' to distinguish from support given by friends and families.

# **Understanding the issue**

The Accessible Information Standard was introduced by NHS England to make sure people who have a learning disability or sensory loss are given information they can easily read or understand with support, so they can communicate effectively with health and social care services.

The standard was introduced after a Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) was undertaken in 2013 by Bristol University. It showed there was a further need to:

"identify people with learning disabilities in a healthcare setting, and to record, implement and audit the provision of 'reasonable adjustments' to avoid serious disadvantage."

In July 2015, the Accessible Information Standard was approved and became a legal requirement on 1 August 2016.

The Standard is important because it aims to reduce the difference between care provided to people with sensory and learning disabilities and other people.

This project looked at the experiences of people with a learning disability or sensory impairment in Peterborough since the Accessible Information Standard was introduced.

## What we did

A survey was produced to find out people's experiences. We received feedback from 45 individuals with a sensory or communication disability, collected from nine visits to local groups.

We worked with five organisations who support people with sensory or communication needs, who promoted the survey to the people who use their services.

We asked Peterborough City Hospital (PCH) to include the Accessible Information Standard in their 15 Steps Challenge assessments for the first time. We used Healthwatch England's 'AIS toolkit' to do the assessment.



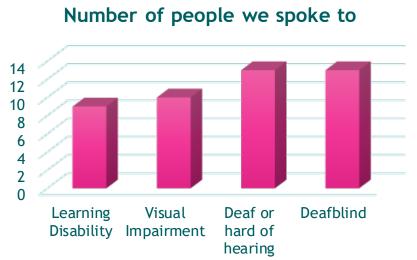






# Who we spoke to and what they told us

We spoke to 45 people with one or more learning or sensory disabilities.



Most people surveyed did not know about the Accessible Information Standard and had not been asked about their access and communication needs.

Some people told us accessible information was available in the form of phone calls, text messages, large print letters and advocates.

- Within GP services, 29% of people reported they got accessible information and communication support whilst 71% said they did not.
- Within dental practices, 36% of people reported they got accessible information and communication support whilst 63% said they did not.
- Within optician services, 41% of people reported they got accessible information and communication support whilst 58% said they did not.

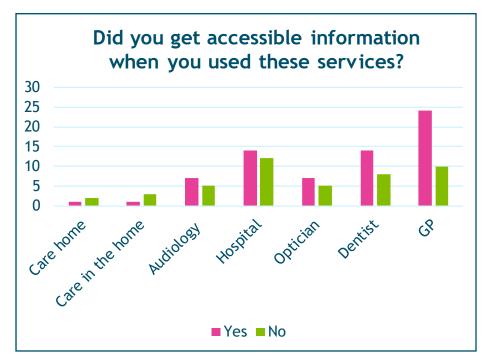
The above three percentages are based on the answers of 35 people as not everyone answered all of the questions.

Within hospital services, including departments, wards and clinics, almost half of those surveyed reported getting accessible information and communication support.



One surprising finding was that only 41% of people reported they received accessible information and communication support from their audiology department.

The chart below shows where people did or did not get appropriate support when accessing NHS or social care services.



The most popular resource needed was someone to speak up for the person. This is mostly provided by family members and support workers rather than a professional advocate provided by the NHS.

The second most popular resource requirement was for a qualified British Sign Language (BSL) interpreter. There was some evidence that family members are used as interpreter.

Large print letters (font size 14 and above) were a popular need, followed by easy read format, and Deafblind manual interpreters.

15 people identified two communication needs, (e.g. a written format and a verbal communication need). Five people identified three communication needs, (e.g., a written format, an advocate and an interpreter). This was related to their complex communication needs and can be attributed to people who are either Deafblind or have a learning disability.



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# **Comments from people we spoke to**

#### From people who need a hearing loop

'I do ask a lot questions and ad lib - sometimes I get things wrong but I am getting better.'

'My husband can't hear things very well even with his hearing aids he misses things, I always go with him.'

#### From people who need easy read

'I don't like it if I can't read things for myself. My dentist and optician phone me when I have an appointment.'

'I get frustrated when communication doesn't work. Easy read format and an advocate would help as I don't get to know people properly'

#### From people who need an advocate or someone to speak up for them

'I have a learning disability and require text messages, easy read and an advocate. I get an advocate from the Volunteer Centre, I find this very useful, it kept me calm when I had to have an injection, I can't always understand things. I get phone calls from the hospital when I need an appointment.'

'I am visually impaired and I would like an advocate - I could then hear it more than one time so I know what is going on.'

'My son acts as my advocate and reads my letters for me.'

'I always have to have a family member or my support worker with me.'

#### From people who need a British Sign Language (BSL) interpreter

'I have had to wait longer for appointments until a BSL interpreter can do my appointment. Having an interpreter explaining results has helped me.'

#### From people who need large print

'It is a relief to be able to read things for myself otherwise my daughter has to read this information for me.'



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## **Other evidence collected**



Peterborough City Hospital (PCH) publicised information about the Accessible Information Standard using posters in the main reception, in lifts, in clinics, and on the PALS desk (pictured).

Following a request from Healthwatch Peterborough to review the Accessible Information Standard provision at PCH, the Trust included an adapted survey as part of their 15 Steps Challenge in October 2016.

**Identification of needs:** NHS services are required to ask people if they have any information and/ or communication needs, and find out how to meet their needs. We were told this is being undertaken at the hospital and there was some evidence to support

this, but consistency, reliability and understanding of information may be an issue.

**Recording of needs:** NHS services should do this in an agreed way. We were told the information is recorded in a set way, but this was not the case on the Pipa boards. These are magnetic boards on the patients' beds with symbols used to identify different disabilities), We would expect both verbal and written communication needs to be recorded - this needs to be verified.

**Flagging of needs:** NHS services are required to highlight needs on a person's file, so it is clear to staff that they have information access needs. It should also clearly explain how those needs should be met. We were told this information was kept on page 3 of the Pas/E-track system. We questioned whether this was 'visible' and felt consideration should be given to putting this on page 1.

Inconsistencies in the use of symbols and understanding were evident on the wards we visited.

**Sharing of needs:** NHS services are required to share information about a person's needs with other NHS and adult social care providers, when they have consent or permission to do so. There was some evidence that some sharing of information happens, e.g. between GPs and the hospital, but again consistency was an issue.



**Meeting of needs:** NHS services are required to make sure that people get information in an accessible way and communication support if they need it. We could not ask anyone if this was their experience as patients were too ill to speak to us.

Note: The data from the 15 Steps Challenge activity was collated from a very small cohort. The full report appears in appendix 2.

# Thank you

Firstly, we would like to give special thanks to those service users and their carers and/or family members who completed our survey and provided us with a wealth of information and experience as feedback.

We were grateful for the opportunities to attend the following events and stakeholder Boards; making presentations on Accessible Information Standard, and using the survey to find out people's experiences:

- Peterborough City Council Learning Disability Partnership Board
- Peterborough City Council Carers Partnership Board
- Peterborough Association for the Blind
- Deafblind UK's Rainbow Club
- Two Hampton Disability & Community events organised by Inspire Peterborough
- Two Peterborough City Hospital engagement events, run in conjunction with Healthwatch Lincolnshire

Many thanks to the following organisations who helped circulate the surveys:





Heather Lord, Information and Signposting Officer, communicated with many of those surveyed using deafblind manual.

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Heather Lord, Information and Signposting Officer, chatting to a member of staff at Peterborough City Hospital.

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