

**Children with special
education needs and
disabilities
(SEND)**

Needs assessment

Phase two: a focus on health and social care needs

July 2021

Foreword

Understanding the needs of our special education needs and disabilities (SEND) children and young people was identified as an area of development in our SEND Written Statement of Action (WSOA) July 2019. Inspectors stated that leaders do not have a breadth of understanding about how children and young people are faring and what they and their families want and need.

This piece of work has been undertaken by the local authority business intelligence team working with SEND professionals across the system. Parents, children and young people's views were collated through surveys.

In phase one of this needs assessment the focus has been on the following:

- definitions, statutory duties and types of support including special educational needs (SENS) and education, health and care plans (EHCP)
- Luton population and demographics
- overview of the Luton SEND population
- special educational needs by age and settings
- what are the primary needs of children?
- what are the other risk factors including long term health conditions?
- assessing and meeting the need of children and young people with SEND

This phase two SEND joint strategic needs assessment sits alongside phase one and will focus on the health and social care needs of SEND children and young people. This will include:

- social and emotional health needs of children and young people with SEND
- neurodevelopmental disorders
- physical disabilities
- short breaks
- transitions

In addition a further joint strategic needs assessment has been completed which focuses on children and young people with learning disabilities.

These SEND joint strategic needs assessments will be used to inform commissioning decisions for SEND children and young people.

The recommendations identified as part of this work, will be reviewed by the SEND operational group and an action plan will support the implementation of these actions. This activity will be reported to the SEND Strategic Improvement Group (SSIG).

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Aim, purpose and scope

Aim and purpose

A needs assessment is a tool to inform commissioning and service planning. The overall aim of the needs assessment is to identify and evidence the needs of a population, making recommendations to meet any unmet needs and ensure the most appropriate targeting of resources. They are collaborative and should involve an identification of need from a number of perspectives:

- from analysis of relative needs of different groups, which will include evidence from the local area in comparison to other locations, or between different groups of people (sometimes referred to as comparative need)
- from professional judgement about what is needed in the local area (sometimes referred to as normative need)
- from the feelings, requirements or expectations of local people and communities (sometimes referred to as felt or expressed need)

The special educational needs and disabilities (SEND) phase two needs assessment aims to cover these requirements in relation to SEND. Specifically:

- to make evidence based recommendations to inform commissioning of SEND services
- to make evidence based recommendations to inform the strategic approach to SEND, guiding the development of a SEND strategy and to feed into the Ofsted written statement of action
- to provide baseline measures and recommendations for outcomes to inform ongoing performance reviews and evaluations
- to identify the gaps and challenges in relation to SEND and to make recommendations in relation to these

Scope

This document is a follow up document to the SEND JSNA produced in November 2020. There is also a needs assessment for children and young people with learning disabilities (October 2020). These are available through Luton Council website¹. This document focuses on:

- neurodevelopmental disorders (NDD)
- social and emotional health
- physical disabilities
- social care aspects of short breaks and respite
- transition for children and young people as they enter adult services

Other related JSNAs and documents are:

- speech and language JSNA²
- learning disabilities

¹ Luton Council JSNA,

https://m.luton.gov.uk/Page/Show/Community_and_living/Luton%20observatory%20census%20statistics%20and%20mapping/Pages/Joint%20Strategic%20Needs%20Assessment%20-%20JSNA.aspx

² Speech, Language and Communication Needs Assessment, Luton Council, January 2020,

https://www.luton.gov.uk/Community_and_living/Lists/LutonDocuments/PDF/JSNA/speech-language-and-communication-full-assessment.pdf

Executive summary

This SEND JSNA phase 2 which focuses on health and social care needs of children and young people with SEND sits alongside the SEND JSNA Phase 1. This needs assessments focuses primarily on local demographics of our SEND children and young people and understanding the usage of local services.

Full report [Phase 1 SEND JSNA full report](#)

Summary report [Phase 1 SEND JSNA summary report](#)

Please also see the speech, communication and language JSNA.

Full report [Speech, Language and Communication JSNA full report](#)

Summary report [Speech, Language and Communication JSNA summary report](#)

The key findings in this needs assessment are:

1. **Autism Spectrum Disorder (ASD)** - For all children and young people with an EHCP at end of April 2021 (5-18years) 38.8% (all EHCPs) were ASD this compared to the national comparison of 29.7% (all settings for age ranges 5-18, latest data for 2019/20 Academic Year).

In the primary phase at end April 2021, 40.1% of children with an EHCP had a primary need of ASD. (No national data which matches phases with SEN need)

In the secondary phase in April 2021, 28.4% of children with an EHCP has a primary need of ASD (no national data which matches phases with SEN need)

2. **Disability** – the number of children with a disability as their primary need of disability with an EHCP (5-18 years) was 3.9% at the end of April 2021, this compares to the national comparison of 4.8% (all settings for age range 5-18, latest data for 2019/20 Academic Year).

In the primary phase in April 2021, 5.1% of children with an EHCP had a primary need of Disability. (No national data which matches phase with SEN need)

In the secondary phase in April 2021, 6.8% of children with an EHCP has a primary need of Disability. (No national data which matches phase with SEN need)

3. **SEMH** – for children and young people with an EHCP at the end of April 2021 (5-18years) 11.0% had SEMH as their primary need, this compared to the national comparison of 14.8%.

In the primary phase in April 2021, 10.6% of children with an EHCP had a primary need of SEMH (no national data which matches phase with SEN need)

In the secondary phase in April 2021, 14.4% of children with an EHCP has a primary need of SEMH (no national data which matches phase with SEN need)

The number of children known to CAMHS who have EHCP and SEN support has now been captured for the first time.

4. **Short breaks** – Two hundred and fifty children and young people received a short break during 2021/2022 from the VCS Short breaks Consortium. This is equivalent to 12,290 hours. Two hundred and seventy seven children and young people received day short breaks in the same period. This is equivalent to 60,838 hours. Of these 54,821 hours of

short breaks were supported by Direct Payments. Fifty seven children and young people received overnight short breaks. The number of short breaks did drop over the year due to CV19.

5. **Transitions** – for young people this process starts at the age of fourteen and in Luton like many other places there is an increasing number of young people reaching the age of 18 with an EHCP who are transitioning to adult services. Planning for transitions to adult services across health, social care and education is a priority to ensure there is sufficient provisions for our young people.

Recommendations

Neuro Developmental Disorder (NDD)	
1	Commissioners are asked to consider the learning from the educational psychologist pilot of ten children on the MDA waiting list and the impact of length of wait for the family and the quality of the assessment.
2	For commissioners to review the business case for the Community Paediatric Service from CCS around capacity and demand ensuring that a multi-disciplinary skills mix is considered to ensure the assessment for 5-13 years olds is NICE compliant
3	Ensure the work being developed by the new NDD pre and post diagnosis task and finish group is delivered in a timely manner to support families.
4	Ensure the new IAPT practitioners are working to support families while they wait for appointments.
5	Make parents aware of the new local information on the Local Offer and aim to have this information available in relevant community languages.
6	Review the “traded offer” for all schools for advisory support from the autism team, and consider the need to remove the criteria of only working with children with a diagnosis.
7	Work with Autism Bedfordshire as third sector provider to support children and families with autism.
Social, emotional and mental health needs	
8	Ensure that CAMHS referrers know what services are available for families and understand eligibility criteria for onward referral, ensure the referral information is robust and considered and provides sufficient information about the needs of the child or young person.
9	Review the terms of reference for the complex case discussion panels to ensure clear clinical decision making between both agencies to avoid cases being inappropriately transferred or delayed unnecessarily.

Neuro Developmental Disorder (NDD)	
10	Ensure that the refresh of the Social and Emotional Mental Health Joint Strategic Needs Assessment has a particular focus on the needs of children and young people with SEND. This should be completed by June 2021.
11	Make use of NHS numbers as a unique identifier for SEND from school census to drill down in data sets to improve our understanding.
12	From a quality assurance perspective, make sure our current offer meets the needs of our SEND children and young people.
Physical disability	
13	The local authority is to commission a new special school and it is recommended that this school should have a nursery which can take children with physical disability.
Sensory disability	
14	Ensure that we can recruit to the qualified teacher visually impaired (QTVI) posts required by the authority, the vacancy should reflect the need to include the role within the senior leadership team in the school and the salary reflects this responsibility. This needs to be reflected through Job Evaluation panel in the local authority.
15	Work with the sensory units to improve their ability to understand local needs using a range of data sets. This will be supported by ensuring clear information sharing arrangements are in place to improve work between outreach services and schools and the Luton and Dunstable hospital
Short breaks	
16	Understand any issues regarding waiting times the lead agency for the VCS short breaks consortium has been asked to provide data on a quarterly basis on length of waiting list to inform our understanding.
17	To promote widely the Short Breaks Offer across Luton to parents and professionals.
18	Further work has been requested to look at alternative options for providing short breaks for children working with local special schools and health providers.
19	Joint work between health and social care to identify any gaps in provision for children and young people with the most complex needs and suitable respite provision.
Transitions	
20	Work with commissioners and Cambridge Community Services to improve these services for young people.

Neuro Developmental Disorder (NDD)

21	Work with commissioners to look at providers for young people who are transitioning into adult services with physical disabilities.
22	Review contracts with provider services to explore possible service redesign to meet the needs of the most complex young people.
23	Review with commissioners, additional day care capacity
24	Review with commissioners, providers who could offer either spot purchasing of floating tenancy support or review the current contract with Penrose.
25	Clear information needs to be made available on the Local Offer to support parents and young people with periods of transitions, this includes information on pathways, where to get support and what to expect.

National context

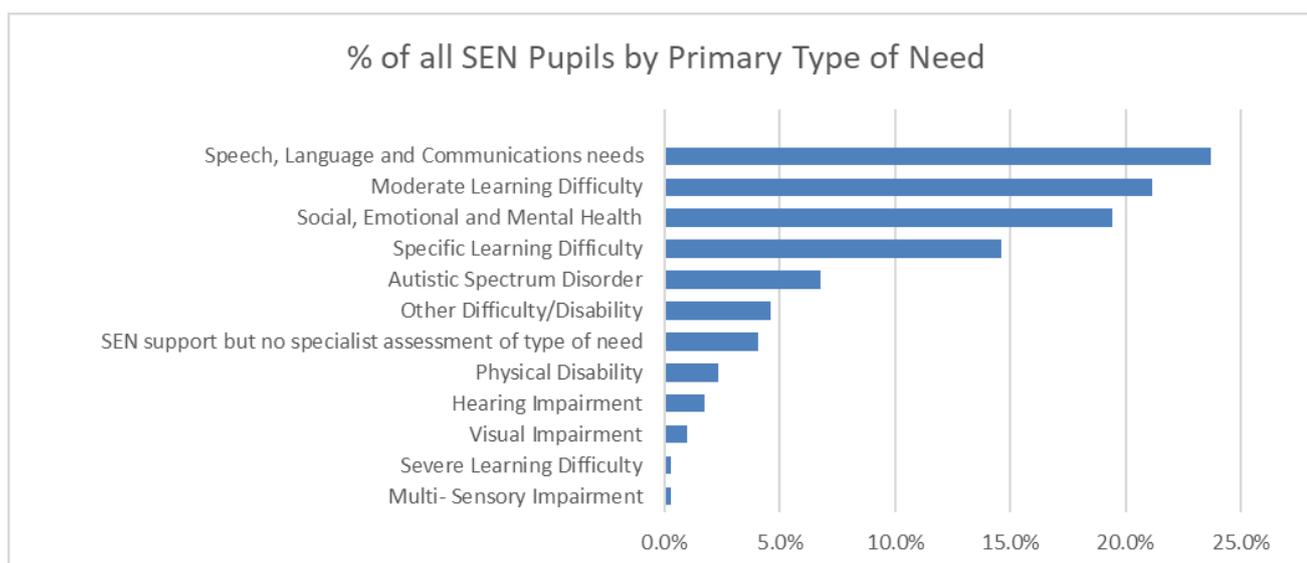
There are around 13 million disabled people in the UK (almost one in five of the population)³. Only 17% of disabled people were born with their disabilities. The majority of disabled people acquire their disability later in life⁴. Around 7% of children are disabled⁵.

In January 2020 **15.4%** of pupils in England have a special education need and **3.3%** of all pupils having an Education, Health and Care plan⁶. The number of pupils with special educational needs (SEN) has increased for a **fourth** consecutive year to **1,373,800** in January **2020**, representing 15.5% of the total pupil population. This is driven by increases in both the number of pupils with an Education, Health and Care (EHC) plan and with SEN support. **294,800** pupils (**3.3%**) of the total pupil population, have an EHC plan and a further **1,079,000** pupils (**12.1%**) are on SEN support.

Please see the first SEND JSNA (November 2020) for further descriptions of the national context of children with SEND and definitions of disability.

Across all pupils with SEN, speech, language and communications needs is the most common primary type of need at 24% of pupils.

Figure 1: Speech, language and communications needs is the most common type of need among SEN pupils in state-funded primary, secondary and special schools, England, January 2020



Source: School Census, Spring 2021

Among pupils on SEN support, speech, language and communications needs is also the most common type of need, at 23.7%.

Of those with an EHC plan, autistic spectrum disorder remains the most common primary type of need with 30.1% of pupils with an EHC plan having this primary type of need. This has increased from 29.0% in January 2019.

³ Family Resources Survey 2015/2016

www.gov.uk/government/uploads/system/uploads/attachment_data/file/600465/family-resources-survey-2015-16.pdf

⁴ The Papworth Trust, 2016

www.papworthtrust.org.uk/sites/default/files/Disability%20Facts%20and%20Figures%202016.pdf

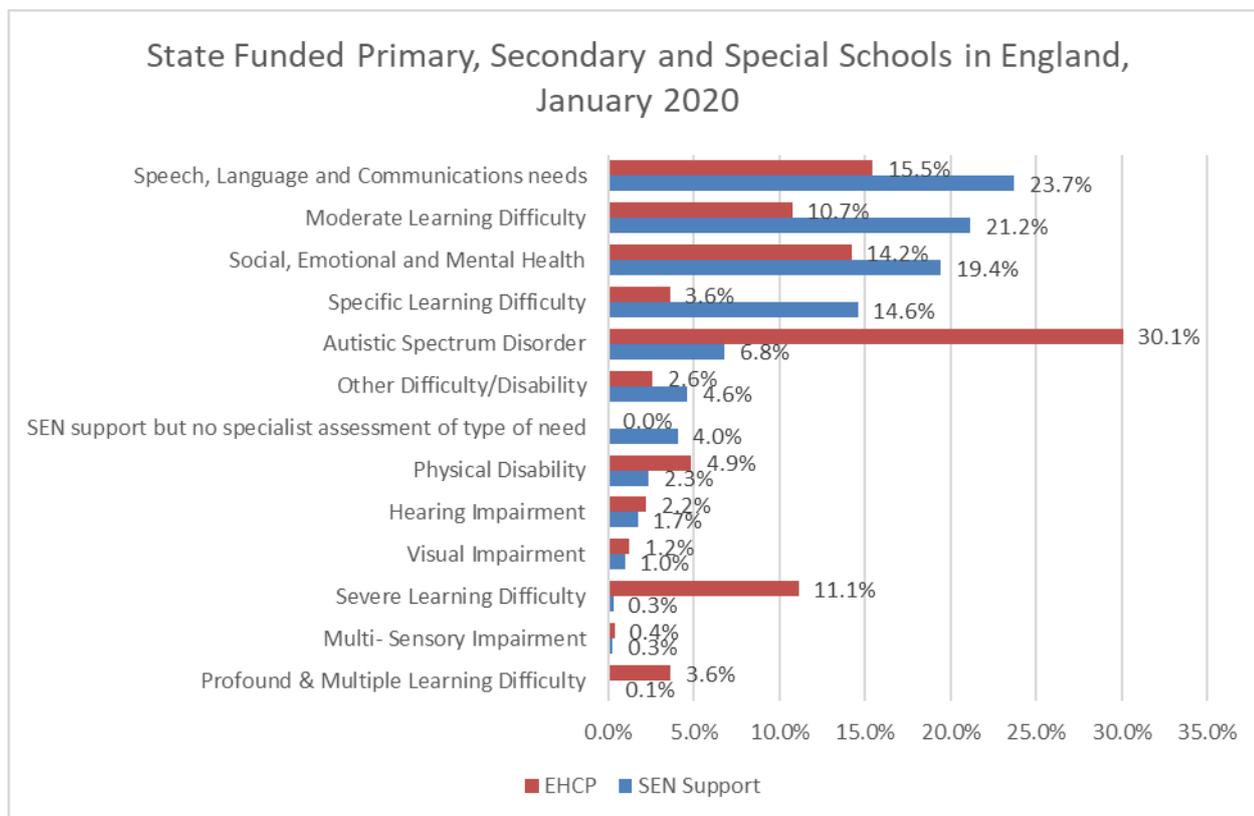
⁵ Family Resources Survey 2015/2016

www.gov.uk/government/uploads/system/uploads/attachment_data/file/600465/family-resources-survey-2015-16.pdf

⁶ Special educational needs in England: January 2020, DfE, July 2020 [Special educational needs in England, Academic Year 2019/20 – Explore education statistics – GOV.UK \(explore-education-statistics.service.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/600465/special-educational-needs-in-england-academic-year-2019-20-exploring-education-statistics.pdf)

Figure 2: The distribution of each primary type of need varies greatly between those who are identified as SEN support, compared to those with an EHC plan

Figure 3: Percentage of pupils by primary type of need and SEN provision, January 2020



Source: School Census⁷

Poor health in childhood and adolescence can have a significant impact on overall life chances, with certain unhealthy behaviours having medium to long-term impacts on health. Studies have shown that the health of young people has remained moderately stable over time, despite the health of infants and older people improving. Young people’s general health has therefore been an area of concern for the government over a number of years.

Self-rated health is seen to be related to behaviours, outcomes and other social conditions such as life satisfaction. There is also a wide variation between individuals and their health, with background, economic status and the area people live in having a significant impact on their general level of health. In order to address this, the 2010 Marmot Review ‘Fair Society Healthy Lives’⁸ emphasised the importance of reducing health inequalities in England.

Who is at risk and why?

Disabilities may be developmental or acquired. Sometimes, several factors may combine to cause a disability and often the exact cause is unknown. There are, however, recognised risk factors:

- chromosomal and genetic abnormalities – disabilities such as Down’s syndrome, sickle cell disease and phenylketonuria can be caused by chromosomal abnormalities or gene mutations

⁷ [Special educational needs in England, Academic Year 2019/20 – Explore education statistics – GOV.UK \(explore-education-statistics.service.gov.uk\)](https://www.gov.uk/explore-education-statistics)

⁸ Marmot Review, 2010, <https://www.gov.uk/research-for-development-outputs/fair-society-healthy-lives-the-marmot-review-strategic-review-of-health-inequalities-in-england-post-2010>

- mother and baby having different blood types – when a mother’s blood type is different to the baby’s, there is risk that the mother’s body forms antibodies that can attack the baby’s blood causing disabilities, such as cerebral palsy and deafness
- infectious diseases suffered by mothers and children – a number of viral and sexual infectious diseases suffered by mothers during pregnancy, including measles and HIV, can cross the placental barrier and cause disabilities. Diseases suffered by children in early childhood, such as meningitis and measles can also cause disability
- premature birth and/or low birth weight babies – babies who are born early and/or have a low birth weight have approximately a 20% chance of having a disability. Premature birth and low birth weight can be caused by maternal lifestyle choices, for example, smoking or poor nutrition. However, for a majority of women who have preterm births, the causes are unclear
- fetuses being exposed to drugs and/or radiation – prescription drugs, environmental pollutants and radiation can cause birth defects
- poor maternal nutrition – deficiencies in key vitamins and minerals can lead to disabilities, for example hydrocephalus and spina bifida
- maternal use of drugs and alcohol – excessive use of recreational drugs and alcohol amongst mothers during pregnancy can lead to developmental problems and/or disabilities in the child
- maternal smoking – smoking restricts the oxygen supply to the baby raising the risk of low-birth weight and premature birth, both of which increase the probability of a child being disabled
- parental age – older and younger parents are more at risk of complications that can result in childhood disability. Those under 20 are more at risk of poor nutrition and poor placental transfer of food and oxygen, whereas those who have children later are more likely to suffer from chromosomal abnormalities
- socio-economic status – children and young people with disabilities are more likely to live in households in lower socio-economic positions and be exposed to poverty. They are more likely to experience recurrent poverty, to become poor and less likely to escape poverty. Children and young people from less advantaged socio-economic backgrounds tend to be disproportionately represented amongst those with disabilities. These households may be more vulnerable to lifestyle factors that can contribute to disability. In childhood these children, like others amongst their socio-economic group will be at risk of poor nutrition, greater rates of injury and poorer mental health. The additional costs in meeting the needs of a child with disability can also itself be a major contributor to material poverty
- physical injury – injury to the mother’s abdomen during pregnancy can result in disabilities when the child is born. Accidents and injuries suffered by children can also result in disability

Understanding the epidemiology of disability is complicated by the differences in the definitions of disability used when prevalence estimates are calculated and in the methodologies used to estimate prevalence.

As a result, there is marked variation in the estimated number of children living with disability when different estimates of prevalence are used. For example:

- a survey of Directors of Children’s Services carried out by the Thomas Coram Research Unit estimated that the prevalence of disability in children was 3.0%-5.4%⁹.
- in contrast a secondary analysis of the Family Resource Survey (2004/05) found the prevalence of disability in children to be 7.0%¹⁰

⁹ Thomas Coram Research Unit & Institute of Education (2008). ‘Disabled Children: Numbers, Characteristics and Local Service Provision’ https://www.researchgate.net/publication/256840534_Disabled_children_Numbers_characteristics_and_local_service_provision

¹⁰ Blackburn CM, Spencer NJ, Read JM. (2010) ‘Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey’. BMC Paediatrics

Disability in children and young people is common. It is estimated from a Family Resource Survey 2018/19¹¹ that there are eight per cent (8%) disabled children in the UK. Disability in children¹² is 7.3% of the population of children and young people aged 0 – 18 years. This study showed 8.8% of boys and 5.8% of girls are disabled. Many of these children and young people have difficulties in more than one area of daily living, with around a third experiencing two to four difficulties and more than 10% experiencing five or more difficulties¹³.

Neurodisability

Neurodisability is an umbrella term for conditions associated with impairment involving the nervous system and includes conditions such as cerebral palsy, autism and epilepsy; it is not uncommon for such conditions to co-occur. Children with a neurodisability have a range of impairments but many have complex and continuing need and as a result are frequent users of the health service at all levels, community, primary care inpatient and outpatient settings.

Many of the conditions that cause neurodisability that require care and specialist advice from specialist teams individually are rare for example:

- neuro metabolic disorders and neurodegenerative conditions Batten's Disease (1 in 12,500 live births), ataxia telangiectasia (< 1 in 40,000)
- neuro cutaneous syndromes e.g. tuberous sclerosis (< 1/ 100,000 live births)
- profound and multiple learning disability (PMLD) groups e.g. Rett syndrome affecting less than 1 in 10,000

Other neurodisabling conditions are more common, e.g. the autism spectrum disorders affect ~1 in 100 of the population and the cerebral palsies ~1 in 400, severe intellectual disabilities ~3 in 1,000. However, the range of associated conditions and nuances of individual presentation are such that specialist neuro disability expertise is required for accurate assessment and management.

For example, 10-15% of all children and young people with cerebral palsies have developmental brain anomalies, some of which are genetically determined and may have implications for the wider family as well as implications for language and learning for the individual.

Autism spectrum conditions - especially when there is uncertainty about the diagnosis or additional difficulties such as language disorders, behavioural and motor co-ordination problems and specific or general learning difficulties. Autism is a disorder of development characterised by impaired social interaction and communication, and by restricted and repetitive behaviour.

Cerebral palsy - an umbrella term describing the physical, medical and developmental difficulties (vision, cognition and communication) resulting from an injury to the immature brain; the injury is non-progressive, but clinical difficulties may change with time.

Dyspraxia and Developmental Co-ordination Disorder - a motor learning difficulty that can affect planning of movements and co-ordination as a result of brain messages not being accurately transmitted to the body.

Epilepsy and associated developmental problems, including difficulties with language, communication, social interaction, learning, behaviour or movement.

Children with little or no vision and severe visual impairment.

¹¹ Family Resources Survey 2018/19, HM Government and Office of National Statistics, March 2020
<https://www.gov.uk/government/statistics/family-resources-survey-financial-year-201819>

¹² www.ukpmc.ac.uk/ukpmc/ncbi/articles/

¹³ NHS Standard Contract for Paediatric Neurosciences – Neurodisability, 2013, NHS England, <https://www.england.nhs.uk/wp-content/uploads/2013/06/e09-paedi-neurodisability.pdf>

Dysphagia - treating children most of whom have some degree of neurological impairment, resulting in severe and specific difficulties with eating and drinking.

Learning disability - it is estimated that around one in 220 children in the UK has some level of learning disability. A learning disability is not a disease and is not an illness and is not acquired in adulthood or as a result of injury or disease. A learning disability will be evident from childhood and in many cases the cause of the learning disability may not be clear. In other cases, genetics, chromosomal abnormalities or environmental factors may be the cause.

Movement disorders (including cerebral palsy) - where there are specific questions regarding diagnosis, prognosis and motor management. There is a particular emphasis on the management of spasticity.

Angelman Syndrome - is a neuro-genetic disorder characterized by intellectual and developmental delay, sleep disturbance, seizures, jerky movements (especially hand-flapping), frequent laughter or smiling, and usually a happy demeanour.

Metabolic disorders where there are concerns about neurological complications. These complications may range through communication and language, learning, behaviour or movement problems and educational issues.

Osteogenesis imperfecta - a condition causing extremely fragile bones.

Sturge-Weber syndrome and associated medical and developmental problems - Sturge-Weber syndrome is a rare disorder that is present at birth. A child with this condition will have a port-wine stain birthmark (usually on the face) and neurologic problems.

Rates of diagnoses for sentinel conditions e.g. cerebral palsies, severe learning disabilities (defined here as IQ<50), autism spectrum disorders should be available and related to population denominators.

One in every 220 children will have a diagnosis of epilepsy¹⁴.

Social, emotional and mental health

SEMH (social, emotional and mental health) is a term that was introduced in the special educational need and disabilities (SEND) code of practice in 2014. It replaced the terms BESD (behaviour emotional social development) and EBD (emotional and behaviour difficulties). The new abbreviation, SEMH, was the first term to drop the word 'behaviour', in an attempt to emphasise that behaviour is only ever a way of communicating something more significant.

In other words, referring to behaviour meant that many practitioners were focusing on the behaviours on display, rather than the needs behind the behaviour. Another key change to the term is the inclusion of mental health. Although the use of this term needs to be carefully managed (not least with the young people themselves) it has increased the focus on tackling issues which have an impact on the mental health of children and young people.

The most common causes of SEMH are believed to include the following: attachment history (lack of acceptance/ needs being met/ emotional warmth/ positive feedback/ managing emotional response by caregiver); trauma history (domestic violence, abuse, neglect, bullying, violent crime, social exclusion, hate prejudice, loss); current family dynamics; other systems around the child (school, community, society).

¹⁴ Epilepsy Action, Facts and Terminology, September 2018,

<https://www.epilepsy.org.uk/press/facts#:~:text=Epilepsy%20affects%20around%20one%20in,have%20a%20diagnosis%20of%20epilepsy>

Children and young people who have difficulties with their emotional and social development may have immature social skills and find it difficult to make and sustain healthy relationships. These difficulties may be displayed through the young person becoming withdrawn or isolated, as well as through challenging, disruptive or disturbing behaviour.

SEMH can manifest as difficulties relating to problems of mood (anxiety or depression), problems of conduct (oppositional defiance and more severe conduct problems including aggression), self-harming, substance abuse, eating disorders or physical symptoms that are medically unexplained. Some children and young people may have recognised disorders such as attention deficit disorder (ADD), attention deficit hyperactive disorder (ADHD) attachment disorder, pervasive development disorder, an anxiety disorder, or, more rarely, schizophrenia or bipolar disorder.

National data shows that children with any special educational need or disability are significantly more likely to leave school without any qualifications, to get stuck in a cycle of unemployment, to develop drug problems, to become involved in criminal behaviour, to become homeless and to be vulnerable to sexual exploitation¹⁵. If the child is also from an economically disadvantaged household all of these risk factors increase significantly.

Children and young people with SEMH are often the most likely to be affected by one, and often a number, of these risks. This is because they are more at risk of being excluded from school, they are more at risk of being branded as 'bad' children due to behaviour which is seen as anti-social by ill-prepared professionals and others and due to the lack of really joined-up thinking on how to help these young people in most cases.

Disabilities

Physical disability

A physical disability affects the mobility of children and young people and impacts their lifestyle, education and development throughout their life. In some cases a physical disability may involve other restrictions such as special dietary requirements or the need to use medical or adapted equipment.

Physical disabilities and health conditions can be classified as congenital or acquired. Congenital conditions refer to children who are born with physical difficulties or develop them soon after their birth. An acquired disability happens through injury or disease during the development of a child. The impact of the disability can depend on age or stage of a child's development.

Sensory impairment

A sensory impairment is when one of the senses – sight, hearing, smell, touch, taste or spatial awareness – is not working as it should. There are approximately 390,000 deafblind people in the UK¹⁶.

Hearing

There are two main types of deafness. The first happens when there is a fault in the inner ear – usually in the cochlea. This is called 'sensorineural deafness' and is permanent. The level of hearing loss may be described as mild, moderate, severe or profound and may not be the same in each ear, with only a few children totally deaf. Amplification of residual hearing may be made possible with a hearing aid.

The more profound the hearing loss, the greater the likelihood that the child will be given a cochlear implant, which allows electrical signals to be sent directly to the auditory nerve, providing a sensation of hearing. The second type happens when sounds fail to pass efficiently through the

¹⁵ Unlocking Potential, What are SEMH Needs? <https://up.org.uk/social-emotional-mental-health/>

¹⁶ Sense, 2010, What is Deafblindness? (Online), Available at: <https://www.sense.org.uk/get-support/>

outer and middle ear to the cochlea and auditory nerve. This is most commonly caused by a build-up of fluid in the middle ear, often referred to as 'glue' ear. This is known as 'conductive deafness' and is the most common type of hearing loss.

A conductive loss is likely to fluctuate and be temporary. It is often treated by inserting grommets into the eardrum: ventilation tubes which allow fresh air to enter the middle ear to keep it free of fluid.

Most children with a significant sensorineural hearing loss will have been identified before they enter an early years setting. Other children, particularly those with a fluctuating conductive loss, may not.

A significant hearing loss can have a major impact on other aspects of a child's development – particularly on communication and social interaction skills. The child may use sign language, speech or a combination of the two. Unless steps are taken to help the child feel confident in social situations, they are likely to be withdrawn – remaining on the edge of groups of children or preferring a one-to-one activity with an adult.

The NHS newborn hearing screening programme aims to identify moderate, severe and profound deafness and hearing impairment in newborn babies. Data published by NHS England shows that 98.5% of all new born babies receive their hearing screening within 4 weeks of birth.

Early identification of hearing impairment gives children a better chance of developing speech and language skills, and of making the most of social and emotional interaction from an early age. If giving birth in hospital, parents may be offered a newborn hearing test for their baby before they are discharged.

There are 50,000 children with hearing loss in the UK¹⁷. Around half are born with hearing loss while the other half lose their hearing during childhood¹⁸.

Vision

The term 'visually impaired' is used to describe a child who has sight problems severe enough to interfere with their learning. The majority of children with a visual impairment still have some vision – only five per cent are totally blind.

Most blind or partially sighted children have their sight problem from birth, though a small number lose their sight later in life following illness or an accident. Most children with a marked visual impairment will arrive in nursery with their condition already diagnosed.

Practitioners will look out for signs of impaired vision in children by noticing the child who:

- displays undue sensitivity to light
- closes or covers one eye when attempting visual tasks
- often trips or bumps into things
- holds books unusually close to their face
- tilts their head to an unusual angle when trying to focus.

Since 80 per cent of communication is non-verbal, the young child with impaired vision is at a huge disadvantage when developing interpersonal skills. Unable to discern the facial expressions of others, they cannot 'read' reactions to things they say and find verbal turn-taking very difficult. These children cannot learn by watching, only by doing. Restricted vision also leads to restricted mobility.

¹⁷ Papworth Trust, Disability Facts and Figures, 2018 <https://www.papworthtrust.org.uk/about-us/publications/papworth-trust-disability-facts-and-figures-2018.pdf>

¹⁸ Action on Hearing Loss, Facts and Figures, (Online), Available at: <https://www.actiononhearingloss.org.uk/about-us/our-research-and-evidence/facts-and-figures/>

In a typically developing child, vision is a huge motivator: seeing a desired toy just out of reach prompts the child to stretch for it or crawl towards it, but the visually impaired child doesn't know the toy exists. The development of play – leading to concepts such as conservation, classification and one-to-one correspondence – is also negatively affected by visual impairment.

When a child cannot observe others at play, it limits their own skills. Finally, independence and self-help skills are significantly delayed in a child with sight problems.

The risk factors for sight loss in children and young people tend to differ from the risk factors for sight loss in adults. Children and young people most at risk of vision impairment or sight loss are those who:

- were born prematurely
- had low birthweight
- were exposed to maternal infections during pregnancy
- were exposed to maternal drug and alcohol consumption during pregnancy
- were exposed to maternal smoking during pregnancy
- have certain genetic conditions, such as Down's syndrome
- have learning difficulties

There is limited data available on the prevalence of some of these risk factors in children and young people.

There is a scarcity of readily available and robust data relating to the eye health of children, therefore this briefing gives an overview of the accessible intelligence rather than a complete picture. Although eye screening is carried out for newborns and 6 week olds, there is no readily available data relating to the rate and outcomes of these examinations.

The UK National Screening Committee recommends that screening of children's eyes should be offered to all children aged 4 to 5 years and that this service should be organised and led by specialists (orthoptists)¹⁹.

However, currently screening during the first year of school is dependent upon local commissioning arrangements by each local authority. Readily available data on the commissioned offer and uptake is not easily accessible. Furthermore, information relating to the diagnosis of eye conditions common in children, such as amblyopia and strabismus, is also not readily available.

Local authorities maintain registers of residents in their area who are registered as blind or partially sighted and hold a certificate of visual impairment (CVI). These registers are intended to provide a formal route to obtaining support from social care services. However, there is no requirement to be on a local authority register which means that the numbers may be underestimated.

It should also be noted that a higher rate of registration may not necessarily indicate that a local authority has a higher rate of visual impairment in 0 to 17 year olds, but could indicate that the residents of that local authority are more likely to register, possibly due to having better information on the process.

In 2013/14, there were 4,275 blind people aged 0 to 17 years on a register in England²⁰. This corresponds to a rate of 37.2 children and young people per 100,000 registered as blind 0 to 17 year olds in England. In comparison, Luton had 35 people aged 0-17 who appear on the register for blindness, which calculates to a rate of 65.2 per 100,000.

¹⁹ Public Health England (PHE). Child vision screening. Available online from: <https://www.gov.uk/government/publications/child-vision-screening>

²⁰ NHS Digital - Registered Blind and Partially Sighted People. Available online from: <https://digital.nhs.uk/data-and-information/publications/statistical/registered-blind-and-partially-sighted-people>

This is the third highest amongst the local authorities shown on the chart below, and well above the England average rate of 37.2 per 100,000.

Short breaks

The term 'short breaks' is used to describe the time off that family carers and disabled people receive. These breaks come in different forms. Some families access short breaks at centres, others are part of schemes involving placements with families. Some receive direct payments to buy their own support.

Research shows that 24% of parent carers of disabled children provide 100+ hours of care every week (the equivalent of three full-time jobs). 56% care 35+ hours a week. Many do this without a break. Breaks are an essential part of the support needed by the whole family. They provide much-needed time off for the carer to rest and focus on other activities and family members.

They also allow those they care for to spend time with others and take part in different activities. A study revealed that 74% of parents of children with life-limiting conditions rated short breaks as having a positive effect on their relationships²¹.

The Department for Education document Short Breaks for Disabled Children²² said that local authorities must:

- provide a range of short breaks services
- give families the choice to access short breaks services using a direct payment
- publish a statement of their short breaks services on their website
- keep their short breaks statement under review
- state in their short breaks service statement the range of short breaks services available, the criteria by which eligibility for services will be assessed, and how the range of services is designed to meet the needs of families with disabled children in their area
- consult parents as part of the review of the statement
- consider the legal implications of the eligibility criteria they apply to short breaks services
- not apply any eligibility criteria mechanically without consideration of a particular family's needs

Local authorities should ensure that:

- short breaks are reliable and regular to best meet families' needs
- local authorities should try to reach groups of parents who may be more difficult to engage
- parents are engaged in the design of local short breaks services
- short breaks can build on and be offered by universal service providers
- they are working in partnership with health services to understand the range of short breaks services in their area and to train the workforce
- short breaks promote greater levels of confidence and competence for young people moving towards adult life
- local authorities should ensure that those who use short breaks services have the chance to shape the development of those services
- they continue to develop their workforce in relation to short breaks services

Transition

Until the age of 18, services for children and young people with long-term health conditions are provided by child health and social care services. From 18, they're usually provided by adult services. Between the ages of 14 and 18, the child will start a "transition" to adult services.

²¹ Disabled Children's Partnership, Short Breaks <https://disabledchildrenpartnership.org.uk/what-are-short-breaks/#:~:text=The%20term%20'short%20breaks'%20is,to%20buy%20their%20own%20support>

²² Department for Education, Short Breaks for Carers of Disabled Children, 2011, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/245580/Short_Breaks_for_Carers_of_Disabled_Children.pdf

This should involve all the services that support areas like:

- health and social care
- mental health
- education
- financial benefits for the young person and their family
- work
- housing

Planning for this transition should begin when a child is in Year 9 at school (13 or 14 years old) at the latest. Transition should be an ongoing process rather than a single event, and tailored to suit the child's needs.

The 2014 Care Act²³ places a duty on local authorities to conduct transition assessments for children, children's carers and young carers where there is a likely need for care and support after the child in question turns 18 and a transition assessment would be of 'significant benefit' (see below). The guidance states that in order to fully meet these duties, local authorities should consider how they can identify young people and carers who are not receiving children's services but are nevertheless likely to have care and support needs as adults. They should consider how to establish mechanisms to identify young people as early as possible in order to plan for or prevent the development of care and support needs and thereby fulfil their duty relating to 'significant benefit' and the timing of assessments.

Local context

Disability in children is 7.3% of the population of children and young people aged 0 – 18 years. Usually children are less than 18 years so this has been used for the estimates projected on to Luton's population (latest ONS population estimates for mid-2019 have been used). This means that 8.8% of boys and 5.8% of girls are disabled. That is 4,200 children in Luton, 2,600 boys and 1,600 girls (rounding applied) have disabilities based on this estimate.

Many of these children and young people have difficulties in more than one area of daily living, with around a third experiencing two to four difficulties and more than 10% experiencing five or more difficulties. Applied to the Luton children population that is 1,400 have two to four difficulties and 420 children with five or more difficulties.

There is a considerable overlap between those with special education needs and those with disabilities.

The following table (Table 1) uses the national prevalence estimates for 2017/18 and applies these to the Luton 0 to 25 year old population for 2018 (ONS mid-year estimate). It calculates that, using this prevalence rate, there would be approximately 6,500 disabled 0 to 25 year olds in Luton. This compares reasonably favourably with those figures shown above for SEN support/ EHC plan, though is using a different methodology and a different population sub-set.

Table 1: National disability prevalence applied to Luton 0 to 25 population

Age group	National prevalence		Applied to Luton population		
	Males	Females	Male	Female	Total
0-4	4%	3%	360	250	610

²³ HM Government, The Care Act, 2014, <https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>
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Age group	National prevalence		Applied to Luton population		
	Males	Females	Male	Female	Total
5-9	11%	6%	960	500	1,460
10-14	11%	7%	850	500	1,350
15-19	10%	13%	660	820	1,480
20-24	11%	13%	730	820	1,550
0-24			3,560	2,890	6,450

Source: Family Resources Survey 2017/18, ONS mid-year population estimates 2018

Table 2 contains more detailed information about the types of impairment that disabled children had. These have been calculated by applying the national prevalence for children to the 0 to 25 age group disabled population in Luton estimated in Table 1 above.

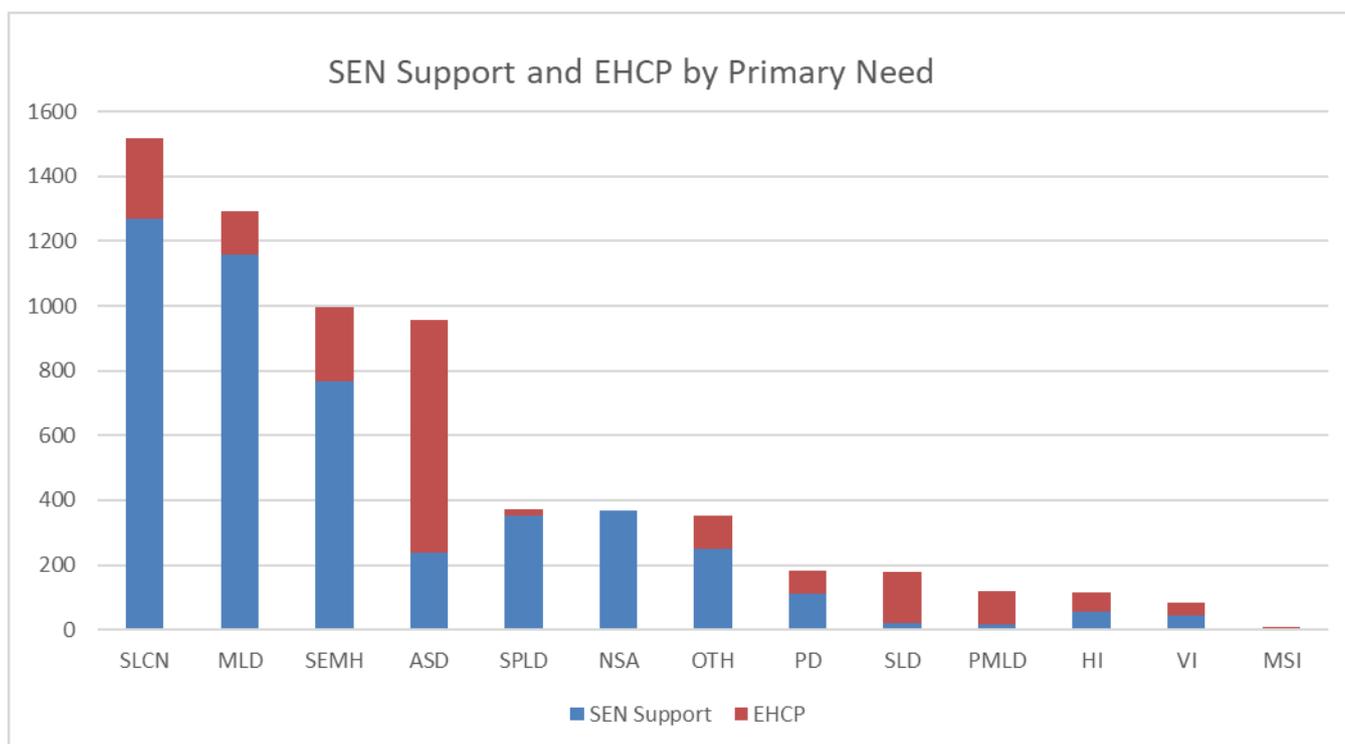
Please note that respondents can be affected by more than one type of impairment and therefore, due to this reason, numbers may not add up with other prevalence tables. This shows that social/behavioural difficulties and learning disabilities are estimated to be the most prevalent impairments.

Table 2: Impairment types reported by disabled children applied to the 0 to 25 year old estimated disabled population for Luton

Impairment type	National prevalence for children	Applied to Luton 0-25 population
Mobility	19%	1,225
Stamina/ breathing/ fatigue	24%	1,550
Dexterity	11%	710
Mental health	23%	1,485
Memory	11%	710
Hearing	8%	515
Vision	9%	580
Learning	36%	2,320
Social/ behavioral	43%	2,775
Other	18%	1,160

Source: Family Resources Survey 2017/18, ONS mid-year population estimates 2018

Figure 4: Children and young people in Luton by primary need for SEN support and EHC plan



Source: Luton Council, School Census January 2021 for SEN Support, EHC Plans April 2021

Table 3 shows the data in figure 4 numerically. They are Luton Council data so the actual prevalence of children identified with special educational needs and disabilities from the School Census (SEN) and internal systems (EHC).

There has been a 1.2% increase in children with an EHC during the two data periods. The highest increases are seen in children with autistic spectrum disorders, and social, emotional and mental Health issues for EHC plans.

Table 3: Prevalence of children with EHC plans and SEND support

Impairment type	Nov 2020		April 2021	
	EHC	SEN	EHC	SEN
Moderate Learning Disability (MLD)	132	1,268	134	1,157
Speech, Language and Communication Needs (SLCN)	246	1,197	248	1,270
Social, Emotional and Mental Health (SEMH)	149	752	164	769
Autistic Spectrum Disorder (ASD)	701	245	720	236
Speech and Language Difficulty (SPLD)	21	414	21	351
Other Disability/ Difficulty (OTH)	120	275	104	249
No Specialist Assessment (NSA)	0	399	0	370
Severe Learning Disability (SLD)	157	17	161	19
Physical Disability (PD)	76	107	74	110
Hearing Impairment (HI)	67	53	63	54
Profound and Multiple Learning Difficulty (PMLD)	103	16	102	16
Behavioral, Emotional and Social Difficulties (BESD)	68	0	62	0
Visual Impairment (VI)	39	46	40	43
Multi-Sensory Impairment (MSI)	3	7	3	4
Blank	9	0	18	
Total	1,891	4,797	1,914	4,648

Source: Luton Council

This shows that the Luton dataset identifies moderate learning difficulties (MLD) as the most prevalent condition for children and young people in Luton, with speech, learning and communication needs (SLCN) not far behind, both with around 1,400 children and young people.

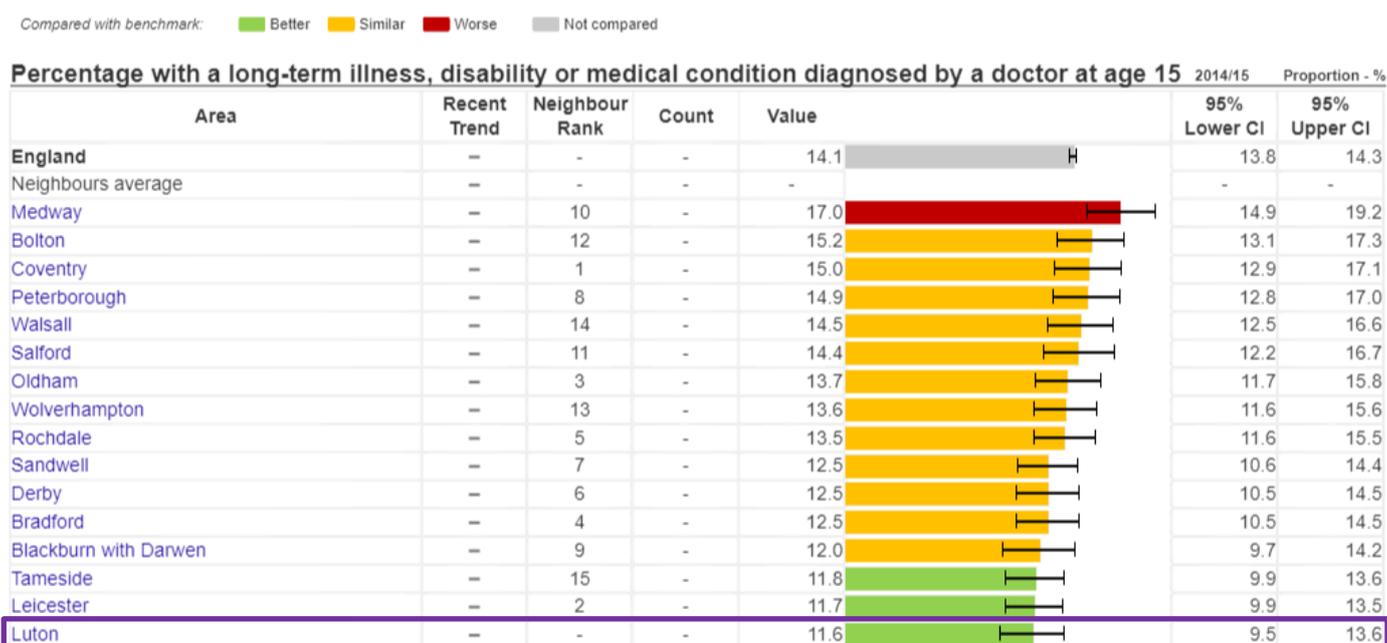
Children with MLD experience difficulty following the national curriculum despite receiving extra help and intervention. This developmental delay results in attainments that are below the expected standards in most areas of the curriculum - generally at or below the second percentile - particularly in literacy and numeracy skills. Children with MLD do not find learning and communicating easy and may display challenging behaviour if their needs are not fully recognised and understood²⁴.

There can often be a crossover between MLD, autistic spectrum disorder (ASD) and speech, learning and communication needs (SLCN) where children and young people can find it difficult to listen, understand and communicate with others. There is also a strong link between SLCN and ASD, which both fall under the 'communication and interaction' broad area of need, with all children with ASD recognised as also having SLCN, and there can often be a blurring in respect of which of these conditions a child may experience²⁵.

Other conditions in Luton that had over 400 recorded children are social, emotional and mental health issues (SEMH), autistic spectrum disorder (ASD), specific learning difficulties (SPLD) and other difficulties/ disabilities (OTH). Other categories with notable numbers of children and young people in Luton include severe learning difficulties (SLD), physical disabilities (PD), hearing impairments (HI), those with profound and multiple learning difficulties (PMLD), visual impairments (VI) and behavioural, emotional and social difficulties (BESD).

Data is published on the children and young people with a long-term illness, disability or medical condition at age 15. These are shown in figure 5. The latest data published are 2014/15 from the What About YOUth survey. This was completed by children in the age cohort through schools. The data shows that Luton has the lowest proportion of children in this group within the ONS cluster of similar local authorities.

Figure 5: Percentage with a long-term illness, disability or medical condition at age 15



Source: PHE Fingertips

²⁴ Good schools guide, [Moderate learning difficulties](#)

²⁵ The Communication Trust (2010), ['Don't get me wrong – Information for supporting children and young people with speech, language and communication needs'](#)

Local Data provided by Cambridge Community Health providers

Cambridgeshire Community Services (CCS) provide the community child health service for Luton residents. They were given details of EHCP and SEN children and young people that may be in their care. The 2019/2020 case load is shown in table 4. There appears to have been a big increase in children and young people accessing speech and language therapy.

There were a total of 6,442 patients aged 2 to 24 in the community child health service across all services. 1,654 EHCP patients and 4,788 SEN patients. 66% were boys. 26% of the caseload were Pakistani, 23% white British, 13% multiple ethnic group, 8% Bangladeshi (30% all other ethnic groups). Data from CCS are based on patients who are registered with a Luton GP practice and so may live in other local authority areas.

Table 4: CCS caseload of children and young people with EHCP and SEN

Service	EHCP		SEN	
	Known within 2019/20	Known up to 2 years prior to this	Known within 2019/20	Known up to 2 years prior to this
Audiology	244	236	453	503
Community Paediatrics	622	867	465	634
Children's Community Nursing	155	196	86	230
Special School Nursing	421	286	19	13
Occupational Therapy Services	220	169	112	136
Dietetics	223	158	119	130
Speech & Language Therapy	626	269	573	292
Continence	254	262	28	21

Source: Cambridgeshire Community Services

Table 5 shows the total number of contacts and average number of contacts (in brackets) children and young people have received from these CCS services. Contacts include face to face and non face to face.

Table 5: CCS contacts for children and young people with EHCP and SEN 2019/ 2020

Service	EHCP	SEN
Audiology	172 (1.1)	205 (1.2)
Community Paediatrics	1,583 (2.6)	1,387 (2.6)
Children's Community Nursing	2,745 (19.9)	2,047 (20.1)
Special School Nursing	2,848 (9.0)	17 (2.8)
Occupational Therapy Services	620 (3.0)	181 (1.9)
Dietetics	533 (2.5)	140 (2.1)
Speech & Language Therapy	1,526 (2.3)	750 (1.8)

Service	EHCP	SEN
Continence	482 (2.2)	22 (1.3)

Source: Cambridgeshire Community Services

The waiting time for children's community services are shown in table 6.

Table 6: Wait in weeks for Children's Community Services

	Audiology	Community Paediatrics	OT services	Dietetics	SALT	Continence
EHCP	9.4	11.4	9.3	13.9	9.0	9.4
SEN	9.3	19.23	9.0	12.9	10.3	6.9

Source: Cambridgeshire Community Services. OT = Occupational Therapy; SALT = Speech and Language Therapy

Neurodisability

Estimated local prevalence of neurodisabling conditions are below in table 7.

Table 7: Estimated prevalence of neurodisability disorders

Condition	Rate	Population Under 18 years n57,487 Under 25 years n74,624 5-16 years n 37,632 (Mid 2019 ²⁶)	Live births n3,256 (2019 ²⁷)
Autism spectrum disorders	1 in 100	Under 18 n549 Under 25 n746	
Learning disability	1 in 200	Under 18 n275 Under 25 n373	
Epilepsy	1 in 220	Under 18 n261 Under 25 n339	
Cerebral palsies	1 in 400	Under 18 n143 Under 25 n186	
CP with developmental brain anomalies	10-15% of CP cases	Under 18 n14-21 Under 25 n19-28	
Severe intellectual disabilities	3 in 1,000	Under 18 n172 Under 25 n224	
Hyperkinetic disorders	1.7%	5-16 years n640	
Attention Deficit Hyperactivity Disorder ²⁸	3-5%	Under 18 n1,725-2,874 Under 25 n 2,239-3,731	
Profound and multiple learning disability (PMLD) groups	1 in 10,000	Under 18 n6 Under 25 n7	

²⁶ Office of National Statistics, mid 2019 Population estimates, 2020, <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland>

²⁷ Office of National Statistics, Live Births, 2019, <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/datasets/birthsummarytables>

²⁸ NHS England, Delivering Good Services for Children and Young People with ADHD, 2018, <https://www.england.nhs.uk/north-west/wp-content/uploads/sites/48/2019/03/GM-wide-ADHD-guidance.pdf>

Condition	Rate	Population	Live births
Neurometabolic disorders and neurodegenerative conditions Batten's Disease	1 in 12,500 live births		n1 in nearly 4 years
Ataxia telangiectasia	<1 in 40,000	Under 18 n1 Under 25 n2	
Neurocutaneous syndromes	< 1/ 100,000 live births		1 in nearly 31 years

Sources: Various prevalence estimates as shown in National Context, ONS for population and live birth data

The estimated prevalence of hyperkinetic disorders in people aged 5 to 16 also comes from the 2004 study. Luton has the same prevalence, 1.7% as areas most similar to it but more than England (1.5%).

A hyperkinetic disorder is attention deficit hyperactivity disorder (ADHD). This would be about 640 children and young people in Luton based on the 2019 population. More recent data (2013) based on a survey in 2007 has been used to generate some alternative estimates and these are shown below. This suggests there are 3,670 young people in Luton with ADHD. This data are estimates and based on old data so should only be used as an indicator.

Figure 6: Estimated prevalence of hyperkinetic disorders aged 5-16

Estimated prevalence of hyperkinetic disorders: % population aged 5-16 2015 Proportion - %

Area	Recent Trend	Neighbour Rank	Count	Value	95% Lower CI	95% Upper CI
England	-	-	114,588	1.5*	-	-
Neighbours average	-	-	11,384	1.7*	1.7	1.7
Leicester	-	3	944	1.8*	-	-
Sandwell	-	8	917	1.8*	-	-
Wolverhampton	-	13	654	1.8*	-	-
Walsall	-	14	734	1.7*	-	-
Rochdale	-	5	562	1.7*	-	-
Salford	-	12	571	1.7*	-	-
Blackburn with Darwen	-	7	427	1.7*	-	-
Coventry	-	1	806	1.7*	-	-
Oldham	-	2	645	1.7*	-	-
Peterborough	-	9	495	1.7*	-	-
Bradford	-	4	1,534	1.7*	-	-
Luton	-	-	589	1.7*	-	-
Tameside	-	15	521	1.6*	-	-
Bolton	-	11	707	1.6*	-	-
Derby	-	6	625	1.6*	-	-
Medway	-	10	651	1.6*	-	-

Source: PHE Fingertips

The estimated prevalence for Luton for young people with ADHD aged 16 to 24 is 3,670. These data are based on the Adult Psychiatry Morbidity Study from 2007, a survey of mental illness. These estimates are included in the absence of an alternative and well validated approach. They should be interpreted with caution and consideration of local data and intelligence, which may generate better estimates of true local prevalence.

Figure 7: Prevalence of ADHD among young people: estimated number aged 16 - 24

Prevalence of ADHD among young people: estimated number aged 16 - 24 ²⁰¹³					Count - population	
Area	Recent Trend	Neighbour Rank	Count	Value	95% Lower CI	95% Upper CI
England	-	-	859,422	*	-	-
Neighbours average	-	-	74,648	74,648	-	-
Bradford	-	4	8,619	8,619*	-	-
Leicester	-	3	7,680	7,680*	-	-
Coventry	-	1	7,335	7,335*	-	-
Sandwell	-	8	5,055	5,055*	-	-
Medway	-	10	4,819	4,819*	-	-
Derby	-	6	4,604	4,604*	-	-
Bolton	-	11	4,467	4,467*	-	-
Walsall	-	14	4,301	4,301*	-	-
Wolverhampton	-	13	4,241	4,241*	-	-
Salford	-	12	4,238	4,238*	-	-
Luton	-	-	3,670	3,670*	-	-
Oldham	-	2	3,618	3,618*	-	-
Rochdale	-	5	3,394	3,394*	-	-
Tameside	-	15	3,349	3,349*	-	-
Peterborough	-	9	2,869	2,869*	-	-
Blackburn with Darwen	-	7	2,390	2,390*	-	-

Source: PHE Fingertips

Data for children and young people with an EHCP in Luton November 2020 show that there were 701 with an autistic spectrum disorder, 132 with a mild learning disability, 157 with a severe learning disability and 103 with a profound or multiple learning disability. This totals to 1,093 children and young people.

Local data provided by Cambridge Community Health Services

Data provided by Cambridgeshire Community Services with children with a neurodisability are shown in table 8 in 2019/2020. Patients are aged 3 to 24 years. The data are based on patients that are registered with Luton GPs and so may live in other local authority areas. 75% of these patients are male. 28% are white British, 24% Pakistani, 12% mixed multiple ethnic group and 9% Bangladeshi (27% all other ethnic groups).

Table 8: CCS patients with a neurodisability, 2019/2020

	ASD	ADHD	Neurological Problems	Development Delay
EHCP	845	231	179	460
SEN	616	346	81	144
Total	1,461	577	260	604

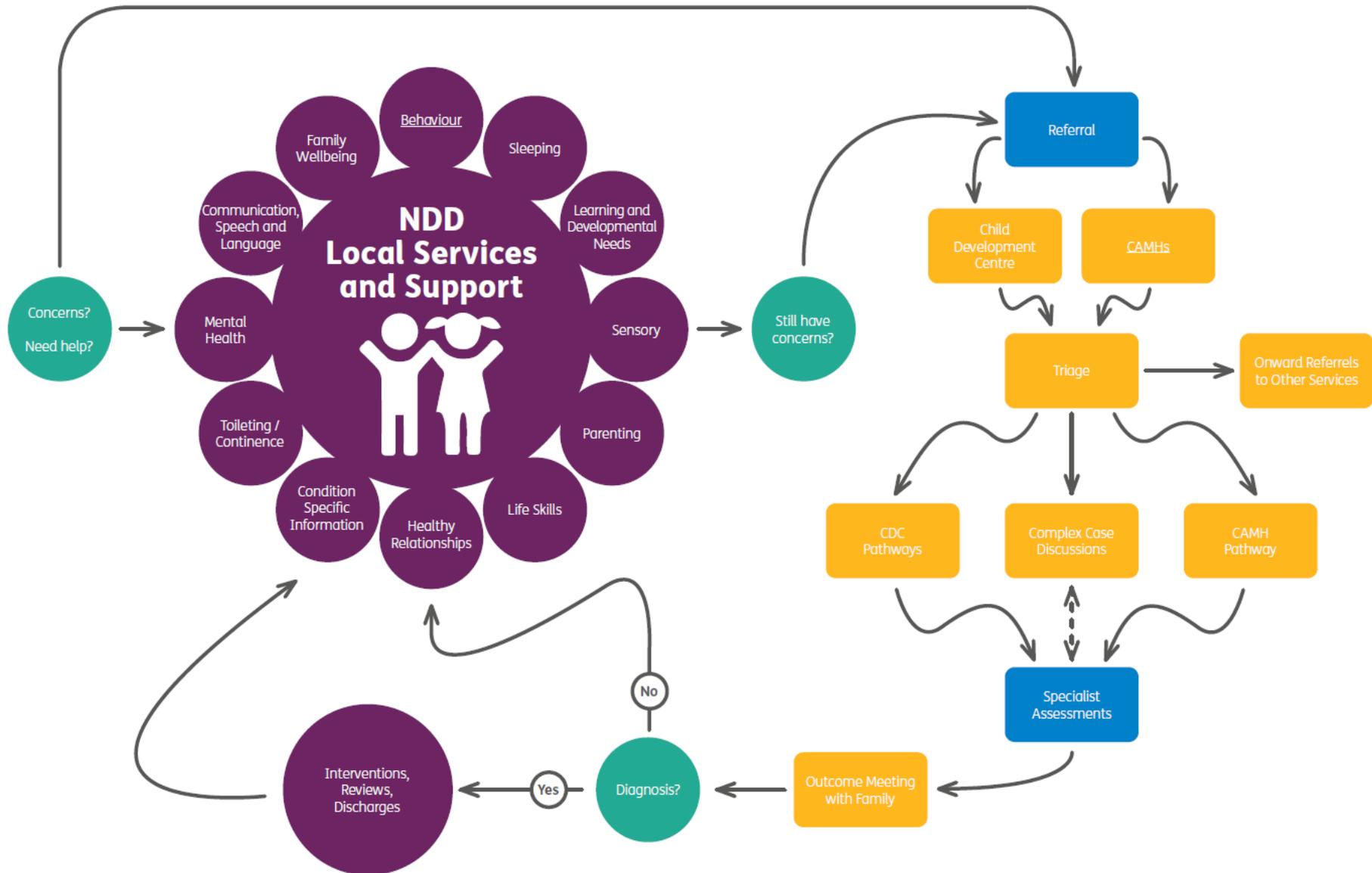
Source: Cambridgeshire Community Services

Local services

Working across Pan Bedfordshire a new pathway of early intervention and support through to assessment, diagnosis and beyond has been developed for children and young people who may have neurodevelopmental difficulties. Created with help from parents and a range of partners in health, education and social care, this pathway of early intervention and support is for children who may have developmental difficulties.

It maps out the pathway of assessment should a child or young person be referred into either community health services or the Child and Adolescent Mental Health Service (CAMHS) for an assessment of a possible neurodevelopmental difficulty or disorder. This could include conditions such as autism or attention deficit hyperactivity disorder (ADHD), a learning disability or another developmental condition. The diagram below shows the pathway.

Bedfordshire Neurodevelopmental Disorder (NDD) Pathway



Complex cases

Sometimes a child's difficulties may be quite complex and it is not clear which service would be best to assess their needs. For these children the referral will be considered at a complex case meeting made up of a community paediatrician, an educational psychologist, a clinician from CAMHS and a member of the Early Help Team. They will decide which service is best to carry out assessment. This model is currently being evaluated to understand parents and professional views and to understand the impact on waiting times.

New developments

Further work to understand the role of educational psychologist as part of the assessment process is underway. Assessment for ASD in the 5 to 13 age group is currently not NICE compliant due to lack of a multi-disciplinary/ agency assessment and specifically, involvement of education and psychology input.

The current model relies on an over-medicalised approach (often community paediatrician in isolation). This can make it difficult for community paediatricians to make safe diagnoses in a timely manner as presentations may be unclear and so more appointments, additional assessment using e.g. the ADOS tool (for which there can be long waits) and/ or visits to observe children in school settings may be required.

This delay can cause frustration and distress for families, referrers (often schools) and community paediatricians and can delay a child and family receiving appropriate support.

As part of a pilot 10 cases of children aged 5 to 13 years have been identified to be assessed by the educational psychologist with the child's school. This assessment will be provided to the community paediatrician and used as part of the holistic assessment of the child's needs.

The evaluation will include comparative measures for (i) diagnosis time and (ii) parent and (iii) referrer satisfaction for with children who are part of the pilot, together with children who are not part of the pilot but for whom share the same criteria (i.e. aged 5 to 13 with no current or recent EP involvement)

Workforce capacity

Nationally there is an ongoing challenge to recruit to community paediatric posts. In addition there are some difficulties to recruit and retain allied health professionals.

Gaps in provision

1. Assessment of a child or young person should follow NICE guidance to be compliant and be multiagency and disciplinary in nature recognising the child's needs. Education should be involved in the assessment process. NICE guidance is designed to ensure practitioners work in a safe manner to ensure the diagnosis is robust. Without education input into the assessment there is a risk decision making is left with paediatricians who may not have the full picture to make the decision.
2. Waiting time for services at the Edwin Lobo Centre remain long and further work is needed on the pre diagnosis support for parents.
3. There continues to be a gap in the post diagnosis support available.
4. Currently children with a diagnosis only are eligible for the support of the Autism Advisory teachers, there is no support for schools with children without a diagnosis. It may be that we

are missing the opportunity to provide early support which could prevent the need for an EHCP.

5. The SEND “traded model” to schools of support may inadvertently increase inequalities between schools. To increase access to the advisory teachers earlier or the training SENCO’s – systems approach linked to traded services may cause inequalities.

Parental feedback

This has been gathered from a range of sources including focus groups with parents in 2019, feedback from surveys and from Feedback from the service. Overwhelmingly the feedback shows

- The referral form for Community Paediatrics is too long
- Parent views not always listened to
- Waiting list for appointment are too long
- Lengthy waiting time impacts upon diagnosis delay and the right support in place and means child does not achieve at school since they can’t support properly
- Need clear pathways and supporting information for parents of CYP with needs eg Autism, Downs Syndrome

Recommendations

1. Commissioners are asked to consider the learning from the educational psychologist pilot of ten children on the MDA waiting list and impacts of length of wait of the family and the quality of the assessment.
2. For commissioners to review the business case for the Community Paediatric Service from CCS around capacity and demand ensuring that a multi-disciplinary skills mix is considered to ensure the assessment for 5-13 years olds is NICE compliant
3. To ensure the work being developed by the new NDD pre and post diagnosis task and finish group is delivered in a timely manner to support families.
4. To ensure the new IAPT practitioners are working to support families while they wait for appointments.
5. To make parents aware of the new local information on the Local Offer and aim to have this information available in relevant community languages.
6. To review the “traded offer” for all schools for advisory support from the autism team, and consider the need to remove the criteria of only working with children with a diagnosis.
7. Work with Autism Bedfordshire as third sector provider to support children and families with autism.

Social, emotional and mental health

Data that compares Luton to areas that are most similar (CIPFA Nearest Neighbour 2018) shows that Luton has 4,700 children between the age of 5 and 17 with mental health disorders. This includes emotional disorders, behavioural disorders, hyperactivity disorders, and autism spectrum, eating and other less common disorders.

The indicator is calculated by PHE, based on results from the 2017 Mental Health of Children and Young People Survey. The 2017 survey was commissioned by NHS Digital and carried out by the National Centre for Social Research (NatCen) and the Office for National Statistics (ONS). A random sample of children and young people were identified. Survey data was collected from a combination of the children, their teachers and their parents (depending on the age of the child).

Local data from the local authority information systems

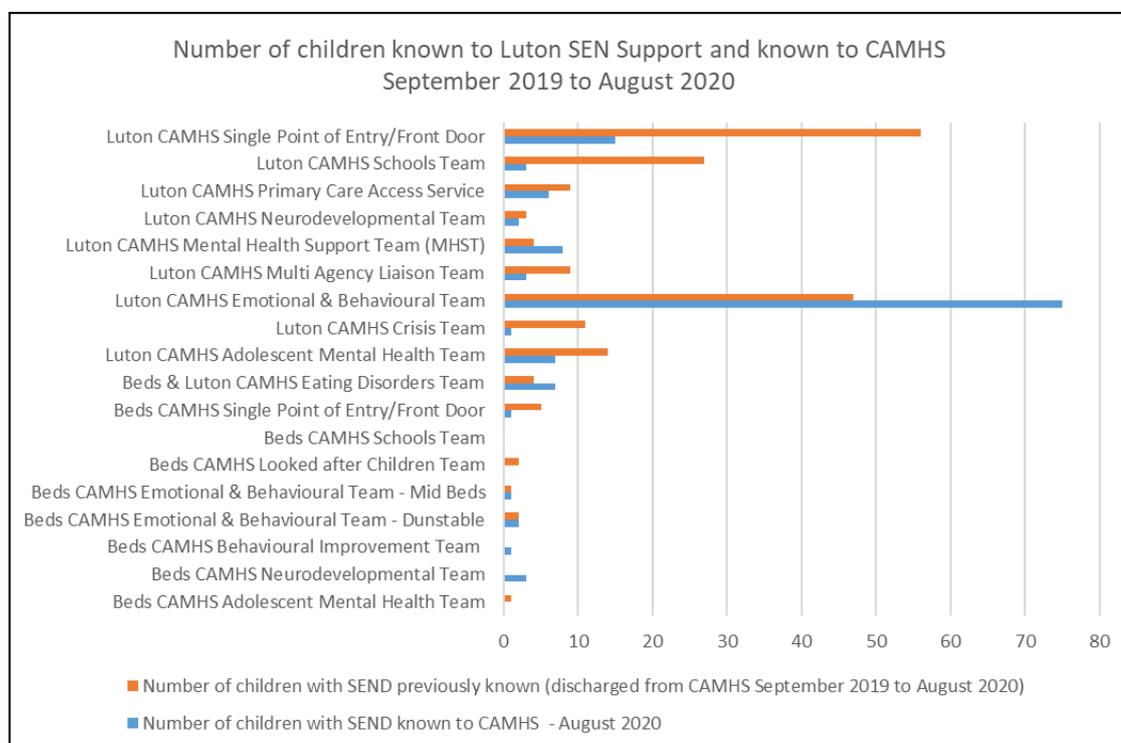
Local EHCP data shows that there are 188 children with social, emotional and mental health disorders as at end of April 2021 (all ages).

Further data is available from our mental health provider East Luton Foundation Trust who were provided with information from the Luton school census which was matched with the NHS number.

Report 1 – to get an understanding of how many CYP with SEND both EHCP and SENS are known to CAMHS to understand demand from this group

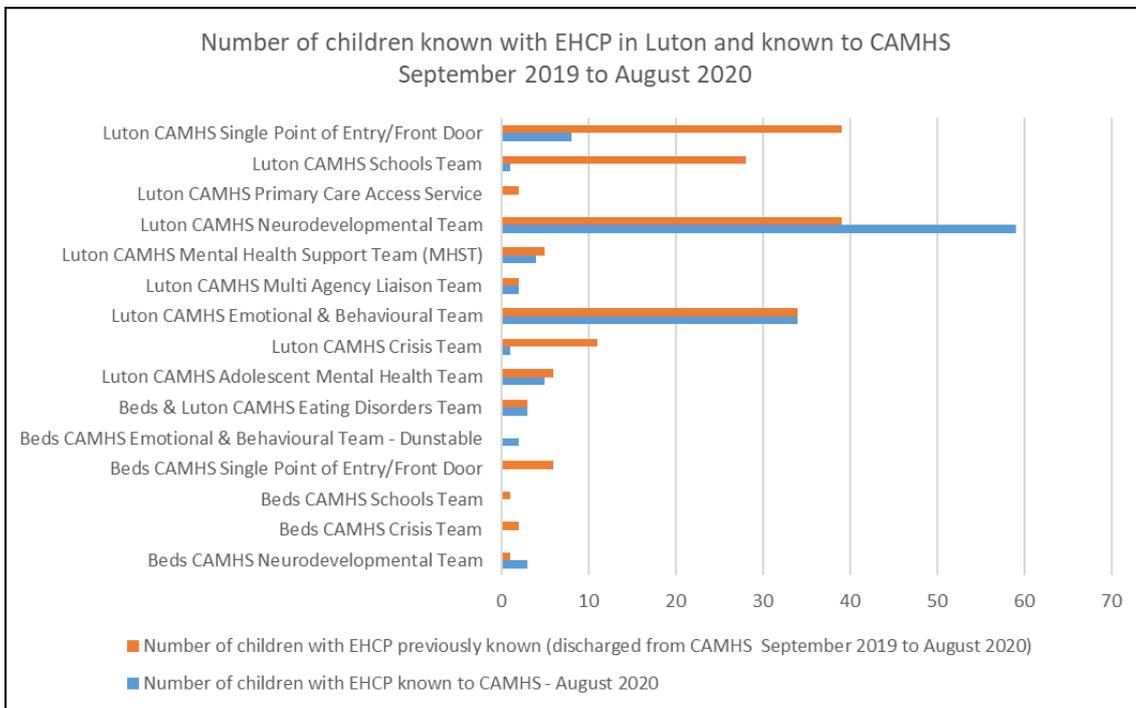
Young people showing as known to CAMHS were open to the CAMHS teams below in August 2020. Those shown as previously known, are young people who were discharged from the service between September 2019 to August 2020. Discharges from the SPE/Front Door Team will include some young people that have been signposted to other services.

Table 9: Number of children and young people known to have been identified as receiving SEN support in school and receiving a service from CAMHS



Number of children with SEND known to CAMHS – August 2020	Number of children with SEND previously known (discharged from CAMHS September 2019 to August 2020)
135	195

Table 10: Number of children and young people known to have been identified as having an EHCP and receiving a service from CAMHS



Number of children with EHCP known to CAMHS – August 2020	Number of children with EHCP previously known (discharged from CAMHS September 2019 to August 2020)
122	179

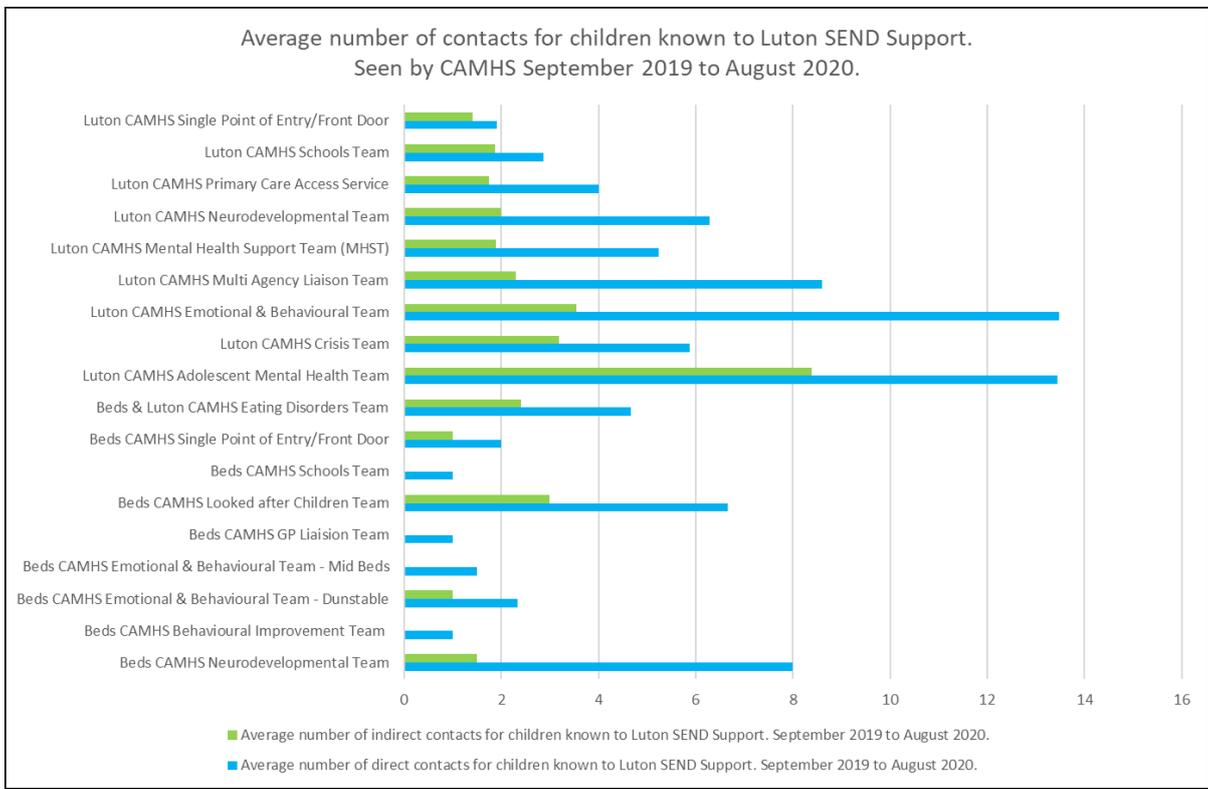
Report 2 – a more detailed insight into the services being used by SEND cohort

Of those known to the relevant services provided by the provider, a breakdown of activity for each service within the time period to show:

1. average number of face to face contacts per service per year
2. average number of non-face to face contacts per service

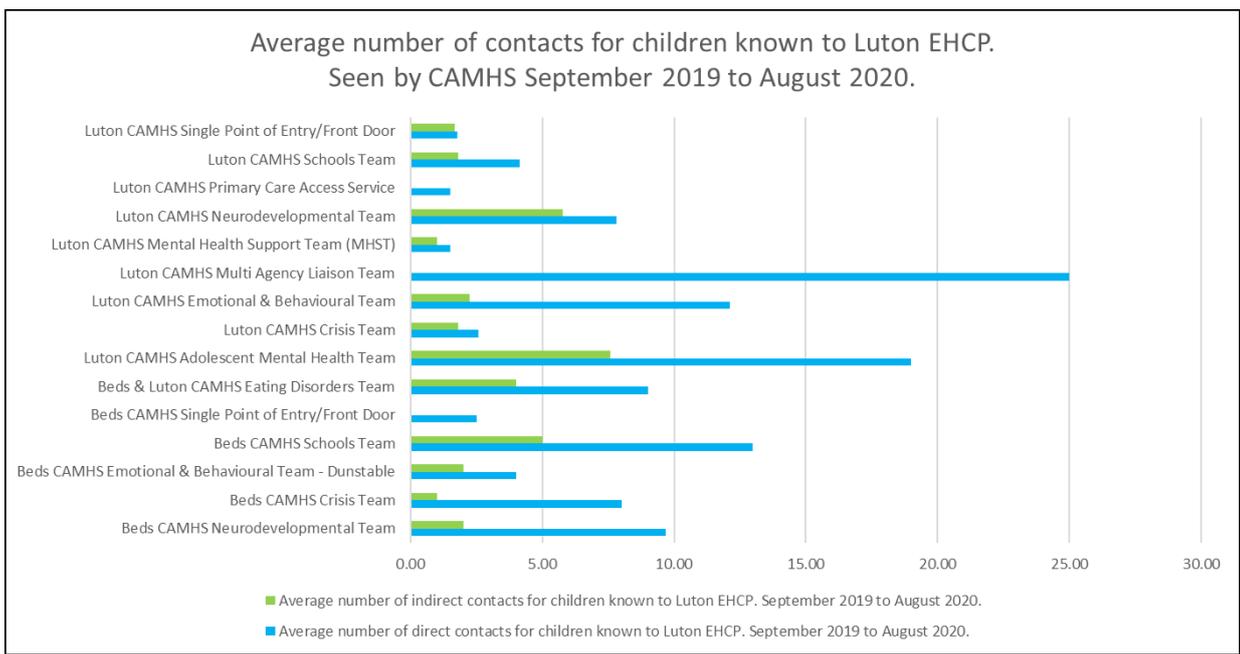
Direct contacts = telephone, video, face-to-face appointments with the young person and/or parent/carers. Indirect contacts = consultations with internal or external colleagues, team meeting discussions, supervision.

Table 11: Average number of contacts for children to Luton who are identified as receiving SEND support in school and have been seen by CAMHS



Average number of direct contacts for children known to Luton SEND Support. September 2019 to August 2020.	8.49
Average number of indirect contacts for children known to Luton SEND Support. September 2019 to August 2020.	2.78

Table 12: Average number of contacts for children to Luton who have an EHCP and have been seen by CAMHS

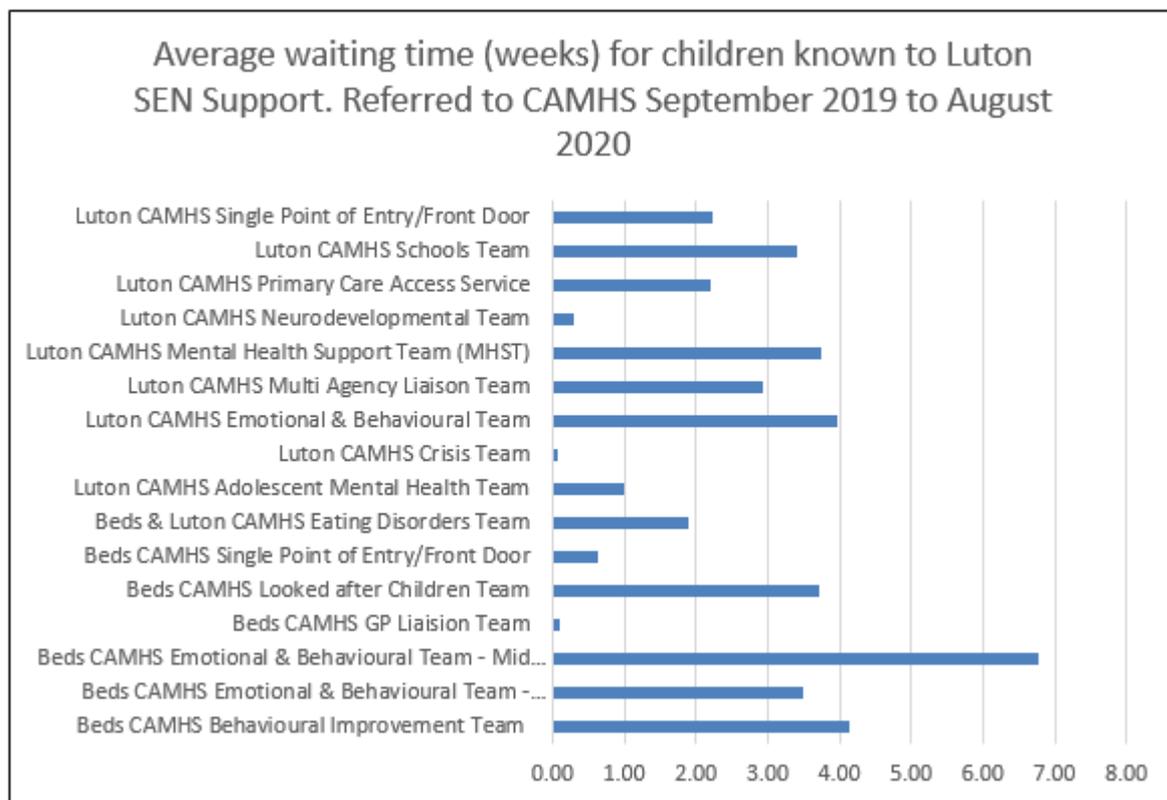


Average number of direct contacts for children known to Luton EHCP. September 2019 to August 2020.	7.99
Average number of indirect contacts for children known to Luton EHCP. September 2019 to August 2020.	3.38

Report 3 – this is about waiting times by service area

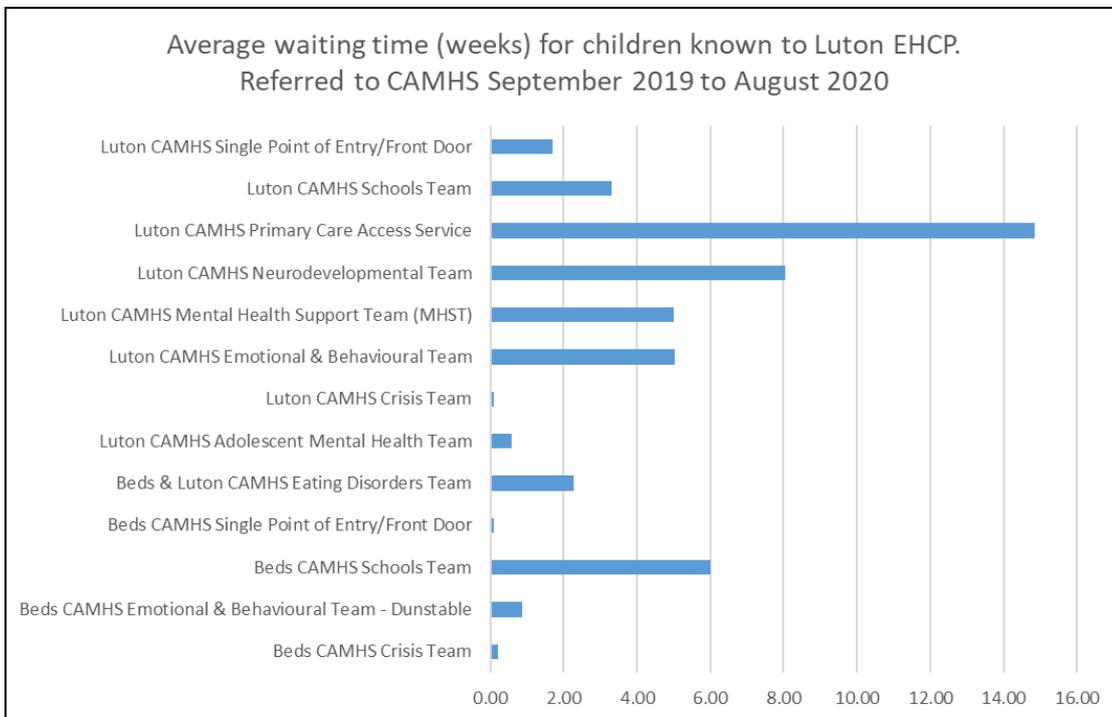
Of those known to the relevant services provided by the provider, who were referred within the time period - Average RTT in weeks

Table 13: Average waiting times for children and young people who have been identified as SEND support for CAMHS



Average waiting time (weeks) for children known to Luton SEN Support. Referred to CAMHS September 2019 to August 2020	2.65 weeks
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Table 14: Average waiting times for children and young people with an EHCP



*The PCAS average waiting time of 14.8 weeks is based on 1 young person only.

Average waiting time (weeks) for children known to Luton EHCP. Referred to CAMHS September 2019 to August 2020	4.4 weeks
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Local services

CAMHS have introduced a self-referral pathway to both improve access to CAMHS and to alleviate pressure on external partners such as GP’s and schools. New referrals received by CAMHS are currently receiving a triage assessment via telephone within 24-48 hours from referral being received.

If assessed appropriate following triage, CAMHS will send out the ASD pre-screening questionnaires to families and schools with a clearly defined timeframe for return, however we do extend this during school holiday periods. Upon receipt they are scored by a triage clinician and then taken back to front door multi-disciplinary team (MDT) for allocation for a further autism diagnostic observation schedule (ADOS) or signposted if not clinically significant to warrant further ASD investigations.

There is a robust ‘step up and step down’ process for SEND patients between CAMHS and CHUMS (our tier 2 emotional wellbeing partners) to continue to ensure a seamless transition of therapeutic support throughout the patient’s journey based upon their need at the time.

Tier 2 services are also provided by Tokko and CHUMS.

Gaps

1. There is no follow up process to be able to monitor new referrals that have been signposted to other external agencies at the CAMHS front door. CAMHS are not aware as to whether that intervention was either taken up or how effective it may have been. Equally there is no feedback process from external agencies to say the same back to CAMHS.

2. Sometimes and despite the complex case discussions at the child development centre (CDC) there can be ongoing clinical discussions about the criteria difference regarding complex presentations. This can mean for some patients we still have them 'bouncing back and forth'.
3. The current social, emotional and mental health joint strategic needs assessment does not have a particular focus on children and young people with SEND.

Parental feedback

A parent carer workshop, co-produced with CAMHS and the Parent Carer Forum, took place on 19 July 2021. The following three discussion questions co-produced by our three Bedfordshire PCF representatives were agreed:

1. What can we do to improve children's mental health services to support children and young people with special educational needs and disabilities?
2. What could the wider system of support do to better support children and young people with special educational needs and disabilities who have mental health and emotional needs?
3. How can we effectively communicate the pathway and offer to the broader system and parents and carers and young people?

A BLMK Health SEND group will review the feedback received and put in place actions to support future service development.

Key recommendations

1. Ensure that CAMHS referrers know what services are available for families and understand eligibility criteria for onward referral, ensure the referral information is robust and considered and provides sufficient information about the needs of the child or young person.
2. Review the terms of reference for the complex case discussion panels to ensure clear clinical decision making between both agencies to avoid cases being inappropriately transferred or delayed unnecessarily.
3. Ensure that the refresh of the social, emotional and mental health joint strategic needs assessment has a particular focus on the needs of children and young people with SEND. This should be completed by June 2021.
4. Make use of the NHS numbers as a unique identifier for SEND from school census to drill down in data sets to improve our understanding.
5. From a quality assurance perspective, make sure our current offer meets the needs of our SEND children and young people.
6. As we are seeing increasing numbers of children and young people with eating disorders, ensure the data is analysed for SEND children and young people.

Physical disability

The phase one SEND JSNA showed data from Disability Living Allowance claimants in November 2018 and it shows that there were 2,150 people with a physical disability in Luton. The data are reshown in table 15. Data are rounded to the nearest 10 and will not cross tabulate to other columns.

Table 15 shows the data by type of disability by age group. Figures in grey text are removed from the main table as covered under sensory impairment and neurodisability disorders. Unfortunately these data have not been updated since November 2018. There are more claims for children aged 5 to 10 years and more boys than girls. Diabetes is the most commonly reported physical disability

after unknown in the under 16s. Disease of muscle, bones or joints is the third most common condition reported in this age group.

Table 15: DLA claims for children and young people aged 0 to 25

Age	Male	Female	Total
Aged under 5	160	100	260
Aged 5 to under 11	600	260	860
Aged 11 to under 16	550	230	790
Aged 16-17	50	30	70
Aged 18 to 25	110	50	170
Total 0 to 25	1,470	670	2,150

Source: DWP via Nomis, November 2018 data. Numbers may not add due to rounding

Table 16: DLA claims for children and young people by disability type

Condition	Aged under 5	Aged 5 to under 11	Aged 11 to under 16	Aged under 16	Aged 16-24	Aged 16-17	Aged 18-24
Disease of the Muscles, Bones or Joints	10	20	20	40	10	~	10
Heart Disease	~	~	~	10	~	~	~
Chest Disease	~	10	~	10	~	~	~
Cystic Fibrosis	~	10	~	10	~	~	~
Diabetes Mellitus	~	30	40	70	~	~	~
Metabolic Disease	~	10	10	20	~	~	~
Major Trauma other than Traumatic Paraplegia/Tetraplegia	~	~	~	10	~	~	~
Renal Disorders	~	~	~	10	~	~	~
Bowel and Stomach Disease	10	10	10	20	~	~	~
Blood Disorders	~	~	10	10	~	~	~
Skin Disease	10	10	~	30	~	~	~
Malignant Disease	~	10	~	10	~	~	~
Unknown / Transfer from Attendance Allowance	50	50	10	120	~	~	~
Total	260	860	790	1,910	240	70	170

Blindness	10	20	10	40	10	~	10
Deafness	10	30	20	60	10	~	10

Epilepsy	~	10	10	20	10	~	10
Neurological Diseases	10	40	40	90	10	~	10
Learning Difficulties	110	470	390	960	120	30	90
Psychoneurosis	~	~	10	10	~	~	~
Behavioural Disorder	20	60	30	110	10	~	~
Hyperkinetic Syndromes	~	70	130	200	20	20	10
Severely Mentally Impaired	~	~	~	~	10	~	10

Source: DWP via Nomis, November 2018 data

The rate at which someone is paid disability living allowance may indicate the severity of the disability. Table 17 shows the DLA data by mobility award.

Table 17: DLA claimants by age, sex and mobility type

	Mobility Award	Male	Female	Total
Under 16	Higher Rate	130	110	230
	Lower Rate	790	240	1,030
	Nil Rate	390	250	650
	Total	1,310	600	1,910
16-24	Higher Rate	40	20	60
	Lower Rate	110	50	150
	Nil Rate	10	10	20
	Total	160	80	240

Source: DWP via Nomis, November 2018 data

Personal Independence Payments (PIP) replaced DLA for working aged people (16-64). Table 18 shows the PIP approved claimants as at November 2020 for those aged 16-24. These data may also be useful for the transition section of this document.

Table 18: PIP payments for Luton by mobility award status

	Aged 16-19	Aged 20-24
Mobility Award - Enhanced	198	212
Mobility Award - Standard	54	99
Mobility Award - Nil (III)	59	102
Total	310	414

Source: Stat-Xplore, November 2020 data

Local data from the local authority information systems

Data from Luton Council shows that there are 76 children with an EHCP with a physical disability at 30 November 2020.

Local services

Luton has a mainstream provision located at Bramingham Primary school for up to 12 children with physical and medical needs. Children learn alongside their peers whilst accessing specialist staffing and support including:

- a physio room to carry out their physiotherapy
- a clean room where medication is administered
- accessible toilets with a hoist and changing bed facilities
- a building on a single storey level, with wide corridors for wheel chair and walking frame access, rise and fall tables, and specialised equipment such as sloping boards and ICT resources if required

Children and young people with the most complex physical needs attend Lady Zia Wernher School (2yrs-11yrs) and Woodlands Secondary School.

Gaps in provision

- 1) Lady Zia Wernher Special School (LZW) take the most children with the most complex physical difficulties. There is no other nursery in Luton that can take this group. This means that places at LZW are highly sought after and some children may remain at home if their main difficulty is physical disability.

Recommendation

- 1) The authority is to commission a new special school and it is recommended that this school should have a nursery which can take children with physical disability.

Sensory Impairment

Hearing

New born hearing screening data is reported for Bedfordshire and Luton as it is based on the screening service rather than local authority. 99.5% of new born babies have their hearing screening performed within 4 weeks of birth in 2017/2018²⁹.

This percentage increases to 99.8% at 3 months. Data for quarter 4 2019/2020 shows a fall in uptake of the new born screening and Public Health England are declaring that is due to the COVID 19 pandemic. 95.7% of new born babies were screened by 4 weeks³⁰. It is unfortunate that we cannot access this data for Luton as the population is quite different to parts of Bedfordshire.

Data from Luton Council show that there are 286 people with hearing impairment between the age of 11 and 22 years. See table 19.

Table 19: Hearing impairment

Age	Amount
11	9
12	10
13	18
14	53
15	50
16	51
17	36

²⁹ Public Health England Screening Programme, 2019 <https://phescreening.blog.gov.uk/2019/10/23/newborn-hearing-screening-annual-data-report/>

³⁰ Public Health England Screening Programme, 2020 <https://www.gov.uk/government/publications/nhs-screening-programmes-kpi-reports-2019-to-2020>

18	34
19	16
20	<5
21	<5
22	<5
<hr/>	
Total	286

Source: Luton Council

Local data from the local authority information systems

Luton Council data for EHCP shows that there are 56 children and young people with a hearing impairment at the end of April. SEN support data show that there were 54 children and young people with a hearing impairment in 2021.

Vision

The Department for Education produces statistics on the number of children attending state primary and secondary schools who have one or more special educational needs (SEN), and gives the primary reason for the need³¹. These data are based on the area in which the child attends school, rather than the area of residence; this means that the data is not comparable with other datasets presented in this briefing.

In 2020, 12.0 per cent of all pupils in England had a special educational need (SEN or EHCP). In Luton, 12.1 per cent of pupils had a SEN or EHCP, which is aligned with the England average. Of these, 1.3 per cent (81 pupils) had visual impairment as the primary need for their SEN which is alongside the national average.

The Family Resources Survey 2017/18 based on mid-2018 population estimates suggest that there are approximately 580 people (9% of the population) with visual impairment between the age of 0 to 25 years.

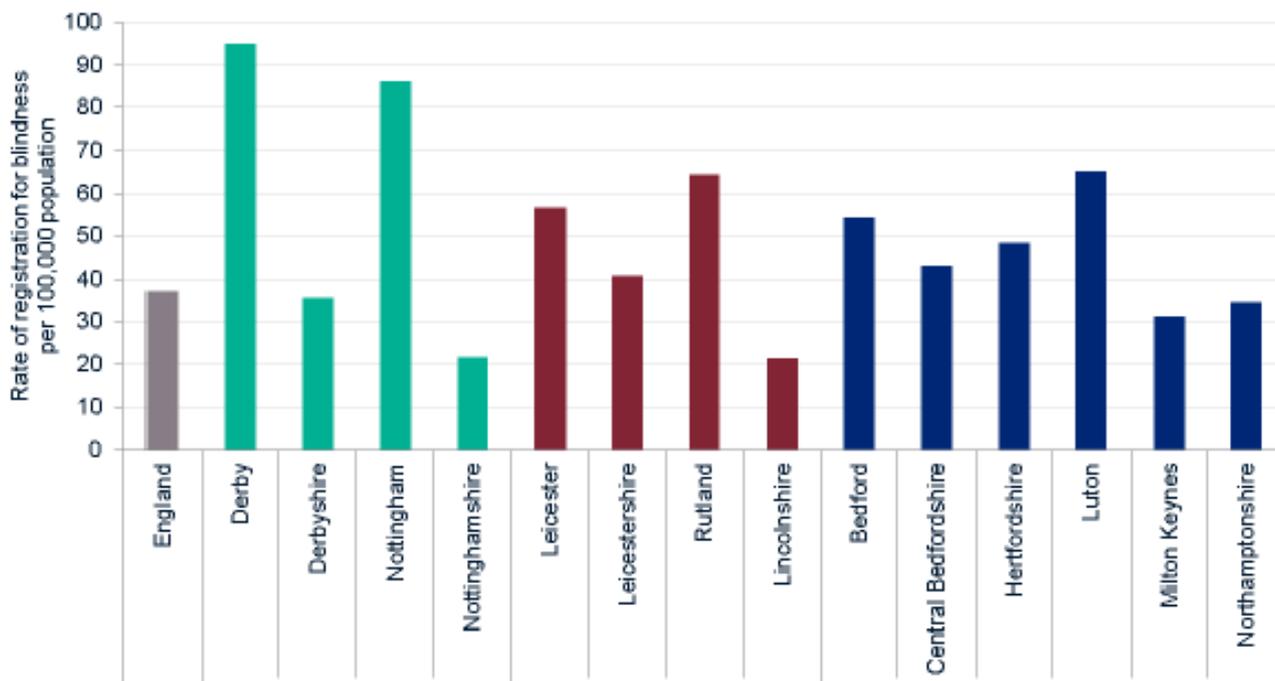
Local data from the local authority information systems

The latest data from Luton Council on EHCPs show that there were 37 visually impaired children and young people (as the primary need for the EHCP at end of April 2021). SEN data show that there were a further 43 children and young people with a visual impairment as primary need in the latest School Census (January 2021).

In 2013/14, there were 4,275 blind people aged 0 to 17 years on a register in England. This corresponds to a rate of 37.2 children and young people per 100,000 registered as blind 0 to 17 year olds in England. In comparison, Luton had 35 people aged 0-17 who appear on the register for blindness, which calculates to a rate of 65.2 per 100,000. This is the third highest amongst the local authorities shown on the chart below, and well above the England average rate of 37.2 per 100,000.

Figure 8: Crude rates per 100,000 children and young people aged 0 to 17 on local authority registers for blindness, 2013/14

³¹ Special Educational Needs in England 2016. Available online from: <https://www.gov.uk/government/collections/statistics-special-educational-needs-sen>



Source: NHS Digital and ONS mid-2013 population estimates

These data were checked for the latest data (2016/17 latest published) shows that there were <10 in the 0-5 age group and 20 for those aged 0-17.

Table 20: Number of children and young people on the NHS sight loss register 2016/17

Category	Age 0-4	Age 5-17
Blind/severe sight loss	<5	20
Partial sight/sight impaired	<5	15

Source: NHS Digital, ³²

Local services

The primary Visual Impairment Provision is based at Chantry Academy. The 16 place provision for children with a visual acuity level of 6/12 or worse offers specialist resources and specialist support. All pupils are taught in mainstream classrooms alongside their peers and are supported in lessons by specialist support assistants or a qualified teacher of visual impairment.

The provision is also home to the outreach service which provides specialist support and advice in the home and in settings and schools up to the end of year six. Currently 80 children are being supported Dec 2020. The frequency of this support has been agreed in line with the National Sensory Impairment Partnership (NatSIP). This is a partnership of organisations working together to improve outcomes for children and young people with sensory impairment.

Luton has two hearing impairment provisions, the first based at Icknield Primary School (25 place) and the secondary age range from year 6 at Icknield High School (16 place). The provisions are for children with bilateral permanent, severe or profound hearing loss and children within the provision have an EHC Plan. Staff including qualified teacher of hearing impairment (QTHI), educational communicators (EC) and teaching assistants (TA) help to support the children in both settings.

In the primary provision a Rogers system is linked to the child's hearing aids or cochlear implants are used to further enable our children to best access spoken language. Both halls have sound

³² NHS Digital, Registered Blind and Partially Sighted People, England 2016-17, <https://digital.nhs.uk/data-and-information/publications/statistical/registered-blind-and-partially-sighted-people/registered-blind-and-partially-sighted-people-england-2016-17>

field systems to ensure that all children have equal opportunity to the auditory experience as well as the visual. Some classrooms also have sound field systems in place and wherever possible we accommodate children within these rooms.

Staff from both provisions provide an outreach specialist advice service to support children with a permanent hearing loss from initial diagnosis. Once a diagnosis of hearing impairment is confirmed, NHS Audiology services or schools can make a referral. The team make visits to homes, nurseries and schools. The levels of support are based on the type and level of hearing loss and if hearing loss is one of many additional needs.

Gaps in provision

1. The role of the qualified teacher of visual impairment (QTVI) is a very specialised role. There is a recognised national shortage of staff with this qualification attached and recruitment for any authority is a challenge.
2. Clear information sharing arrangements need to be established for both the hearing impairment and visually impaired cohorts to improve service delivery.

Recommendations

1. To ensure that we can recruit to the QTVI posts required by the authority, the vacancy should reflect the need to include the role within the senior leadership team in the school with a salary to reflect this responsibility. This needs to be reflected through Job Evaluation panel in the local authority.
2. Work with the sensory units to improve their ability to understand local needs using a range of data sets. This will be supported by ensuring clear information sharing arrangements are in place to improve work between outreach services and schools and the Luton and Dunstable hospital

Short breaks

Data is collated by the Luton short breaks consortium and by the local authority on the provision of short breaks and respite support provided. During 2019/2020 the following data is available.

In 2019/20 there were 348 children and young people who received community based short breaks through the VCS short breaks consortium of six providers. This amounted to 30,534 hours of support. A further 288 children and young people received short breaks in Luton via the Children with Disability team following a section 17 assessment of need.

These children and young people, received 62,280 hours of support. Of these 88% of these hours were funded from direct payments. This is an average of 245 children per quarter. This is also reflected in data to date for 2020/21 although the number of hours has increased per quarter from an average of 15,570 hours to 17,240 hours.

Table 21 Showing the short breaks provided by the VCS Short breaks consortium and the Local Authority

Source Luton Council May 2021

SC11	2019/20		2020/2021									
	VCS	LA	VCS					LA				
	Full Year	Full Year	Q1	Q2	Q3	Q4	Full Year	Q1	Q2	Q3	Q4	Full Year
Short breaks day time												
Number of children (aged 0-17 years old)	348	288		147	139	119	250	237	248	246	277	277
Total number of hours	30,534	62,280		5,592	4245.5	2453	12,290	15,267	19,227	14,202	12,142	60,838
Of above hours number of hours of short breaks supported by Direct payments	0	54,791						14,081	17,351	12,400	10,989	54,821
siblings	74	0		2	19	3		0	0			
Overnight short breaks												
number of CYP up to 18 years supported		57						22	35	35	29	44
number of nights		1,105						164	202	231	186	783

Table 22 Showing Direct Payments made by Luton Council

In 2019/2020	241
In 2020/2021	233

Source Luton Council May 2

Local services

For children and young people under 18

Luton offers parents and carers of SEND children and young people a range of short breaks services. At the universal level there are a range of opportunities including after school and holiday clubs run by local schools and voluntary organisations, social, leisure and sports activities including youth clubs e.g. Tokko and leisure centres provided by Active Luton.

There are also some childminders who are specialist disability childminders who provide support and childcare providers throughout the town. Uniform clubs e.g. brownies and guides, cubs and scout groups will support children with SEND.

A short break offer is also provided in the community by the Autism Bedfordshire Short Break Consortium which is funded by LLAL. This consists of six voluntary sector organisations who offer short breaks for children and young people from 3-23 years. The organisations include:

- CHUMS
- Family United Network
- Friends of Bright Eyes
- CYCD
- Autism Bedfordshire
- SNOOSC – Special Needs Out Of School Club

The offer is varied and aimed at different age groups and children with different needs. The offer includes after school clubs, youth clubs, weekend clubs, holiday clubs and activities.

The VCS provision is available without a formal statutory assessment, while the local authority offer is made after an assessment of needs. The local authority offers the following support:

London Road

London Road Resource Centre is our residential short breaks unit that offers overnight care for young people who have severe and complex disabilities. Often these young people would find it very difficult to access other short breaks services or clubs and activities because of their behaviour or the complexity of their health needs. For young people to access London Road, they will need to be referred to our children with disability service via the MASH, have an assessment and have the case considered at our Resource Allocation panel.

Shared care

Shared care is our short breaks fostering service. Our shared carers are assessed under the fostering regulations to offer day care and/or overnight care in their homes. The carers are all experienced in working with/supporting young people with disabilities. The young people who access this service require a high level of support and intervention. They require a referral to our children with disability team via MASH, have an assessment completed and have the case considered at our Resource Allocation panel.

Direct payments

Direct payments are monies awarded in lieu of commissioned care. The allocation of hours is based on an assessment by the children's disability service and considered at the Resource Allocation panel.

Respite and short breaks for young people over 18 to 25 years

A request can be made for anyone for a Care Act Section 9 Assessment of need (if unknown to adult social care) or a Section 27 Review of care and support plan (if known to adult social care). Or via a transition to adulthood referral.

Preventive options will be explored to maximise the individual and their family's strengths and independence as well as e.g. support from family and friends, non-commissioned community groups and personal technology. Once all preventative options have been explored an adult social care worker will be allocated and an assessment completed within 28 days of referral.

The assessment will determine the person's eligible needs. When determining eligibility, the local authority will consider the following three conditions - the adult's needs are relating to **physical or mental impairment or illness**, the adult is unable to achieve two or more of the outcomes in the regulations and these will impact on the individual's wellbeing.

The assessment will take into account the individual's needs and the needs of the informal carer who will be offered a Section 10 Assessment of the carer's needs for support.

If following the assessment it is determined that the person is eligible and their needs require care and support commissioned by the local authority this may offered in several ways depending on the individual and their preference:

- day care - in a range of options including Community Choices, Haywood House, YAWN
- home care - domiciliary care in your own home
- Direct payments - this is when you are given a budget to purchase personal assistance or agencies
- shared lives - staying with an approved carer or family
- building based respite - staying a residential home setting with 24 hour care

Parent's feedback

Luton Parent Carer Forum undertook a survey with parents about short breaks in 2019 with 49 parents. The recommendations from this report were:

- To ensure that all key service providers such as GP's Social Worker, SENCOs', Family Workers, and others in an Educational setting have a clear understanding of the services are offered by Short Breaks, and are aware of how to access these services, so that they can help parent cares find the right support for their child young person quickly
- To improve all VCS Short Breaks providers' visibility in terms of better marketing off their offer - regardless of them holding waiting lists; and for service providers to record the numbers of parents who are unable to access their services due to them having reached fully capacity. The aim is to accurately record unmet need.
- To invest in more Short Break services so that more sessions can be accessible to those with Mild to Moderate needs.
- To find innovative way of increasing services capacity, and frequency of sessions so that more options can be offered. This may include reaching out to new partners to create new

service options and working in partnership with LA to use Direct Payments in a more creative way to support new development

- To find innovative ways of expanding and not cutting services that have a small, but faithful group of attendees, as this may be the only Short Break service this child / young person is accessing. E.g. Baylands.

Gaps in provision

1. Waiting times for VCS short breaks community provision has been identified by parents as an area for review.
2. There has been a reduction in the community based short breaks services by the VCS due to reductions in grants from London Luton Airport Ltd linked to the COVID 19 pandemic.
3. Identify from data if there are gaps in our provision for those children and young people where it is difficult to identify respite options to understand the demand for these services.

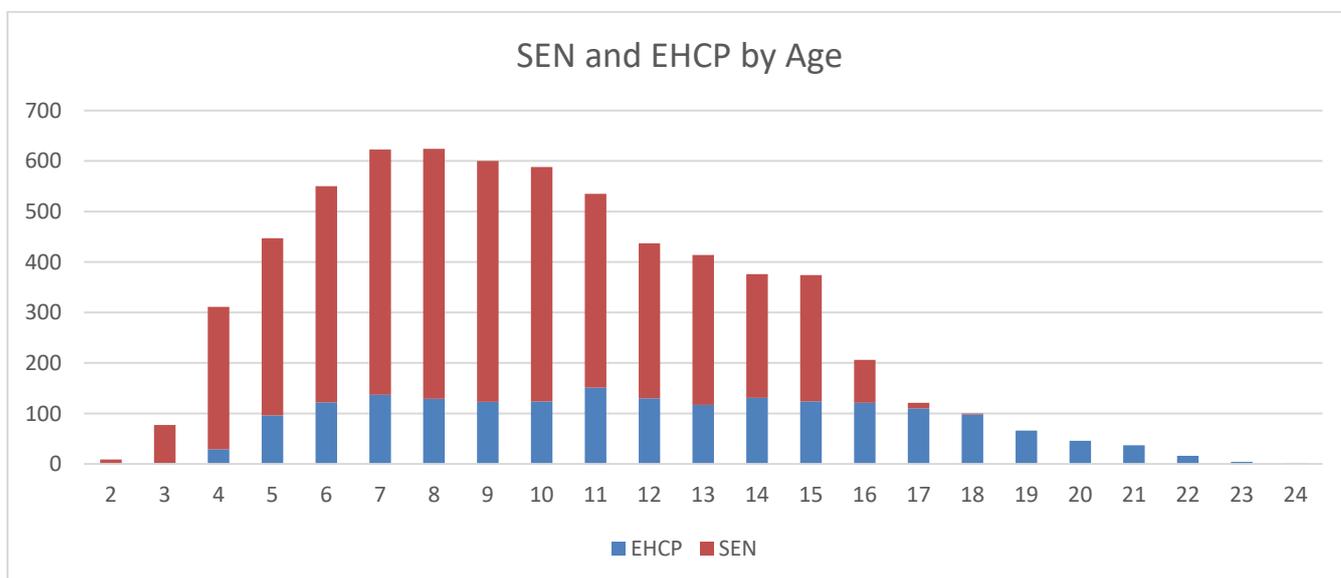
Recommendations

1. To understand any issues regarding waiting times, the lead agency for the VCS short breaks consortium has been asked to provide data on a quarterly basis on length of waiting list to inform our understanding.
2. To promote widely the Short Breaks Offer across Luton to parents and professionals.
3. Further work has been requested to look at alternative options to provide short breaks for children, working with local special schools and health and leisure providers.
4. Joint work between health and social care to identify any gaps in provision for children and young people with the most complex needs and suitable respite provision.

Transitions

The process of transitions starts at 14 years of age and for each young person with an education, health and care plan (EHCP) they will be supported through their transition from children to adult services across education, health and social care. Data taken from the SEND phase one report shown below shows how many young people with an ECHP will be supported through transitions.

Figure 10: Luton SEND information broken into single year of age as of January 2019

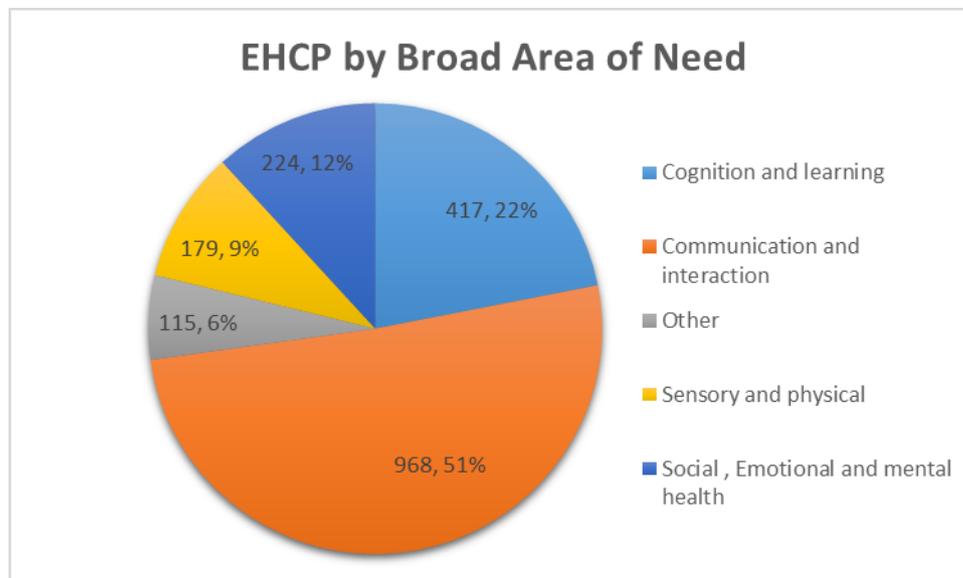


Source: Luton Borough Council, SEN School Census January 2021, EHCP April 2021

What is most noticeable from this figure is the increasing number of young people with EHCP who will be moving through transitions in the coming needs, the demands for these services will be increasing over the coming years

The figure below shows the primary needs of young people aged 16 plus with an EHCP in Luton Taken from Capita system (Feb 2021)

Figure 11: Primary needs for young people with EHCP in Luton



Source: EHC Plans in Luton as at end of April 2021

This figure shows the largest need of young people is that related to Communication and Interaction needs including ASD and SLCN, the second largest group is young people with Cognition and Learning issues.

Local services

Services work together to support the transition of children to adult services. Professionals across health, social care and education will provide support through the transition journey from 14 years.

For young people with the most complex needs health colleagues work with the young person and their families to plan transitions and have recently completed an agreed framework to ensure this process is as smooth as possible.

The transitions nurse in Cambridge Community Services working with the transition nurses in adult social care and the post 16 transitions education officer work to support young people offering holistic support to each young person.

Parent's feedback

Consultation activities were undertaken with parents in focus groups during 2019, of the parents consulted a number highlighted their concerns about transitions and how to find out about what is available.

Gaps in provision

- 1) There needs to be more support from the adult health service to support the clinical inputs PEGS/ suctioning across home care, respite care and day care.

- 2) There needs to be more residential supported living for young people with more physical disabilities transitioning to adulthood.
- 3) We need to have a more flexible seven day support for young people across day care and respite to allow a more bespoke offer to wrap the carers support package.
- 4) We are reaching capacity in our day centre provision for those young people with more challenging behaviour.
- 5) There is a lack of medium to long term floating tenancy service to support young adults who are more independent but still need some support.
- 6) Clear information needs to be made available on the Local Offer to support parents and young people with periods of transitions, this includes information on pathways, where to get support and what to expect.

Recommendations

- 1) Work with commissioners and Cambridge Community Services to improve these services for young people.
- 2) Work with commissioners to look at providers for young people who are transitioning into adult services with physical disabilities.
- 3) Review contracts with provider services to explore possible service redesign to meet the needs of the most complex young people.
- 4) Review with commissioners, additional day care capacity.
- 5) Review with commissioners, providers who could offer either spot purchasing or floating tenancy support or review the current contract with Penrose.

Data Gaps

Social and emotional mental health prevalence estimates are based on old survey data and may need reviewing if newer survey data becomes available.

The richest health data relating to children and young people and those with SEND, would be captured in the Community Services Dataset. Although, data capture and submission to this has been mandated since October 2015, compliance with this is low and so we have taken the decision not to include data relating to this dataset at the moment since compliance is patchy. The Council for Disabled Children hope to work with NHS Digital and local areas to encourage increased data input and we will then include this data in their dashboard.

Data from Cambridgeshire Community Services for the children's community service are for patients registered with a Luton GP practice. It may be advisable to review data for those that are Luton residents only.

Appendix 2: Guidance

Nice Guidelines

- [NG43](#) - Transition from children's to adults' services for young people using health or social care services
- [NG11](#) - Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges
- [NG93](#) - Learning disabilities and behaviour that challenges: service design and delivery
- [CG170](#) - Autism spectrum disorder in under 19s: support and management
- [NG87](#) - Attention deficit hyperactivity disorder: diagnosis and management
- [CG158](#) - Antisocial behaviour and conduct disorders in children and young people: recognition and management
- [NG54](#) - Mental health problems in people with learning disabilities: prevention, assessment and management

Key guidance

The government sets out a [range of guidance materials](#) for schools, colleges and children's services in providing for children and young people with SEND. This is encapsulated in the [SEND Code of Practice for 0 to 25 years](#), however specific guides are also provided for schools, social care professionals, parents etc. Further guidance is given on subjects such as supported internships, short breaks, and education for children who cannot attend school. Early years provision and the identification of SEND, as it applies to children under primary school age, is discussed in the [Early Years](#) guide and [statutory framework](#).

The [Learning Disability Transition Pathway Competency Framework](#) was developed by Health Education England and published in October 2016. It is aimed at service providers and addresses the needs of young people with learning disabilities as they move from children's to adults' services.

List of acronyms

ADHD	Attention Deficit Hyperactivity Disorder
ADOS	Autism Diagnostic Observation Schedule
AHMT	Adolescent Mental Health Team
ASD	Autism Spectrum Disorder
BESD	Behavioural, Emotional and Social Difficulties
BME	Black and Minority Ethnic
CAMHS	Child and Adolescent Mental Health Service
CCS	Cambridgeshire Community Services
CDC	Council for Disabled Children
CIPFA	Chartered Institute of Public Finance and Accountancy
CWD	Children With Disabilities
DLA	Disability Living Allowance
EB LT EB EB1 EB2 EB3	Emotional and Behavioural Team Luton EB Dunstable EB Mid Bedfordshire EB Bedford Borough EB
EC	Educational Communicators
EHC (P)	Education, Health and Care (Plan)
ELFT	East London Foundation Trust
FRS	Family Resources Survey
HI	Hearing Impairment
IMD	Index of Multiple Deprivation
JSNA	Joint Strategic Needs Assessment
LA	Local Authority
LT	Luton CAMHS
MALT	Multi Agency Liaison Team
MHST	Mental Health Support Team
MLD	Moderate Learning Difficulty

ADHD	Attention Deficit Hyperactivity Disorder
MSI	Multi-Sensory Impairment
NatSIP	National Sensory Impairment Partnership
NICE	National Institute for Health and Care Excellence
NDD	Neurodisability Disorders
NDT	Neurodisability Team
NSA	No Specialist Assessment
ONS	Office for National Statistics
OT	Occupational Therapy
OTH	Other Disability/ Difficulty
PCAS	Primary Care Access Service
PD	Physical Disability
PHE	Public Health England
PMLD	Profound and Multiple Learning Difficulty
QTHI	Qualified Teacher of Hearing Impairment
QTVI	Qualified Teacher of Visual Impairment
SALT	Speech And Language Therapy
SEMH	Social, Emotional and Mental Health
SEN	Special Educational Needs
SEND	Special Educational Needs and Disability
SENS	Special Education Needs Service
SLCN	Speech, Language and Communication Needs
SLD	Severe Learning Difficulty
SPE	Single Point of Entry
SPLD	Specific Learning Difficulty
TA	Teaching Assistant
VI	Visual Impairment
WHO	World Health Organisation