



healthwatch
Luton



Summary Findings 2019 Public Forum with Panel: 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 or autism in Luton (PHE, 2018).

Why carry out a Public Forum?

As part of a wider project and research Healthwatch Luton 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 give those who have a caring responsibility for, or are an individual living independently in the community, with a learning disability the opportunity to share their experiences of health and social care.

Professionals were invited to attend from a variety of backgrounds. In attendance on the day was Amy Kay - Luton Clinical Commissioning Group, Val Sheridan - Luton Borough Council, Yvonne McKinley - POhWER and Kamal Benpali - Community Outreach (Belle Vue Residential Home).

There were 15 attendees, who were parents and carers of those with a learning disability, people with a learning disability, and support workers who were attending with their clients.

The topics covered did not invite individuals to disclose any medical diagnosis or concerns. There was an opportunity at the end of the forum, for questions to be asked of the panel to garner their professional opinion.

This forum is part of the wider research and intelligence gathering for the Learning Disability project. Healthwatch Luton also ran a professional forum, a baseline survey, attended a variety of Boards, were involved in SEND workshops and carried out targeted engagement.

What is a learning disability?

The term 'learning disability' is interchanged by professionals and individuals alike

Healthwatch Luton asked the attendees what they felt the definition of a 'learning disability' was.

The phrase is interchanged by a lot of people for 'learning difficulty', 'additional needs' and 'special needs' to name a few. Some attendees felt that the definition was 'unfair to include about intellectual ability' as they felt learning difficulties like dyslexia were a learning disability.

Healthwatch Luton's definition was taken from The Department of Health and Luton Borough Council. For the purpose of the project, the definition was decided as:

"Someone with a learning disability has a significantly reduced ability to understand new or complex information and has a reduced intellectual ability, resulting in a reduced ability to cope independently, socially, financially and every day. This starts before adulthood. People with a learning disability may also have physical and mental disabilities. People with learning disabilities tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people. The level of support an individual needs depends on individual factors, including the severity of their learning disability.

The term 'learning disability' does not include all those who have a 'learning difficulty', such as dyslexia or dyspraxia, which is more broadly defined within education legislation.

For the purpose of this definition of learning disabilities, autism is a separate condition and remains so"

What works well?

When asked what was working well, attendees felt **training**. 'All professionals receiving the training required to carry out their role' and the **right professionals** doing the job roles, such as a 'change of SENCO' were working well. Some felt 'good health professionals' were what was working well. 'The **care** you get from the front line staff' was also a positive. Having 'teachers who care' and 'correct individual support' was working well for some individuals.

'Family **support** often works better than paid support' for some families, and others mentioned 'support from staff [was] is helpful'. Some individuals noted 'going to day care is good' and 'sign language helps'.

One family felt 'obtaining a **EHCP**' was what had worked well for them. One attendee stated that 'if you don't break their **routine**' that works well for them.

Annual Health Checks

Attendees were asked:



'Do you or your child, have your Annual Health Check with your GP?'

80% responded 'No' with 20% stating they were 'not sure'

What does not work so well?

A lot of people gave feedback when asked what was not working so well

Those who were parents of children and young people felt there was a need for **more training** for staff. 'SENCOs are there for a wage, not a service'. Some people felt it was a 'fight to get an EHCP' for some young people, and their voices as 'parents [was] **not being listened to**'. It was felt there was 'a **lack of support** from school' and 'no understanding or care' given to children and young people who had a **diagnosis**. Parents or carers felt there were 'barriers' to getting diagnosed, 'a long time to [be] diagnose[d]', with some feeling they had faced 'a fight to be diagnosed'.

People felt the way staff **treated** individuals was something that was not working so well. Individuals felt **communication** was a frequent concern. Individuals felt they were 'rushed', 'not listened to' and professionals 'tone or voice [was] too loud'. Feedback included: 'sometimes people talk too fast', there were 'too many people talking at the same time at me', and they were 'not breaking information down'. Individuals also felt they were not spoken to directly by professionals by 'not explaining things to me, just talking to my staff' and 'not making eye contact when talking to me'. It was felt 'presumptions when doing capacity tests' meant that it showed 'professionals [have an] inability to know when a person understands a questions'.

There were concerns **accessing the GP**. People stated they were 'not able to book appointments in advance' and had long waiting times in other services. 'Long queues in hospital emergency department' were felt to be of concern to some. It was felt 'not being able to see the same GP' and 'consistency' 'needed to be taken seriously' by professionals.

It was felt that the **information** shared was not always done so in the best manner or was 'disjointed' or 'not available'. It was felt that the

What is most important?

Everyone was asked what was most important to run a service and what could be done to improve systemically in Luton

One of the most important things for the attendees was the **'consistency'** of care, for example 'seeing the same GP'.

Having **'clear pathways'** and 'carer support' were important. There was a feeling of needing **support** post diagnosis to 'support parents with diagnosis' and to 'support children with diagnosis'.

There needs to be 'co-ordinations of care and appointments' and **'communication'** between professionals'. People wanted to 'be listened to and taken seriously', by the 'professionals willing to listen [to me]'.

It was felt the individuals should be 'proud of themselves about achieving something' and trying 'to get the people to have most **independent life** as much as possible'.

Time was considered important and 'health professionals having time and resources to be able to understand individuals health needs', as well as 'dealing with people as **individuals**, not conditions'. It was felt that 'care providers delivering safe and personalised care to individuals' was important.

'Personal relationships', 'speaking with friends', 'visiting friends' and [attending] 'social clubs' were all noted as being important to individuals.

Key to change

Whilst considering the most important thing to them, attendees were asked how this would be achieved

It was felt '**listening to parents**' and those who 'know the child best' would help to achieve the change. It was felt that '**support** from the school' was also key to change.

Professionals 'having [their] **training** kept up to date' and 'GP and staff training' about learning disabilities were felt to be key to change. 'Consistent and continuity of care' from 'support staff and health professionals' were felt to be a key to change.

'**Knowledge**' and '**active listening** from professionals' was key to change. Individuals felt 'medical staff, consultants and specialists need to talk to each other to improve and resolve patients needs' and having '**joined up care**' would help.

It was felt that '**funding** specifically for people who are not assess for social care needs, but stil have needs that block access to life' would help, as well as 'maybe each [individual] having a '**support worker**' whose duty it is to advise, befriend and mentor the child/young person and their family'.

It was felt that 'working around the **individual's needs**' would help. Having 'smoother **transition** from child to adult services' would be key to change for some individuals.

'As part of their job description, any Heads of House, Head Teachers, Heads of Years, SENCOs, should be told to attend parent and professional forums' - parent of children with learning disabilities

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



What next?

Healthwatch Luton will continue their project on 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.

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