



Snap shot study into GP Access & Quality of Experience for People with Learning Disabilities

February 2017

1. Introduction

It is estimated that 2% of the population in England have a learning disability, as many as 1,043,449 people, yet it is approximated that only 1 in 5 are known to services (Learning Disabilities, 2016).

Currently, in Bexley the number of adults with a learning disability known to GP's and the Local Authority is lower than the national average (Bexleygovuk, 2016).

Many people with a learning disability may in general be poorer due to living on benefits or having a low income which can lead to an unhealthy lifestyle and poorer health. Having complex needs can mean that they are less likely to access healthcare services and routine screening. Furthermore, not accessing services in time can lead to conditions presenting too late for the appropriate preventative care or treatment. Failure to meet the needs of a person with learning disabilities may lead to the inability to maintain good health and ultimately premature death.

A key to being able to participate in society is having good quality and meaningful information available, which is a fundamental human right. To be able to access information which is understandable enables a person to have choice and control over their own lives. It is especially significant to have medical information which is clear and understandable at crucial times.

Policies state that any person with a learning disability is entitled to have their health needs met (JRN, 2010).

Studies have shown that some people with learning disabilities are currently failing to attend an annual GP health check, which are necessary to identify and treat problems in order to maintain health and well-being.

In addition, a person with a learning disability may find it hard to communicate and may be seen as a low priority and due to this may put up with a lot of pain and discomfort before seeking help. Even then they may find it difficult to describe symptoms and understand what they are being told. Consequently, it is felt that a lack of awareness and understanding can lead to a wrong diagnosis (Mencaporguk, 2016).

2. Purpose of engagement

This snapshot study seeks to explore the experience of people with learning disabilities when accessing their GP surgery, in addition to the quality of care they receive when accessing the service.

3. Methodology

This study was undertaken by engaging with 61 respondents in the form of a short questionnaire at the 'Big Health Check Event' on 18th October 2016.

There are a number of limitations with this study. The study recognises that participants have different disabilities and the information collected may not be generalised to a wider set of people with learning disabilities. It must be noted that some participants seemed unsure how to interpret the questionnaire and needed guidance from their carer/support worker.

4. Results of the survey

Q1. How do you make an appointment with your Doctor?

32 people needed help when making an appointment, with 27 doing it by phone, 8 people went into the surgery and 2 made their appointment online.

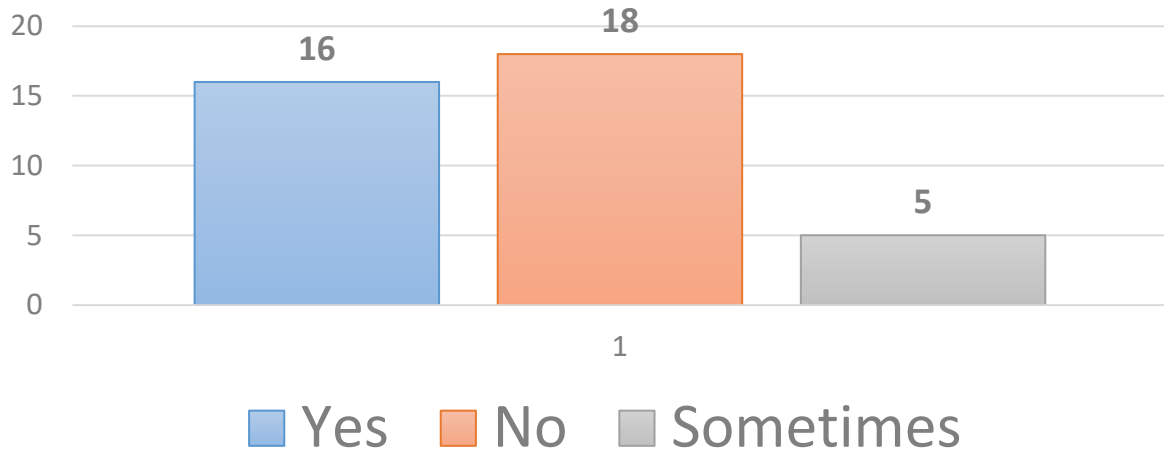
Recommendations:

To provide clear information that online booking is available.

Q2. If by phone, do you find this easy to do?

18 people found it difficult to make an appointment by phone, with 16 saying they found it easy. Getting an appointment can be difficult and help may be needed to make a phone call from a family member, support worker or carer. One participant quoted 'Appointments also need to suit my carer and also prompt appointments as my carer's time'.

Do you find it easy to make an appointment by phone?



Recommendations:

To have a record system in place to identify people with a learning disability, to then be able to make reasonable adjustments.

Staff to provide clear information, offer longer appointments and a reminder to take the black book to the appointment.

Q3. Do staff speak clearly?

23 people felt the staff spoke clearly, 10 sometimes and 5 said that the staff did not speak clearly. A person with a LD may feel that if medical staff do not understand what it is like to have an LD it may make them feel that they are not receiving the right support which can lead to non-compliance of treatment. Disability Awareness Training may help staff understand the difficulties that people have accessing services.

Recommendations:

To provide a system where all staff know if a patient has a learning disability so the support is in place.

To consider Disability Awareness training for all members of staff.

Q4. Do you get to see the same Doctor every time?

16 people said sometimes they saw the same doctor. 14 said they did not, with 10 saying they did always see the same doctor. People with a learning disability may feel the need to see the same Doctor for the importance of continuity of care, this will make them feel well supported, and to keep repeating to different medical staff the same thing can be difficult and make them feel uncomfortable. One person cited “I do not seem to have any continuity of care. I keep having to repeat things to different doctors or clinicians when the information should be clear in my notes or in supporting documents”.

Recommendation:

Where possible appointments to be booked more consistently with the same medical staff for continuity of care and support.

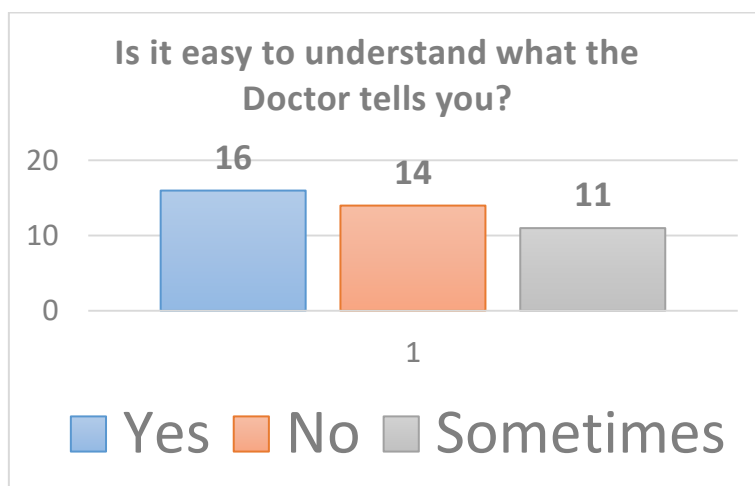
Q5. Do you find it easy to talk to your doctor?

20 people felt it was easy to speak to their doctor, 12 said it was not easy, with 11 people feeling it was easy sometimes. People with a learning disability are more likely than the rest of the population to have an impairment to communication and therefore require special consideration (Gmc-ukorg, 2017) in order to explain symptoms, understand their condition/conditions and to comply with any treatment.

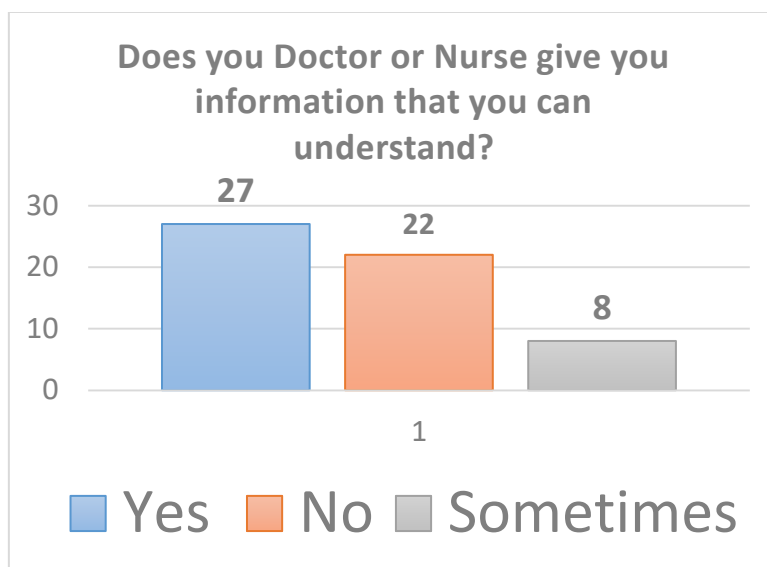
Recommendation:

To have prior knowledge of the patient in order to provide the best form of communication.

Q6/Q9. Is it easy to understand what the Doctor/Nurse tells you? (Please note 2 questions have been answered jointly)



16 people found it easy to understand what their doctor told them, 14 did not, with 11 sometimes. One participant cited 'Need to speak slowly, clearer, no medical jargon, simplify the information, need support as words get mixed up and forget at times'.



27 people said that the Doctor or nurse gives information that is understandable, but 22 other people said that the information is not understandable, 8 felt sometimes it was.

Recommendations:

All healthcare staff to be aware of a person with a LD.

Staff should try not to talk too fast and give the patient time to respond to what has been said, as it can take time for many people to process the words they hear (Gmc-ukorg, 2017).

To provide information that is accessible, for example Easy Read or braille, this can help enhance the person's experience of care and also inclusion of their health.

Q7. Have you had a health check at the Doctors in the past year?

31 people have had a health check within the last year, 10 have not.

Bexley have performed significantly worse than the national and regional average for carrying out health checks (Bexleygovuk, 2016). Annual health checks are critical to improve health outcomes, to help identify /treat medical conditions early, for health promotion and to develop relationships with medical staff (RCGP, 2010).

Recommendation

To increase the uptake of routine health checks

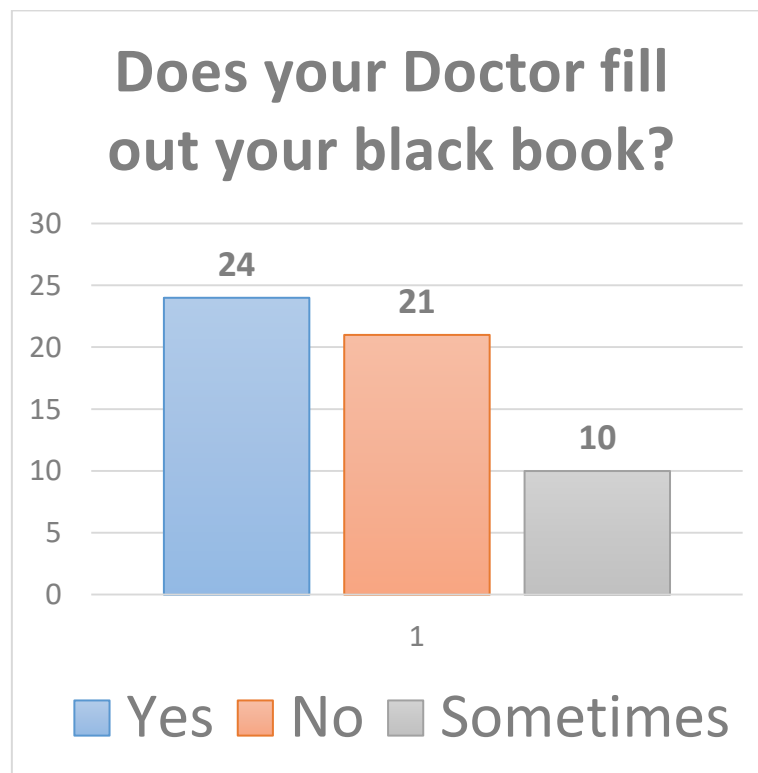
To follow up if a patient does not attend.

The health check should be explained fully, including the health benefits and the dangers of delaying or deferring action on symptoms.

Offer choice and try to make the appointment at a time of the week convenient to the person and their family/carers.

Follow up any actions/referrals.

Q8. Does your Doctor fill out your black book?



24 people said they have not had their black book filled out by the Doctor, 21 said they had, with 10 saying sometimes. Comments from participants included:

'Book is too small, not getting the right information across, need more easy read',

'They are not good, Doctor said they had never seen a black book'

'Sometimes I forget to take the book'.

'GP fills out if time or not at all'

'Doesn't ask for the book'

A support worker cited 'The black book is a waste of NHS money because the information is all over the place. Spaces are not big enough and there is no consistency to understand the patient's treatment plan.

Three participants said they did not have one.

The black book is designed to ensure that all the necessary facts about the owner are in one safe place and easy to find for continuity of care between the health professionals.

Recommendations:

Individual to be reminded on booking an appointment to bring black book.

To be used routinely, to be kept up-to-date by health professionals

To consider what format each individual's book should take

To re-assess the black book so it works to provide the correct and necessary information for other healthcare professionals.

Q10. Would it be better to have a longer appointment with your Doctor?

87% of participants said that it would be better to have a longer appointment with their Doctor



34 felt it would be better to have a longer appointment with the Doctor, only 6 said they did not need longer.

Recommendation:

To offer an individual a longer appointment on booking, this needs healthcare staff to be knowledgeable on who has a learning disability.

5. Conclusion

This study demonstrates that respondents were not always having their needs met, failure to do this may in some cases result in the inability to maintain good health and the premature death of a person with a learning disability.

The study further highlights the vulnerability of people with learning disabilities and their health conditions, and how a person's individual health has an impact on their experiences and ability to access services. Crucially, the study demonstrates that health checks should be followed up if a person does not attend, with longer appointments if necessary and understandable information provided taking into account the individual's needs.

It also needs to be considered that an individual with learning disabilities will have different needs and this should be taken into account by staff. As the number of residents with a learning disability is significantly lower in Bexley than national/regional averages, the correct data should be established to fulfil these needs, furthermore, to include those with mild to moderate learning disabilities. Reasonable adjustments should be made so an individual with a learning disability can use the service as well as anyone else and with the same dignity, care and compassion.

Healthwatch are in the process of working with 2 other organisations within the borough, Mencap and Speaking up. Following this, together we intend to further investigate the above issues arising from GP access and the quality of patient experience.

Recommendations:

1. To provide the opportunity for people with a learning disability to book a longer appointment.
2. To provide accessible information.
3. To increase the uptake of routine health checks.
4. To re assess the black book so as it works to provide the information necessary for healthcare professionals.
5. Collect patients from waiting room to assess mobility.
6. Healthcare staff training for understanding the wide range of learning disabilities and each individual as a whole.
7. To explain the dangers of delaying or deferring action on symptoms.

Additional:

On the day, attendees were asked to take part in an interactive survey where results were instant. The following questions in regard to GP's were asked:-

1. Are you registered with a GP?

98% said yes

2% were unsure

2. If you are registered with a GP (a doctor in your community) how good do you think they are at meeting the needs of people with a learning disability?

47% really good

29% ok

16% not good

9% awful

3. What is the most difficult thing about your doctor?

50% they never realise that I need additional help or support

50% it is difficult to book appointments on the phone

4. If you were in charge of healthcare in Bexley for people with learning disabilities would you spend money on.....?

28% making seeing a doctor easier for you

2% making seeing a dentist easier for you

14% put the money into big hospitals

56% teaching people with learning disabilities about healthcare



References

Mencaporguk. (2016). *Mencaporguk*. Retrieved 12 December, 2016, from <https://www.mencap.org.uk/sites/default/files/2016-06/DB/report.pdf>

Bexleygovuk. (2017). *Bexleygovuk*. Retrieved 19 December, 2016, from <http://www.bexley.gov.uk/CHttpHandler.ashx?id=13861>

Gmc-ukorg. (2017). *Gmc-ukora*. Retrieved 6 January, 2017, from <http://www.gmc-uk.org/learningdisabilities/302.aspx>

<http://jrn.sagepub.com/content/early/2010/06/01/1744987110370019.full.pdf> (Accessed: 21 November 2016)

Learning disabilities (2016) Available at: <https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/l/learning-disabilities> (Accessed: 14 November 2016). **In-line Citation:**