

LEARNING DISABILITIES CELEBRATION DAY & MENCAP: BIG DAY OUT

This is a joint report for Healthwatch Bath and North East Somerset (B&NES), Healthwatch Bristol and Healthwatch South Gloucestershire capturing feedback gathered at two celebration events run by Mencap and Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) in June 2017.

LEARNING DISABILITIES WEEK MENCAP BIG DAY OUT June 2017

Mencap ran their annual 'Big Day Out' event at @ Bristol to celebrate their work over the last 12 months working with the learning disability community. The three local Healthwatch from B&NES, Bristol and South Gloucestershire attended to raise awareness, and emphasise the importance of sharing experiences of health and social care services.

Our focus for the day was on the Accessible Information Standard (AIS), legislation that was brought in on 1 August 2016 to support people with communication needs to access services, as well as speaking to attendees about how the information they receive from health and social care services is understood. Local Healthwatch took part in two health workshops during the day to learn about Mencap's forthcoming campaign around accessible information.



Please see the "You Said" section of this report for some of the views and feedback gathered at the workshops.

THE ACCESSIBLE INFORMATION STANDARD

The Accessible Information Standard (AIS) came into force in July 2016. It aims to ensure that disabled patients and service users receive information in formats that they can understand and have appropriate support to help them to communicate.

All NHS and publiclyfunded adult social care services must follow AIS by law, under section 250 of the Health and Social Care Act 2012.

The Standard will apply to people that have a disability, impairment or sensory loss, and to their carers or parents.

"My consultant was able to adapt his methods of communication to meet my communication needs by listening to what I asked and responding appropriately by drawing body charts and highlighting areas where the cancer is for me to have a record of conversations".

Avon and Wiltshire Mental Health Partnership Learning Disabilities Celebration Day

16 June 2017



AWP collaborated with a huge number of organisations and stakeholder groups from across the local area to put on this event in celebration of people with learning disabilities. The event was inspired by Bristol's Recovery Festival. The event was full of energy and joyful activities. The event was held at the Trinity Centre in Easton, Bristol and attracted well over 300 attendees from across the west of England.

It was an inspiring day as attendees were introduced to Peaches Golding OBE, Her Majesty's Lord Lieutenant of the County and City of Bristol. Those who attended were also serenaded by a number of community group performances, which comprised of people with learning disabilities from across the west of England. However, the performance of the day came from special guest Daniel Wakeford, star of television show 'The Undateables', who sang a selection of his own compositions.

Local Healthwatch attended with an interactive and engaging information stall. We spoke to over 50 people at the event, ensuring that at least 50% of the information we had available was in a format that was accessible for people with a learning disability to read and understand.

Healthwatch also signposted attendees to The Care Forum's information and signposting



service, Well Aware, which also provides information in a format that is accessible and available online, by telephone or in hard copy.

Please see the Engagement section of this report for more information.

LOCAL HEALTHWATCH: B&NES, BRISTOL AND SOUTH GLOUCESTERSHIRE

Healthwatch is the official framework through which local people can have their say about health and social care services. Local Healthwatch works on behalf of the whole of the community – children, young people and adults – all of our work is based on the feedback that people provide us.

Healthwatch shares the feedback it receives about patients' experiences of care with service providers, commissioners and regulators in order to highlight areas of best practice and areas that require improvement. Where possible, Healthwatch seeks responses from providers and commissioners about the feedback it has received, and has the ability to hold them to account to try to ensure that service improvements are made. Healthwatch is also able to fulfil its statutory right to 'enter and view' services, such as care homes and hospitals, in order to observe what is happening first-hand, speak to service users , their families and staff, and report their findings.

Healthwatch knows that people can feel excluded from services and that access to services and treatment is not always equal to all, so Healthwatch also has a signposting function to help people to navigate the health and social care system. The Care Forum is proud to provide three local Healthwatch projects in B&NES, Bristol and South Gloucestershire. We are independent, accountable and powerful, with the strength of the law and the national influence of Healthwatch England behind us. To find out more **W**: <u>www.thecareforum.org/healthwatch</u>

The engagement

Mencap Big Day Out

In addition to attending with an information stall, the three local Healthwatch also facilitated two smaller group workshops during the day, which comprising of professionals and people with learning disabilities.

The main workshops of the day were facilitated by Bindya Mistry, Mencap's Campaign Officer. Local Healthwatch got a lot of feedback from the service users who participated in these workshops. Further to this event, local Healthwatch will be engaging with Mencap on their recently launched health campaign. The campaign will enable people with a learning disability to be aware, or at least think about, their rights when they access any health settings, for example, hospitals for treatment, and to understand as a patient with additional needs their rights to have reasonable adjustments.

AWP Celebration Day

Local Healthwatch engaged with the attendees by hosting an interactive stall, which provided information in an accessible format that people with learning disabilities were able to read, understand and interact with.

Healthwatch asked individuals three questions:

- 1) Do you find it easy to communicate with the health services you use?
- 2) Do you get information from services in an easy to understand way?
- 3) Are you happy with the Care you receive from Primary Care Services?

Attendees were then asked to rate their experience in relation to the questions highlighted above by placing a red, yellow or green ball in each of the cylinders, which had a question attached to it.

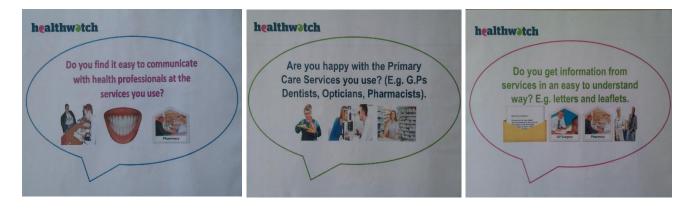
The colour coding:

Green
Red
Yellow

Yes No Maybe (Good or positive experience) (Negative or mixed experience) (Mixed views neither positive or negative)

You said...

Data analysis from the AWP Celebration Day



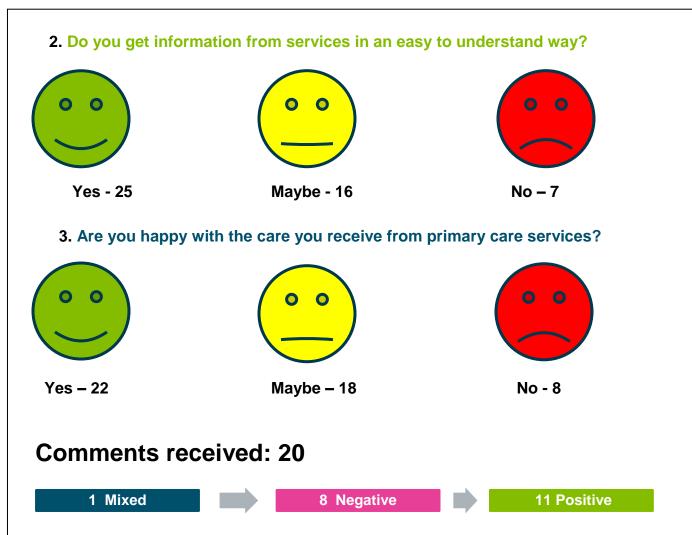
1. Do you find it easy to communicate with the health services you use?



Yes – 27







Primary care

Charlotte Keel Health Centre

- The commentator stated that they are able to get an appointment when needed. The commentator further stated that they are happy with the care and treatment received from both the doctors and nurses.
- The commentator highlighted their satisfaction with the service, in relation to the care they receive from the staff at the Charlotte Keel practice, particularly the reception staff, who were very respectful and professional.
- The commentator commented on the care they received from the treatment room at Charlotte Keel. The commentator stated that the healthcare assistants were very helpful and that they explained why the blood tests were being conducted and how long the results would take to be ready.

Wellsprings Surgery

• The commentator stated that they were prescribed a course of antibiotics by their GP to treat tonsillitis. However, the course of treatment was too short which resulted in the

infection not being treated effectively. Therefore, they were ill for a longer period of time than necessary.

• The commentator informed Healthwatch that the treatment and care they received at the Wellsprings practice was a positive experience.

Greenway Community Practice

 Commentator commented on their experience of accessing treatment at their Greenway Practice. The commentator stated that their experience has been generally positive which includes all aspect of their experience of accessing NHS services in Bristol in general.

Unnamed services

- "GP services are really good it helps with promoting my independence and information I receive from my GP is in easy read".
- "I don't understand what the doctor is saying to me. I need to take a support worker with me to appointments because they speak in jargon or use big words". N
- "Speech and language support is good at GP practices and hospitals".
- "Doctors don't speak to me directly, they speak to my carer which is not very good as a person who has an identity".
- "Having to wait a long time to get an appointment or to get seen by a medical professional is really hard".
- "Very good experience when visiting the hospital. I was given a separate room with own bathroom. Hospital food needs to be improved".
- "Good experience at the dentist because when I had an injection they explained what was going to happen after the injection".
- "Doctors and medical professionals don't speak with patients with LD".
- Positive experience as a patient with a learning disability who has a diagnosis of cancer. (P
- "My consultant was able to adapt his methods of communication to meet my communication needs by listening to what I asked and responding appropriately by drawing body charts and highlighting areas where the cancer is for me to have a record of conversations".
- "Waiting times for appointments are too long and too often people have to wait for them in pain".

- "Access to annual health checks is good and have a good dentist to support and treat me, and the nurses explain in detail what they are doing". (P)
- "Seeing the same GP would be good and communication across multiple health professionals is poor and needs to improve. (N)
- "Some staff not confident at talking to people with a learning disability".

KEY THEMES AND RECOMMENDATIONS

As highlighted above a total of 20 comments were received from commentators in relation to both primary care and secondary care services located in B&NES, Bristol and South Gloucestershire. These comments were analysed and key themes identified. The comments and feedback received about the services was generally positive: of the 20 comments received 11 were positive, eight negative and one of mixed sentiments

Data analysis in relation to:

- Staff and staff attitudes: the majority of commentators highlighted positive experiences in relation to the attitudes of reception and clinical staff at GP practices and hospitals, although Healthwatch heard several comments from people suggesting that communication needed to improve, with staff confidence in communicating being specifically highlighted.
- **Dignity and respect:** a lack of dignity and respect is sometimes experienced by people with a learning disability, especially when accompanied by a support worker to appointments. Some commentators reported feeling that medical professionals ignore their presence and instead, speak to their support workers rather than speaking to them directly.
- Administration: appointment availability and appointment booking systems were highlighted as an issue at some practices where patients are not able to get an appointment by calling the appointment line. Two commentators expressed their dissatisfaction with the time spent waiting for an appointment.
- Treatment and care: Healthwatch heard mixed feedback regarding patients' experiences when accessing treatment. Some commentators shared positive experiences, for example where treatment explanations had been provided clearly, and in formats that were accessible to them. In a few cases, commentators shared examples of practitioners going above and beyond to ensure patients understood what was going to happen and why.

This was not the case for all, with two commentators sharing that they do not always understand what medical professionals say due to the use of long words and jargon, which leads to them needing to be accompanied to appointments in order to be clear on what is wrong and what is going to happen.

• **Communication:** five commentators specifically highlighted communication as an issue; expressing their dissatisfaction with the way in which practitioners communicate with patients with learning disabilities and the need for this to improve.

Healthwatch will.....

The feedback Healthwatch gathers is used to inform Healthwatch Feedback Feed Forward quarterly reports, which are shared with key partners and stakeholders, including Clinical Commissioning Groups, Health and Wellbeing Boards, local authorities, the Care Quality Commission, NHS England and Healthwatch England. Where a service is named, Healthwatch will share feedback with them and offer an opportunity for providers to give a response to the comments received about their services.

The quarterly report is also presented to Healthwatch's Advisory Group for further engagement and action to be considered.

Looking forward...

Local Healthwatch welcomes and encourages the communities of B&NES, Bristol and South Gloucestershire to contribute to contribute their feedback to us using the communication methods included at the end of this report.

Healthwatch also supports members of community groups to become Volunteer Champions so that they can represent the experiences and needs of their members and help to spread the word.

Tell Us Your Story...

Local Healthwatch wants to hear from you about your experiences so that we can tell services your needs to create the best local services.



Email us: B&NES: <u>info@healthwatchbathnes.co.uk</u> Bristol: <u>info@healthwatchbristol.co.uk</u> South Gloucestershire: <u>info@healthwatchsouthglos.co.uk</u>



Call us: 0117 965 4444

Write to us at: The Care Forum, The Vassall Centre, Gill Avenue, Fishponds, Bristol, BS16 2QQ

Or visit our websites:

B&NES www.healthwatchbathnes.co.uk

Bristol www.healthwatchbristol.co.uk

South Gloucestershire www.healthwatchsouthglos.co.uk