



healthwatch
Luton



Summary Findings 2019 Baseline Survey Collation: Learning Disabilities

Supporting
NHS70

Why are Healthwatch Luton focusing on learning disabilities?

Healthwatch Luton are the independent consumer champion for health and care services in Luton

Healthwatch Luton gather feedback from all areas of the community and during the last twelve months noticed there was feedback about diagnosis of children with a learning disability and a lack of support for those awaiting a referral or diagnosis. After further research it was clear there was not as much feedback from adults who are living independently with a learning disability or from those caring for an adult with a learning disability in the community.

Cambridge Community Services (CCS) provide the community paediatric service for Luton at the Edwin Lobo Centre, where they provide secondary care and diagnosis for children in Luton who have a developmental, physical or learning disability. Luton have several Boards that run to engage with the community, such as the Learning Disability Partnership Board.

The NHS Long Term Plan (LTP) has a focus on those with a learning disability, autism or both. There is a focus to ensure everyone has a healthy start in life, they have access to the right care and support and medication is given when needed. This is to be done by focussing on timely diagnosis, the right support in the right environment and training staff to a more competent level.

Within Luton, there is a population of around 216, 800 people. Of this population, there is 684 people who are registered within their GP practice as having a learning disability (JSNA 2015). There are 5467 estimated children who have a diagnosed learning difficulty, learning disability and/or autism in Luton (PHE, 2018).

Why carry out a survey?

As part of a wider Learning Disabilities project and research wanted to hear from the wider population of Luton about learning disabilities

People often use the term 'learning disability' and 'learning difficulty' interchangeably. For the purpose of this project, Healthwatch Luton wanted to focus on those who have a learning disability and those with autism, or both.

Healthwatch Luton wanted to find out how people were living independently and how they found accessing certain aspects of every day life. The purpose was to collate a baseline of those individuals living independently or caring for someone with a learning disability and the effect it has on their every day living within Luton.

The survey was available in an easy read format, as well as online.

The questions asked did not invite individuals to disclose any medical diagnosis or concerns.

This survey was part of the wider research and intelligence gathering for the Learning Disabilities project. Healthwatch Luton have also run professional and public forums, attended a variety of Boards, were involved in SEND workshops and carried out targeted engagement.

What was in the survey?

Questions asked in the survey were kept to yes or no answers for ease and speed of completion

The latest strategy from Luton Borough Council for those who have a learning disability and autism, or both, focusses on ensuring the people of Luton are 'living a good life'. This strategy was used by the workstream, which includes staff, Champions and Board Members of Healthwatch Luton, to create the questions.

There were six questions in the survey that required a yes or no answer:

- *What sort of accommodation are you living in?
- *Are you currently in paid employment?
- *Are you currently volunteering?
- *Are you able to access sports and leisure activities?
- *What time are you able to access public transport?
- *Do you have a Health Action Plan?



How was information gathered?

The survey was available online and was taken to all engagement including targeted engagement and forums. The survey was available in easy read format.

Targeted Engagement is where Healthwatch Luton speak to Luton residents about their general health and social care experiences, out in the local area, by attending local groups, organisations and service providers.

Healthwatch Luton hold forums, where there is a specific focus on an area of the health and care system, or to speak with a particular audience, such as professionals, or patients of a certain condition.

Individuals were asked to mark yes or no to the questions, and there was an option to have free text to elaborate on any of the questions. Individuals were not asked to disclose personal diagnosis or medical concerns, but did have the option to provide further feedback.

Patients were able to leave personal details if they would like to take further opportunity to provide feedback to Healthwatch Luton.

The forms were collected at the end of the targeted engagement and returned to the office, where they were collated together to draw any themes or any further need for information.

Findings

Most responses were from adults with a learning disability

With regards to **accommodation**, 50% of people were living in a supported living environment. One person was living alone. 20% of people were living with their parents.

Of the responses, 20% of individuals were in **paid employment**, and 50% were currently **volunteering**.

70% of people felt they were able to **access sport and leisure** activities, with some individuals noting the cost of activities as a barrier to carrying them out, specifically swimming stating 'I only swim because of my legs, but only if my mum has the money' and 'I swim for my asthma, but that's only when I can afford it'.

Regarding **public transport**, individuals were less positive with only 50% of people able to use or access it. Two people noted time restrictions with one person stating they use it 'when it runs! And that's not after 7pm!'. Another patient felt able to use it on weekends and weekdays 'after 9.30am'.

Only 20% of people had a **Health Action Plan**, with one individual stating that they 'don't want to bother with a health action plan, [as they] can't keep up with it'.

'Paid opportunities for people with learning disabilities are few and far between. Lots of restrictions are put in place. Not everyone wants to volunteer. Voluntary services put barriers up too (No insurance, Health and Safety concerns etc)' - carer of an adult with learning disabilities

Highlights



~ Cost can affect how and where people are able to access services

~ The use of a Health Action Plan needs to be reviewed as it is not really used by many service users

~ There is not enough paid job opportunities for those with learning disabilities

In conclusion

The survey could have garnered more responses, but perhaps needed to be in a different format or environment.

Healthwatch Luton will inform people to improve care and will review these findings and share them with providers.

The results of this survey will feed into the larger thematic report on learning disabilities, due in late March 2020.



What next?

Healthwatch Luton will continue to work on their long term project about learning disabilities

We will continue with the project of learning disabilities, to ensure the voice of those is heard who are using services. There will be a report at the end of March 2020.

We will continue to gather feedback from the public about learning disability services at public events and through our targeted engagement.

We will make recommendations system wide within Luton, to improve knowledge, support and care for those living with, supporting others to live independatly with a learning disability.

What does Healthwatch Luton do?

We are the independent consumer champion for health and social care in Luton

We listen to your experiences about health and social care



We provide Commissioners and Providers your feedback to help improve the services



We signpost and provide information and advice for people in Luton



We report our findings to Healthwatch England, the CQC and NHS England



We scrutinise services and make recommendations for change based on your feedback



We represent your voice for health and social care services in Luton

**Have
your
say**

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