



**healthwatch**  
Bexley

**healthwatch**  
Greenwich

**healthwatch**  
Lewisham

---

## **Snap shot study - Looking After Your Mental Health**

### **Big Health Day October 2019**

---

#### **Big Health Day**

Working together, three south-east London Healthwatch organisations supported the Big Health Day. Organised by Lewisham Clinical Commissioning group, the Big Health Day was aimed at residents with learning disabilities, their families and carers, in Bexley, Greenwich and Lewisham.

Held in October 2019, the day offered advice on general health, mental well-being, information on cancer awareness and prevention, an opportunity for mini-health checks, eye tests and the chance to take part in sports, dance and other fun activities. Over 300 people took part in the day.

#### **1. Introduction**

It is estimated that around 2% of the population in England have a learning disability, as many as 1,500,000 people, but 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 at 902. 1,323 people with learning disabilities are registered with GPs in Greenwich, again lower than the national average) and In Lewisham 1,440 individuals with a learning disability are registered with a GP (Public Health England 2017/18)

People with a learning disability have worse physical and mental health than people without a learning disability. Life expectancy for women with learning disabilities is, on average, 18 years shorter than for women without a learning disability. For men, the difference is 14 years.

Evidence suggests that mental health problems may be higher in people with a learning disability. Some studies suggest the rate of mental health problems in people with a learning disability is double that of the general population (Mencap-Mental health Research)

There are many reasons why people with a learning disability are more likely to experience poor physical and mental health. A lack of access to resources and a higher incidence of negative life events is likely to contribute to poor health.

Many people with a learning disability are poorer as a result of living on benefits or low wages, making it harder to live healthy lifestyles. Healthcare services are not as accommodating as they could be for people with learning disabilities, making it harder for those with complex needs to access services and routine screening.

In 2017/18, just over half (52.5%) of women with a learning disability had been screened for breast cancer, compared to 68% of women without a learning disability. Less than a third (31.2%) of women with a learning disability received cervical smear tests, in contrast to 73.2% of women with no learning disability. Of those eligible for colorectal cancer screening, 77.8% of people with a learning disability were screened, compared to 83.7% of those without (NHS Digital, 2019)

Multiple studies (Mencap-Mental health Research) identify barriers stopping people with a learning disability accessing healthcare including:

- lack of accessible transport
- not being identified as having a learning disability
- staff having little understanding about learning disability
- failure to recognise that a person with a learning disability is unwell
- failure to make a correct diagnosis
- anxiety or a lack of confidence for people with a learning disability
- lack of joint working from different care providers
- not enough involvement allowed from carers
- inadequate aftercare or follow-up care

Barriers accessing healthcare can lead to late presentation and even more complex health needs which are then not amenable to preventative care. A lack of reasonable adjustments to access healthcare has been identified as a contributory factor in a series of avoidable deaths. The Confidential Inquiry into premature deaths of people with a learning disability found that 38% died from an avoidable cause, compared to 9% of people without a learning disability (Heslop et al,2013)

As part of the NHS Long Term Plan, the NHS wants to help people with a learning disability to live healthier lives by making services easier to use, investing in training, and offering more wellbeing support. This report will contribute to ensuring services meet the needs of people with learning disabilities living in Bexley, Greenwich and Lewisham (NHS Long Term Plan 2019).

## 2. Purpose of engagement

This snapshot study seeks to explore the experience of people with learning disabilities in regards to looking after their mental health.

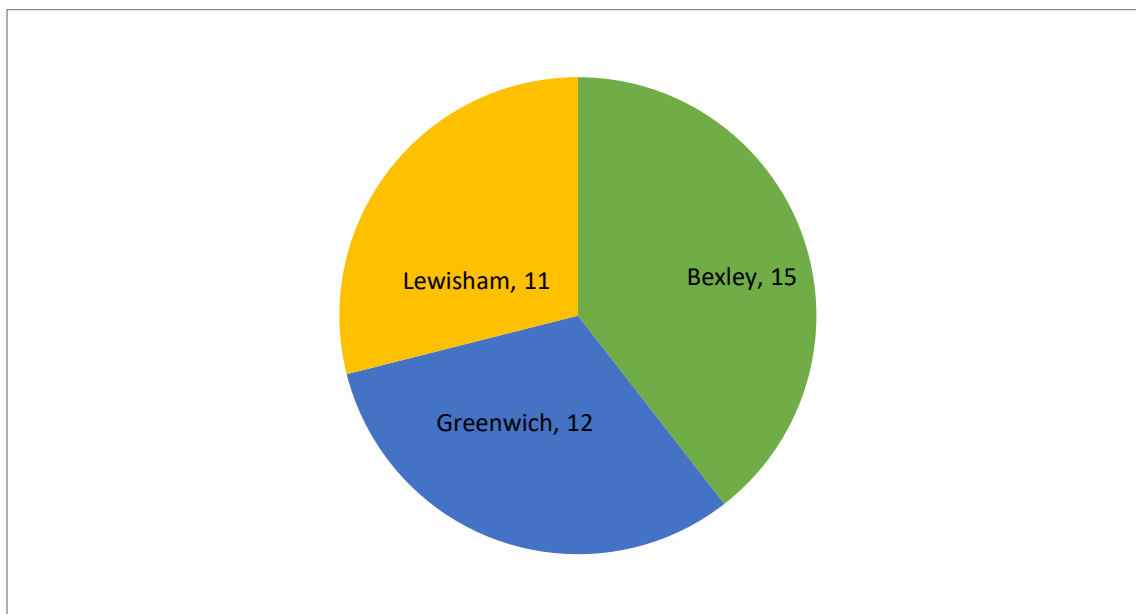
## 3. Methodology

This study was undertaken by engaging with 51 respondents in the form of a short questionnaire (38 completed) and a focus group (13 attendees) at the 'Big Health Day' on 25<sup>th</sup> October 2019.

We recognise participants have different disabilities and the feedback we were given, and our analysis of this information, cannot be generalised to a wider group 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 questionnaire

### Q1. Where do you live?



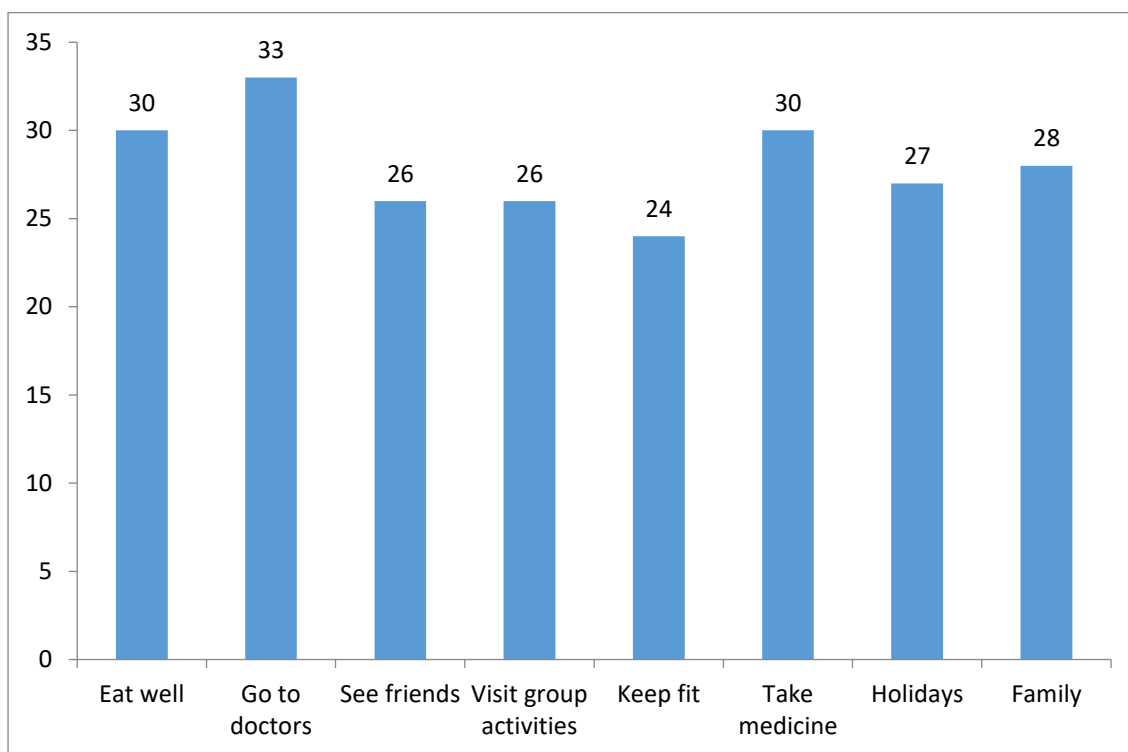
Of the 38 people who answered this question, most lived in Bexley, followed by Greenwich and Lewisham. Several Bexley residents lived on or near the Greenwich border and accessed joint or Greenwich based services.

## **Q2. Do you have poor mental health and if so, how does it affect you?**

Seven people did not respond to this question. Nine answered 'No'. Most of the remaining 22 respondents told us they felt sad, depressed or stressed. A range of reasons was given to explain low mood and the impact of low mood made it hard to get on with everyday activities, reduced appetite and created feelings of anger.

- *'I suffer with depression and hear voices'*
- *'Depressed'*
- *'Sometimes feel disillusioned. I have been on anti-depressants in the past'*
- *'Depression, worry, stress and lack of confidence'*
- *'Stressed as the authorities do not listen to needs of users'*
- *'Stress, hearing voices'*
- *'Affects everyday activities, interferes in normal functioning'*
- *'Sometimes is sad, happy when on medication'*
- *'Feel sad when it comes to my Fathers anniversary of death. When I feel sad it makes me feel better to talk'*
- *'Yes, sometimes I feel frustrated and angry'*
- *'Sometimes I feel very sad, next week I have my friends funeral'*
- *'Difficulty doing things on a daily day'*
- *'Mostly sad mornings and evenings, medications make me feel sick and light headed'*
- *'Sometimes feel sad'*
- *'Poor appetite'*
- *'Happy most of the time, sad when not taking medications'*

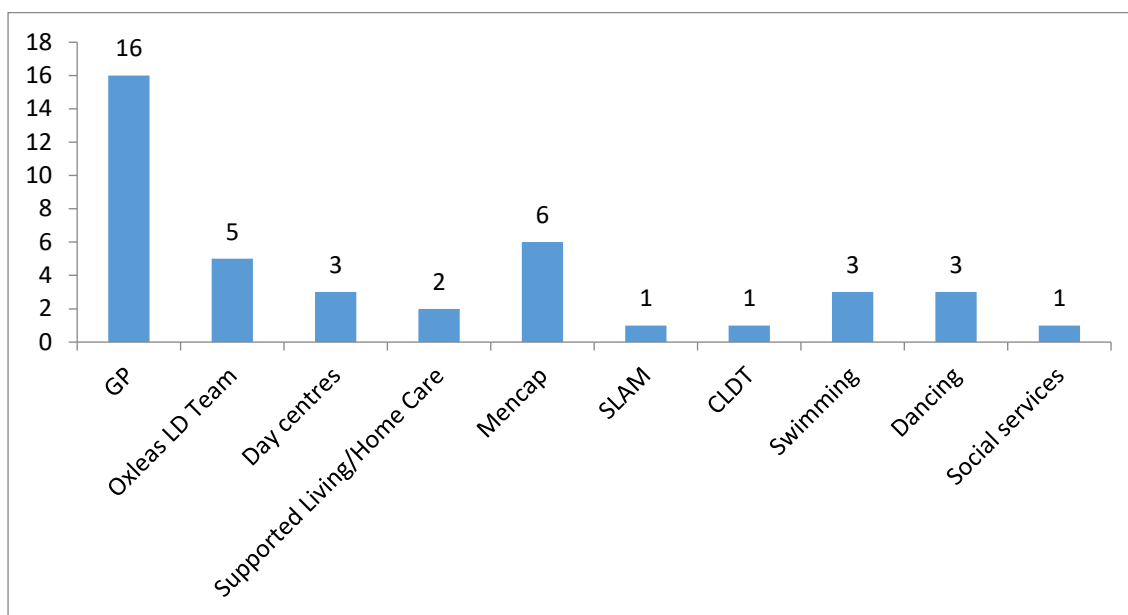
### Q3. What do you do to keep yourself mentally well?



The most popular responses included seeking medical advice (when feeling depressed or down), taking medication and eating well. Spending time with family, friends and going on holiday were also used to lift mood or avoid feeling down. Taking part in group activities and keeping fit were also suggested but were slightly less popular options.

Other ways to keep mentally well included: shopping, visiting the cinema, days out, dancing, playing music, pampering yourself, chatting with friends/staff, relaxation, going to church, art, knitting, swimming, yoga, going to the library, meeting people, going to parties and playing or watching sport.

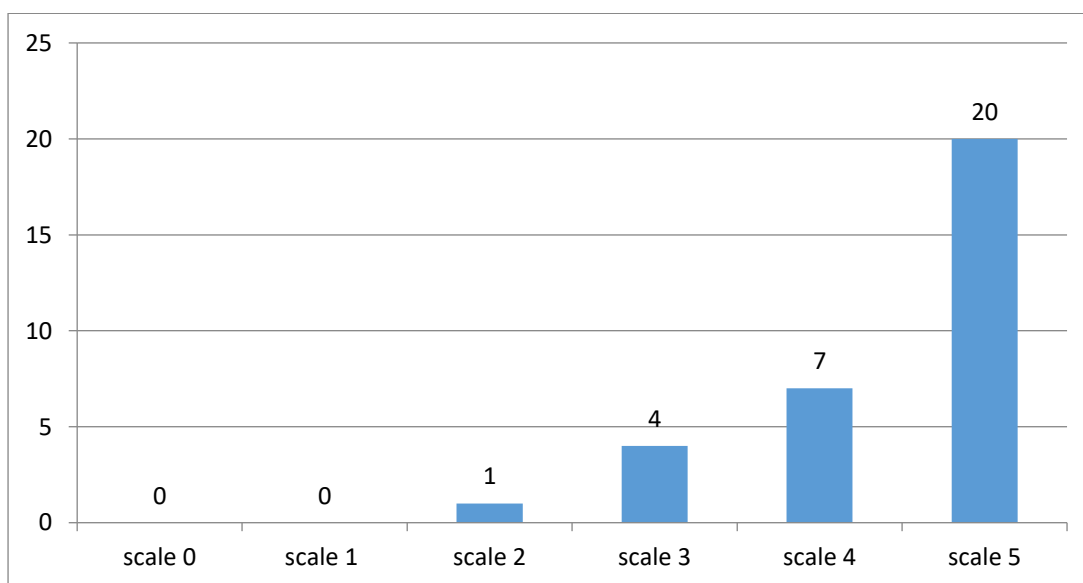
#### Q4. What services do you use that help you with your mental health?



Seeking advice from their GP was overwhelmingly the main source of help for our respondents.

#### Q5. On a scale of 0 to 5, what do you think about the services you receive.

0 being not good and 5 being very good?



Most people, their families and carers, told us they were very happy with the services they received.

## **Q6. How can we (Healthwatch) help you with your mental health?**

Many of the people we spoke to told us they wanted to take part in more activities. For some this meant more information on what leisure pursuits and volunteering opportunities were available. Access to information on how to stay healthy and how to access healthcare services was also suggested.

Some said services were difficult to access or had long waiting times and they were not always properly listened to.

- *'More information on services and what they offer'*
- *'Better assessment'*
- *Allowing me to eat whenever I want.*
- *'Look after myself'*
- *'If people feel down, go out and get help - go to doctor'*
- *'More volunteering with Healthwatch'*
- *'If a service could be provided for the learning disabilities to practice what to expect when visiting the GP'*
- *'More dancing, swimming'*
- *'By making things more easy to access and to be listened to'*
- *'More activities to do'*
- *'Encourage me to motivate myself'*
- *'More doctors and nurses'*
- *'More helpful people. More things to help people with depression'*
- *'I'm happy at the moment'*
- *'Long wait for appointments'*
- *'I'm ok at the moment, I know where to seek help if I need it'*
- *'Providing more activities for the students'*
- *'Give us more activities, like more for learning difficulties'*
- *'Better availability / ease of access to therapy'*
- *'Counselling'*
- *'Continuing to do a good job and researching'*
- *'More exercise'*

## **Q7. Have you got a message you want to share with services to make things better?**

Access to services was an issue for several of the people we spoke to. We were told about difficulty booking appointments, long waits for assessments/appointments, lack of support for families, poor communication and a lack of understanding from service providers. Others

said they wanted to see the same doctor, who knew them, when visiting their GP surgery because they felt they were not always understood by new doctors.

- *'The GP is now very good and not too far to travel to and very handy'*
- *'Better access to the services, better understanding of the conditions and illness. Better communication between the family and the service provider'*
- *'Happy service'*
- *'Better assessment and support for family'*
- *'Want to see the same doctor when they visit the GP'*
- *'Would like to see the same doctor whenever he visits the GP. Three different GP's are not good enough for him, he prefers to keep just one and to see only the same one always'*
- *'Need to be honest about how you are feeling, don't pretend everything is ok'*
- *'Happy with everything'*
- *'To talk to someone, especially at the Carlton Centre, they are really good listeners'*
- *'More visits'*
- *'Meet MPs and understand more about their work and how we can influence them'*
- *'When there is a visit to the GP, the doctor should concentrate on the one patient and not the staff working with them. If they can't answer before the doctors should turn to the staff. Also they would prefer to have the same doctor always and having a female doctor, preferable, talking to them about smear test'*
- *'Very difficult to get appointments, usually up to 4 weeks wait'*
- *'I would like to see more services please'*
- *'I'm happy and hopefully services will help me in the future when I use them'*
- *'Make sure to give the right support to help people with depression. It's really important'*
- *'Getting appointments sometimes very difficult'*
- *'Make it more enjoyable for us (people with a LD)'*
- *'Easy ways of booking appointments'*
- *'Happy with all the services'*
- *'More activities to do to keep mental fit, more education, more support from the community'*
- *'What to make everything better for the service is getting'*
- *'Open more centres for people with learning difficulties'*



## **5. Bexley Speaking Up Group- Mental Health Focus Group**

During the Big Health Day, Bexley Speaking Up Group held a session on Mindfulness and Mental Health. 13 people attended the session.

### **Q1. Describe what the term 'Mental Health' means to you.**

*Depression                      Stress                      Anxiety                      Bi-polar*

*Schizophrenia                      PTSD                      Paranoia                      Hospital*

*Being Sectioned                      Mis-treatment*

*Not being looked after in hospital properly / tossed aside / locked up*

*Winterbourne View Hospital-where people were locked up*

*Seeing people on television in Asylums*

### **Q2. What makes you feel stressed?**

*Bereavement / Traumatic events*

*Lots of noise*

*Not having a voice – being silenced*

*The weather, especially rain. It makes my legs hurt*

### **Q3. Top Tips to make you feel better**

*Watch television*

*Word searches / colouring*

*Going on a trip / holiday*

*Going out with friends to the theatre or pub*

*Go to the All Stars fitness group*

*Do something that distracts you*

### **Q4. What makes you feel mentally unwell?**

*Hearing bad news on the television- especially if people have died*

*Lack of sleep, because I am thinking about things*

*If someone hurts my feelings / arguments*

## **Q5. Top tips to make you feel better**

*Talk to the person who has upset you*

*Talk to a support worker / member of your family*

*Get some exercise and fresh air- walk the dog, go swimming, do some gardening*

*Go to the pub and have a drink*

## **The Speaking Up group advised that the best ways to feel better were to:-**

*Relax your muscles and mind*

*Try to move every day, being active reduces stress and helps you sleep better*

*Do more feel good things and if you can write these things down*

## **Have you been worrying about anything?**

Using the NHS / One you / every mind matters quiz, we asked the group to share anything they were worrying about ( <https://www.nhs.uk/oneyou/every-mind-matters/your-mind-plan-quiz/>)

Lack of support for housing problems, financial difficulties, significant life changes and ill-health were all raised as areas of concern. Many told us that talking about these things in a group was hard for them and most wanted support on a 1 to 1 basis, in a private space, but these services were not available or available, but not accessible. For example, one respondent told us about a housing support service that holds sessions in local libraries where conversations and personal information can be overheard.

## **6. Conclusion**

Most of the people we spoke to are happy with the services they receive, although we were told that not all services meet their needs, and some are difficult to access.

Many of the residents with learning disabilities we spoke to told us they experience poor mental health and seeing their GP was the main source of support when feeling low. Many try to keep themselves as mentally well as possible by spending time with family and friends or taking part in leisure or fun activities.

Those we spoke to wanted to be better supported to make healthy life choices. This included more accessible information on how to stay healthy and what leisure and volunteering opportunities are available.

A smaller number told us they did not always feel understood by healthcare services.

### **Recommendations:**

- Health and care services should support people with learning disabilities to make healthy life choices
- Encourage local mental health services in all boroughs to organise events / develop easy read materials that raise awareness about mental health for people with learning disabilities
- Further research projects looking to explore the experiences of people with learning disabilities and their mental health
- Health and care services should raise awareness of leisure and volunteering opportunities available to people with learning disabilities
- Healthcare professionals should be trained in communicating effectively with people with learning disabilities, making sure they understand the issues that affect them, and involving them and their families in any decisions made around their health.
- Ensuring continuity of care for people with learning disabilities, seeing the same health professional can create a more relaxing environment for patients
- Health and care services should make reasonable adjustments to ensure the needs of people with learning disabilities are met
- (If not already existing) Work with local advice organisations to offer information and advice hubs for people with learning disabilities which discusses issues relating to housing, money, life changes etc

### **Acknowledgements**

We would like to thank everyone who took part and generously shared their views with us and we would like to thank our volunteers for their support on the day.

## References

<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health-research-and-statistics>

<https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/l/learning-disabilities>

<https://www.longtermplan.nhs.uk/areas-of-work/learning-disability-autism/>

<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics>

<https://www.nhs.uk/oneyou/every-mind-matters/your-mind-plan-quiz/>

*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:**



Questionnaire for health day 2019.pub