



‘Champions and challenges’

An in depth look at the health and social care experiences of those who have a learning disability and/or autism within Luton



Acknowledgements

Healthwatch Luton would like to thank all the residents of Luton, service users of organisations and professionals who have been willing to share with us their experiences and journeys with health and social care in the Borough. Without people sharing their experiences with us, Healthwatch Luton would not be able to provide recommendations and changes to commissioners and service providers to improve service delivery.

Healthwatch Luton would like to thank the providers, professionals, and organisations for taking the time to have independent conversations with us over the last year. Also, we wish to thank those for inviting us to participate in forums, events and workshops, and to opening up to us the services they run.



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What is Healthwatch Luton?

Healthwatch Luton is the independent consumer champion for health and social care within Luton.

There is a local Healthwatch within every local authority area, independent of the local authority. All Healthwatch are set up independently and can be in a variety of ways such as a charity or Community Interest Company. Healthwatch Luton is a Community Interest Company.

Healthwatch Luton is part of a network of local Healthwatch. Healthwatch England is an overarching organisation offering support to the network of local Healthwatch organisations across the country and who sit as a committee of the CQC.¹ Healthwatch Luton gathers feedback from the public of Luton and shares this with the commissioners and providers of our local health and social care services to ensure the views of the community are represented. The feedback we gather influences decisions and enables people to access advice and information about their local services.



Healthwatch Luton staff June 2019

Healthwatch Luton are part of the BLMK (Bedfordshire, Luton and Milton Keynes) ICS (Integrated Care System)². BLMK covers all of Bedfordshire, Luton and Milton Keynes. The ICS includes the local Clinical Commissioning Groups (CCGs), NHS organisations and local organisations who will be able to share resources and provide a more joined up approach to care and treatment.³

¹ <https://www.healthwatch.co.uk/node/1102>

² <https://www.england.nhs.uk/integratedcare/integrated-care-systems/>

³ <https://www.blmkpartnership.co.uk/>



Healthwatch Luton workplan

Why was there a focus on learning disabilities in Healthwatch Luton's workplan for 2019 -2020?

Healthwatch Luton aim to gather feedback from all areas of the community and during the prior twelve months noticed there was feedback about the 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.

Healthwatch spoke to around 130 people for the purpose of this project. The project was made up of some primary research into what was currently happening within Luton for this cohort of people. This included assessing what meetings took place and ensuring representation at these meetings. Healthwatch Luton reached out to different groups, such as The Parent Carer Forum and the Learning Disability Partnership Board. The Ofsted

Report that took place (Local area SEND inspection) ⁴ was published late in 2018 and there was specific work taken on for this in the local area, which Healthwatch Luton were able to attend, taking the public voice and be involved in workshops for the co-production for improving the outcomes for children and young people with SEND (Special Educational Needs and Disabilities) in Luton. Healthwatch Luton held forums for the public and for professionals to be able to share their experiences of health and social care in Luton. During this project we also carried out a baseline survey to gather feedback about how individuals were able to access services in Luton. We wanted to ensure this seemingly seldom heard group of people were able to share their experiences and have their voices heard. Most data and feedback gathered was by Healthwatch Luton attending places where there were already individuals meeting or attending.

Healthwatch Luton wanted to hear more from those who were living independently or with caring responsibilities of those with learning disabilities in Luton

⁴ <https://files.ofsted.gov.uk/v1/file/50056374>



Introduction

There are a variety of different learning disabilities that are diagnosed in the UK. Most learning disabilities are diagnosed in early childhood and are the result of serious illness in childhood or individuals are born with them. ⁵

According to the JSNA (Joint Strategic Needs Assessment) for Luton Borough Council, a learning disability is life-long and affects all aspects of an individual's life. People with learning disabilities are noted as having a lower life expectancy than the wider population, due to the challenges they face in life. The JSNA recognises it is important to realise that needs change over the person's lifetime and that services need to support this and change with the individual. Many people with learning disabilities live at home with their parents, who in turn age and then the individual with learning disabilities can take on the role of a carer at times.

It is believed there are approximately 1.5million people in the UK who have a

learning disability and around 350,000 of which the diagnosis will be severe.⁶

NHS digital published a report in March 2019 which stated in England there are more males than females with a learning disability, and those with a learning disability are less likely to age well. Those with a learning disability are more likely to have a comorbidity, such as dysphagia or epilepsy. It has become more apparent that those with a learning disability are less likely to be tested for certain kinds of cancers and are also more likely to have high blood pressure. Illnesses, such as COPD, are less prevalent in those with a diagnosed learning disability.⁷

The NHS Long Term Plan: Learning Disabilities and Autism (NHS LTP) has a focus on learning disabilities and autism.⁸ There is a hope to increase annual health checks of those with a learning disability, so around 75% of eligible people are having them. This should significantly impact and tackle comorbidity and reduce preventable deaths within this cohort of people. There is a desire to improve the overall understanding of the needs of people with learning disabilities and

⁵ JSNA 'Adults with learning disabilities' Luton Borough Council 2015

⁶ NHS Choices What is a Learning Disability

⁷ Health and Care of People with Learning Disabilities, Experimental Statistics 2018 – 2019

⁸ <https://www.longtermplan.nhs.uk/areas-of-work/learning-disability-autism/>



autism. This will involve working together to improve their overall health and wellbeing. There is a hope to reduce waits for diagnosis of autism and associated learning disabilities. This is to be done by working collaboratively with social care to ensure all of those with a learning disability or autism diagnosis, have a key worker. There will be a need to invest more appropriately to ensure that the individuals are able to live a fulfilling life, in the best way for them. This could involve working together to improve the quality of care provided in the community.⁹

Part of the LTP is aiming to improve the oral health care of children, young people and adults with a learning disability and/or autism. The Chief Dental Officer in England plans to launch a wider project that includes dentistry, audiology and optometry.

In the 2018 -2019 figures, it was estimated there were around 4 people per 1000 with a learning disability and/or autism in Luton.¹⁰ This is above the national average for England. Luton reported lower

than the national average of Section 42 Safeguarding enquiries of vulnerable adults with learning disabilities. The CQC have recently published a report that focuses on a closed culture within services. The idea is to give inspectors and their managers information on how to identify a closed culture and to act accordingly. This should prevent incidences of hidden abuse and how it is better for the inspectors to respond in such instances.¹¹

Assessment and Treatment Centres (ATUs) have been pulled into the spotlight through programmes such as Panorama and through journalistic reporting.¹² The people who are within these ATUs are often detained under The Mental Health Act and have a learning disability and /or autism. The government had pledged to reduce the numbers of people who are inpatients in these ATUs by 30-50% by March 2019. This target has not yet been met. It was felt that restraints are used disproportionately to the needs of the individual in these settings, and as such, medication is given.

⁹ <https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/a-strong-start-in-life-for-children-and-young-people/learning-disability-and-autism/>

¹⁰ LBC Living a Good Life in Luton Strategy 2019 -2024

¹¹ https://www.cqc.org.uk/sites/default/files/20191104_clos_edcultures_supportinginformation_full.pdf

¹² The failings in learning disability services in six charts - BBC



STOMP (Stop The Over Medication Of People with a learning disability) is a national NHS campaign¹³ that is looking to stop the over medication of those with a learning disability and/or autism. In Luton, this is something that ELFT and LCCG are working towards. The purpose is to ensure those who have a learning disability and/or autism are not medicated using medication such as anti-psychotropics when there is no need to be. It is believed by Public Health England, that around 30,000 – 35,000 adults are taking these kinds of medication without a need to be. Healthwatch Luton have been involved in some of these conversations locally and are aware of the plans and actions in place to ensure this work is carried out in Luton. Healthwatch Luton have links between ELFT and LCCG to support in any way needed, ensuring the public voice is represented.



¹³ <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>



In Luton

As of 2016, around 5% of adults with learning disability in Luton, have been part of the support placement scheme 'Shared Lives'.¹⁴

Nationally there is a desire to reduce inpatient bed capacity (of those with a learning disability). Luton and Dunstable University Hospital (LDH) have a strategy¹⁵ in place for those with a learning disability and they also have learning disability nurses available to assist both inpatients and outpatients during hospital attendance.

Within Luton there is a population of around 214,100 people.¹⁶ Of this population, there are 684 people who are registered with the GP Practice as having a learning disability, according to the JSNA (2015)¹⁷. There are 5467 estimated children who have a diagnosed learning difficulty, learning disability and/or autism

in Luton¹⁸. Healthwatch Luton fed into the JSNA 2015 figures and it is worth noting, the local JSNA is due to be updated shortly, and Healthwatch Luton have given some input into this also.

More recent data from NHS Digital, based on the year to date from April 2019 until now suggests there are 729 people registered with GPs on the learning disability register, and 202 have already had their annual health check this year. Data from 2018 -2019 evidenced that 44% of people with a learning disability registered with a GP, were receiving their annual health check. In the last year (cumulatively to date) 96 out of 729 who are over 18-year-old and registered on the GP register in Luton as having an annual health check, as well as a Health Action Plan, equating to 13%. A further 106 (15%) have received their annual health check, and 'who had neither received nor declined a health action plan'.¹⁹

¹⁴ LBC Living a Good Life in Luton Strategy 2019 – 2024 Priority/Workstream breakdown

¹⁵ Learning Disability Strategy 2019 -2021 Luton and Dunstable University Hospital

¹⁶ Public Health England data

¹⁷https://www.luton.gov.uk/Community_and_living/Lists/LutonDocuments/PDF/JSNA/12.2%20Adults%20with%20learning%20disabilities.pdf

¹⁸ <https://fingertips.phe.org.uk/profile/learning-disabilities/data~page/1/gif/1938132702/pat/6/par/E1200006/ati/102/E06000032/iid/200/age/1/sex/4>

¹⁹ <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-health-check-scheme/england-quarter-2-2019-20>



Within Luton, there are figures available for the number of people within Luton registered with a learning disability accessing social care. These are the current (July 2019) figures shared within a meeting from LBC.

Age	Male	Female
Under 24	150	56
25-34	137	65
35-44	68	57
45-54	64	39
55-64	23	25
65-74	11	6
75+	3	0

These charts show the breakdown of feedback overall that Healthwatch Luton had gathered throughout the last 12 months prior to the project, and the feedback about the Edwin Lobo Centre in Luton.

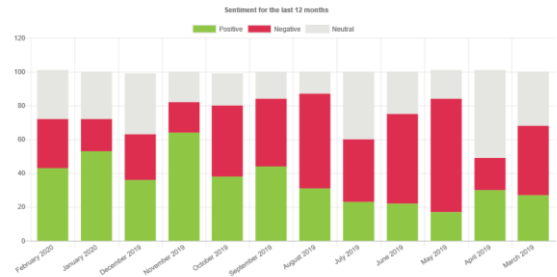
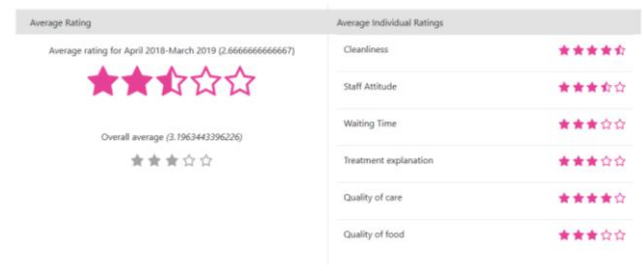


Chart 1: Sentiment shown from March 2018 to March 2019



Picture 1: Showing Edwin Lobo (CCS) April 2018 to March 2019



Picture 2: Showing Families United Network (FUN) from April 2018 to March 2019



Learning Disabilities Definition

When starting this project, Healthwatch Luton created a workstream which was made up of staff and volunteers. It was felt that Healthwatch Luton needed to have a definition to be able to know exactly what groups of people we were gathering feedback from.

The workstream deliberated the definitions held by several organisations and focused on the local authority and the Department of Health. The definition of a learning disability for Healthwatch Luton is:

‘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.’

This definition is something that was discussed at all forums, to gauge the opinions and the thoughts of those in the room. It was noted that a lot of people, both professionals and public, interchange the words when they are referring to a learning disability, and also some include a learning difficulty. It was made clear that for the purpose of the project a learning difficulty was inclusive of conditions such as dyslexia and dyscalculia.

A lot of individuals felt that a learning disability did not need to be diagnosed, and it was a barrier to learning. It was felt it affected people in their education, socially, financially and living independently. It was felt that a learning disability was a ‘lifelong condition’ and affected education, employment and the safety of individuals. It was thought to affect physical abilities, learning, health, understand and communication. It was described by some as ‘somebody who has impaired health needs and needs a little bit of support’ as well as ‘learning disability means lifelong condition that



affects day to day living for which they may need a level of support to live as independently as possible.'

Diagnosis was also discussed alongside the definition and how diagnoses were made. It was felt that most learning disabilities are from birth and they can be diagnosed by health professionals in various ways, including different assessments, health checks and day to day observations.

Some attendees felt that the definition ought to include learning difficulties as they are life long and they can affect numerous aspects of a person's life.

Some people felt that a diagnosis leads to being 'labelled' and some learning disabilities can be hidden. It was felt also by one person, that there ought to be a focus on abilities, rather than the disabilities, to promote a better level of self-esteem. One carer queried if there was a need to include intellect as they felt this was not appropriate.



Learning disabilities forum (October 2019)





Key findings

Healthwatch Luton identified some good practice in Luton during this project. The project work drew some overarching themes that Healthwatch Luton would like highlighted for the providers and commissioners in Luton to review:

Staffing

It was mentioned at most of the engagement throughout the project that the 'right staff' need to be available at the 'right time' to support individuals and the staff need to be best suited to the job roles. This ranged from schools and the SENCOs, right through to accessing the GPs at the time when needed. Learning Disability Nurses were mentioned as being really good, but not available all the time and in all settings.

Annual Health Checks

All those aged 14 years and over with a learning disability ought to be having a yearly health check. This annual health check is the responsibility of Primary Care (GP Practice) and should include general health check-up, medications reviews and other areas of health. These checks were not well known amongst some service users. When the question was asked at

forums and workshops, very few parents and carers knew they existed.

Access to services

It was mentioned by professionals and service users alike, that there was some trouble accessing services. Some people mentioned the GP or the Accident and Emergency department at the hospital as being difficult to access for those who did not have the understanding to wait or the ability to wait due to their diagnosis. Some professionals mentioned access to services such as sexual health being inaccessible to those with a learning disability. There are Health Facilitation Nurses who are part of ELFT, who support those with a learning disability at these appointments and can explain what to expect from screenings such as mammograms prior to appointments.

Criteria

The criteria and pathways to assessment services for children and young people is confusing for a lot of parents. It would seem there is not a lot of availability of what to expect when a referral for assessment is made, nor does there seem to be a lot of support for behaviours and what to expect.



Integrated approach

It was felt by professionals and carers that there needed to be a joined-up approach to individuals care. It was felt that there were gaps in the care individuals were receiving and there were some individuals who felt they were not getting the best treatment and care as people were not working together.

Definition

When discussing learning disabilities during our engagement and activities, there was much discussion about learning disabilities and what individuals felt were classed as learning disabilities. Some people felt the definition needed to include learning difficulties, whilst others felt it should not include intellect.

Listening

It was noted by parents and carers that their voice was not always listened to. Some felt they were ignored, others felt they were not considered. Equally, some individuals felt the way they were spoken to by professionals was less than ideal, with them not being spoken to directly, or not spoken to in a manner that suited them causing some confusion. However, it was noted there were some areas of good

practice in the way patients' individuality was taken into consideration; they were communicated with using methods such as writing it down to take away to have someone assist and go through with them afterwards.



Outline of project

During the project, Healthwatch Luton carried out a range of activities. Some of these activities have a separate and more detailed report.

The activities included:

- + Attending meetings and Boards on behalf of Healthwatch Luton
- + Meeting with commissioners and key professionals in services
- + Holding forums

Further details of recommendations can be found towards the end of the report on page 43.

Areas of impact are noted throughout the report, however, full impact is in the individual activity reports and at the end of this main report.

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What is happening in Luton?

Healthwatch Luton researched and spoke with professionals from a variety of providers within Luton. For this project Healthwatch Luton were not able to engage with all providers, but those that they were, are detailed below.

Cambridge Community Service (CCS) provides paediatric community services in Luton. This includes **the Edwin Lobo Centre**. The Edwin Lobo Centre is based at Redgrave Children's and Young People's Centre. Children and young people are referred to this service for multi-disciplinary medical assessments, medication reviews, and medical diagnosis. Edwin Lobo provides secondary care and diagnosis for children who have a developmental, physical or learning disability. This service includes diagnosis of other conditions, such as ADHD. Carers and parents of children and young people who have special educational needs (SEN) can also be offered advice. Another service provided by CCS is child medicals for adoption and child protection, which would not be necessarily due to SEN.

Currently the wait for these assessments is over the 18-week limit.

The children and young people who are in need of psychological care/assessment receive these via the School Psychological services which is being paid for by the school as it is a 'tendered service'.

Healthwatch Luton found the contact with CCS quite positive. Healthwatch Luton were able to understand what CCS were putting in place to work with the families who had been referred into the service for assessments, and able to attend a few workshops. However, it would seem their services were not well publicised or shared and as such, attendance was quite low. Healthwatch Luton were able to use this knowledge to signpost individuals and also be aware of feedback about this service when speaking in forums. There is an emphasis of a vision of an ideal future system where children receive the support based on their need, rather than their diagnosis.

Healthwatch Luton were able to create relationships with those who worked in the different areas of CCS. This has benefitted not only the area of learning disabilities, but also other areas, including primary care.

East London Foundation Trust (ELFT) have a dedicated team for those individuals who have a learning disability. Their



definition of a person with a learning disability (LD) is a person who has an IQ below 70, is unable to manage life as well as other people (socially, financially, independently) and who has a prior diagnosis (from childhood/adolescence). This team is based in Clapham, Bedford. The LD team have a separate inpatient unit based in Bedford, although they try to make reasonable adaptations to mainstream/general mental health wards for individuals. Within the mental health project that Healthwatch Luton completed, staff within ELFT acute wards mentioned they would like further training on the area of learning disabilities, and those within the CMHT noted as using the learning disabilities team within ELFT to support them in making their care and treatment plans for individuals who were not open to the IST (Intensive Support Team).

Also, at this site is the **Adult Autism Assessment Service**. This is a team that is commissioned separately but fits within this remit and area. Referrals to this team come from all over the county and from a variety of providers and individuals. When discussing this service with the providers, there is not a follow-on service for those who are diagnosed. Individuals are given a single follow up appointment after diagnosis and then discharged into the care of ELFT or back into the care of their

GP. When working within this project, most individuals had received a diagnosis in childhood.

The Luton Memory Assessment Unit (MAS) is based within Luton and Dunstable University Hospital grounds, although provided by ELFT. This is a service that individuals are referred to if there is believed to be a concern surrounding things such as dementia, Alzheimer's or other memory conditions. This is a service that is referred into by medical professionals. Healthwatch Luton were not able to speak with staff or service users from this service.

The two projects for this year were closely linked with ELFT. Healthwatch Luton were able to speak with ELFT on several occasions regarding individuals who had a diagnosis of learning disabilities or it was considered they may have a learning disability, and the team at ELFT were able to provide professional opinion and support for working with these individuals.





The Learning Disability Partnership Board meets quarterly and is run by Luton Borough Council (LBC). It is open to anyone who has a learning disability, cares for someone who has a learning disability or supports and works with people with a learning disability. When attending the meetings, there are a high number of professionals in attendance from a variety of organisations. Some professionals bring along service users from their organisation, such as residential homes, other professionals support service users to attend as they are acting as carers.

The co-chairs of the Partnership Board are service users. There are reasonable adjustments made to suit individual service users and there is the opportunity for service users to learn about the professionals who attend through networking at refreshment breaks. Information is provided in an easy read format, and a card system is used to assist in understanding and to participate in the meetings.

As a result of attending this Board, Healthwatch Luton were able to make contact with two different residential providers for those with a learning disability. Healthwatch Luton carried out targeted engagements with some individuals living within Aldwyck Supported Living and also Belle Vue Residential Home. Healthwatch Luton

would not ordinarily have been able to speak with these individuals who are seldom heard. Healthwatch Luton feel that going forward, this is a Board that will be used to inform those with learning disabilities of change within Luton and work that Healthwatch Luton are carrying out.

IMPACT: Healthwatch Luton were able to target engage with different residential settings as a result of attending this meeting, meaning voices not yet heard were gathered and shared with the relevant organisations.

There are three subgroups held in addition to the main meeting, facilitated by POhWER. These are for: Housing, Health and Day Opportunities, Employment and Training. **POhWER** are a charity who provide information, advocacy and advice. The sub-groups are for professionals and service users to specifically discuss the subjects and professionals are invited to present at these meetings too.

Healthwatch Luton have a representative attend all three of the subgroup meetings, and whilst they can be informative, they are not always so. These do not seem very well attended as there does not appear to be many professionals, and very few



services and organisations are represented.

The Learning Disability Partnership Board meetings are an opportunity for individuals to learn about services that are changing, services that are newly commissioned in the area or are of a particular interest to some attendees. There is an executive function of the LD Partnership Meeting who set out the agendas.

There is a **Think Autism Partnership Board**, that is a county wide Board with all three local authorities involved. The Board recently held a survey at a meeting to ensure the purpose of the meeting met the needs of the service users and their families and carers. It was noted that the format of the meeting was not inclusive for those who are on the autistic spectrum and that with it covering a wide group, it was hard to discuss those issues that affected the individuals on a local level. Overwhelmingly, 80% of responses stated that they would like a smaller meeting in a local venue. 73% of people felt they were not getting the results they wanted from the board and there needed to be more attendance from providers and commissioners. Around 80% of responses stated they did not want the meetings to continue in the current format, although 53% were happy with the regularity of the meetings.

Healthwatch Luton only found out this meeting was running a few days before the most recent one. It would seem that this is a meeting that is not very well promoted and would benefit from having much more publicity to local organisations and service users. Those service users and families and carers who attended the meeting who spoke with Healthwatch Luton also had not heard of the meeting until a few days prior and had not previously attended.

Healthwatch Luton were able to share information about the upcoming public forums being held and signpost to other meeting, such as the Learning Disability Partnership Board.

Families United Network (FUN) is a local charity, set up by families with children with disabilities in Luton. The charity supports families in both the academic world and in social environments, to ensure children, young people and their families are able to enjoy a life that is good. Healthwatch Luton have previously carried out targeted engagement with this group and have found the feedback from them very rich. Service users have told us how they would be 'devastated if [this] ever ended' and how they 'love the atmosphere' and use it because it has a 'Non judgement attitude, as it is perfect atmosphere for vulnerable children to let of steam'.



Luton Borough Council have the **Community Learning Disability Team**, which is made up of social workers, the Enablement Team and community nurses. The purpose of the team is to work with those who have a learning disability over the age of 18 years and ensure they are receiving an integrated and person-centred service. They will look at all aspects of an individual's life including housing and care. Healthwatch Luton were able to be part of the Health Week that the Enablement Team ran. Healthwatch Luton would not have known about this, was it not for the contacts made through this project.

There are a variety of day centres within Luton, including **Community Choices** and **YAWN Life**, which offer activities for those with a learning disability to interact with others and develop in all areas. Unfortunately, there has not been an opportunity to attend these groups and gather feedback from the service users who attend.



Luton Borough Council strategy

Luton Borough Council created and ratified a new strategy for people with learning disabilities and/or autism 'Living a Good Life in Luton'.²⁰

This strategy focusses on everyone having the right to lead a fulfilled and happy life. There are four key areas of local priority within the strategy:

- + Strategic commissioning
- + Health and Wellbeing
- + Accommodation and support
- + Work, leisure and learning

Within each of these key areas, there are specific deliverables and outcomes, as well as expected KPIs to ensure these outcomes are being met.

Strategic Commissioning

This area focusses on ensuring the correct information is held about the population in Luton who have a learning disability or

ASD. There is an aim of a consistent approach to provide integrated health and social care using this information.

There will be a reduction in waiting times for those who have been referred for assessments, by developing the workforces in specialist and mainstream services. The effectiveness of the service will improve.

The aim is to ensure those who have a learning disability and/or ASD are able to follow clear pathways and have a degree of control over their own lives, whilst ensuring sustainable plans are in place for individuals.

In terms of transitions, there will be 'integrated personalised commissioning' as well as long term planning between children's services and adult services.

The transforming care agenda for those with a learning disability includes improving access to health care for those with a learning disability and upskilling the work force and increasing respite provisions in Luton.

There is a recognition that autism is not a learning disability, and this does need a separate pathway. The Think Autism Strategy 2010 will be used in collaboration

²⁰ 'Living a good life in Luton' A strategy for people with learning disabilities and/or autism – 2019 - 2024



with the LBC strategy to ensure those are included who have ASD as well as a learning disability.

Health and Wellbeing

This is a focus on preventions, self-care and effective assessments for those with a learning disability. It is ensuring those with a learning disability can access mainstream services within primary care and mental health services.

It is to ensure that any vulnerable adults feel safe in the community and those with caring responsibilities for a person with learning disabilities are also able to access the support they need.

Social prescribing is available and should be used to promote the aspect of a healthier lifestyle and living well. The number of annual health checks needs to be increased and locally there will be a focus on improving these numbers as part of the strategy. Systematically, this will also increase the number of Health Action Plans.

There will be improved access to dental health checks and to other health screening and immunisations.

The advocacy of the STOMP (Stop the over prescribing of medication for those with a learning disability) will also be a focus of the strategy.

Accommodation and Support

This is linked with the local housing strategy of ensuring a reduction out of area placements where possible, supporting transitions for those who wish to live elsewhere and ensure, where possible, people have their own home.

There will be the right support at the right time and ensuring individuals are able to have input into the providers they use for their care.

Work, leisure and learning

The main aim of this area is to ensure people with a learning disability have an 'active citizenship'. This is to make sure people are able to have meaningful social relationships and interactions, whether that is through paid employment, volunteering, or attending social groups and having memberships.

This also aims to make sure there are transport links for people to access the facilities and groups available to them.

Neurodiversity strategy

LBC are currently (February 2020) in the process of creating a neurodiversity strategy for those in the community who have additional needs, not met by a learning disability diagnosis.



This will cover individuals with a whole range of needs, without the need of a diagnosis of neurodiversity of some form.

Healthwatch Luton are unsure exactly of when this will be ratified, however it is being worked on currently by the local authority and LCCG and should be in place in early 2021.





SEND Ofsted Report

In December 2018 Ofsted carried out an inspection of SEND services within Luton. Provisions offered in school settings, as well as providers of services were included.

The inspection raised significant concerns about the effectiveness of the local area. The key points that came from the report were issues with EHCP (Educational, Health and Care Plans), wait times for appointments (and what to do in the interim whilst waiting), a lack of children and young people's voices (regarding care, treatment, access etc), a lack of strategy from the local authority surrounding those with learning disabilities and the communication of the 'local offer'.

The local authority held a series of workshops in response to the Ofsted report, to enable the co-production of improvements for children and young people with SEND in Luton. The workshops focussed on the following areas:

- + Principles for co-production and SEND needs assessment
- + Improving EHCP process
- + Outcomes for children and young people (CYP) with SEND

- + Improving local offer
- + SEND Strategy and plans

The attendance at these increased as the sessions went on. Attendees were from a variety of backgrounds – professionals and parents as well as strategic leads. The work was quite interactive throughout the sessions. On discussing the workshops with professionals, it became apparent the meetings were not known to a lot of people who are working within learning disabilities.

There was discussion over what co-production meant to those who attended and there was a decision to change the name of the plan. It became 'Working together for children and young people with special education needs and disabilities'.

During one session, lists were made of what people felt were the most important outcomes for individuals. Frameworks such as Hertfordshire's '6Bs' and Notts City outcomes framework were shared. Once outcomes were decided and voted on, the final few were chosen:

- + Be healthy – physically and mentally
- + Keeping safe
- + Potential/achievement
- + Independence



- + Being heard
- + Employment

These were then looked at in further detail – how these can be measured and how they can be achieved. A task and finish group were created to work on this further. There was a suggestion that Luton adopt the sunflower lanyard scheme that a lot of areas are using to identify when a person is in need of extra care or consideration due to an invisible need.

Surprisingly, the annual health checks for those with a learning disability over the age of 14 were not known by most who were spoken to. During one session a discussion was had about EHCPs (Education and Health Care Plans) and it was discussed how if English is not the first language of the parents or carers, little to no support is provided by the local authority to complete forms or attend meetings. It was suggested by more than one provider that this falls to the educational provider, such as a nursery to assist the family. There were two parents in attendance who agreed with this being the case for people who they knew in their communities. When this was queried with other professionals in attendance, it was suggested there were concerns about funding for this.

Following on from these sessions, a consultation was opened up for parents and carers to complete to provide their feedback.

By attending these sessions Healthwatch Luton were able to signpost individuals to NHS England to understand the right to an annual health check. Healthwatch Luton were able to share the information about the upcoming forums and provide direction for the support for care and educational needs of individuals. There were three people who attended these workshops who went on to contact Healthwatch Luton for support and signposting.

IMPACT:

Signposting to other services. Advice and support given after the workshops.

Awareness of Healthwatch Luton

Recommendations:

Spread awareness of the annual health check.

Improve the translation services in relation to the EHCPs



Parent Carer Forum

The Parent Carer Forum (PCF) is a group commissioned by Luton Borough Council. During this project, Healthwatch Luton made contact with Luton Parent Carer Forum, but it was felt by the Chair of the PCF that Healthwatch would be gathering feedback and carrying out work that was already being covered by current workplans, which included the workshops being run by Sam Carr, Project Lead.

It was suggested that Healthwatch Luton should look at specific areas of health which would in turn encourage different parents and carers to meet with Healthwatch Luton and attend forums.

However, Healthwatch Luton did attend one of the Parent Carer Forum meetings, which was part of the series 'Meet the Directors'. The purpose of the meeting was for the professionals to share what has been happening since the Ofsted report and what actions were in place to make improvements. It was stated that the first Statement of Action was submitted to Ofsted on 22/05/19, which was 'not good enough' and was resubmitted on 08/07/19. It was an

organic document where nothing was fixed. All progress was RAG rated. Sam Carr is the Senior Officer on this project.

The session was meant to be general, with an opportunity for speaking about personal situations at the end of the session. It was difficult for those attending to share their opinions without including personal experiences. It was clear that the parents need to be able to understand the structures and who will be able to help them with the different aspects that effect their children and young people. One parent mentioned that a lot of children and young people are being diagnosed with Sensory Processing Disorder, but there is not a service provided locally for this, nor is a diagnosis that is recognised by some professionals. This was the only time this was mentioned throughout the whole project. It was also noted that there is a mentor scheme being run by parents and carers at Edwin Lobo to support parents post diagnosis, but there is not a room available to book for meetings with them. This means parents either must discuss quite personal things in the café or waiting room area or hope that a room is available for them to 'borrow' for their meetings. It was pointed out by a parent that in their experience, CCS do not ask for feedback after their appointments. This was corroborated by other parents in the room. Some parents felt that after



diagnosis there is not enough, if any information available. They felt there was not a consistent package after diagnosis.

It was noted there are around 1600 families in Luton who do not access the PCF. It was suggested that this would be something that would be shared via schools to encourage membership. With that in mind, there is currently around 500 families signed up to the PCF. This does not seem representative of meetings that have been attended by Healthwatch Luton in the past, and more recently. When this was queried with PCF, it was suggested that only certain families engage as they are interested or have a particular interest. There was not a mention of how to engage the other families or to expand this from the 30 – 50 families who do engage regularly.

IMPACT:

Healthwatch Luton will continue to work with PCF and attend meetings hosted by PCF to gather anecdotal feedback from the service users, carers and families who engage with PCF

Recommendations:

Support PCF to engage with the families who are not currently actively engaging

Healthwatch Luton would welcome working with PCF families and carers to understand the needs they feel are not being met in their experiences.

WHAT NEXT? After meeting with the Chair of the PCF, Healthwatch Luton were able to redirect their engagement towards areas of the system that were ready to engage





Mental Health Services

Healthwatch Luton were told by professionals that The Coppice unit has been closed since summer 2019. This has meant that those who have a learning disability and also have mental health concerns that need acute services are admitted onto the main stream mental health wards.

Commissioners for adult services have stated it will take around two to three years for the wards to be entirely equipped to provide care suitable for those individuals who are neurodiverse, including creating spaces for those with sensory concerns or those who need a quiet space. One professional felt that this ensures 'mental health standards are brought up, like those physical health standards' to ensure there is no 'substandard care given' because a person has a learning disability. The Intensive Support Team (IST) feel this is working. The IST support individuals who are admitted, by being with them on the ward from 7am until 9pm if needed. Others had been regularly receiving daily visits of a few hours to maintain the support and relationships.

When speaking with staff who work on the inpatient wards, they had mentioned there had been a number of patients admitted over recent months who had additional needs. In order to integrate these people into mainstream services, they had been supported by the IST to input into care plans and interventions with patients. Some staff had mentioned training 'would be good to have' around learning disabilities, suggesting they had not previously had this training.

IMPACT:

Healthwatch Luton were able to use this information and knowledge to feed into the mental health project and to support individuals who came to us about mental health services and had a learning disability

Recommendations:

There is good practice within the IST in mental health services that should be shared with the wider health system.

Staff noted training of learning disabilities would be beneficial for all staff to have



Transitions

It had been mentioned by both professionals and service users carers and families, that when a young person reaches the end of the school system, there is not any support and expectations are high.

One parent reported feeling as though her son had ‘fallen off the cliff’ when he reached an age where he was no longer in a school provision. Problems occur when a young person has complex needs, which cannot be met by the provisions offered. This results in parents and carers being unable to continue to lead a life independent of the young person. Day opportunities are offered for the young people and adults with learning disabilities, in a variety of settings, however, they do not always meet the expectations of the families, who have been used to receiving multi disciplinary care for them as a child.

Transition services, such as those provided by the Intensive Support Team (IST) which is part of the service given by East London Foundation Trust (ELFT), begin around six months before a person is due to leave the educational setting they are in. It is felt by professionals that this needs to be earlier. Day opportunities, such as Community Choices and Yawn Life, attend different

educational settings, such as Woodlands Secondary School, where they can meet with parents and carers when their children are as young as 13 and 14 years old, to discuss transition.

It is felt by commissioners and adult services that expectations need to be managed by the children services, as to what will be provided by the adult services. As a child there is ‘open access’ to services, but as an adult this moves to what is a clinical need. It has been suggested that the Annual Health Check for those aged 14 years and older, need to address what provisions are available as a young person ages. This could be by having the 14-year Annual Health Check to include a wider multi-disciplinary team (MDT). It was agreed by attendees at the POhWER subgroup for the Learning Disability Partnership Board there will be a dedicated project from Luton Clinical Commissioning Group and Luton Borough Council, to address transitions and look at them from both a health and social care stance.

IMPACT: Transitions will be looked at as a workstream project within LCCG and LBC

Recommendation:

Promote and increase awareness of post 16-day opportunities at a younger age



Annual Health Checks

Everyone over the age of 14 years old who is diagnosed as having a learning disability, is entitled to a yearly annual health check (AHC). This health check should include a physical check (height, weight, blood pressure), discussions surrounding general wellbeing, medication reviews and any long-term condition reviews.

The purpose is to make sure there are no underlying concerns and also to ensure the medical professionals know the individual well enough, to be able to notice signs for concern early to treat them.²¹

There is a Quality Statement²² that must be met for those with a learning disability and having an AHC is one of them. There is a national expectation from NHS England, that at least 75% of people registered with a learning disability need to have the AHC.²³

Throughout this project it has become apparent that Annual Health Checks are not being completed for those who are registered as having a learning disability at their GP Practice. As of February 2020, there were 1607 people registered as having a learning disability on the GP systems. Data from LBC suggested there had been just over 51% of individuals over the age of 25 years who had their AHC completed by their surgery, and 14% of 14 to 25 year olds. This equated to around 720 all age individuals. It is perceived that the coding on the GP systems is still not entirely correct for those who have a learning disability and as such, further review of this data by the local authority is ongoing.

When querying this, it was felt that some checks were not deemed 'complete' as there had been parts of it missing, such as a decline to have the blood samples taken. When a patient declines a blood test, it is down to the primary care service to decide if this is something that is imperative or would be more punitive to impose on the individual.

²¹ <https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/>

²² <https://www.nice.org.uk/guidance/qs187/chapter/Quality-statement-4-Annual-health-check#quality-statement-4>

²³ <https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/a-strong-start-in-life-for-children-and-young-people/learning-disability-and-autism/>



In Luton there is a lead, Dr Kirti Singh, Clinical Director LCCG - Mental health, Learning disability and End of life care) who is working to improve the AHC rate amongst Luton practices. In her own practice, Dr Singh has a very good system which means her patients requiring an annual health check receive a double appointment, with both nurses and the doctor, to ensure the annual health checks are completed. There are few within the practice who are still waiting their annual health check, and those that are incomplete have a reason for this. As a side, this surgery has also trained their reception staff to be able to complete basic medical checks such as weight and height, to assist in all health checks.

IMPACT:

Healthwatch Luton will continue to promote the annual health checks in Luton to those with a learning disability and their carers. Healthwatch Luton will work to support the system with annual health checks to ensure greater uptake

Recommendations:

Further coding analysis and changes need to be made to ensure all those who have a learning disability are traceable within the system and receiving their AHC, which Healthwatch Luton will review at a later date

The promotion of AHC and the understanding of them needs to be improved





LeDeR

In Luton, the LeDeR (Learning Disabilities Mortality Review) programme²⁴ has been underway since 2017. There have been 27 deaths due for review in Luton. There are currently five reviewers.

This has meant there is a back log in implementing the reviews and the learning gained is delayed.

The learning so far has shown three main areas: sepsis, constipation and aspiration pneumonia. The areas are a local focus. There is a working group, led by ELFT that is looking at aspiration pneumonia.

IMPACT: The reviewers do not need to have any clinical experience and can be experts by experience. With this in mind, Healthwatch Luton agreed that one member of staff will complete training to carry out reviews.

Healthwatch Luton engagement events

Healthwatch Luton carried out a series of engagement events with the public and professionals of Luton. The events were carried out over a period of six months.

They were:

- + Learning disability baseline survey (page 33)
- + Learning disability public forum with professionals (page 35)
- + Learning disability professionals forum (page 38)
- + Learning Disability Partnership Board (page 40)

Further details of recommendations can be found towards the end of the report on page 43.

²⁴ <http://www.bris.ac.uk/sps/leder/about/>



Baseline survey

Healthwatch Luton wanted to hear from those who are living independently with a learning disability, or who have a caring responsibility for a person with a learning disability.

This was to find out how people were finding accessing certain aspects of everyday life, such as accommodation, leisure and fulfilment. The purpose was to collate a baseline and the effect it has on their everyday life. The survey was available in an easy read format and online. The questions did not ask individuals to disclose any personal information, diagnosis or medical concerns, however, individuals were invited to leave their contact details if they wanted to have any further information or signposting from Healthwatch Luton.

The questions in the survey were created by the workstream, which included staff and volunteers of Healthwatch Luton. The workstream used the latest strategy from Luton Borough Council (LBC) 'Living a good life in Luton' for people with a learning disability and/or autism to focus the questions.

The questions were multiple choice with an option to leave free text if they chose to. The survey was taken to targeted

engagement and other meetings that Healthwatch Luton attend. The survey was open for around twelve weeks. Most of the ten responses were from adults with a learning disability.

The survey did not garner many responses. This could be due to the places it was taken to, the need to support those completing the survey, the lack of knowledge of the reason for the survey or unawareness of the survey in general. The survey, if opened again, would need to be shared in a different manner. It would be better to sit with individuals at the places it was taken to, and complete together, rather than leave the forms to be completed by individuals. Individuals understanding the purpose of the survey and how their input was important would be a help also.

'I don't bother with my Health Action Plan as I can't keep up with it'

- **adult with learning disabilities**

The results from the survey included:

- + 50% of people were living in a supported living environment, and 20% were living with parents. One person was living alone



- + 20% of individuals were in paid employment, 50% were currently volunteering
- + 70% of people felt they were able to access leisure and sport
- + 50% of people were able to access public transport
- + 20% had a Health Action Plan

It was noted that cost can affect how and where people are able to access services, especially with the local bus pass scheme and there are not enough paid job opportunities for those with learning disabilities.

IMPACT:

Awareness of Healthwatch Luton

Understanding areas of need of local people with learning disabilities

Quantitative data to support anecdotal information received

Understanding how Healthwatch Luton needs to adjust future engagement

Recommendations:

Look at what paid employment opportunities there are for people with learning disabilities

Understand why people do not use HAPs and how to encourage use of them

‘paid opportunities for people with a learning disability 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

WHAT NEXT? The baseline survey influenced some of the activities and questions addressed within the public and professional forums



Public forum with professionals

Healthwatch Luton wanted to give those who have a learning disability, or caring responsibilities for an individual with a learning disability the opportunity to share their experiences of health and social care.

Professionals were invited to attend on the day from a variety of backgrounds. In attendance on the day were Amy Kay (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 did not invite attendees to disclose any medical diagnosis or concerns, however, there was an opportunity at the end for questions to be asked of the panel to find out their professional opinion.

The definition of a learning disability was discussed, and opinions sought on what it meant and should include.

When discussing what worked well, attendees mentioned:

- + Teachers who care
- + Family support
- + Keeping routines
- + Obtaining an EHCP
- + Having the right professionals in the right role



Learning disabilities forum (October 2019)

Feedback was gathered on areas that people felt were not working so well. This included the SENCOs (Special Educational Needs Co-ordinators) at schools, and there being a need to train these staff to the same level. There was a feeling that parents and carers were not listened to and a lack of support within schools. There was also a concern that barriers to getting a diagnosis is preventing children and young people getting the support they need.



‘as part of their job description, any Head of House, Head Teachers, Heads of Years, SENCOs, should be told to attend parent and professional forums’

- parent of children with learning disabilities

People felt their treatment by professionals and the way they were communicated with could be improved. It was felt information could be disjointed and the manner in which people were spoken to at times could be improved. There were concerns about accessing primary care also, whether that was seeing the same professional more than once or getting appointments in the first instance.

‘to get the people to have the most independent life as possible’

- carer of a person with a learning disability

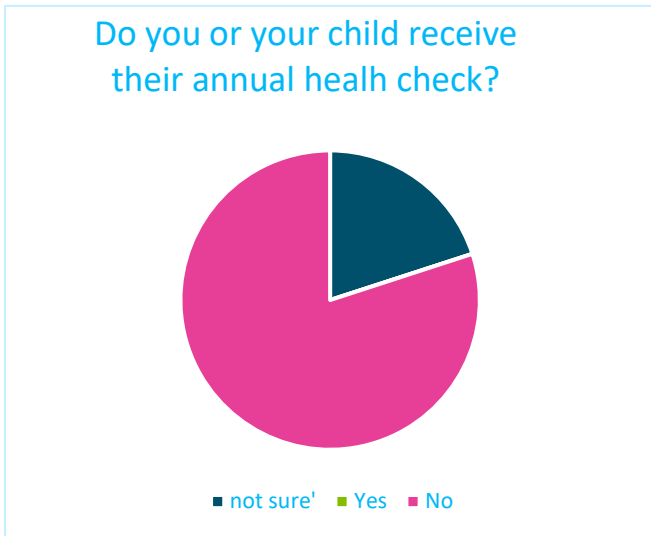
When everyone was asked what they felt was most important to run a service and what could be done to improve systematically in Luton, the responses were varied, but followed a few themes:

- + Consistency – there needs to be a consistency of care
- + Clear pathways – there needs to be clear pathways and support post diagnosis
- + Independent life – where possible individuals should be supported to live as independently as possible
- + Time – ensuring individuals have the time they need with the professionals and services they need
- + Individuality – treating people as individuals and not conditions

The attendees felt this would be achieved by:

- + Listening to parents and carers
- + Support from schools
- + Professionals having the appropriate training
- + Knowledge and ‘active listening’ from professionals
- + Joined up care
- + Smoother transitions in to adult services
- + Working to the needs of the individual

Chart 1: Responses of those in attendance when



asked if the person with learning disabilities received their annual health check

IMPACT:

Healthwatch Luton enabled the voice of the service users to be heard directly by professionals in the forum. The public were able to know and understand how Healthwatch Luton can support them. Individuals were signposted who otherwise may not have been

Recommendations

- See the same professionals where possible and build up relationships with more than one professional
- Training for staff for learning disabilities
- Accessing primary care

Annual health checks need promoting and carrying out

Share the knowledge and understanding of criteria for different referrals and assessments

' to be proud of themselves about achieving something'

- family member of a person with a learning disability

WHAT NEXT? This forum prompted Healthwatch Luton to engage with professionals within learning disabilities in Luton, to be able to understand from their perspective what they felt were the challenges for the individuals they worked with or supported.



Learning disabilities public forum (October 2019)



Professionals forum

Hearing from the public is at the core of Healthwatch Luton's role as an organisation, however, to ensure we addressed any bias through our research framework,²⁵ it was important to hear from local organisations and see how they worked with people who were diagnosed with a learning disability.

The professionals were from a range of providers including Luton Clinical Commissioning Group, Luton and Dunstable University Hospital, East London Foundation Trust and Luton Borough Council. Five attended on the day, and another provided feedback by other means. Whilst organisations and job roles were important, professionals' experiences of working with or for those with a learning disability was more so.

Service providers discussed a range of topics, including what was working well and not so well for the individuals they work with, what was needed to improve the service received by them, whether

that was in their own organisation, or others they have referred to. There was an opportunity for service providers to share best practice and ideas within the session.

Professionals agreed the term 'learning disability' and its use and changeability is something that is 'highly debated'. It was felt that within 'health services' there is 'some confusion as to the definition of learning disability'.

When discussing what worked well, it was found that the Learning Disability Nurses at Luton and Dunstable University Hospital have a good strategy which works well and a good system for supporting those with a learning disability. Also, the Health Facilitation Nurses (also provided by ELFT) were seen to work well in the community in their support provided to individuals. The multi-disciplinary approach within organisations represented worked well. It was felt the changes in the revision of The Mental Capacity Act (due to come into effect in October 2020) will work well for individuals.

It was felt communication between services and transitions between children and adult services were challenging. It was felt that 'schools do not take

²⁵ Healthwatch England Research Framework



responsibility’ for their input into individuals with learning disabilities.

Professionals felt that GPs were getting better with carrying out Annual Health Checks, although they did feel that they were not well known or promoted to those who needed them.

It would have been better had there been more attendees inputting to the feedback. Professionals who attended felt that there should be more attendance encouraged to such events. In future, Healthwatch Luton will make a stronger promotion of the event and encourage higher attendance. That said, those who attended gave invaluable insight into their experiences working with or for those with a learning disability

IMPACT:

Professional relationships to assist the future project work

Understanding professional point of view to prevent bias

Sharing of best practice

Recommendations:

Annual health checks need to be promoted and understood why so important

Best practice needs to be shared

‘patients don’t know about them, only some do’

- professional within learning disabilities

To run a service and make changes system wide, professionals felt inter agency communication was key. Joined up working and attendance by all professionals involved in a person’s care at professionals meetings would help. It was felt there needs to be more commitment to the LeDeR programme locally to ensure that Luton can learn. Sharing of good news stories was also seen as important.

‘budgets need to be pooled from Local Authority and Health to bring provision in a more local manner’

- Professional within learning disabilities

WHAT NEXT? The professionals forum was able to influence the overall recommendations by showcasing what is already happening within the system



Learning Disability Partnership Board

Healthwatch Luton felt it would be of a benefit for the attendees to learn who Healthwatch Luton are and give attendees the opportunity to provide some feedback about health and care experiences within Luton.

Healthwatch Luton were able to present to around fifty people over the course of the year and gathered feedback from seventeen people at the July Board meeting.

Attendees were asked what worked well for them as service users with a learning disability. Luton and Dunstable University Hospital was mentioned as having 'brilliant nurses who provide a brilliant service' and the dietician service was also mentioned as being 'good'. It was felt the training provided for things such as catheter awareness and diabetes was working well. Some felt that dentists, opticians and their GP practice were good. However, there was some disparity between feedback regarding the primary care experiences. Over half of those who gave feedback about their GP Surgery encountered problems. This was with

things such as access to appointments, length of appointments and communication with their GP. The response time to referrals by the GP was not working so well.

It was felt by one professional that there was 'resistance to having visits by opticians to care homes', as well as the cost of chiropody and accessing it in the community. The availability of the learning disability nurses outside of the core hours of 9am to 5pm was seen as not working so well too. The length of time and the suitability of the waiting areas of the hospital were mentioned by some individuals.

When asked what might help individuals better access services or support them when accessing service, people stated:

- + Waiting times for those who cannot or do not understand the need to wait
- + Length of appointment times should be double when a person has a learning disability
- + Awareness of Annual Health Checks needs to be improved
- + Having quiet rooms in organisations and services, including the hospital
- + Availability of learning disability nurses outside of core hours, and in more places



- + Easier access to specialist services such as drugs and alcohol
- + More sexual health resources

Availability of the learning disability nurses in terms of hours and providers/organisations they are available

IMPACT

Awareness of Healthwatch Luton to a seldom heard cohort of people and more professionals aware of Healthwatch Luton's remit

Maintaining presence at the LD partnership Board will ensure people are aware of us and how to access us

Healthwatch Luton were able to carry out targeted engagement at two different residential settings from relationships made at the LDPB

WHAT NEXT? Whilst Healthwatch Luton have attended these meetings for some time, attendance at these meetings in recent months meant Healthwatch Luton were able to attend two separate targeted engagements within supported living units in Luton to gather more detailed feedback from individuals who did not attend this meeting.

Recommendations:

Understanding of the importance of annual health checks and what they involve

Access to GP appointments



Outcomes

As well as the recommendations Healthwatch Luton has suggested for this area in this report, there are some outcomes that have already been implemented or are happening within the system.

It was agreed by attendees at the POhWER subgroup for the Learning Disability Partnership Board there will be a dedicated project from Luton Clinical Commissioning Group and Luton Borough Council, to address transitions and look at them from both a health and social care stance.

Healthwatch Luton are one of the partnership organisations working with LCCG and LBC to create the neurodiversity strategy.

Healthwatch Luton have created an easy read version of the leaflet outlining what Healthwatch Luton do and how to make contact. This has been well received in a variety of different occasions, at Boards, engagement and in general. This is something that will be considered going to formal print in future.

The LeDeR Programme needs support locally. Healthwatch Luton will have one member of staff trained up within the next few months to be able to carry out reviews for Luton.





Recommendations

Having carried out this project, Healthwatch Luton have some recommendations for health service providers, commissioners and practitioners within the Luton wide system.

As agreed at the POhWER subgroup there will be a focus on addressing transitions between children's and adult services. It would be a recommendation of this report **to involve the patient voice and the professionals involved in care of the individuals, to ensure there is a greater understanding of what concerns there are and what expectations need to be addressed.** To ensure a smoother and fulfilling transition.

Within Luton there are a number of people with a learning disability over the age of 14 years who are not having their Annual Health Check. It would be a recommendation of this report **to ensure these are carried out regularly and in a comprehensive manner, perhaps drawing on the best practice of some local surgeries who have a high level of completed Annual Health Checks.** Healthwatch Luton have met with Dr Kirti Singh and understand this work is being looked at. Healthwatch Luton will review this once the data has been rectified and

support to share the promotion of annual health checks where able to.

With learning disability accommodation and support being an area that is part of the LBC strategy, it would be a recommendation of this report **to evaluate the needs of those who are reaching an age where they will be leaving children's services and entering adult service be identified earlier, to enable a smoother transition into adult services.** This might include support from The Enablement Team and being involved at an earlier point than what they are now.

Luton and Dunstable University Hospital have a strategy that is well received by patients and professionals, in place for those with a learning disability. It would be a recommendation **to share the best practice of the strategy with other organisations and use this strategy to make improvements where necessary to their own strategies for people with learning disabilities.** This will enable learning across the whole of the health system, and other areas of good practice can be pulled upon from other organisations to share.



It would seem, that despite them belonging to individuals, the use of the Health Action Plan is not well utilised. It would be a recommendation of this report **to review the use and promotion of the Health Action Plan and perhaps gather feedback from service users as to the benefits and preferences around them.** Healthwatch Luton would be happy to support the promotion of this, should the GPs and leads for the Health Action Plans within the Primary Care Networks want this. It may be a piece of work is needed to understand the lack of use of Health Action Plans and why this is the case. The PCN (Primary Care Network) that is focussing on the learning disability population of Luton may be able to assist with this.

From speaking with carers, family members and some professionals, it was told to Healthwatch Luton on several occasions that individuals with learning disabilities need to be able to feel a sense of purpose, and for some that is in the form of paid employment. It would be a

recommendation of this report **for there to be more focus on engaging local organisations and companies in employing those who have a learning disability and want to have paid employment.** This may be something that is an option of a couple of hours a week, or more hours if suitable. Support will need to be provided by organisations already carrying out training and involving people within working programmes, such as Penrose, The Shaw Trust and The Enablement Team. Organisations will need training to do this, as well as continuous support for the individuals.

Parents and carers mentioned that they felt the 'right staff' are not always in the 'right roles' and that training may need to be improved. It would be a recommendation of this report that **training within schools is reassessed and the staff in those roles understanding the needs of the parents and carers who rely on them for support.** Compulsory training or workshops regularly to ensure the latest and best practice is shared amongst all schools in the local area, if they do not already happen, would also be a recommendation. This is something LBC teams could take part in monitoring. It is understood SENCOs meet regularly and this could be an opportunity to discuss this

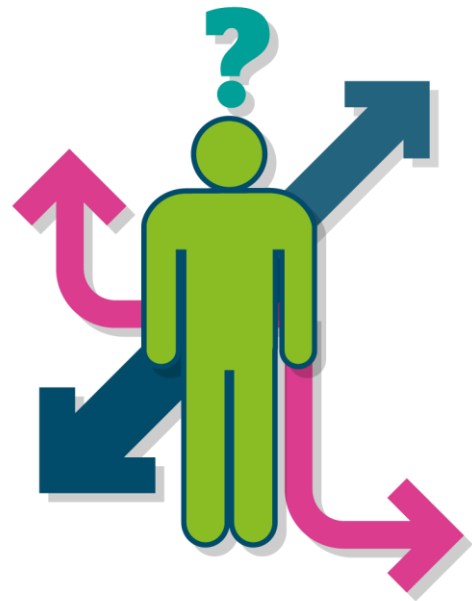


and share training opportunities and share to disseminate at a school setting.

Whilst Healthwatch Luton are aware of sessions being run by CCS for parents and carers of those who have been referred but are awaiting an assessment, there would appear to be a need to share this support and information with the wider parent and carer community. It would be a recommendation of this report that there **is information available to those based on a need rather than a diagnosis.**

This could be in the form of an information pack or sessions that were open to a wider group than those with a referral or diagnosis.

It was felt that once people had a diagnosis, there was not much support for them, particularly if the assessment was carried out and then there was no need to be held within the case load. It would be a recommendation of this report to have **post diagnosis plans in place, that are agreed by the service users and their families or carers, and to ensure there are ways that further understanding and accountability can be found for the care.** This could be produced by the teams carrying out the diagnosis.



Whilst it is not always practical, a consideration could be made to ensure the same professionals see the same service users. It would be a recommendation of this report, that when an individual is registered in a practice or service where there are more than one professional, where possible **the individual sees the same professional.** Having more than one professionals familiarise with individuals may also benefit those with a learning disability and support capacity of the professionals.

The definition used by Healthwatch Luton, adapted from Luton Borough Council and Department of Health's definitions of a learning disability, is quite lengthy. It would be a recommendation of this report, for there **to be a more succinct definition of 'learning disability' used and**



shared locally. The local authority may already have one, which could be shared across the whole system.

The Parent Carer Forum felt that Healthwatch Luton ought to focus more specifically on certain areas of health, which in turn would generate more feedback and interest in speaking with Healthwatch Luton. It would be a recommendation of this report that **Healthwatch Luton understand what these areas are, and potentially work with Luton Parent Carer Forum to gather further feedback from this cohort of people.**

It would seem there are a lot of families in Luton who would benefit from the support that the Luton Parent Carer Forum can provide. Healthwatch Luton have been told there are in excess of 1500 families that could access the PCF, around half of which are accessing them. Although, it would appear the same 50 families are engaging. It would be a recommendation of this report that **the Luton Parent Carer Forum be better promoted, and their work shared more widely within Luton,** in the relevant places such as special educational establishments and main stream schools via SENCOS.

Healthwatch Luton believe the **Think Autism Partnership Board** to be reviewing the format and location of their meetings.

It would be a recommendation of this report that **the meetings be promoted wider within Luton** to encourage further attendance from service users and providers.

Whilst there appears to be a **mentor programme running via the PCF,** it would seem that there is not an option to book a private room for these meetings. It would be a recommendation of this report that **a better booking system or alternative venue be found for the mentoring to occur.** This could be done collaboratively between the Edwin Lobo Centre (CCS) and the Parent Carer Forum.

Healthwatch Luton feel, based on the feedback provided by the public and professionals, that there would be a benefit to giving those who need it, **a small card that would fit inside their wallet or purse that stated their name and that they needed 'More time'**, whether that is for appointments, to encourage reception staff to look at notes on the computer before booking people in or to use in environments such as the opticians, where there may not be more information available. This was suggested at the Learning Disability Partnership Board and was welcomed by all service users and professionals in attendance. It would be a recommendation of this report that this is rolled out system wide in Luton. Healthwatch Luton are happy to work



collaboratively on this and partner with the LCCG or other local organisations to do this.

Education and Health Care Plans (EHCPs) are used by professionals when a child or young person has needs, not specifically a diagnosis. If a parent or carer is unable to understand this document or understand at the meetings associated with it, there can be concerns about the accuracy of the document. It would be a recommendation of this report that **translation support is provided by the local authority for the completion of this and any subsequent meetings.**

It has become apparent that the pathways for learning disability diagnosis and care is not always apparent, nor the criteria for diagnosis. It would be a recommendation of this report **that criteria and referral pathways are shared with parents and carers when first discussing learning disabilities** with them, so they are able to understand and engage with services to achieve the best outcomes. This is something an organisation, such as Healthwatch Luton could collate and share with the local providers.





Conclusion

Healthwatch Luton found the work carried out in this report stimulating. It is evident a lot of work is happening locally and driven from a national level also.

Healthwatch Luton took the approach to focus on two areas and aim a bulk of the workplan towards this. Healthwatch Luton were able to focus on finding out more about the experiences of those with a learning disability in Luton, as well as understand the professionals perspective.

Healthwatch Luton would like for this report to be read and reviewed system wide, for providers of services to embed some of the good practice where applicable and enhance their offer in response to the patients views gathered.

It would be preferable for the commissioners of services and service providers to ensure the provision offered to those with a learning disability in Luton is aligning with the LBC Strategy. Healthwatch Luton would like for commissioners to use the findings in this report to influence the decisions made when looking at recommissioning.

Healthwatch Luton will create a project wide Recommendations: Action and Review (RAR) for the recommendations made within this report, and this will be

reviewed and followed up within the next year, based on the timescales within the document. This is an internal document for Healthwatch Luton.

There are some areas that Healthwatch Luton would have liked the opportunity to have explored further, however, as this project was so broad in its scope, a focus on a particular area to gain deeper knowledge and understanding was not possible.

Accessing services does appear problematic for some individuals, and it would be interesting to understand the different areas that effect the different age groups most. Healthwatch Luton could further explore this. Healthwatch Luton could further explore the offer available for those without a learning disability diagnosis, or who fall into the areas that are defined as a learning difficulty. Healthwatch Luton could develop the relationship between local organisations, such as Luton Parent Carer Forum, to understand what areas of health and social care affect them.

The area of learning disabilities is so vast, and a lot of support for individuals is found in the third sector or private organisations. This has been a great way to hear some of the experiences of this seldom heard group and begin to understand the needs that are not being met through current commissioning.



Useful Information

Abbreviation	What it means
AHC	Annual Health Check https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/
CCS	Cambridge Community Services https://www.cambscommunityservices.nhs.uk/
CQC	Care Quality Commission https://www.cqc.org.uk/
CYP	Children and young people
EHCP	Education and Health Care Plan https://www.gov.uk/children-with-special-educational-needs/extra-SEN-help
ELFT	East London Foundation Trust https://www.elft.nhs.uk/
HAP	Health Action Plan https://www.mencap.org.uk/sites/default/files/2016-06/What%20is%20a%20health%20action%20plan%3F.pdf
IST	Intensive Support Team
JSNA	Joint Strategic Needs Assessment https://www.gov.uk/government/publications/joint-strategic-needs-assessment-and-joint-health-and-wellbeing-strategies-explained



LBC	Luton Borough Council https://www.luton.gov.uk/Pages/Homepage.aspx
LCCG	Luton Clinical Commissioning Group https://www.lutonccg.nhs.uk/home/
LD	Learning Disabilities
LDH	Luton and Dunstable University Hospital https://www.bedfordshirehospitals.nhs.uk/
LTP	Long Term Plan https://www.longtermplan.nhs.uk/
NHS E	NHS England / National Health Service: England https://www.nhs.uk/
PCF	Parent Carer Forum
PHE	Public Health England https://www.gov.uk/government/organisations/public-health-england/about
SENCOs	Special Educational Needs Co-Ordinator
SEND	Special Educational Needs or Disabilities
STOMP	Stopping the over medication of people with a learning disability and/or autism https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/



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