



Joint Strategic Needs Assessment (JSNA) February 2020 Adults with a Learning Disability in Cheshire West aged 14 and over

Contents

1. Purpose of this report	Page 1
2. Definition of a learning disability.....	Page 2
3. Summary of key findings.....	Page 3
4. Prevalence of learning disability in Cheshire West and Chester.....	Page 8
5. Population forecasts.....	Page 15
6. Causes of learning disability.....	Page 16
7. Who is at risk? Preventative measures.....	Page 17
8. Service provision.....	Page 24
9. Local health and care needs.....	Page 39
10. Outcomes for people with a learning disability.....	Page 42
11. Key issues.....	Page 58
12. National recommendations and best practice.....	Page 63
13. Future developments in Cheshire West.....	Page 66
14. Strengths in Cheshire West and Chester.....	Page 68
15. Key areas for improvement.....	Page 69
16. Recommendations.....	Page 71
17. Appendix.....	Page 74

1) Purpose of this report

The purpose of this report is to describe the needs of people with learning disabilities in Cheshire West and Chester (CW&C) aged 14 plus.

Partners from across health and social care have contributed to this document and the content within this report will provide an overview of the current needs, future needs and levels of need presented by people with a learning disability (LD) in our community.

The report will aim to offer an insight into the current outcomes being achieved for our service users, and look to identify gaps or inequalities in the care provisions available.

Information gathered will then be used to generate recommendations that will inform the development of local strategy and commissioning intentions for people with an LD in CW&C.



2) Definition of a learning disability (LD)

Adults with an LD can have many complex care needs that cover a wide spectrum of support requirements that may have been necessary since childhood.

For instance, in childhood, people with an LD may require specialist education support and when transitioning into adulthood; help may be required with everyday living, employment support and social integration.

In addition, adults with more severe or complex learning disabilities may require lifelong support delivered through social care supported living and residential accommodation. They are also more likely to have co-existing health conditions that require continued support from NHS services.

Whilst this JSNA will focus on adults with an LD aged 14 and over only, it is important to acknowledge that during 2018/19, CW&C provided care packages to 1,167 people with a learning disability and/or autism. This was out of a total general population of 338,000 and represented a 9% increase in the number of people with learning disabilities and/or autism from only two years prior.

For this publication, Autism without an LD will be dealt with separately.

It is therefore especially important that as a borough, we define the term 'Learning Disability' and look to assess the needs of this section of our community to ensure the high quality care and provision is provided.

Definitions of learning disability vary; however for the purposes of this report, a learning disability will be considered to be:

"A significant general impairment in intellectual functioning that is acquired during childhood."

The 2001 Department of Health White Paper, "Valuing People – Health and Social Care of People with Learning Disabilities" further defines a learning disability as:

- "A significantly reduced ability to understand new or complex information, to learn new skills, with;
- a reduced ability to cope independently;
- which started before adulthood; with a lasting effect on development."



3) Summary of key findings

A. Prevalence
<ul style="list-style-type: none"> • There are an estimated 5,100 adults aged 18 plus with a learning disability of some sort living in CW&C. This is 1.87% of the 18 plus population, a rate of 18.6 per 1,000 residents. • Approximately a quarter of adults with an LD have an LD that can be classed as severe, an estimated 1,220 residents. • Of the 1,220 adults with a severe LD, approximately 360 will have co-existing autism, and 120 will have Profound and Multiple LD which may require intense support. • Estimates indicate that the greatest number of adults with an LD will be seen in the 45-64 age group, and in the areas of Northwich, Ellesmere Port and Chester East care communities. • LD population forecasts indicate that the LD population will remain fairly static over the next 20 years at around 6,400 residents. However the makeup of the cohort will change with an increased proportion of older people with LD.
B. Development of a learning disability
<ul style="list-style-type: none"> • Causes of LD include illness during pregnancy, problems during birth, the inheritance of genes that make LD more likely, and illness and injury in early childhood. • Health behaviours by the mother during pregnancy can impact on the development of the unborn child such as smoking during pregnancy, alcohol and drug consumption, obesity and poor nutrition. This can lead to low birth weight, premature pregnancy and poor development of the baby. These are preventative and can be influenced. • CW&C has a higher proportion of pregnant women accessing maternity services at the recommended 10 weeks or under compared to the England average, and since 2012-14 the rate of babies born prematurely has generally been decreasing. The percentage of term babies born a low birth weight is also lower than the England average; however figures increased in 2017 to the highest in the last ten years. • Almost two thirds of births at the Countess of Chester Hospital during 2018/19 were categorised as having 'complications', with this increasing by a 2% average each year. • Smoking during pregnancy has improved in CW&C with 2018/19 rates now in line with the England average. However rates in the Vale Royal CCG footprint are significantly higher. • In CW&C, the rate of hospital admissions for an injury in the under 15's has been consistently higher than the England average.
C. Local health needs
<ul style="list-style-type: none"> • Of LD service users who had information recorded about their disability, 15% had physical disabilities alongside their learning disability, and 10% had further neurological disabilities. • 70% of LD respondents to the Adult Social Care User Survey 2018/19 rated their health as very good or good and 7% as bad or very bad. Although general health was considered good or fair for most respondents, 40% said that they have pain or discomfort; 6% extreme pain or discomfort. • 2018-19 GP data for patients on the LD register showed that in CW&C the top five conditions affecting the LD population is obesity, epilepsy, depression, chronic



constipation and gastric oesophageal reflux disease (GORD). Except for epilepsy, all of these conditions are preventative. CW&C has a higher proportion of the LD population who are obese and have GORD than the England average.

- GP data also highlighted that 18% of those with LD aged 18 plus had depression and 10% had a mental illness. Also raising the issue of mental health – 57% of respondents to the Adult Social Care User Survey reported they were anxious or depressed.
- Compared to the non CW&C LD adult population, those with an LD are more likely to be obese, and have epilepsy, asthma, hypothyroidism, diabetes and a severe mental illness.
- Of social care service users with LD, half had a carer with the majority being cared for by a parent. As age increased the likelihood of having a carer decreased.

D. Services for those with an LD

- Those with an LD have a wide range of needs that can span health, social care and community support systems. They are more likely to experience poorer physical and mental health compared to the rest of the population; and may need a range of support and provision to ensure they are supported to live healthy fulfilled lives.
- GP practices in CW&C provide annual health checks to known patients with an LD. Current targets for LD annual health checks are nationally set at 75% of the cohort aged 14 plus – CW&C falls short of this with 34% having had their annual health check between January-November 2020. This has been impacted by the Covid pandemic with a fall of over 20% compared to the previous year.
- Specialist secondary care services for people with an LD include Cheshire Wirral Partnership NHS Foundation Trust; providing home based and community services for people with LD, autism and mental health diagnoses. At February 2020 there were 292 episodes of care registered for the community learning disability team.
- CW&C Council provide a range of social care and support facilities for people with LD in accordance with The Care Act 2015. At November 2019, there were 1,254 adults known to the LA or receiving support. This suggests that around 25% of the estimated LD population aged 18 and over are accessing LA services.
- 70% of LD social care service users have low level support needs, 23% higher support needs, and 6% intensive needs. At November 2019, over half of adults aged 18 plus with LD accessing a social care service were receiving home care (53%) and 45% received personal support/ day care.
- The number of LD services users accessing social care services increased by 6% between 2017 and 2019. In terms of services being received, there has been a 9% increase in service usage with increased demands in home care, and increased usage of services by 18-24 year olds.
- At January 2019, there were 254 young people aged 14 to 23 with an Education, Health and Care Plan for a LD in CW&C. Around 30% have a severe or a profound and multiple LD. A range of support is available to children and young people with an LD. More detail is available in the Special Educational Needs and Disability JSNA.
- Community run groups, third sector organisations, and charities also provide support and services for people with LD across CW&C. Key ones to note include The Peoples' Choice Group and DIAL West Cheshire.

E. Outcomes

- Education and post 16:



- At Key Stage Four, pupils in CW&C with an EHCP for a moderate LD achieved less than pupils with an EHCP nationally.
- Educational outcomes for young people with LD are not reported but data is available for young people with an EHCP as a whole. For young people with an EHCP: participation of 16/17 year olds with an EHCP in education and training was above the national average in 2018-19; 19 year olds qualified to level two has generally been lower than the England average and is at its lowest since 2014; 19 year olds qualified to level three increased in 2018 and is higher than the national average.
- Employment and volunteering:
 - Adult Social Care Outcomes Framework measures (ASCOF) report 6.4% of LD clients aged 18-64 were in paid employment in 2018/19, an improvement from the previous year (5.7%) and the England average (5.9%).
- Housing:
 - At November 2019, 90% of adult social care LD clients were in settled accommodation.
 - ASCOF measures for 'the proportion of adults [aged 18-64] with LD who live in their own home or with family' show CW&C has consistently been above the national average and in 2018/19 was 88%.
 - 2018-19 responses to the Adult Social Care Survey showed 70% of respondents with an LD said their home meets their needs very well and a further 20% said their home meets most of their needs.
- Health outcomes:
 - GP LD registers record 40% of LD patients as obese and a further 28.5% as overweight.
 - Cervical screening for eligible females shows a significantly lower uptake of females with an LD compared to those without, although it is in line with the England average. 35% of the eligible cohort who had LD had cervical screening in the last five years, compared to 80% of those without an LD.
 - Breast screening and cervical screening for those with LD is lower than for the non-LD population, with colorectal screening being better.
 - Around half of LD patients (48%) who are eligible for a free flu jab received one in the last twelve months in 2018-19. Although this is in line with the England average (44%) it should be a focus for improvement, especially as the top cause of death according to the Learning Disabilities Mortality Review Programme for those with LD in CW&C is diseases of the respiratory system.
 - In CW&C in 2018-19, 20% of patients on the LD register had epilepsy and of these around a quarter had a seizure frequency record known to their GP which is lower than the England average. However of those with a record, three quarters had remained seizure free in the previous 12 months which is significantly better than the national average.
 - In 2018-19, 8.5% of the patients on the LD register in CW&C had diabetes (type 1 and non-type 1) and almost all (93%) had a HbA1c diabetes record. Of these patients, 80.7% had a record of 'satisfactory' levels; similar to the England average.
- Adult Social Care User Survey (2018-19):



- Although there has been some fluctuation in responses over the last three years to the ASC user survey, over 90% have remained satisfied with the care and support services they receive.
- There has been an increase in the proportion of service users saying that they have as much social contact as they want with people they like. However compared to the previous year, there was a decrease in the proportion of service users feeling that they have as much control over their daily life as they want; that feel clean and able to present themselves the way they like; that get all the food and drink they like when they want; their home is as clean and comfortable as they want; and feeling as safe as they would want.
- Over the last three years, there has been a decrease in the proportion of LD respondents saying 'yes' – "care and support services help me", in all of the adult social care survey measures, except feeling safe which has remained the same.
- There has been an increase in the LD cohort finding it difficult to, or being unable to, get to all the places in their local area that they would like.

F. Current and future developments

- Within social care, a re-commission of the LA's Learning Disabilities Framework will begin in 2020. This will look to recommission services that are community based services offering information and advice; services that provide low level support such as domiciliary care; specialist support in the community for those with more complex needs; and accommodation-based support.
- Partnership work taking place across both health and social care through the Transforming Care Programme will in 2020 focus on: reducing the number of patients with LD and Autism in inpatient beds; increasing the number of eligible people with an LD to access their yearly GP health check; further understanding of the outcomes of the LeDeR reviews of deaths to inform the local picture; and as part of a national initiative, stop over medication of people with an LD, autism or both (STOMP).
- In order to better understand the number of young people accessing care services and their needs a Preparation for Adulthood Group has been established. The group is undertaking a preparation for adulthood audit to highlight current delivery, and the development of clear quality driven datasets to allow assessment of current outcomes being achieved.
- A grant from the sub-regional European Social Fund will fund work during 2020-2023 to increase access to employment support for people with LD. This will include a dedicated support officer to work alongside adult social care teams to provide a referral route into education and employment support.

G. Key strengths in CW&C

- ASCOF measures highlighting the proportion of adult social care clients with an LD living in their own home or with family has been consistently better than the England average. ASCOF measures for employment in 2018/19 also showed an improvement in the proportion of people with an LD aged 18-64 in paid employment and is higher than the England average.
- Participation of young people aged 16 and 17 with an EHCP in CW&C is high and is above the England average.



- Feedback from the Adult Social Care User Survey 2019 showed that the majority of service users with LD were satisfied with the care and support services they received and felt they had a good quality of life.
- Smoking rates at time of delivery for pregnant women improved in CW&C during 2018-19 bringing it in line with the national average. Work in this area is ongoing with smoking in pregnancy a targeted work stream at the Women, Children, Young People and Families Group, and a priority area of improvement for West Cheshire CCG's Maternity Network.

H. Key areas for improvement

- There is a need to understand reasons for the increasing number of complicated births taking place at the Countess of Chester Hospital – almost two thirds of births during 2018/19 were classed as with complications or complicated.
- CW&C are significantly higher than the England average for injury in under 15's and understanding the reasons behind this is a key role of the Unintentional Injuries Partnership Group.
- At the present time, our understanding of the needs and outcomes of young people with LD is limited and this work will be part of the Preparing for Adulthood work stream.
- More work needs to be done in primary care and with GPs to increase the uptake of preventative measures such as GP health checks, screening, and flu immunisation.
- Data highlights problems with mental wellbeing for the LD cohort. More understanding is needed on how mental health and wellbeing needs are provided for in conjunction with providing care and support for physical needs.

I. Key issues

- Limited data is available in CW&C from the LA and partners to understand the needs of those with LD and to understand how well the LA and partners are meeting these needs. Additional data issues exist:
 - We are unable to obtain data regarding the number of admissions, discharges or re-admissions into acute hospitals across CW&C for people with LD and the type of health services they access.
 - Data measuring children and young people outcomes does not allow for an understanding of those with an LD, but for all children with an EHCP.
 - Service level data can only tell us the number of people accessing those services not what the impacts of the service is on the user, if their needs are being met, and where gaps exist.
 - Data from social care systems does not allow us to look at the numbers of people with an LD accessing specific social care services, and data quality issues exist in terms of collecting information so that it is reportable and trackable. Future report development will enable us to access this information.
 - Data quality concerns were also raised by the CCG in relation to GP records and this has been a key area of improvement.
- Population forecasts show an ageing population in CW&C and future planning must consider how supported living and residential accommodation is fit for purpose with increased demand.

J. Recommendations

- Improve health outcomes and life expectancy



- It is recommended that an informed analysis of local deaths is undertaken through the Strategic LeDeR Steering Group.
- Working in partnership across organisations to implement the prevention agenda including joint commissioning across social care and health.
- A focus on achieving the 75% health check uptake for people with LD and implementing individual health action plans to support the prevention agenda.
- Also in line with the prevention agenda, increasing the uptake of the annual flu jab and cancer screening checks, particularly cervical cancer.
- Evaluate and monitor reasonable adjustments being made across all sectors of the NHS including primary care, acute hospitals and community settings.
- Developing community opportunities
 - Review the range of services commissioned to meet 'social' needs (building relationships, taking part in activities, life skills) to ensure provision and a greater choice of groups available to join. In line with this, ensure community spaces are available.
 - Provide easy access to transport and access to services and groups.
 - Consider Relationship and Sex Education for those with LD.
 - Availability of information about services and support available for those with LD and their caregivers; and advice and guidance for employers, educational settings and communities about how to make reasonable adjustments to ensure inclusivity.
- Young people and transitions
 - To help address the lack of data readily available to understand needs and outcomes of young people with LD, the Preparation for Adulthood Partnership Group is to review the availability of data collected on young people with a LD in CW&C, identifying data streams and where gaps exist in collection and reporting.
 - Agreement of measurable and reportable outcomes to benchmark, monitor and understand if we are meeting the needs of young people with an LD.
- Future planning for an ageing population
 - Future commissioning intentions should consider how current services provided can be shaped to adequately provide for an ageing LD population and changes in informal networks of care.
 - Greater aligned working between NHS and social care teams with a focus on joint commissioning arrangements, the development of specialist multidisciplinary teams and training/ skills of care staff.
 - Development of bespoke property that can cater for an ageing population with potential mental health and dementia needs. To ensure best practice principles of independent supported living.
- Data development for learning disabilities
 - Review the information inputted into social care systems to assess if the coding and reporting of care and support provision is adequate to understand service usage.
 - Clinical Commissioning Groups to consider the contracting opportunities available to them to enable data to be collected on the number and type of services being accessed by people with LD including admissions and discharges to acute hospital.



4) Prevalence of learning disability (LD) in Cheshire West and Chester

In order to explore the current levels of LD within CW&C, an overview of prevalence of LD and levels of need is given below.

4.1) Estimated prevalence

Calculation of local prevalence rates in CW&C indicates that 1.87% of the population will have an LD of some sort. This is a rate of 18.6 per 1,000 residents. When applying this to the CW&C adult resident population, this is 5,100 adults aged 18 plus with an LD of some sort within the borough. This is similar to the national prevalence rate of 2%.

Of these adults with an LD, an estimated 1,220 will have an LD that can be classed as severe. This is around a quarter of those with an LD. Approximately 3,880 are estimated to have a moderate LD.

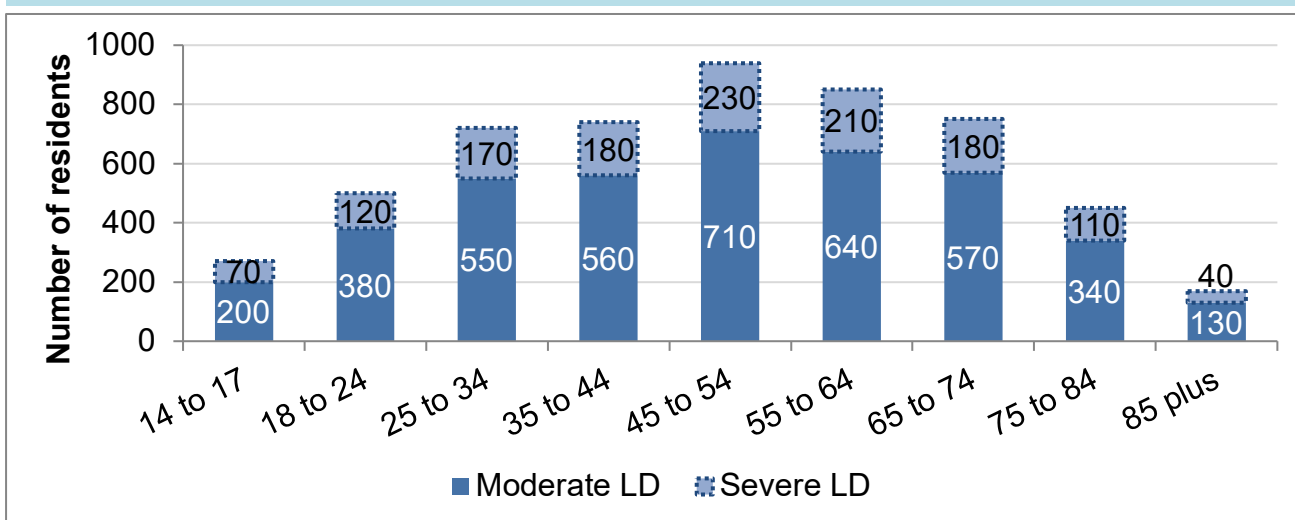
4.2) Young people of transition age

Between the ages of 14 to 17 years, young people with an LD will be preparing for transition from children to adults services. In CW&C, there are an estimated 270 young people aged 14 to 17 with an LD going through transition. Around 70 of these young people will have a severe LD.

4.3) Estimated prevalence by age group

Based on local population estimates, we would expect to see the greatest numbers of people with an LD in the 45 to 54 age group followed by those aged 55 to 64. This can be seen in chart one.

There are an estimated 5,350 residents aged 14 and over with a LD in CW&C. The greatest numbers can be seen in the 45 to 64 age groups.



Source: Chart 1 Estimated prevalence of learning disability in Cheshire West and Chester by severity; prevalence calculated from SEN2 January 2019 for learning disability types Moderate, Severe, Autism (age 8-15) and Profound and Multiple (age 5-15). Numbers



rounded to nearest 10. Applied to 2018 Mid-Year Population Estimates, Office for National Statistics.

4.4) Prevalence by type of LD

To begin to understand prevalence rates by the type and nature of LD, the following descriptions have been taken from the NHS (accessed via NHS website December 2019).

The NHS defines learning disabilities in the following categories

- **Moderate learning disability** – those with a mild or moderate learning disability are likely to be able to talk easily, look after themselves, and live independently, but may need a bit longer than usual to learn new skills.
- **Severe learning disability** – those with a severe learning disability may have difficulty communicating, need help with everyday tasks, and depending on their ability; need care and support.
- **Profound and multiple learning disability (PMLD)** – those with PMLD have a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent. They may have difficulty seeing, hearing, speaking and moving. They are likely to have complex health and social care needs that will require a carer(s) to help with most areas of everyday life.

However, it must be kept in mind that each person will be affected by their LD in a different way and their abilities, experiences and circumstances will vary. Five categories of need can be seen in table one. We can use these categories to understand the cohort further.

Table one shows the category of need and estimated prevalence of adults in the CW&C population.

In CW&C it is estimated that 1,220 adults aged 18 and over have a severe learning disability. Of these approximately 360 will have co-existing autism and 120 will have a Profound and Multiple Learning Disability, a very severe learning disability.

Type of learning disability	Rate per 1,000 residents	Number of adults aged 18+
Moderate	10.14	2,760
Moderate with coexisting autism	4.07	1,110
Severe	2.71	740
Severe with coexisting autism	1.36	370
Profound and multiple (PMLD)	0.47	130

Source: Table 1 Estimated prevalence of learning disability in Cheshire West and Chester by type; prevalence calculated from SEN2 January 2019 for learning disability types Moderate, Severe, Autism (age 8-15) and Profound and Multiple (age 5-15). Applied to 2018 Mid-Year Population Estimates, Office for National Statistics.

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to other people, and how they experience the world around them (National



Autistic Society). Over half of all those with Autism will have a learning disability of some sort (Mentalhealth.org). Autism without a learning disability is not in the scope of this JSNA so residents with autism are not included in population numbers unless their autism co-exists alongside a learning disability.

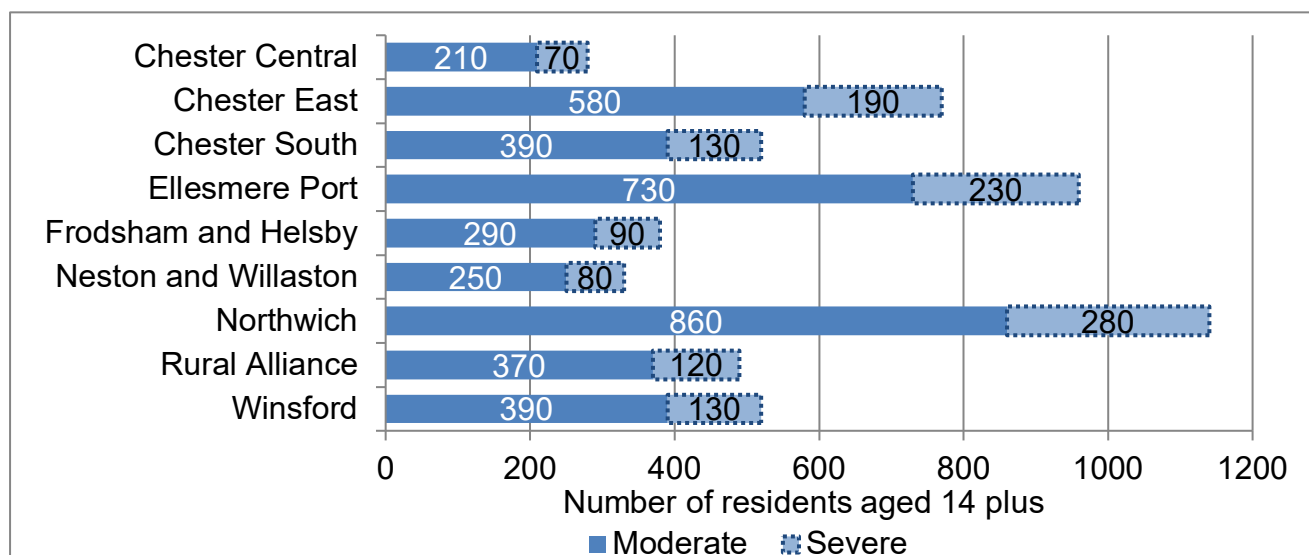
The population rate of each type of LD can be applied to the CW&C population by age group. This can be seen in table two which shows type of LD by the estimated number of people in each age category.

Age group	Moderate LD: Counts		Severe LD: Counts		
	Moderate LD	Autism and a moderate LD	Severe LD	Autism and a severe LD	Profound and multiple LD
14 to 17	140	60	40	20	10
18 to 24	270	110	70	40	10
25 to 34	390	160	100	50	20
35 to 44	400	160	110	50	20
45 to 54	500	200	140	70	20
55 to 64	460	180	120	60	20
65 to 74	410	160	110	50	20
75 to 84	240	100	60	30	10
85 plus	100	40	30	10	*

Source: Table 2 Estimated prevalence of learning disability in Cheshire West and Chester by type; prevalence calculated from SEN2 January 2019 for learning disability types Moderate, Severe, Autism (age 8-15) and Profound and Multiple (age 5-15). Numbers rounded to the nearest 10. Numbers less than 10 denoted with *. Applied to 2018 Mid-Year Population Estimates, Age, Office for National Statistics.

4.5) Estimated prevalence by care community footprints

Northwich Care Community has the greatest number of residents aged 14 plus with a learning disability followed by Ellesmere Port and Chester East Care Communities.





Source: Chart 2 Estimated prevalence of LD by Care Community; prevalence calculated from SEN2 January 2019 for learning disability types Moderate, Severe, Autism (age 8-15) and Profound and Multiple (age 5-15). Numbers rounded to nearest 10. Applied to 2018 Mid-Year Population Estimates, Office for National Statistics.

Table 3 below shows the estimated number of adults with LD in each care community by five year age band.

Care community	14-17 years	18-24 years	25-34 years	35-44 years	45-54 years	55-64 years	65-74 years	75-84 years	85 plus
Chester Central	10	90	60	30	30	30	20	10	10
Chester East	40	60	110	120	130	110	100	60	30
Chester South	30	50	70	70	90	80	70	40	20
Ellesmere Port	50	90	140	130	170	130	120	70	30
Frodsham and Helsby	20	30	40	50	70	60	60	40	10
Neston and Willaston	20	20	30	40	50	60	60	40	10
Northwich	60	90	140	160	210	190	160	90	40
Rural Alliance	30	30	40	60	90	80	80	50	20
Winsford	30	50	80	70	100	80	60	40	10

Source: Table 3 Estimated LD prevalence by care community and age group; prevalence calculated from SEN2 January 2019 for learning disability types Moderate, Severe, Autism (age 8-15) and Profound and Multiple (age 5-15). Numbers rounded to nearest 10. Applied to 2018 Mid-Year Population Estimates, Office for National Statistics.

4.6) Known prevalence of LD in Cheshire West

GP data at January 2020, tells us there were 1,782 patients aged 14 plus with a diagnosed LD registered with a GP in Cheshire West (West Cheshire Integrated Care Partnership (ICP) area). This indicates that 0.6% of the estimated registered population have a diagnosis of LD; a shortfall of around 4,228 adults aged 14 and over (1,782 diagnosed compared to 6,010 expected to have an LD across the ICP area.)

However, the 0.6% figure is slightly higher than the 0.5% prevalence rate for those expected to have a severe LD in CW&C. This suggests that those with a diagnosis known to their GP are likely to be those more severely affected by their LD. It is important to recognise that not all those with an LD will be known to health and public sector services, but it is likely that those with a severe LD will be flagged on the LD GP register. Those with a moderate LD may also have a diagnosis if they have chosen to pursue this route.

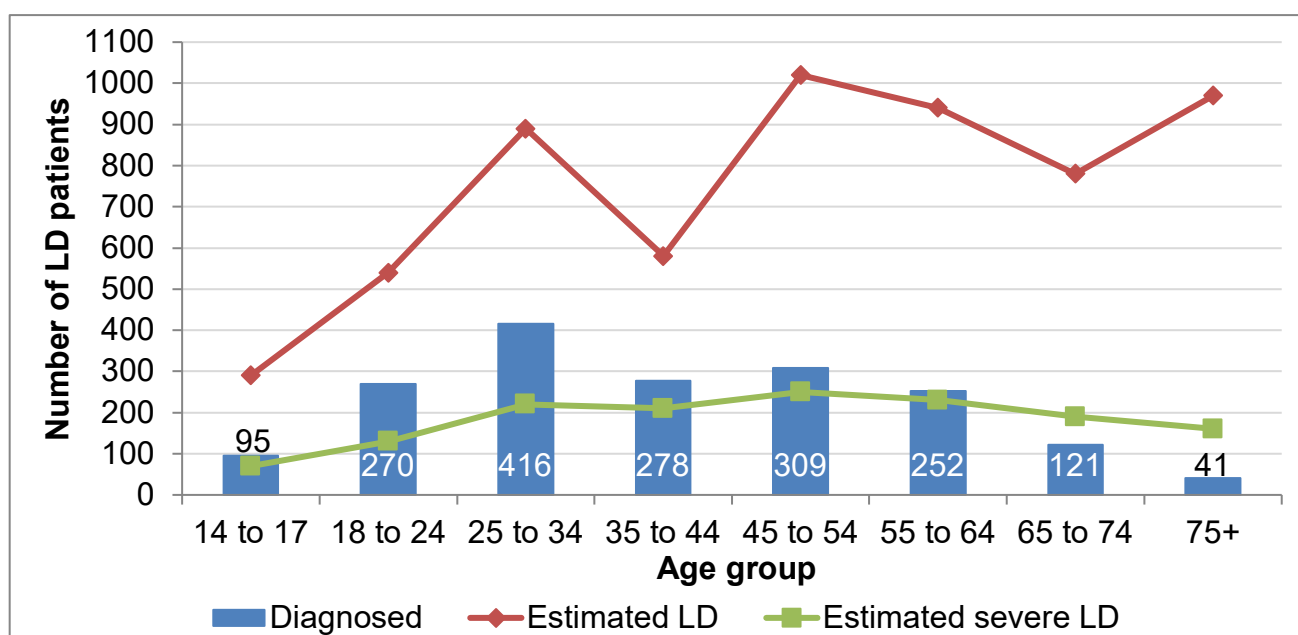
Some people with an LD will not have a diagnosis. This maybe because as a child a specific diagnosis of LD is not required to receive support. Therefore if the individual or their care giver, felt no further support from health and care services was required in addition to



the support offered as a child, then it is possible that an official diagnosis may never have been given. However it should be noted that changes to coding in 2018/19 removed some historical codes used by practices, which had an impacted on these figures.

The charts and tables below, show numbers of adults with an LD by their current age group, and care community location compared to estimated numbers in the registered population given the 18.6 per 1,000 residents LD prevalence rate.

There are higher numbers of 25-34 year olds with a diagnosis, while older patients aged 65 plus are less likely to have a diagnosis.



Age group	Number of patients LD diagnosed	Estimated registered population with LD	Estimated registered population with severe LD
14 to 17	95	290	70
18 to 24	270	540	130
25 to 34	416	890	220
35 to 44	278	580	210
45 to 54	309	1,020	250
55 to 64	252	940	230
65 to 74	121	780	190
75+	41	970	160

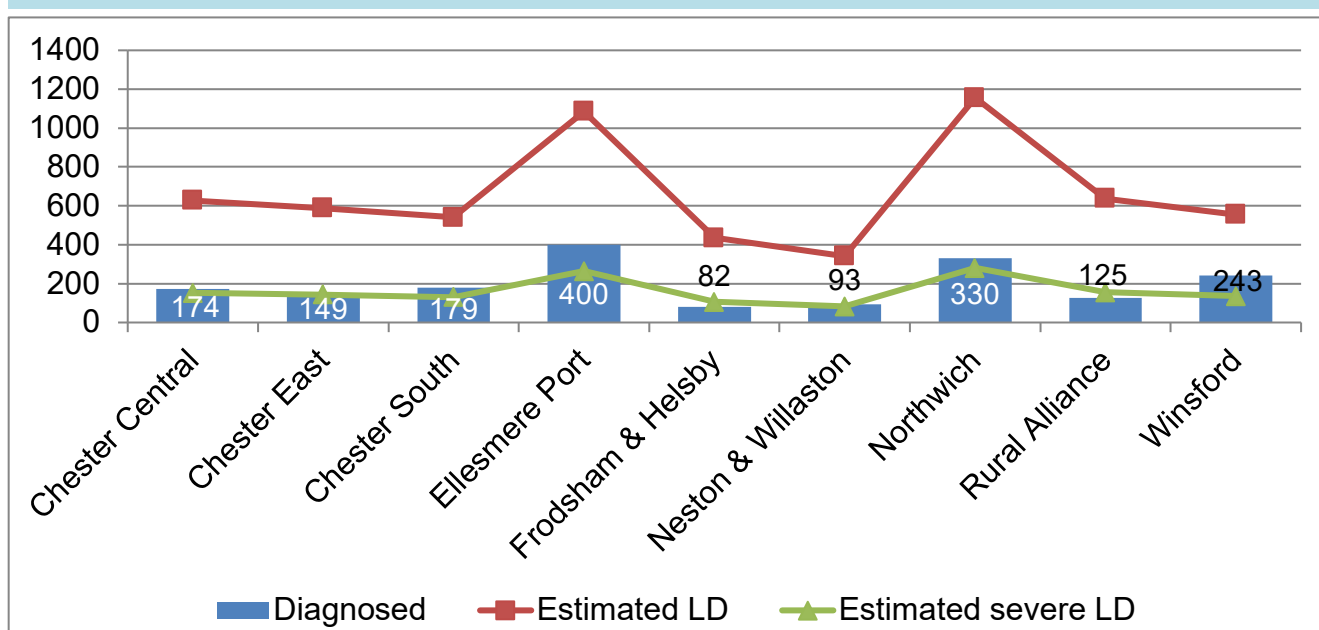
Source: Chart 3 and Table 4 Diagnosed patients with LD compared to estimated number by age group. Number of patients with a diagnosis of LD by age, GP Practice records, January 2020; Estimated prevalence of LD by registered population by age; prevalence calculated from SEN2 January 2019 for learning disability types Moderate, Severe, Autism (age 8-15) and Profound and Multiple (age 5-15). Numbers rounded to nearest 10. Applied to 2018 Mid-Year Population Estimates, Office for National Statistics.



GP data also tells us that:

- As expected, actual numbers of patients with a diagnosis of LD are lower than estimates indicate but closer to the estimated number with a severe LD.
- This suggests that GPs may be aware of those with a severe LD, except for those in the 65 plus age group.
- The 'pattern' of number diagnosed by age group generally matches the 'pattern' of numbers expected; with lower numbers diagnosed and expected in the younger and older age groups

The highest numbers of patients with a diagnosed LD can be seen in Ellesmere Port care community followed by Northwich care community.



Care community	Number of patients diagnosed	Estimated registered population with LD	Estimated registered population with severe LD
Chester Central	174	628	152
Chester East	149	588	143
Chester South	179	540	131
Ellesmere Port	400	1,086	264
Frodsham and Helsby	82	436	106
Neston and Willaston	93	341	83
Northwich	330	1,156	281
Rural Alliance	125	638	155
Winsford	243	555	135



Source: Chart 4 and Table 5 Diagnosed patients with LD compared to estimated number by care community. Number of patients with a diagnosis of LD by care community, GP Practice records, January 2020; Estimated prevalence of LD by registered population by care community; prevalence calculated from SEN2 January 2019 for learning disability types Moderate, Severe, Autism (age 8-15) and Profound and Multiple (age 5-15). Numbers rounded to nearest 10. Applied to 2018 Mid-Year Population Estimates, Office for National Statistics.

GP data by care community shows that the 'pattern' of number of patients diagnosed by care community generally matches the 'pattern' of numbers expected. The exception are Rural Alliance and Frodsham and Helsby, where there appears to be particularly lower numbers of people registered with LD than we would expect to see in these areas, and Winsford and Ellesmere Port with higher numbers of people registered with LD than we would expect to see.

5) Population forecasts

Locally calculated LD population forecasts indicate that the LD population will remain fairly static over the next 20 years at around 6,400 residents. Therefore there will be no or little change in numbers of residents with a severe LD.

However, when we look at forecasts by broad age groups, we see that the makeup of the LD cohort will change over the next 20 years. This predicts there will be an increased proportion of older people with LD, and to a lesser extent, an increased proportion of under 18's with LD. As a result there will be fewer adults aged 18-64 with an LD.

Adults with an LD aged 65 plus will see a plus 18 per cent change between 2018 and 2038. This is compared to a minus 3 per cent change for all adults aged 18 plus.

Children 0-17						% change 2018 to 2038
	2018	2023	2028	2032	2038	
Moderate LD	1,000	1,000	1,000	1,000	1,000	9%
Severe LD	300	300	300	300	300	9%
LD	1,300	1,300	1,300	1,300	1,300	9%
Adults 18 plus						
	2018	2023	2028	2032	2038	
Moderate LD	3,900	3,800	3,800	3,800	3,800	-2%
Severe LD	1,200	1,200	1,200	1,200	1,200	-5%
LD	5,100	5,000	5,000	5,000	5,000	-3%
LD all age						
	2018	2023	2028	2032	2038	
Moderate LD	4,800	4,800	4,800	4,800	4,900	0%
Severe LD	1,500	1,500	1,500	1,500	1,500	-2%
LD	6,400	6,300	6,300	6,300	6,400	0%



LD aged 65 plus						
	2018	2023	2028	2032	2038	
LD	1,400	1,400	1,400	1,500	1,600	18%

Source: Table 6 LD forecasts locally calculated by Insight and Intelligence, Cheshire West and Chester Council, based on the principals Emerson and Hatton (2012), Estimating the need for Adult Social Care Services for adults with disabilities in England 2012-2030

Increasing numbers of older people will start to show from around 2028 onwards. This will mean CW&C will have an ageing population with learning disabilities which will impact on all health and social care services.

As well as having an LD, this population will have increased likeliness of co-existing conditions associated with ageing which can include; chronic disease(s), dementia, arthritis, osteoporosis, cataracts and mobility issues. This means that those with LD who are older in age have complex health needs that will require additional coordinated support. There will also be a reliance on social care as this age group are more likely to live alone and increased demand might be placed on extra care housing, residential and nursing support.

Forecasts also show an increase in children and young people aged under 18 with an LD; though the percentage change between 2018-2038 is smaller than that for over 65s at 9%; an increase of approximately 100 young people.

However, these forecasts indicate that this change is likely to be for moderate forms of LD and these changes won't be seen until at least 2033, with those with severe LD remaining static. This will however, result in a higher number of children and young people being supported for an LD in educational settings, LD Child Adolescent and Mental Health Services, and by the Prepared for Adulthood pathway.

6) Causes of learning disability

The NHS stipulates that a learning disability is caused when an individual's brain development is impaired either before they were born, during their birth, or in early childhood (taken from the NHS website December 2019).

Causes of learning disability can be both genetic and non-genetic factors.

Some causes for a learning disability can be linked to:

- A mother becoming ill during pregnancy.
- Problems during birth that prevent enough oxygen reaching the babies brain
- The unborn baby inheriting certain genes from its parents that make having a LD more likely – known as an inherited learning disability (genetic factors)
- Illness such as meningitis, or injury in early childhood.



Specific conditions are also associated with an LD. For example almost everyone with downs syndrome has some form of LD, as do many people with cerebral palsy. It is also estimated that around 30% of people with epilepsy also have a learning disability and more than 50% of those with autism.

According to Public Health England, health behaviours during pregnancy can also impact on the development of the unborn child.

7) Who is at risk? Preventative measures

Some of the causes of LD; such as poor health behaviours during pregnancy, are preventative; or can be influenced early on, if identified by timely prenatal screening (Public Health England).

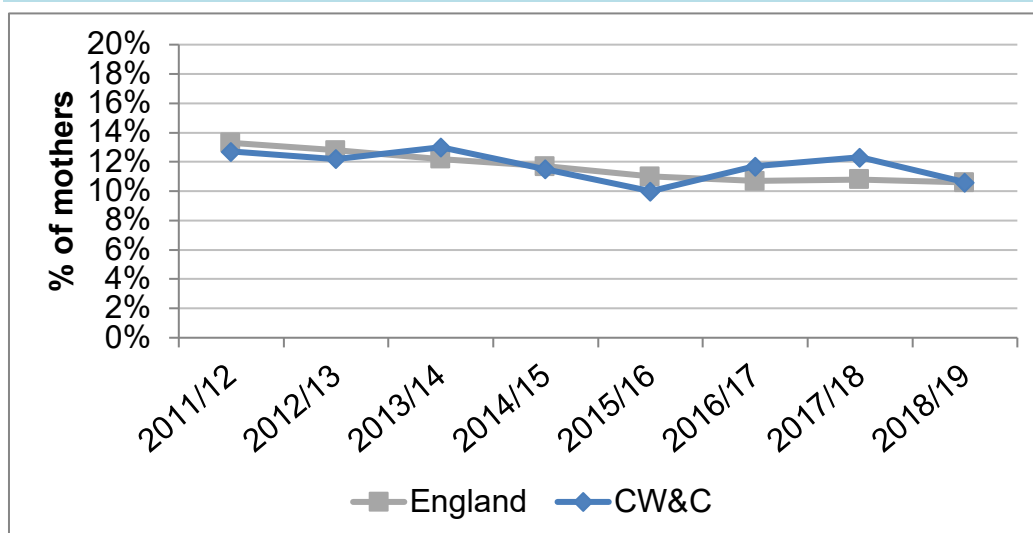
The local authority and health partners can therefore play a role in mitigating some of the risks linked to causes of learning disabilities associated with poor health behaviours in pregnancy. This can be achieved through public health promotion, supporting mothers during pregnancy, and monitoring risks that could impact on premature birth.

Measures related to preventive risk factors linked to the cause of LD will be explored in the following sections.

7.1) Smoking during pregnancy

Smoking in pregnancy has well known detrimental effects for the growth and development of the baby. According to Public Health England, smokers on average have more complications during pregnancy and labour, including bleeding during pregnancy, placental abruption and premature rupture of membranes. These can affect the development of the baby, and increase the risk of miscarriage, premature birth, stillbirth, low birth-weight and sudden unexpected death in infancy.

In 2018/19, 10.6% of pregnant females were smoking at the time of delivery (SATOD) (349 women) which is equal to the England average and an improvement from the previous year.





Source: Chart 5 Percentage of mothers smoking at time of delivery, calculated by PHE from the NHS Digital return on Smoking Status at Time of Delivery (SATOD).

At CCG level, West Cheshire CCG had a SATOD rate of 9.5% in 2018/19, lower than the England average (10.6%) but statistically similar. In Vale Royal CCG, SATOD rates were 13.1% in 2018/19, significantly higher than the England average.

The Tobacco Control Plan contains a national ambition to reduce the rate of smoking throughout pregnancy to 6% or less by the end of 2022. West Cheshire CCG forecast they will achieve the national target by 2022 by seeing a 0.5% year on year reduction in SATOD but there is still headway to be made in Vale Royal CCG.

Much work is being done by CCGs and Public Health to improve SATOD rates locally. Smoking in pregnancy is one of the targeted work streams at the Women, Children, Young People and Families group that covers Vale Royal footprint, and a priority area of improvement for West Cheshire CCG's Maternity Network. Other actions include:

- All pregnant women who are smokers are referred to smoking cessation advisors
- Mid Cheshire Hospital has a smoking cessation midwife who attends a weekly antenatal clinic
- Awareness raising of smoking cessation support and smoking risks takes place through posters in antenatal clinics and social media
- Training of community midwives is being undertaken to ensure understanding of smoking cessation and all midwives have equipment to perform carbon monoxide testing.
- Carbon monoxide monitoring is a mandatory field on the maternity system completed at the booking visit and is monitored weekly and reported at departmental meetings.
- Collaborative working to further raise awareness of smoking in pregnancy is underway including supporting women accessing childrens' centres; which included a stop smoking session.
- Contractors used for smoking cessation will be challenged to deliver their targets and ensure positive outcomes are achieved.

In addition to smoking during pregnancy, alcohol consumption during pregnancy can also seriously affect the development of the unborn child which could cause learning difficulties. Drinking heavily throughout pregnancy can cause a serious condition called foetal alcohol syndrome which includes learning and behavioural problems along with poor growth and facial abnormalities. However, we currently have no available data to explore this in CW&C.

7.2) Premature birth and/ or low birth weight

Babies who are born early and/or who have a low birth weight have a higher chance of having a disability. This is not always preventable but Public Health England highlight that it



is sometimes linked to poor health behaviours within pregnancy such as smoking, alcohol, drug use, and a poor diet.

During 2015-17, 855 babies were born less than 37 weeks gestation, a rate of 79.8 per 1,000 births which is similar to the England rate of 80.6 per 1,000 births.

In 2017, 2.41% of term babies were born a low birth weight, 79 babies. This is an increase from 2016 (2.26%) but remains below the England average (2.82%).

Though small numbers, the proportion of term babies born a low birth weight was in 2017, the highest it has been in the last ten years.

	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
CW&C	2.33%	2.06%	2.29%	2.27%	2.12%	1.74%	2.19%	2.12%	2.38%	2.26%	2.41%
England	2.91%	2.89%	2.92%	2.85%	2.84%	2.80%	2.82%	2.86%	2.77%	2.79%	2.82%

Source: Table 7 Low birth rate trend, Office for National Statistics

7.3) Premature birth and/ or low birth weight

Complex pregnancy is a higher risk pregnancy where: the woman or baby is more likely to become ill or die, complications are more likely to occur before or after delivery, or child and maternal health outcomes are poorer compared to other groups (NHS Scotland).

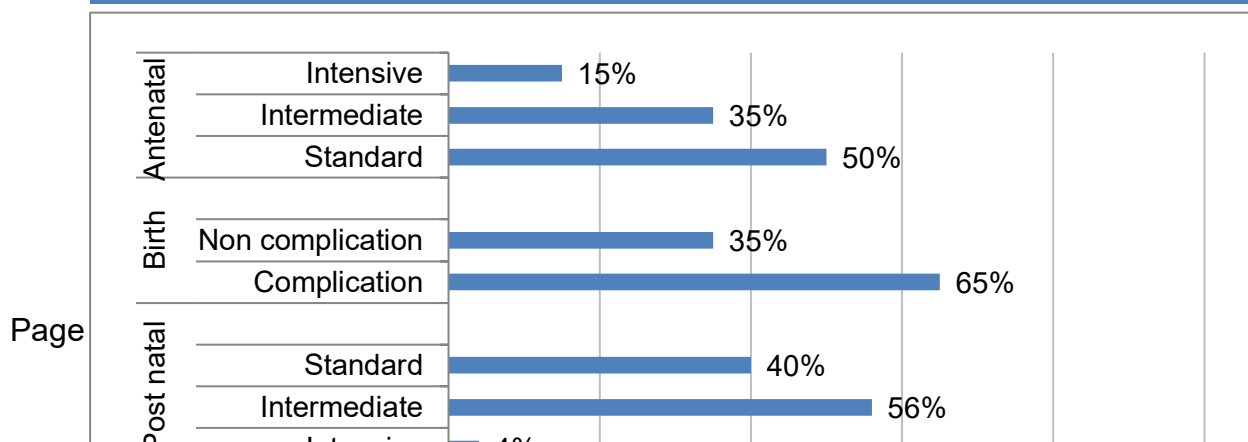
A learning disability may result if the baby's oxygen supply is interrupted for a significant length of time; or if the baby is born premature and becomes ill shortly after birth.

Several factors can make a pregnancy high risk including;

- Existing health conditions such as high blood pressure, polycystic ovary syndrome, diabetes, kidney disease
- Mother's age; (teenagers and those over the age of 35)
- Lifestyle including alcohol use, tobacco use, drug use and obesity
- Conditions of pregnancy including multiple gestation, gestational diabetes, previous preterm birth, birth defects or genetic conditions in the foetus, preeclampsia and eclampsia (increase in high blood pressure affecting organs and can be fatal).

2018/19 pregnancy data has been provided from the Countess of Chester Hospital.

Almost two thirds of births at Countess of Chester Hospital during 2018/19 had complications.





Source: Chart 6 Countess of Chester Hospital Antenatal, Birth and Postnatal Data, 2018/19, Countess of Chester Hospital (Mid Cheshire Hospital data is not available).

At the Countess of Chester Hospital during 2018/19, 50% of antenatal care was standard care which is an increase from 44% the previous year. This change has seen a corresponding reduction in intermediate care, whereas intensive antenatal care has remained steady.

However, the majority of births were complicated (65%). Complicated births have been increasing by, on average, 2% each year. For postnatal care, just over half of women received intermediate care (56%). This is a decrease from 63% in the previous year with a corresponding increase in 2018/19 in women receiving standard care from 35% to 40%.

Data for England is unavailable, so unfortunately there is no method to compare the Countess of Chester Hospital to understand if this is a 'typical' pattern of complex pregnancy, or if this figure is unusually high.

Specialist services must be available to women and babies with more complex needs and they should receive consistently high quality treatment in centres with the right facilities and expertise as close to their homes as possible. These services will include, but are not limited to; maternal and foetal medicine, specialist mental health services and neonatal care.

7.4) Access to maternity services

High quality antenatal care gives a better chance of a healthy pregnancy and a healthy baby. A healthy pregnancy is vital to a child's development, whilst effective and timely maternity care provides the best start in life. Early access to antenatal care is essential for early identification of safeguarding issues to reduce infant mortality and risks to the baby.

The National Institute for Health and Care Excellence (NICE) guidance on antenatal care (2008); recommends that women should access maternity services before they reach 12 weeks of pregnancy. Ideally this assessment should take place at 10 weeks of pregnancy to allow women to have the full benefit of personalised maternity care and improve outcomes for mother and baby.

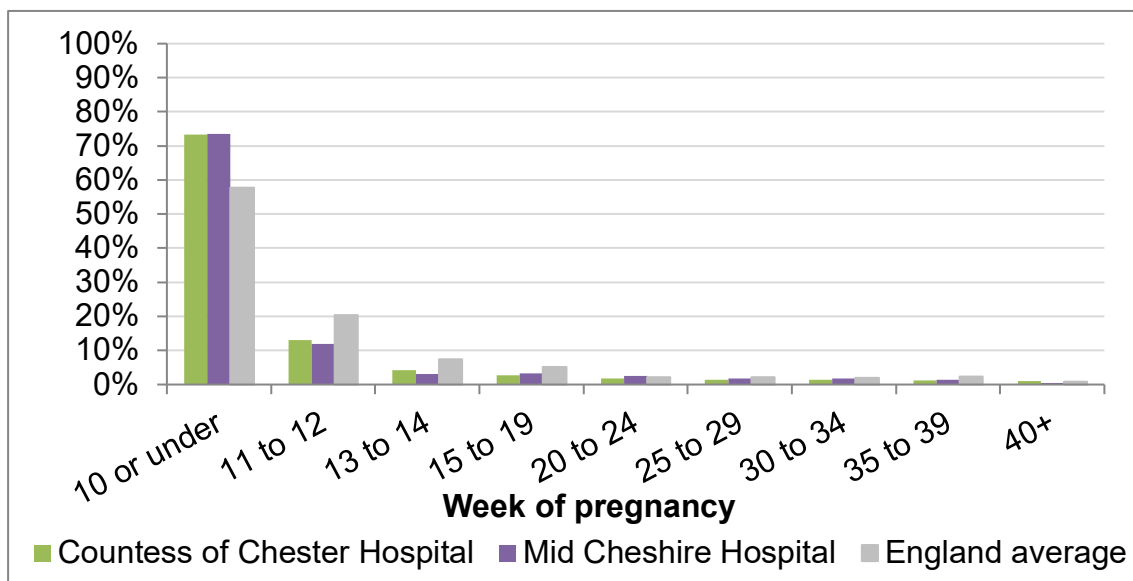
During 2017-18, there were 5,760 births at Countess of Chester Hospital and Mid Cheshire Hospital. Of these, the stage at which maternity services were accessed is known for 5,290 women:

- 81.2% of women accessed maternity services under 12 weeks of their pregnancy compared to 70% nationally
- 73.5% accessed at 10 weeks or under compared to 57.8% nationally.



Both hospitals have a similar proportion of females accessing maternity services under 12 weeks (82% Countess of Chester Hospital and 82.4% Mid Cheshire Hospital) and 10 weeks or under (73.3% Countess of Chester Hospital and 73.5% Mid Cheshire Hospital). Mid Cheshire Hospital has a higher proportion of pregnant women with time of access unknown, 9.4% compared to 6.8% at the Countess.

A higher proportion of pregnant women access maternity services at the recommended 10 weeks or under compared to the England average.



Source: Chart 7 Week of pregnancy at which maternity services were accessed, 2017-18, NHS Maternity Statistics

The Saving Mothers Lives Report (2007) found that women who booked into antenatal care after 20 weeks or who missed more than four routine appointments were more likely to be vulnerable women, including black African or Caribbean females, those experiencing domestic violence and abuse, misusing substances, known to social services, aged under 20 years, or unemployed.

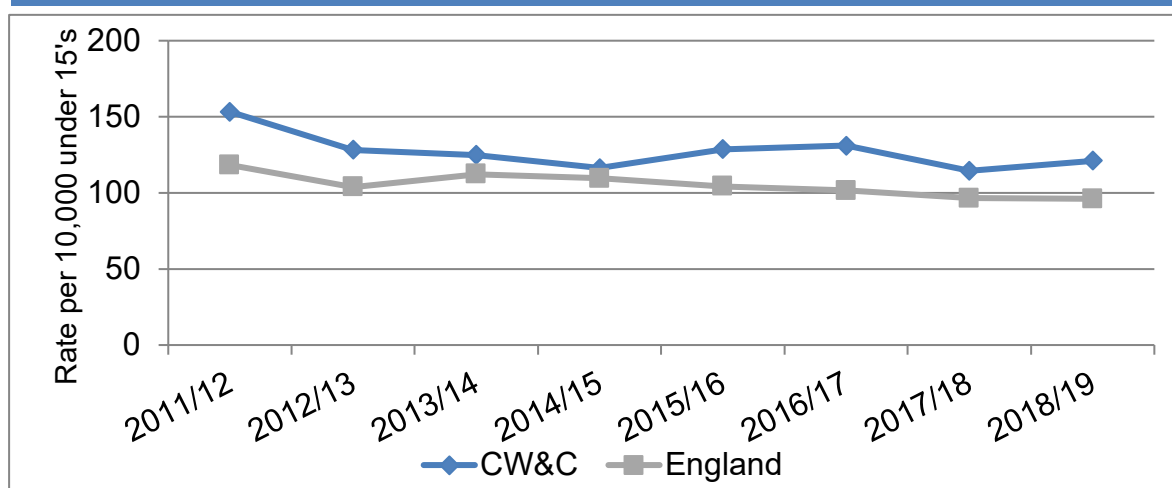
7.5) Injury

In addition, injury such as brain injury or damage; can result in life changing disabilities including learning difficulties and can cause additional mental health issues such as post-traumatic stress disorder and anxiety. Accidental injury is the leading cause of acquired disability for children over one year of age (Effects of Paediatric Head Trauma for Children, Parents and Families, Youngblut et al).

During 2018/19, there were 697 children aged 15 and under admitted to hospital with an unintentional or deliberate injury, a rate of 121.2 per 10,000 children aged 0-14 years which is significantly higher than the England average of 96.1 per 10,000.



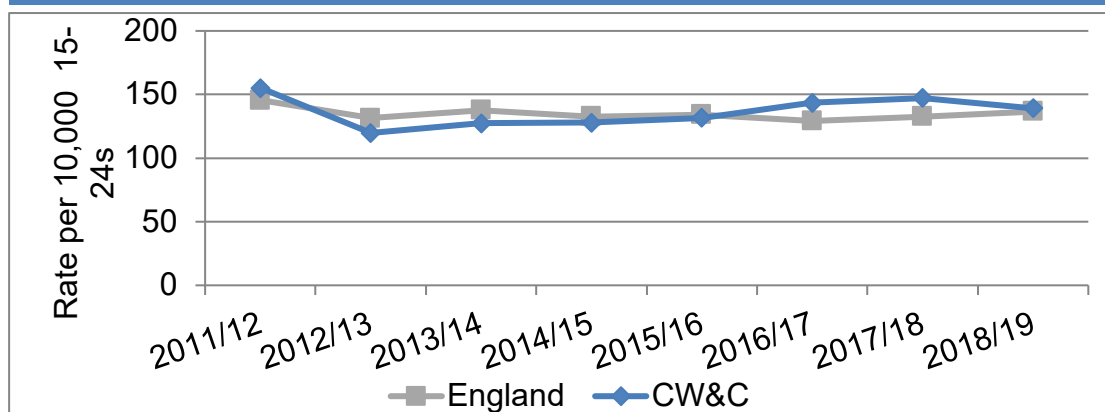
The rate of hospital admissions for under 15's for an unintentional or deliberate injury has been consistently higher than the England average



Source: Chart 8 Rate per 10,000 hospital admissions for under 15's, Hospital Episode Statistics

For young people aged 15-24 years, the rate of hospital admissions caused by unintentional and deliberate injury was statistically similar to the England average. There were 522 young people; a rate of 139.2 per 10,000 compared to 136.8 in England.

The rate of hospital admissions for 15-24's decreased in 2018/19 bringing it in line with the England average.

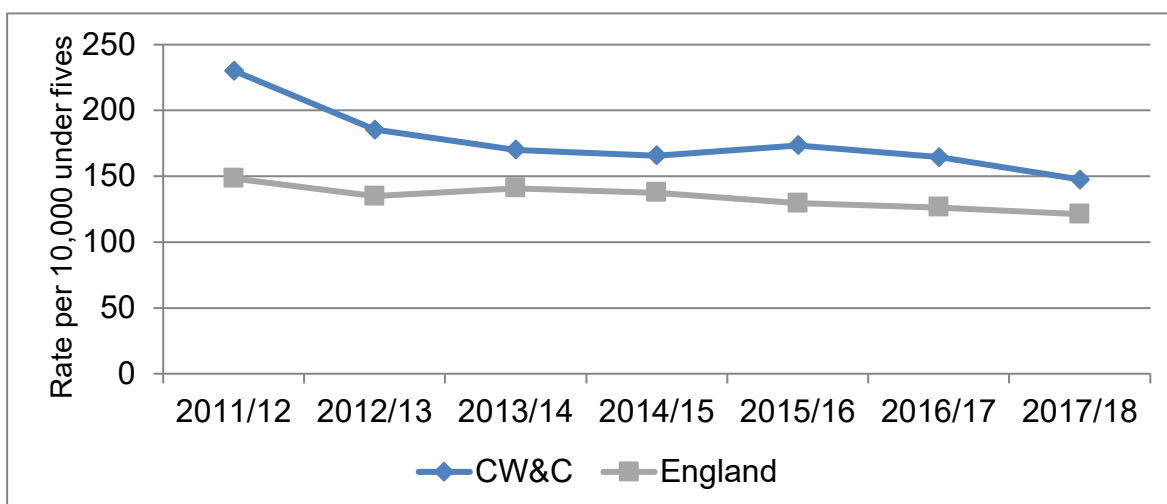


Source: Chart 9 Rate per 10,000 hospital admissions for 15-24 year olds, Hospital Episode Statistics



Data indicates that in those aged under five, the most common injury is a head injury that occurred in the home. Hazards, including those that can cause injury to small children, have been a key focus of Cheshire Fire and Rescue and their 'Safety Central' interactive centre. CW&C has a significantly higher rate of injury in children aged under five than the England average (147.6 per 10,000 compared to 121.2 per 10,000).

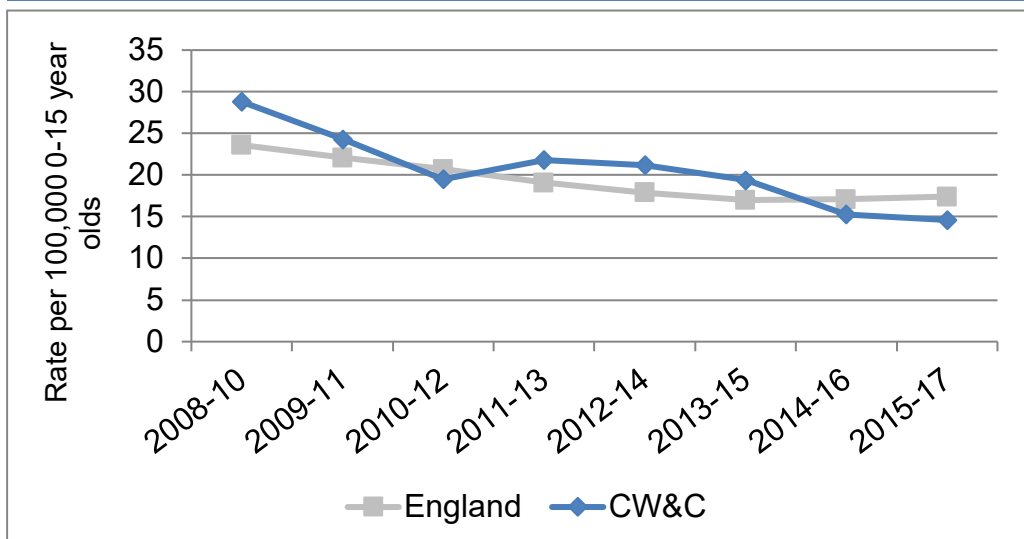
The rate of hospital admissions for under 5's for an unintentional or deliberate injury has been consistently higher than the England average



Source: Chart 10 Rate per 10,000 hospital admissions for under-fives, Hospital Episode Statistics

Road traffic collisions are a major cause of serious injury. In CW&C, the number of children killed or seriously injured (KSI) has decreased from 55 incidents in 2008-10 to 26 incidents in 2015-17, a rate of 14.6 per 100,000 children aged 0-15 years. This is lower than the England rate of 17.4 per 100,000 0-15 year olds.

In CW&C the rate of children aged 0-15 years killed or injured on CW&C roads has been decreasing.





Source: Chart 11 Rate per 100,000 hospital admissions for under-fives, Hospital Episode Statistics

8) Service provision

Having discussed the risks and associated causes of learning disabilities, as well as local levels of LD within CW&C, the next section of the JSNA will explore the current services available for people with an LD.

Often people with an LD have a wide range of needs that can span health, social care and community support systems. It is also likely that they will suffer from poorer physical and mental health when compared to the rest of the community; so it is essential that there is a range of support and provision available across both health and social care systems to ensure people with an LD are supported to live as healthy fulfilled lives as possible.

Support needed for people with an LD may include:

- Help to carry out daily activities such as preparing food, getting dressed and maintaining everyday living.
- Housing support such as supported living schemes
- Help in finding a job/ through work experience and support / development in the workplace
- Help to take part in leisure and social activities
- Healthcare support
- Interventions and therapies
- Medical support
- Carers support
- Financial support

Current services available across the community can be categorised as below:



8.1) Primary Care Services

Across CW&C, all 49 GP practices have a Learning Disability Register and have signed up to the Direct Enhanced Service (DES) to provide Learning Disabilities Annual Health Checks (AHCs). This register sets out the criteria for an annual health check, a health action plan and enables GPs to monitor when patients' next annual health check is due. It also requires practice staff to undertake annual LD training on reasonable adjustments and LD awareness training.



GP Health Checks

Available information from NHS England for LD health checks shows that people with an LD often have poorer physical and mental health than other people, and an annual health check can improve peoples' health by spotting problems earlier.

At least 75% of patients on the GP learning disability register aged 14 and over should have an annual health check; this figure has been agreed by the General Medical Council (GMC) and NHS England (NHSE) and takes into account that there are a proportion of those with LD that cannot tolerate the full requirements of the health checks due to their presentation, particularly those with autism.

Health checks are important for those with learning difficulties as sometimes they can find it hard to know when they are unwell or when they should tell someone about it. A health check once a year gives people time to talk about anything that is worrying them and means they can get used to going to visit the doctor (Taken from NHS England website, Annual health check web page, accessed 14 January 2020). As part of the annual health check a health action plan is produced.

In West Cheshire ICP area, 602 individuals on the LD register had their annual health check since January 2020 (data extracted November 2020). This equates to approximately 34% of the cohort eligible. This is more than a 20% decrease since the beginning of the year. COVID playing a strong role and virtual/shielding data is being sourced by the CCG.

Table eight and nine show annual health checks at Care Community and GP practice surgery for West Cheshire ICP.

Only around a quarter of eligible patients in Chester East, Chester South, Northwich and Winsford had their annual health check between January 2020 and November 2020.



Care community	Proportion of LD register aged 14+ who had a health check (target 75%)
Chester East	27%
Chester South	26%
Ellesmere Port	43%
Neston and Willaston	50%
Northwich	25%
Rural	44%
Winsford	25%

Source: Table 8 Proportion of patients on the LD register aged 14+ who had an annual health check since January 2020 by care community, Business Intelligence and Performance Management, Cheshire CCG November 2020.

GP Practice	Total eligible for a health check	Annual health check completed	% of health checks completed Jan-Nov 2020
Boughton Health Centre	37	0	0%
Bunbury Medical Practice	10	8	80%
City Walls Medical Centre	98	80	82%
Danebridge Medical Centre	115	70	61%
Drs Adey & Dancy	23	7	30%
Firdale Medical Centre	33	11	33%
Great Sutton Medical Centre	107	37	35%
Heath Lane Medical Centre	30	2	7%
High Street Practice Winsford	50	0	0%
Hope Farm Medical Centre	42	33	79%
Kelsall Medical Centre	17	8	47%
Lache Health Centre	36	2	6%
Launceston Close Surgery	32	1	3%
Laurel Bank Surgery	29	6	21%
Middlewich Road Surgery	60	10	17%
Neston Medical Centre	21	15	71%
Neston Surgery	55	25	45%
Oakwood Medical Centre	42	5	12%
Old Hall Surgery	45	13	29%
Park Medical Centre	61	36	59%
Swanlow Practice	67	0	0%



Tarporley Health Centre	21	11	52%
The Handbridge Med.Ctr.	24	1	4%
The Village Surgeries Group	13	4	31%
The Weaverham Surgery	30	13	43%
The Willaston Surgery	15	5	33%
Upton Village Surgery	34	14	41%
Watling Medical Practice	28	0	0%
Weaver Vale Surgery	54	29	54%
Western Ave Medical Centre	24	3	13%
Westminster Surgery	12	5	42%
Whitby Health Partnership	135	93	69%
Willow Wood Surgery	75	51	68%
Witton Street Surgery	35	2	6%
York Road Group Practice	77	2	3%

Source: Table 9 Proportion of patients on the LD register aged 14+ who had an annual health check since January 2020 by GP Practice, Business Intelligence and Performance Management, Cheshire CCG November 2020



The majority of GP surgeries fall below the target of 75%, although data is not for a full 12 month period. However in the previous 12 months between January 2019-January 2020, the completion rate was still below the target at 57%.

To be offered an annual health check, the GP needs to know that the patient has an LD so they can be included on the GP LD register. Nationally and locally, work is being undertaken to improve the accuracy of the LD register through improved communication to practices by health and social care partners and coding by practices on receipt of data.

In addition, the GP needs to explain to patients on the LD register what the health check is and actively encourage the patient to take up the offer. To support this work, the Cheshire CCGs have commissioned expert LD nurses as health facilitators to support individuals accessing practice Annual Health Checks in their practice. Additionally, there has been an increase in the payment incentives available to GPs providing annual health checks and the introduction of a national health check template and learning disability toolkit to support clinical practice. The toolkit supports GPs and practice nurses to carry out health checks to the highest standard and aims to ensure those with an LD get timely access to the healthcare they need in the right place, at the right time. (Taken from NHS England website, Annual health check web page, accessed 14 January 2020).

STOMP and STAMP

STOMP stands for 'Stopping over Medication of People' with a Learning Disability, Autism or both with psychotropic medicines. STAMP stands for 'Supporting Treatment and Appropriate Medication in Paediatrics'.

Children and young people with a learning disability, autism or both should only be prescribed psychotropic medication when clinically indicated. Other therapies and support (including family support) should be offered before prescribing and while taking psychotropic medication.

The experience of parents, carers, clinicians and young people would indicate that psychotropic medication prescribed in childhood is often continued long past its original prescribing rationale. This could be because of poor monitoring and reviewing, and an unwillingness to challenge the originating prescriber about the appropriateness and/or efficacy of a particular psychotropic medication. Some medications may not be necessary as the young person grows into adulthood and the medication side effects may be detrimental to their health and wellbeing.

When the needs of children and young people with a learning disability, autism or both are not met, they can sometimes behave in ways that can be described as challenging to others. Too often when this occurs, psychotropic medication is inappropriately prescribed because of a perceived lack of readily available alternatives. Clinicians, families, carers and individuals should work together to find alternatives to psychotropic medication (such as Positive Behaviour Support).

For some children and young people, medication can be useful in enabling them to function and help them to achieve their potential. Regular and timely reviews should be undertaken so that the effectiveness of the medication is evident and balanced against potential side effects. This will mean that children and young people are only getting the right medication, at the right time, for the right reason



In 2018/19 the Medicines Management team supporting practices in the Northwich and Winsford areas supported primary care to audit the use of psychotropic medication in patients with Learning Disability, Autism or both. The audit identified 143 adults and 45 children and young people taking psychotropic medication for an appropriate indication and under the care of both a GP and a specialist clinician, a further 147 adults and 5 children and young people taking psychotropic medication appropriately under the care of their GP. 15 adults and 5 young people were identified as requiring a review of treatment.

In November 2019, the Medicines Management Team support practices in the Northwich and Winsford to re-audit the patient cohorts.

Table 10 below shows the number of people identified as needing a review in 2018/19 and how many of them had a review completed by November 2019.

	Patients identified as requiring assurance review of psychotropic medication in 2018/19	Patients with an assurance review completed by Nov 2019
Adults	15	10
Children and young people (<18 years)	5	4
Total	20	16

Source: Table 10 Assurance review data 2018/19, Medicines Optimisation Cheshire CCG November 2020

Following the merger of predecessor CCGs into NHS Cheshire CCG, the Prescribing Scheme for 2020/21 includes an expectation that all practices within the Cheshire West and Chester area will audit the use of psychotropic medication in adults and children/young people in November 2020.

8.2) Secondary Care Services Cheshire and Wirral Partnership NHS Foundation Trust

Cheshire and Wirral Partnership NHS Foundation Trust (CWP) is a specialist mental health, learning disability and community physical health provider that provides specialist in-patient and community-based services for people with LD and additional complex needs.

Individuals may have a number of co-occurring conditions including autism, mental health diagnoses or complex physical health conditions.

Other non-specialist services provided by CWP are also accessed by people with learning disabilities and the Trust works to ensure that treatment, interventions or support are adjusted to meet the needs

In recent years, alongside Clinical Commissioning Groups, the Local Authority, NHS England and Experts by Experience, the Trust has played a key role in the Transforming Care agenda; which aims to improve the lives of people with a learning disability, autism or both, with behaviour that challenges including those with a mental health condition, by developing community services to reduce reliance in inpatient provision.

CWP provides a range of services from inpatient to community-based care for people with learning disabilities as well as providing specialist information, advice and training for family carers and support staff. Key services provided include the 0-19 Starting Well Service, the



West Cheshire Learning Disabilities CAMHS and the West Cheshire Community Learning Disability Team.

At February 2020, there were 25 specialist community services provided by CWP being accessed by people with a learning disability (registered with a West Cheshire or Vale Royal GP).

Community Team	Episodes of Care
Community Learning Disability Team (Cheshire West & Chester)	292
Learning Disability Child and Adolescent Mental Health Service (West Cheshire)	65
Learning Disability Child and Adolescent Mental Health Service (Central Cheshire)	26
Forensic Support Team	13
Adult Community Mental Health Recovery Team (Vale Royal)	<10
Adult Community Mental Health Recovery Team (Chester)	<10
Adult Community Mental Health Review Team (Ellesmere Port & Neston)	<10
Adult Community Mental Health Review Team (Chester)	<10
Adult Attention Deficit Hyperactivity Disorder Assessment and Diagnostic Service	<10
Adult Community Mental Health Recovery Team (Ellesmere Port & Neston)	<10
Complex Recovery Assessment and Consultation Team (CRAC)	<10
Early Intervention Team (West Cheshire)	<10
Adult Community Mental Health Recovery Team (Vale Royal)	<10
Adult Community Mental Health Review Team (Vale Royal)	<10
Criminal Justice Liaison and Diversion Team (West Cheshire)	<10
CYP IAPT 16-19 (Vale Royal)	<10
Older People's Memory Service (Oakmere – Vale Royal)	<10
Older People's Recovery Service (West Cheshire)	<10
Community Learning Disability Team (Wirral)	<10
Complex Needs Service	<10
Child and Adolescent Mental Health Service 0-16 (Vale Royal)	<10
Child and Adolescent Mental Health Service 16-19 Service (West Cheshire)	<10
Primary Care Child and Adolescent Mental Health Service (West Cheshire)	<10
Older People's Community Mental Health Recovery Team (Oakmere – Vale Royal)	<10
Older People's Memory Service (West Cheshire)	<10
Grand Total	454

Source: Table 11 Number of current episodes of care for people with learning disabilities accessing CWP services, Cheshire and Wirral Partnership Trust, February 2020. Data excludes inpatient, short breaks (respite) and community physical health services including GPs.



8.3) Social Care Services

CW&C council provide a range of social care and support facilities for people with LD in accordance with The Care Act 2015.

The local authority will not know the number of people in the borough with an LD, only those that have requested and are eligible for support under The Care Act 2015. For adults, this is most likely to be those with a severe learning disability or multiple disabilities.

At November 2019, there were 1,254 adults aged 18 plus with an LD known to the Council. Of these 1,100 adults were receiving support at that time. This suggests that approximately 25% of the estimated LD population aged 18 and over are receiving services, or are known to the council. This is a similar proportion to the estimated 24% of the LD population aged 18 plus having a severe LD.

Local service data indicates that:

- 70% of LD service users are people requiring low level support needs, such as low level support at a day service, low to medium level support in shared tenancies, and regular respite.
- 23% have higher support needs, such as intensive one to one support on a regular basis.
- 6% of service users have intensive needs, which for example might require two to one support due to behaviour that challenges.
- A small proportion of service users (1%), require a bespoke service; this is usually no more than five or six clients at a point in time. Estimates of number of service users in each category can be seen in the table below.

Category of need	Estimated number of clients	Estimated cost of care package per client per month
Category one	880	Less than £1,000
Category two	290	£1,000-£2,000
Category three	75	£2,000-£3,000
Category four	10	Over £3,000

Source: Table 12 Cheshire West and Chester Adult Social Care finance estimates, applied to number of LD service users from Liquid Logic extract November 2019, Cheshire West and Chester Council.

Note: The above is a simple representation of LD service users, and costs and estimates used were based on service users currently funded, wholly or partly, by the local authority. There will be service users funded by the Clinical Commissioning Group who are detained under the Mental Health Act who haven't been considered in estimates above.



Adults aged under 55 with an LD are more likely to be in receipt of services than adults aged 55 and over, 73% compared to 27%. Of adults receiving support, 22% were aged 25-34 years. There were fewer adults aged 65 and over receiving support at 9%.

Adults with an LD receiving support	18-24 years	25-34 years	35-44 years	45-54 years	55-64 years	65-74 years	75 plus years	Total
Total number	186	237	177	206	190	84	20	1,100
Total %	16.9%	21.5%	16.1%	18.7%	17.3%	7.6%	1.8%	

Source: Table 13 Number and proportion of adults with a learning disability receiving support by age group, Liquid Logic extract November 2019, Insight and Intelligence, Cheshire West and Chester Council

57% of those known to the local authority are male and 43% are female (please note a small number of clients, less than five, identify as transgender and are not included in these percentages).

Types of services provided by social care to meet the needs of known clients in the borough include:

- **Day services / community and building based**
Day services can be described as support activities provided in a community setting or set location by social services, the NHS and voluntary organisations. Day services help people to carry out everyday activities, provide opportunities to learn and develop new skills or hobbies, to socialise and to travel out on trips and leisure activities. Day services are vital for connecting people with an LD to their community and helping them to live independently. Without day services, there is a risk of people becoming isolated and as a result, health needs may remain unspotted. Day services also give carers and family members opportunity for respite.
- **Home care** – can incorporate a number of types of care and support including:
 - Outreach Services
These services focus on having a support worker visit the client in their home to assist with key tasks.
 - Supported Living
These are services for residential living, often in an apartment style complex where care and support providers deliver daily support whilst trying to foster independence. Apartments are entered into via a tenancy contract with a private or council associated landlord.
 - 1:1 support in the day
Provided by care workers
 - 2:1 support in the day
Provided by care workers
- **Short breaks/ respite**
A short break might include a temporary short stay in a care home whilst a carer has a holiday or recovers from an illness. Some charities also offer respite holidays for those with a disability. A night break is also available.



- **Residential /Nursing services**

Some people with LD and autism may be unable to live independently and live in a care home to better support their needs. For those with complex needs and behaviour that challenges, nursing support may also be required.

- **Carers support**

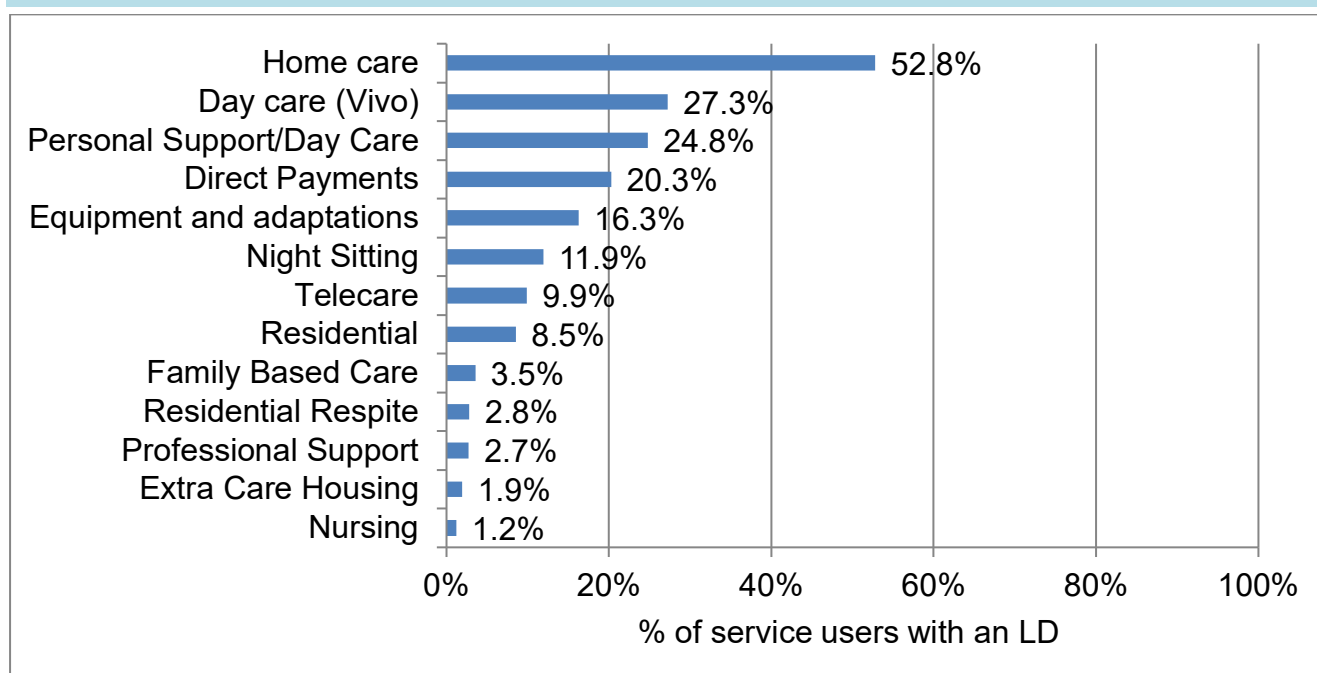
Loved ones who are caring for an adult with learning disabilities and autism may be eligible for support themselves and have the opportunity to undertake a carer's assessment

- **Telecare**

The use of technologies such as emergency alarms to help an individual live independently.

Unfortunately data availability meant it wasn't possible to look at the numbers of people accessing specific services over a year but we are able to look at a point in time.

At November 2019, over half of adults aged 18 plus with LD accessing a social care service were receiving home care (53%) and 45% received personal support/ day care.



Source: Chart 12 Type of support received by social care service users with a learning disability, Liquid Logic Extract 25 November 2019, Insight and Intelligence, Cheshire West and Chester Council

Male and female adult social care clients with LD use services to a similar extent, with most commonly used services being home care and personal support/ day care (Vivo and non Vivo based). However males are more likely to be in receipt of direct payments, day care from Vivo, and residential care than females, and females are more likely to be in receipt of home care, night sitting and telecare than males.



Adult social care service	Number of females	% of female LD client cohort	Number of males	% of male LD client cohort	Total	% of total LD client cohort
Day care (Vivo)	138	29.0%	162	26.0%	300	27.3%
Direct Payments	90	18.9%	133	21.3%	223	20.3%
Equipment and adaptations	83	17.4%	96	15.4%	179	16.3%
Extra Care Housing	10	2.1%	11	1.8%	21	1.9%
Family Based Care	14	2.9%	25	4.0%	39	3.5%
Home care	280	58.8%	301	48.2%	581	52.8%
Night Sitting	72	15.1%	59	9.5%	131	11.9%
Nursing	7	1.5%	6	1.0%	13	1.2%
Personal Support/Day Care	121	25.4%	152	24.4%	273	24.8%
Professional Support	11	2.3%	19	3.0%	30	2.7%
Residential	36	7.6%	58	9.3%	94	8.5%
Residential Respite	10	2.1%	21	3.4%	31	2.8%
Telecare	55	11.6%	54	8.7%	109	9.9%
Cohort	476		624		1,100	

Source: Table 14 Type of support received by gender, Liquid Logic extract November 2019, Insight and Intelligence, Cheshire West and Chester Council

If we look at services being provided by age, home care and personal support/ day care are the most commonly used services by all age groups (note: if we remove direct payments).

Service being received	% of 18-24 cohort	% of 25-34 cohort	% of 35-44 cohort	% of 45-54 cohort	% of 55-64 cohort	% of 65-74 cohort	% of 75 plus cohort
Day care (Vivo)	4.8%	23.2%	29.4%	39.8%	36.8%	29.8%	35.0%
Direct Payments	41.9%	26.2%	23.7%	11.7%	7.9%	1.2%	5.0%
Equipment and adaptations	25.3%	16.9%	12.4%	10.7%	16.8%	15.5%	15.0%
Extra Care Housing	0.0%	0.4%	0.0%	1.5%	3.7%	6.0%	25.0%
Family Based Care	1.1%	1.3%	5.1%	6.3%	4.2%	3.6%	5.0%
Home care	43.0%	56.5%	45.2%	55.3%	57.4%	63.1%	55.0%
Night Sitting	0.0%	8.0%	15.3%	14.6%	20.5%	16.7%	10.0%
Nursing	0.0%	0.4%	0.0%	0.0%	3.7%	3.6%	10.0%
Personal Support/Day Care	24.2%	25.7%	23.7%	26.7%	20.0%	28.6%	40.0%
Professional Support	0.0%	4.6%	1.7%	2.4%	2.6%	6.0%	5.0%
Residential	1.6%	6.8%	7.3%	7.8%	18.4%	10.7%	10.0%
Residential Respite	2.2%	3.0%	4.5%	2.4%	3.2%	1.2%	0.0%
Telecare	3.2%	9.7%	11.9%	13.1%	10.5%	10.7%	15.0%

Source: Table 15 Type of support received by age group, Liquid Logic Extract November 2019, Insight and Intelligence, Cheshire West and Chester Council



In addition, analysis of services received by age group; tell us that:

- Receipt of direct payments is highest for those aged 18-24 years and receipt generally decreases as service users get older.
- Those aged between 55 and 64 years are most likely to be receiving residential care and a night sitting service. A greater proportion of adults aged 65-74 are receiving home care.
- Older adults aged 75 plus are more likely to be in extra care housing, have telecare and receiving personal support/ day care that is non Vivo provided.
- Those aged 18-24 are less likely to be accessing personal support/ day care from Vivo, a night sitting service, professional support, telecare and residential care; and along with those aged 25-34, less likely to be receiving family based care (1%).
- Those aged 35-44 years are most likely to be receiving residential respite.
- A higher proportion of 18-24 year olds received equipment and adaptations- other age groups may have already had their needs met.
- Extra care housing was not used by younger age groups until the 45-54 age group where usage gradually increases with age. Similarly with nursing, where this is received by those aged 55-64 years onwards.

The above points reflect the ageing population and worsening health of people with LD with age. It also indicates how changes in family structures or informal care structures due to age or bereavement can impact on the levels of social care required.

Future commissioning strategies and plans should consider how a growing ageing LD population can have their needs supported.

8.4) Changes in Adult Social Care service use over the last three years

Comparing November 2017, November 2018 and November 2019 snapshot data, number of service users with an LD accessing social care services has increased by 6% between 2017 and 2019. This is around an additional 60 service users. However in terms of services being received by those service users there has been a 9% increase in usage.

When reviewing services received by service type, there are some large changes which can be seen in table 16.



Service being received	Number of users at Nov 2017	Number of users at Nov 2018	Number of users at Nov 2019	Difference 2017 to 2019	% change 2017 to 2019
Day Care (Vivo)	334	314	300	-34	-10%
Direct Payments	234	229	223	-11	-5%
Equipment and adaptations	150	174	179	29	19%
Extra Care Housing	15	23	21	6	40%
Family Based Care	36	35	39	3	8%
Home care	289	529	581	292	101%
Night Sitting	120	177	131	11	9%
Nursing	12	13	13	1	8%
Personal Support/Day Care	439	269	273	-166	-38%
Professional Support	43	34	30	-13	-30%
Residential	88	93	94	6	7%
Residential Respite	33	27	31	-2	-6%
Telecare	66	84	109	43	65%
Total services accessed	1859	2001	2024	165	9%
Cohort	1039	1086	1100	61	6%

Source: Table 16 Type of social care support received at Nov 2017, Nov 2018 and Nov 2019 along with % change difference, Liquid Logic Extract November 2019, Insight and Intelligence, Cheshire West and Chester Council

The data shows that:

- The largest percentage change increase in service use has been for home care (+101% percentage change).
- Telecare and extra care housing also shows a percentage change increase.
- The largest decrease in service use is seen in personal support/ day care (non-Vivo provision) and professional support.

We are able to look at changes in service usage by age group.

The number of 18-24 year olds using adult social care services is higher in November 2019 than in November 2017, and usage of services by this age group increased by +77% change.

Age group	18-24	25-34	35-44	45-54	55-64	65-74	75+
Percentage change in service usage Nov 2017 compared Nov 2019	100%	2%	1%	10%	9%	-2%	13%
Number of additional services used Nov 2017 compared Nov 2019	73	-2	-4	7	-7	-4	-2

Source: Table 17 Percentage change in service usage November 2017 compared to November 2019, Liquid Logic Extract November 2019, Insight and Intelligence, Cheshire West and Chester Council Note: The above figures do not include the receipt of direct payments.



The snapshot of data at November 2017 and November 2019 shows an increase in the number of service users aged 18-24 from 113 to 186 (73 extra young people). The receipt of services for that age group is a 100% change which is much higher than other age groups.

Direct payments had already been removed from this calculation, if equipment and adaptations is also removed, the percentage change increases to 107%. This shows that it is direct support that has changed in usage. Further analyse of data shows that the largest increase in service received for this age group was for home care (+ 567 % change).

Receipt of direct payments is lower at November 2019 than 2017 for all age groups except young people age 18-24 where numbers are higher.

We do not know if the differences in service being accessed are due to changing needs or changes in services being offered to users.

8.5) Community Third Sector Organisations & Charities

In addition to NHS services and social care, community run groups, third sector organisations and charities are also worthy providers of services for people with LD across CW&C.

The Peoples' Choice Group, run by SEE Communications, deliver a service that reduces social isolation, raises self-esteem, increases confidence and improves social interaction amongst adults with learning difficulties and associated mental health conditions.

This is achieved through linking people to social activities within their areas of interest in their local community. For 2018/19, approximately 265 people all identifying as having an LD (average age 43), accessed services run by the Peoples' Choice Group.

In addition, DIAL West Cheshire, deliver an in-house supported volunteer programme aimed at users with a learning disability profile. This includes offering a community café, developing people to help others in the community, training opportunities and support with benefits information and advice.

Dial also runs an Access Group, which supports people to comment on initiatives being developed to help those with an LD. More recently an Experts by Experience project has also been piloted by the Dial community, which has seen service users with an LD become forefront to reviewing the quality of services being provided in day care and supported living services across social care. For 2018/19, 13 users accessed this service who identified as having an LD.

8.6) Education - Young people with an Education, Health and Care Plan (EHCP)

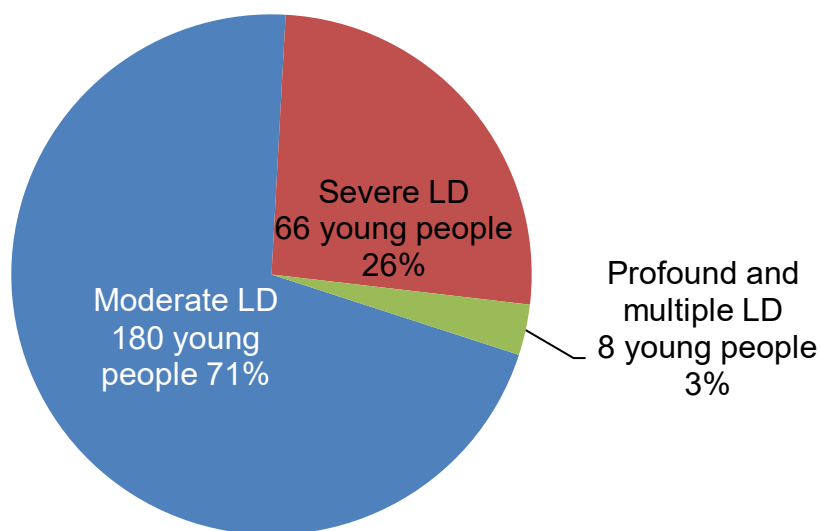
How people with an LD are supported in education as well as finding future employment is vitally important to help build fulfilling lives.



Below is a synopsis of what we know about the current support and services offered for people with LD in education.

At January 2019, there were 254 young people aged 14 to 23 with an EHCP for a learning disability in CW&C. The majority, 71%, had a moderate LD equating to 180 young people, 26% had a severe LD (66 young people) and 3% had a profound and multiple LD (8 young people).

The majority of young people with an EHCP, 71%, had a moderate LD equating to 180 young people. 26% had a severe LD (66 young people) and 3% had a profound and multiple LD (8 young people) increased by +77% change.



Source: Chart 13 Number of children with a EHCP by type of LD, SEN2

Table 18 below shows the type of learning disability by age for those aged 11 onwards.

Age	Moderate LD	Severe LD	Profound and Multiple LD	Total
14	45	11	0	56
15	42	11	<5	56
16	25	7	<5	35
17	21	6	<5	28
18	24	10	0	34
19	8	5	<5	14
20	11	7	0	18
21	<5	6	0	9
22	<5	<5	0	<5
23	0	<5	0	<5
Total	180	66	8	

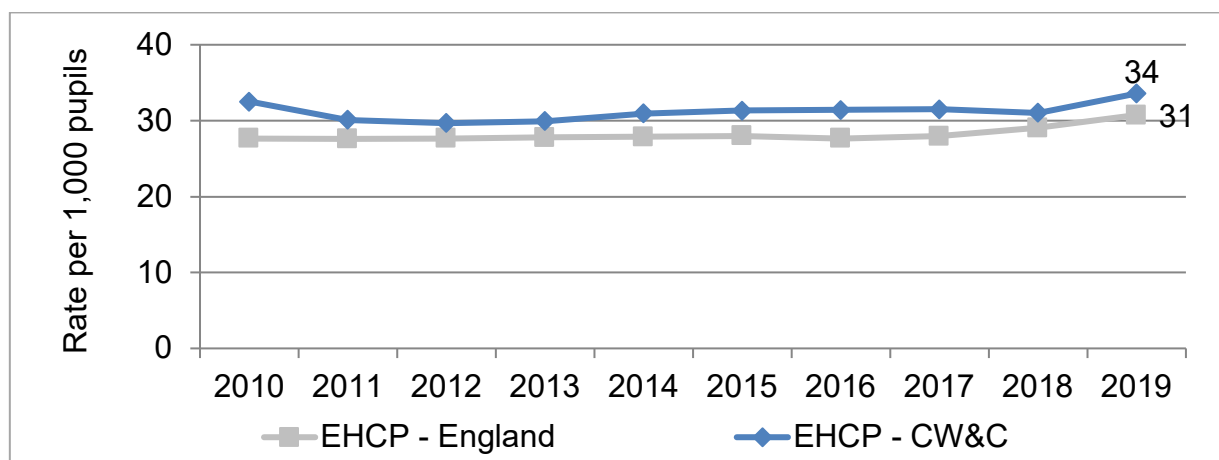
Source: Table 18 Number of children with a EHCP by type of LD, SEN2



This shows the number of young people with an EHCP will reduce after age 18 as fewer young people remain in education. However, they may still be receiving support from social care and health but will no longer require a EHCP.

Analysis of data by age shows that a greater number of 14 and 15 year olds have an EHCP. Between the ages of 14 and 17, young people are transitioning from children to adults services. Data shows that there were 175 young people of transition age at this time.

The rate of young people with an EHCP in CW&C educational settings had remained fairly steady until 2019 where it increased to the highest rate in the last nine years and is higher than the England average (an increase from 31 per 1,000 pupils in 2018 to 34 per 1,000 pupils in 2019).



Source: Chart 14 Rate of young people with an EHCP in CW&C by year, SEN2

Note: More information about childrens education and children social care services can be found in the Special Educational Needs and Disability JSNA.

The Education Directorate report an increased demand for EHCPs (please note this is for all pupils with an EHCP not just those with an LD).

8.7) Adult Education

Meanwhile adult education up take in CW&C for learners self-reporting as having a learning disability can be seen in table 19.



Primary disability	Enrolments	%
Visual impairment	51	3.56%
Hearing impairment	50	3.49%
Disability affecting mobility	178	12.43%
Profound complex disabilities	10	0.70%
Social and emotional difficulties	104	7.26%
Mental health difficulty	421	29.40%
Moderate learning difficulty	42	2.93%
Severe learning difficulty	13	0.91%
Dyslexia	105	7.33%
Autism spectrum disorder	19	1.33%
Asperger's syndrome	22	1.54%
Temp disability after illness/accident	11	0.77%
Other physical disability	60	4.19%
Other specific learning difficulty	9	0.63%
Other medical condition	261	18.23%
Other learning difficulty	24	1.68%
Other disability	33	2.30%
Not Provided/No Data	19	1.33%
	1432	

Source: Table 19, Primary disability reported by Adult Education Service Users, Cheshire West and Chester Council

Out of a total of 4,136 adult education enrolments for the 2018/19 academic year, 1,432 enrolments recorded a learning disability/difficulty as per the table above. This represents 34.6% of the overall enrolment.

Of the 1,432 adult education enrolments in 2018/19 that have a recorded positive disability status, according to the data 74 enrolments considered themselves to have a specific learning related disability, ranging from profound complex disabilities to moderate learning difficulties, severe learning difficulty or other specific learning difficulty. This shows an increase of 1.5% on 2017/18 statistics for the overall adult education programme, with 3.2% of those considering themselves to have a specific learning related disability representing a decrease of 1.97% for the 2018/19 academic year.

9) Local health and care needs

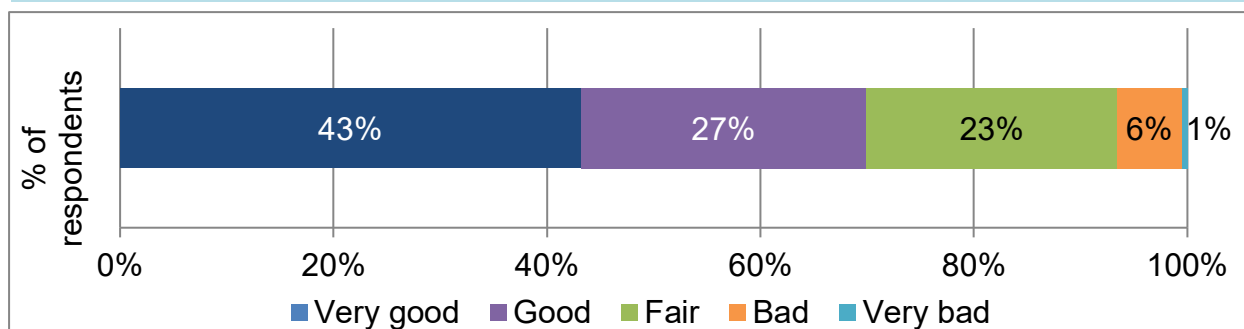
In the next section, the JSNA will explore local health and care needs for people with LD in the Cheshire West and Chester community.

9.1) Adult social care users

In the Adult Social Care User Survey 2018-19, 70% of respondents with an LD rated their health as very good or good and 7% as bad or very bad.



The majority of respondents to the Adult Social Care Survey who had an LD said that their health was good or very good.



Source: Chart 15 How is your health in general? Adult Social Care User Survey 2018-19, Insight and Intelligence, Cheshire West and Chester Council

Although general health was considered good or fair for most respondents, 40% of respondents said that they have pain or discomfort; of which 6% extreme pain or discomfort.

In terms of needing support, the Adult Social Care Survey also asked service users how easily they could do every day task.

Service users with an LD particularly need help with washing, getting dressed and dealing with finances and paperwork. Just 10% are able to deal with finances and paperwork by themselves.

I can easily manage too...	% LD respondents who agreed
Get around indoors by myself (except for steps)	86%
Get in and out of a bed or chair by myself	88%
Feed myself	93%
Deal with finances and paperwork by myself	10%
Wash all over by myself using a bath or shower	64%
Get dressed and undressed by myself	75%
Use the toilet by myself	87%
Wash my face and hands by myself	87%

Source: Table 20 Responses to the Adult Social Care User Survey 2018-19, Insight and Intelligence, Cheshire West and Chester Council

9.2) Carers

Of 1,254 LD adults aged 18 plus known to the Local Authority, half (49.8%) had a carer. On average around two thirds of under 45's had a carer, a third of those aged 45-64 and a quarter of those aged 65 plus.

Of those with a carer, 81% were being cared for by a parent. Although the majority of these were younger people aged under 45, 21% of those who said their parent cared for them were over 45 and would have elderly parents. 10% of those with a carer were being cared for by a sibling.



9.3) Multiple disabilities, conditions and illness

Of those people with LD known to the council who had their condition detailed; including severity and co-existing conditions noted, 15% had physical disabilities/ conditions, alongside their learning disability, and 10% had further neurological disabilities.

Coexisting conditions of LD service users known to the council (of those recorded)	% LD service users
Physical conditions	15%
Neurological conditions	10%
Mental health issues	7%
Sensory impairments	6%
Autism	2%
Dementia	1%

Source: Table 21 Coexisting conditions LD service users known to the Council where recorded, Liquid Logic extract November 2019, Cheshire West and Chester Council

During 2018-19, data was collected by NHS England from Clinical Commissioning Groups to understand the key health issues for people who are recorded by their GP as having an LD. Comparative data was collected for those recorded as not having an LD. Conditions and illnesses recorded along with an England average comparison can be seen below.

Except for epilepsy, the top five conditions affecting the LD population are all preventative.

	CW&C: LD 18+	CW&C: Non LD 18+	CW&C: LD all age	CW&C: Non LD all age	England: LD all age
Obesity	42%	34.1%	40.2%	32.5%	37.5%
Epilepsy	19.9%	0.7%	18%	0.6%	17.3%
Depression	17.8%	18.6%	15.4%	14.8%	14.4%
Chronic constipation	15.3%	NA	14.4%	NA	13.1%
Gastric oesophageal reflux disease	12.6%	NA	12.1%	NA	9.8%
Hypertension	11.8%	17.7%	10.2%	14.1%	9.8%
Asthma	10.3%	7.1%	10.5%	6.5%	9.2%
Severe mental illness	9.9%	1%	8.5%	0.8%	7.9%
Hypothyroidism	9.2%	4.8%	8.4%	3.7%	8.1%
Diabetes not type 1	9.0%	5.9%	7.8%	4.7%	7%
Down Syndrome	8.7%	NA	9.5%	NA	8.6%
Dysphagia	7.6%	NA	6.8%	NA	5.8%
Chronic kidney disease (stages 3-5)	2.5%	3.7%	2.1%	3%	2.9%
Cancer	2.3%	4.3%	2.0%	3.5%	1.6%
Stroke or transient ischemic attack	1.9%	2.4%	1.7%	1.9%	1.6%
COPD	1.8%	2.6%	1.5%	2.1%	1.2%
Heart failure	1.4%	1.5%	1.2%	1.2%	1%
Coronary heart disease	0.8%	4.2%	0.7%	3.3%	1.1%
Dementia	0.8%	1.1%	0.7%	0.9%	1.4%
Type 1 Diabetes Mellitus	0.7%	0.5%	0.7%	0.5%	0.8%

Source: Table 22 Health and care of people with learning disabilities, experimental statistics, 2018-19, NHS digital



Points to highlight include:

- CW&C have a higher proportion of the LD population who are obese and have Gastric Oesophageal Reflux Disease (GORD) than the England average.
- Compared to the non CW&C LD adult population, those aged 18+ with an LD are more likely to be obese, and have epilepsy, asthma, hypothyroidism, diabetes and/or a severe mental illness.

In regards to mental health, 18% of those with LD aged 18 plus had depression and 10% had a severe mental illness. For all age, 15% had depression and 9% had severe mental illness showing it also affects young people.

The importance of mental health was also highlighted in the Adult Social Care User Survey 2018-19 where 57% of respondents with LD reported they were anxious or depressed.

At November 2019, the LD Children and Adolescent Mental Health Service reported a caseload of 76 young people.

10) Outcomes for people with a learning disability

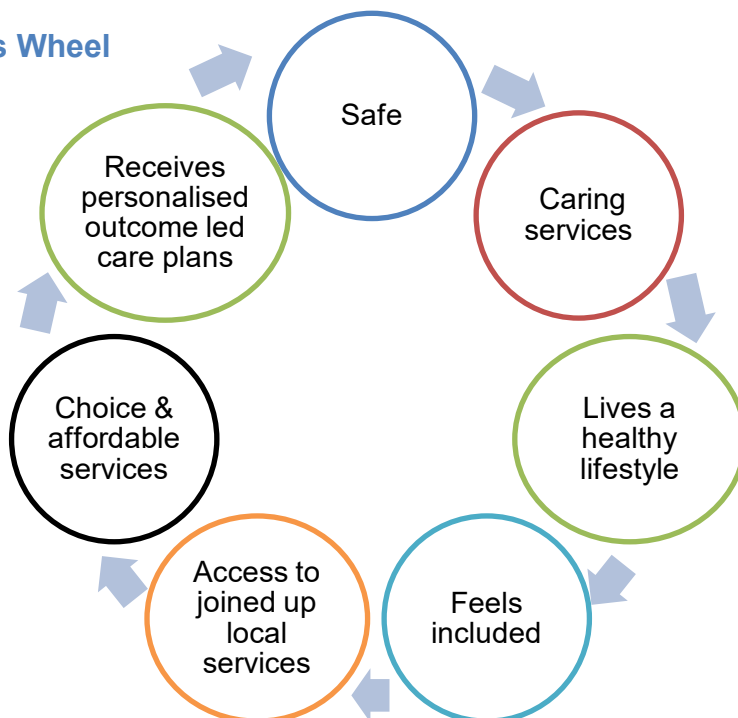
When providing services across CW&C, the Council's Learning Disabilities Commissioning Strategy states the following outcomes should be met for all people in our community with LD:

- **Outcome 1:** More people with learning disabilities and/or autism will be supported to live a good quality and meaningful life.
- **Outcome 2:** People with a learning disability and/or autism will be supported to live, work, socialise and be as independent as possible throughout their life, within the local community, close to family, and friends.
- **Outcome 3:** Support for people with a learning disability and/or autism will be person-centered and effective to help ensure that they can achieve their goals, aspirations and person-centered outcomes.
- **Outcome 4:** People with a learning disability and/or autism and their carers are able to access the appropriate level of information and advice when they need it.
- **Outcome 5:** People with a learning disability and/or autism feel safe in their community.
- **Outcome 6:** Services provided will be of high quality, safe, caring and responsive to peoples' needs.
- **Outcome 7:** People will be supported to maintain an optimum level of physical and mental health.
- **Outcome 8:** People will be supported to access coordinated health and social care services when they need them.
- **Outcome 9:** Services will be cost effective, innovative and provide value for money for both the Council and people with learning disabilities and/or autism and their families.



These outcomes are simplified in the LD outcomes wheel:

LD Outcomes Wheel



An insight into some of the outcomes currently been achieved for people with an LD across CW&C can be seen in the following section.

10.1) Education

Our future opportunities in regards to employment and quality of life can be influenced by our education and preparation for adulthood. Young people with an LD may need extra support to reach their aspirations and plan for their future especially when transferring from education into adult support services.

All young people are expected to stay in education or training until their 18th birthday. CW&C Council have a 'Prepared for Adulthood' pathway, and young people with an LD and an EHCP receive support from a variety of services, including support from educational settings, educational psychologists, the Autism Service, Youth Service, Post 16 Learning Providers and the Skills and Employment Team.

Key stage four

At KS4, achieving level four is a standard pass and the target level students must achieve in order to not re-sit English and Maths post-16 (if they choose to continue to study post 16). However, employers, colleges and other educational or training settings set the KS4 levels they require for entry.

There are also special schools and colleges providing post 16 education, as well as options for supported internships, traineeships and apprenticeships. Entry to these courses and training would not require achievement of level four.



Children with LD will find it more difficult to learn than children of the same age without an identified LD. Therefore meeting age related expectations may be a challenge and inappropriate for people with LD, so it is important to look at the progress pupils make from their starting point, and compare progress to other pupils with LD nationally in order to gain a true picture of achievement in the locally.

In the 2019 key stage four cohort, there were 42 young people with an EHCP for a moderate learning disability (there were no pupils with a severe LD and less than five with a PMLD who will not be included here).

The progress 8 score indicates that in 2019 pupils with a moderate LD in CW&C achieved lower grades than pupils with a moderate LD nationally. 2.4% of pupils in CW&C with a moderate LD achieved a level 9-4 at KS4. When looking at level 9-2, achievement increases with 16.7% achieving in English and 14.3% achieving in Maths.

Attainment and progress 8		Level 9-4		Level 9-3		Level 9-2	
Attainment 8	Progress 8	English	Maths	English	Maths	English	Maths
5.6	-1.35	2.4%	2.4%	7.1%	9.5%	14.3%	16.7%

Source: Table 23 KS4 results for pupils with a EHCP for a moderate LD in CW&C, KS4 Provisional data 2019, Department for Education

Post 16

Local Authorities are required to track and submit information about young people up to the end of the academic year in which they have their 18th birthday i.e. academic age 16 and 17 year olds.

This data is available for young people with a special educational need but unfortunately we are unable to extract just those young people with an LD. However the data for all young people with SEND still provides an insight.

Participation in education and training

Participation of 16/17 year olds in education and training increased between March 2018 and March 2019 for all cohorts of young people including those with an EHCP. The gap in 2019 has narrowed between those with an EHCP and those with no identified SEND. CW&C is above the England average with our young people participating more.

Participation in education and training	16-17 year olds with a EHCP		16-17 year olds without a EHCP	
	CW&C	England	CW&C	England
March 2019	90.8%	88.6%	97.0%	92.9%
March 2018	87.7%	88.5%	96.5%	92.1%

Source: Table 24 Participation in Education and Training, Department for Education, NEET

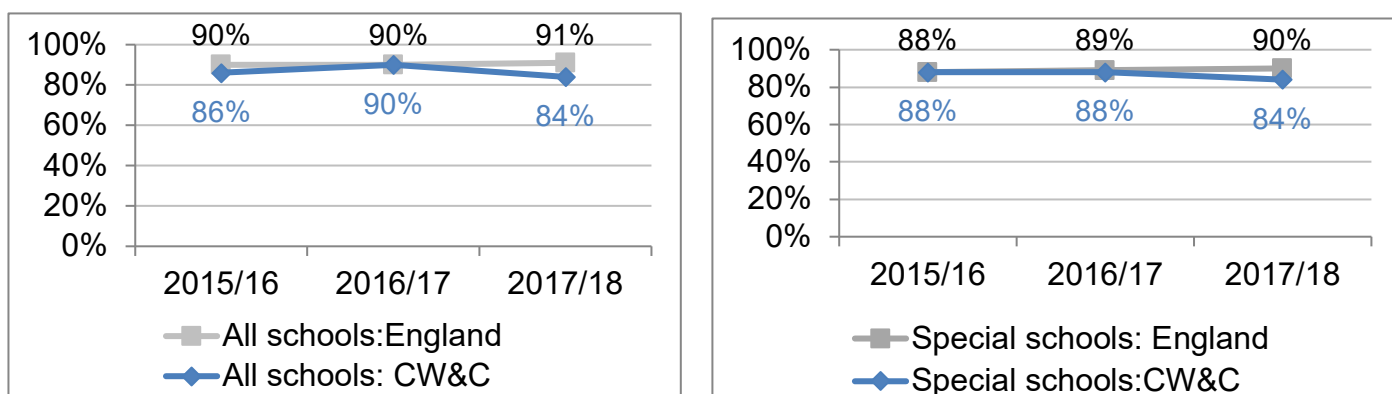


Destinations at KS4

Data is collected to understand destinations from KS4. The most recent data is 2017/18 destinations for the 2016/17 cohort. For young people with an EHCP who were either in a mainstream or special school, 84% were in sustained education, employment or apprenticeships in the year after key stage four. This is lower than the previous year.

When looking at this for pupils in a special school only, 84% were in sustained education, employment or apprenticeships in the year after key stage four. Again this is lower than the previous year.

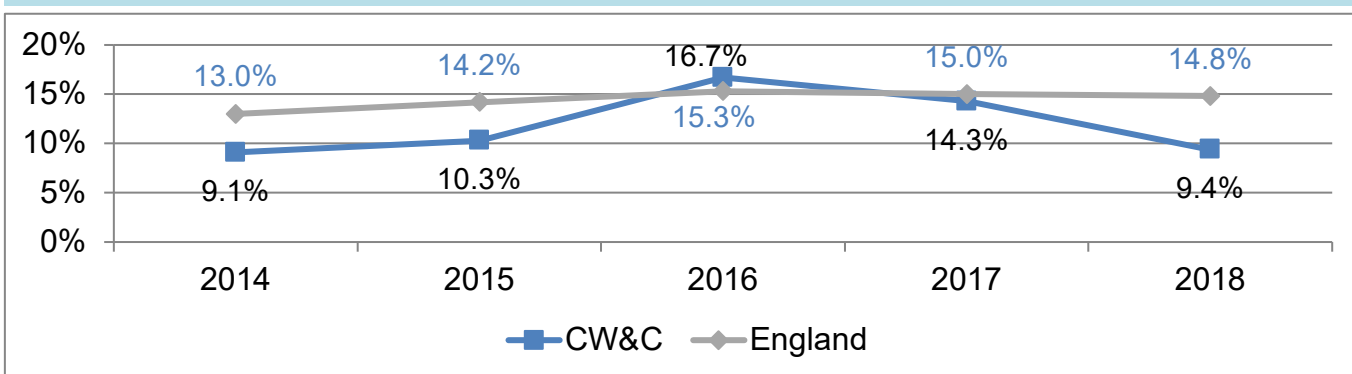
The proportion of pupils with an EHCP in sustained destinations after key stage four has decreased in CW&C, and over the last three years has been below the England average.



Source: Chart 16 and 17 Pupils with an EHCP going to EET from KS4 by school, from Destinations at KS4, Department for Education

Level two qualifications equate to achievement of five or more GCSEs at levels 9-4 (or grades A*-C) or equivalent level 2 diploma or award. In 2018, the number of young people with an EHCP in CW&C aged 19 qualified to level two dropped to 9.4% from 14.3% the previous year. This was lower than the England average of 24.8%.

19 year olds in CW&C with an EHCP who are qualified to Level Two has generally been lower than the England average and was in 2018, at its lowest since 2014.



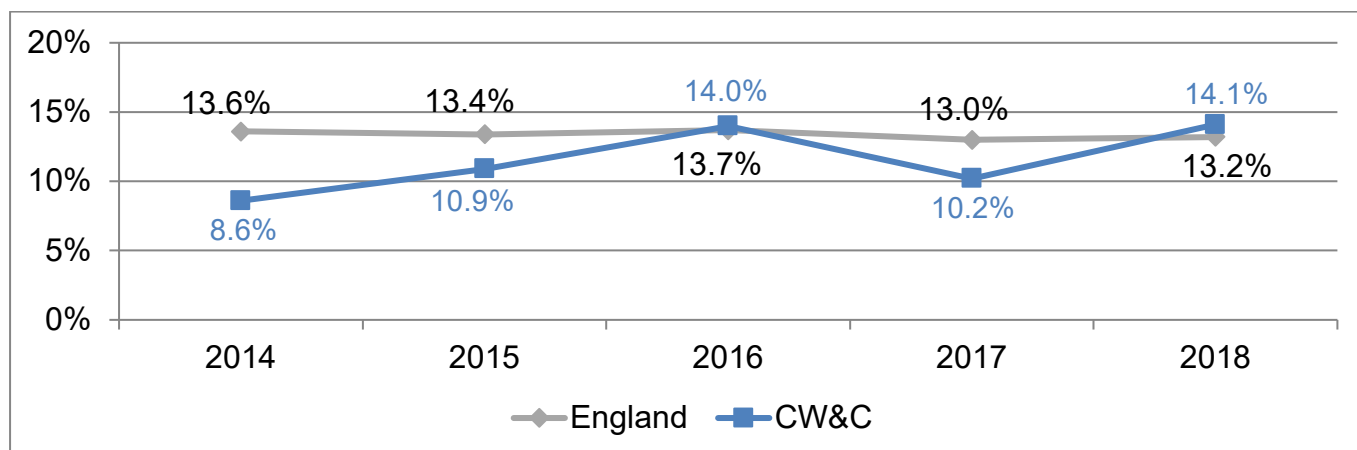
Source: Chart 18 % of 19 year olds with an EHCP qualified to level two, from Attainment at 19 years, Department for Education

Level three qualifications equates to an A level or vocational qualification of equivalent size.



Performance at level three is better in CW&C than at level two. In 2018, 14.1% of 19 year olds who had an EHCP were qualified to level three. This is better than the England average (13.2%), and an increase from 2017 when 10.2% were qualified to level three.

19 year olds in CW&C with an EHCP who are qualified to level three increased in 2018 and is now higher than the England average.



Source: Chart 19 % of 19 year olds with an EHCP qualified to level three, from Attainment at 19 years, Department for Education

10.2) Adult Employment and Training

According to MENCAP people with an LD are far less likely to have a job than the general population. The Centre for Disability Research (2008) estimated that 17% of all adults with an LD in England are in paid work. If this is applied to local LD estimates, of the 5,100 adults aged 18 plus, around 870 would be in paid employment.

Once a young person is no longer in a learning provision, their EHCP will end and they will not be tracked by the Local Authority. This means a full picture of employment status of all adults with an LD in CW&C cannot be analysed, only those adults that are accessing Local Authority services.

One of the services offered by the council to support people into work, including people with LD, are four borough-wide Work Zones. These zones provide employment support including a full employability curriculum and access to one to one employment mentoring.

In 2019/20; for the first time, CW&C Work Zones located in Chester, Ellesmere Port, Winsford and Northwich began to record the number of registrations of people with an LD.

Table 25 shows the number of registrations for people with an LD up to December 2019. This shows that for the nine month period between April 2019 to December 2019, Work Zone reported 38 adults with self-reported LD were supported in to work. These customers will all have an individual journey that is recorded on the Work Zone database including length of time taken to secure employment. These 38 job outcomes do not directly relate to the 63 registered in the same time period.



No: LD Work Zone Registrations	63	7 average per month
No: LD people registered who were supported into work	38	4.2 per month

Source: Table 25 Work Zone data, Cheshire West and Chester Council

Measures taken are based on self-reporting of an LD by a customer or by a formal judgement made by staff.

In addition to the above, a Department for Work and Pensions (DWP) project which ran for 15 months until April 2018, targeted adults with learning disabilities referred from Adult Social Care and also adults in Secondary Mental Health. Through this project, 41 adults with LD were identified and took part in the project. Out of the people 41 involved, 18 were moved into paid employment. This equates to 43% of the cohort. For those people with an LD who moved into paid employment, the majority of the jobs recorded were under 16 hours per week due to benefits rules around permitted work; so whilst of huge significance to the beneficiary, they were not recognised as job outcomes by DWP. These job outcomes were monitored for 13 weeks to ensure sustainability, though some jobs did not reach this stage before the project ended. Job outcomes were not monitored beyond the life of the project due to capacity.

Due to insufficient recording, it is not possible to provide data on trends over time regarding the numbers of adults with LD accessing employment support, however, anecdotally, it is increasing due to increasing awareness.

10.3) Employment status of adults known to Local Authority services

Adults with LD may need support to find and maintain employment. In addition employers may need support to understand what information and changes they can put in place to ensure an inclusive workplace.

Of the 1,254 adults with LD known to the Local Authority in November 2019, employment status was only captured for 303 clients; 23% of the cohort. Of these 303 clients:

- 29% (87) were in paid employment
- 41% (125) were in a voluntary role
- 6% (18) were retired
- 24% (73) were unemployed and seeking work. Of those seeking work, 30% were aged 18-24.

(Note: There are also 92 clients aged 65 and over whose employment status is marked as unknown but are likely to be retired though we cannot presume this).

The ASCOF measures (measures from the Adult Social Care Outcomes Framework) quantify how well care and support services achieve outcomes that matter most to people. Paid employment is considered an important outcome that 'provides recognition of a valued social role, useful day time occupation, important social opportunities, and in a few cases, a helpful level of financial reward' (Public Health England).



Government policy has emphasised the importance of maximising work opportunities for people with LD. Employment is an ASCOF measure and shows the proportion of adults with a primary support reason of learning disability who are re-coded as being in paid employment. The definition is restricted to those adults aged 18-64 (of working age) and is focused on 'paid' employment; voluntary work is not collected and excluded from the measure.

In 2018/19, 6.4% of LD clients aged 18-64 were in paid employment, an improvement from 5.7% the previous year and higher than the 5.9% England average.

The proportion of LD adults social care users in paid employment has been increasing in CW&C and in 2018/19 is better than the England average.

	2016/17	2017/18	2018/19
CW&C	5.6%	5.7%	6.4%
England	5.7%	6.0%	5.9%

Source: Table 26 Proportion of Adult Social Care clients with LD in paid employment, Adult Social Care Outcomes Framework

Note: Measure for adults aged 18-64 years with a primary support reason of learning disability support who received long term support during the year in the settings of residential, nursing and community

10.4) Housing

The Local Authority works with partners to ensure that those with LD have an appropriate housing offer to support them to be as independent as possible. There are several housing options available to adults with LD depending on the level of support needed and co-existing conditions.

Many people with LD successfully live independently in their own home, with some accessing floating support and/or adaptations and technologies to assist them further. Others may live in their own home with a carer. For those who need a high level of support, residential care homes and supported living are options offering 24 hour support.

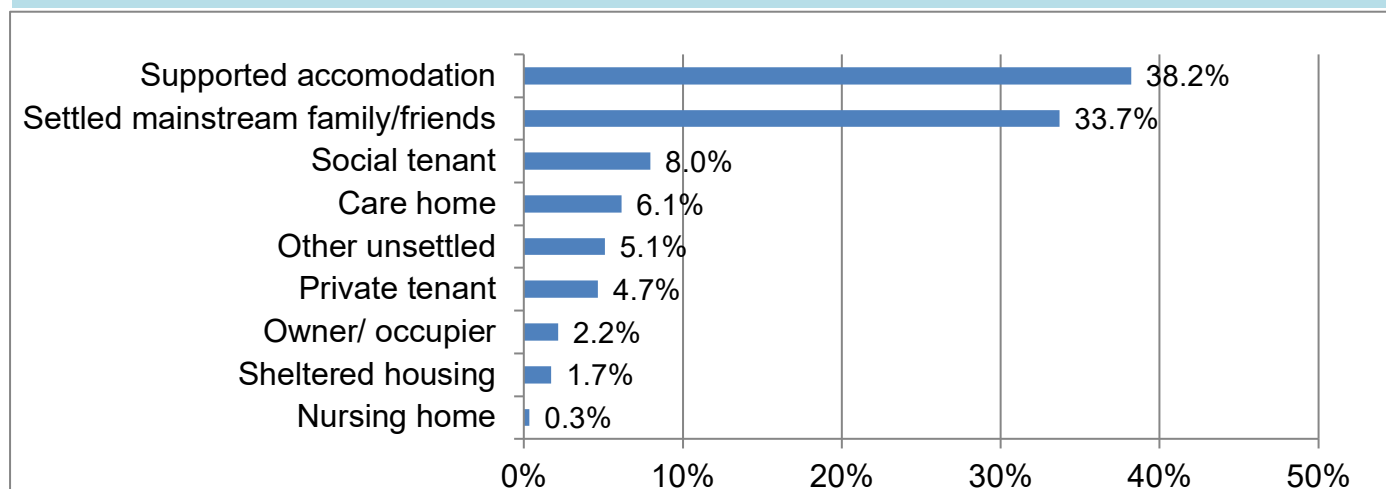
We do not know the housing status of all adults with LD in the local area, but data is collected on adult social care users.

Of the 1,254 adults with adult social care known to the Local authority at November 2019, accommodation status is known for 1,157 clients (92%).

Information about their housing status tells us that the majority are in settled accommodation (90% 1,037 clients). This means they are living in their own home, or living in a family home, or shared home with friends/ other loved ones, or are in supported accommodation or a Shared Lives Scheme. 10% (120 clients) were in non-settled accommodation. This includes acute/long stay health care residential facility or hospital, registered care home, staying with friends or family on a short term basis, or other temporary accommodation.



The majority of LD clients are either living in supported accommodation or at home with family or friends.



Source: Chart 20 Accommodation of LD clients aged 18+, Liquid Logic extract November 2019, Cheshire West and Chester Council

ASCOF measures are also in place for accommodation measuring 'the proportion of adults with LD who live in their own home or with their family'. This only includes adults aged 18-64.

Over the last two years the proportion of LD adult social care clients living in their own home or with family has remained stable at around 88%, and has been consistently higher than the England average.

	2016/17	2017/18	2018/19
CW&C	85.1%	88.2%	88.3%
England	76.2%	77.2%	77.4%

Source: Table 27 Proportion of Adult Social Care clients with LD living in their own home or with family, Adult Social Care Outcomes Framework

Note: Measure for adults aged 18-64 years with a primary support reason of learning disability support who received long term support during the year in the settings of residential, nursing and community. Situations included within the scope of 'living on their own or with their family': Owner occupier or shared ownership scheme; Tenant (including local authority, arm's-length management organisation, registered social landlord, housing association); Tenant – private landlord; Settled mainstream housing with family/friends (including flat-sharing); Supported accommodation/supported lodgings/supported group home (i.e. accommodation supported by staff or resident caretaker); Shared Lives Scheme (formally known as Adult Placement Scheme); Approved premises for offenders released from prison or under probation supervision (e.g. probation hostel); Sheltered housing/extra care housing/other sheltered housing; and, Mobile accommodation for Gypsy/Roma and Traveller communities.

As part of the Adult Social Care Survey, respondents are asked if their home meets their needs. In 2018-19, 70% of the LD cohort said that their home meets their needs very well, and a further 20% said their home meets most of their needs.



Accommodation by age highlights the changing need for support from care services as carers get older, with the proportion of adults living in settled accommodation with family and friends decreasing with age, and those in supported accommodation increasing with age.

	18-24	25-34	35-44	45-54	55-64	65-74	75+
Owner/ occupier	6.9%	1.4%	1.6%	0.9%	1.5%	1.2%	0.0%
Care home	0.6%	3.6%	6.6%	7.2%	13.1%	7.1%	0.0%
Nursing home	0.0%	0.0%	0.0%	0.0%	1.5%	1.2%	0.0%
Settled mainstream family/ friends	59.2%	51.1%	35.0%	23.0%	11.6%	8.3%	5.3%
Sheltered housing	0.6%	0.4%	0.5%	1.4%	3.0%	7.1%	10.5%
Supported accommodation	22.4%	27.9%	37.2%	47.7%	48.2%	53.6%	57.9%
Social tenant	2.9%	6.5%	7.1%	11.3%	9.5%	9.5%	21.1%
Private tenant	2.3%	3.6%	7.1%	4.1%	5.5%	8.3%	0.0%
Other unsettled	5.2%	5.4%	4.9%	4.5%	6.0%	3.6%	5.3%

Source: Table 28, Accommodation status by age for LD cohort, Liquid Logic

Over the last three years there has been a reduction in the proportion of LD respondents to the Adult Social Care Survey who said their home meets their needs well.

LD respondents who said...	2016/17	2017/18	2018/19
My home meets my needs very well	76%	75%	70%
My home meets most of my needs	20%	16%	20%
My home meets some of my needs	3%	5%	5%
My home is totally inappropriate for my needs	1%	4%	4%

Source: Table 29 Responses to the Adult Social Care Survey from the LD cohort, Adult Social Care Survey 2018-19, Cheshire West and Chester Council.

In the following sections further outcomes related to health and the Adult Social Care Survey will be explored.

10.5) Health Outcomes

Those with an LD are more likely to experience health inequalities and carry an increased risk for a number of health conditions than the wider population, including but not limited to, obesity, mental ill health, poor physical health, epilepsy, dementia, and oral health. As a result, the LD population has a lower life expectancy than the wider population. The unmet needs section of this JSNA describes some of the above in more detail and suggests some deaths are avoidable.

In regards to capturing current health outcomes being achieved for people with an LD in CW&C from Health care services, (e.g. Hospitals, community nurses, community services etc), the national data set currently does not include the reporting of whether the individual has an LD diagnosis or not, making further analysis difficult. Consequently, no data could be obtained regarding the number of admissions, discharges or re-admissions into acute hospitals across Cheshire West for people with learning disabilities and the type of services being accessed.



Details of relevant health outcomes related to maintaining a healthy weight, epilepsy, diabetes, inpatient admissions avoided are reported by GP Practices and an overview is given below.

Healthy weight

Weight data is available from GP records. Of the 1,782 adults aged 14 plus on the LD register at January 2020, weight information was available for 1,355 individuals.

At January 2020, GP's recorded 40% of LD patients on the LD register as obese and a further 28.5% as overweight. Just over a quarter were considered a normal weight.

	Number of LD patients	% of LD patients
Underweight	66	4.9%
Normal weight	360	26.6%
Overweight	386	28.5%
Obese	543	40.1%

Source: Table 30 BMI of LD patients aged 14 plus on the GP LD register, GP Practice Records, extract January 2020

This suggests that further education and provisions are required to support people with an LD to eat and maintain a healthy diet.

Managing Epilepsy and Diabetes

Further data indicates that those with LD are more likely to have epilepsy than those without an LD, as epilepsy is often caused by the same brain damage or development problems that caused the learning disability. In CW&C in 2018-19, 20% of patients on the GP LD register had epilepsy. The management of epilepsy is important to reduce risk of physical harm and sudden unexpected death. Seizures can be controlled by drugs and GPs can record information about seizure frequency.

In 2018-19, just over a quarter (27%) of LD patients with epilepsy had a seizure frequency record known to their GP (approx. 73 individuals out of a possible 272 patients). This is slightly lower than the 30% England average. Of those who did have a record, three quarters (66%) had remained seizure free in the last 12 months. This is significantly better than the England average of 45% seizure free in the last 12 months.

Diabetes is also more common in people with an LD than the general population (Diabetes UK) and is linked to a higher proportion of the LD population being obese and inactive than the non LD population. In 2018-19, 8.5% of the patients on the LD register in CW&C had diabetes (type 1 and no-type 1), higher than the 5.2% for patients without LD. In addition, 40% of LD patients on the LD register were obese compared to 32.5% of non LD patients.

In England, the average LD obesity rate is 37.5% and a diabetes rate of 7.8%.

The management of diabetes is important as if unmanaged this can lead to hypoglycaemia, diabetic ketoacidosis and damage to vital organs. GPs are required to provide diabetes care for those with an LD. Controlling diabetes means keeping glucose levels in a desired range. The HbA1c test is a blood test that is used to monitor people diabetes. In CW&C,



93% of LD patients with diabetes had a HbA1c diabetes record. Of these patients, 80.7% had a record of 'satisfactory' levels; similar to the England average of 82.8%.

The proportion of LD patients with an epilepsy seizure record is lower than the England average, however for those that are recorded, a higher proportion of patients are managing their epilepsy and have been seizure free for the last 12 months. The rate of patients with diabetes that have a HbA1c diabetes record is high and a higher proportion are managing their diabetes.

	CW&C: LD cohort	CW&C: Non LD cohort	England: LD cohort
Proportion of patients with epilepsy with a seizure record	26.8%	11.6%	30.1%
Proportion of patients with a seizure record who were seizure free in the last 12 months	65.8%	58.8%	44.9%
Proportion of patients with diabetes that have a HbA1c diabetes record	93%	91.5%	92.7%
Proportion of patients with a HbA1c record 'satisfactory'	80.7%	87.2%	82.8%

Source: Table 31 Health and care of people with learning disabilities, experimental statistics, 2018-19, NHS digital

Preventing Inappropriate Admissions to Specialist Hospitals

Building the Right Support (NHS England, 2015) was published as part of the national Transforming Care programme and set the direction for the improvement of the quality of life and quality of care of people with learning disabilities, autism or both and for the development of community services.

The Borough Council works with partners across health and social care, including Cheshire and Wirral Partnership NHS Foundation Trust and the Cheshire CCGs as part of the Transforming Care Partnership (TCP) in Cheshire and Merseyside.

This programme aims to improve the quality of life and quality of care through a reduction in inappropriate reliance on inpatient services and the development of new specialist community services and improvements to generic services.

Key to the programme is avoiding inappropriate admissions to specialist hospital settings such as specialist acute inpatient services for the purposes of assessment and treatment of mental health beds, shifting resources into enhanced community services. Any admissions should be appropriate to need with an emphasis on high quality person-centred care and robust discharge planning. CWP's assessment and treatment wards were rated 'Outstanding' by CQC in 2015.

As part of Transforming Care all CCGs were required to develop risk registers to identify individuals at risk of admission to specialist hospitals. To support this CWP developed a risk stratification tool, renaming this the 'Dynamic Support Database' (DSD) in response to feedback from local self-advocates. This clinically-validated tool provides an objective RAG rating which is used to drive targeted interventions.



Using transformation funding from the Transforming Care Programme, CWP developed intensive support as an integrated function of its community learning disability teams designed to:

- Provide enhanced and intensive community-based support to individuals and families
- Support providers to avoid inappropriate admissions to specialist settings
- Facilitate safe and timely discharges
- Build resilience in the independent provider sector.

The DSD RAG ratings determine the intensive support caseload.

Inpatient Admissions from RAG rating	Total 2018/19
Admission Avoided from Amber RAG	28
Admission Avoided from Red RAG	10
Admissions for Red RAG	5

Source: Table 32 RAG ratings of inpatient admissions, 2018/19, Dynamic Support Database, Cheshire and Wirral Partnership NHS Foundation Trust

This means that of 43 people at risk of hospital admission, 38 were supported in the community and avoided admission. Through deployment of the DSD and intensive support, admissions have reduced by 79%, significantly above expectations.

Other components of the Transforming Care programme include:

- Stopping over-medication of people with learning disabilities (STOMP-LD)
- Learning Disability Mortality Review (LeDeR)
- Improvement in the uptake and quality of annual health checks.

Learning Disabilities Mortality Review Programme (LeDeR)

National and local work has been undertaken to review causes of deaths for people with LD.

During the period 1 July 2016 to 30 November 2017, the National Learning Disabilities Mortality Annual Report (December 2017), investigated 1,311 deaths of people with a learning disability notified to the LeDeR programme.

Of those deaths, the proportion of people with LD who died in hospital was greater than that of the general population (64% compared to 47%), and younger people with learning disabilities were more likely to die in hospital than older people, with 76% of those under 24 having a death reported, compared to 63% of deaths reported with people with a learning disability who were aged 65 or over.

In addition, almost a third of deaths (31%) had an underlying cause related to a respiratory disease, with the second most common cause of death being diseases of the circulatory system (16%).



For Cheshire, LeDeR 2019 / 2020 data similarly reflects the national picture with intelligence gathered showing us diseases of the respiratory system are the most frequent cause of death for people with LD.

Cheshire and Merseyside LeDeR Data 2019/2020

Most frequent causes of death recorded
Pneumonia and chest infection (26%)
Congenital malformations and chromosomal abnormalities (16%)
Cancer (21%)
Medical conditions most frequently cited in Part I of the Medical Certificate of Cause of Death were:
Pneumonia and chest infection (26%)
Congenital malformations and chromosomal abnormalities (16%)
Stroke and Sepsis (5%)
Dementia (syndrome) (5%)
Heart disease and Cardiac arrest (11%)
Epilepsy and Sudep (11%)
Cancer (21%)
Severe bowel disease (5%)

Source: Table 33 Cheshire Learning Disabilities Mortality Review Programme, 2019/20

At November 2020, there were 5 reviews either in process or received by Cheshire CCG taking it to 9 active cases as that point in time.

Local Area Coordinators are reporting to NHSE every two weeks via a data set. This informs NHSE of the 'active review statuses' of every CCG in the country. This enables NHSE and CCG's to; closely monitor the current situation of reviews, employ additional support for reviewers for completion if needed and inform NHSE of any potential problems with the aim of preventing a future backlog occurring.

During the first wave of COVID 19, 72 Hour Rapid Reviews were completed. These were then assessed by an independent panel for lessons learned. The 72 Hour Rapid Reviews have not been expected during this second wave.

Cheshire CCG are now at the stage whereby learning from the reviews and identified themes can be cascaded to the local CCG LeDeR Steering Hub for attention and sharing more widely with the Cheshire and Merseyside LD Steering group.

NHSE are in the process of setting up a Reviewer Guidance Working Group, the LAC is a member of the group.

NORHLDA are also launching the working groups for Health Promotion. The LAC has been identified to work with the cancer health promotion group. Cancer care and equity of services, diagnostics and follow up is a frequent topic for underperformance highlighted in LeDeR reviews.



As the number of LeDeR reviews increase locally, it will allow statistically relevant data to be reported for individuals with LD in Cheshire. Further work is being undertaken by local Cheshire CCGs on the outcome of the LeDeR reviews of deaths in the learning disability population to obtain a more informed local picture.

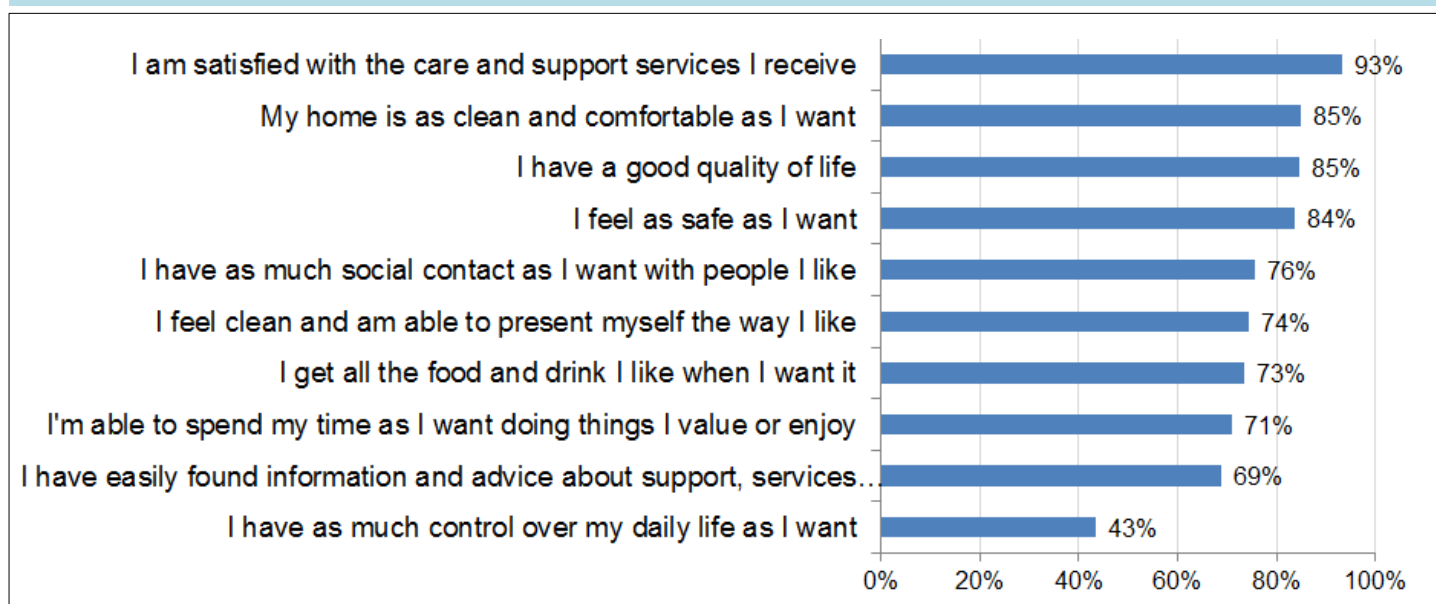
To support this work a Strategic LeDeR Steering Group has been established in the local health system and a robust plan is now in place to ensure a LeDeR review is undertaken within six months of notification of death.

10.6) Service User Outcomes – What our community tells us

The Annual Social Care Survey seeks the views of service users across CW&C to gain their opinions on a range of outcomes areas. Key questions asked aim to measure the effectiveness of services provided across the borough by asking key questions related to service users feeling safe, living independently in their own homes, as well as quality of life.

Analysis has been carried out on responses from the LD cohort of service users and results weighted. Unfortunately national comparison for this cohort is unavailable.

The majority of LD Adult Social Care users are satisfied with the care and support services received. The lowest satisfaction was for having as much control over their daily life as they want.

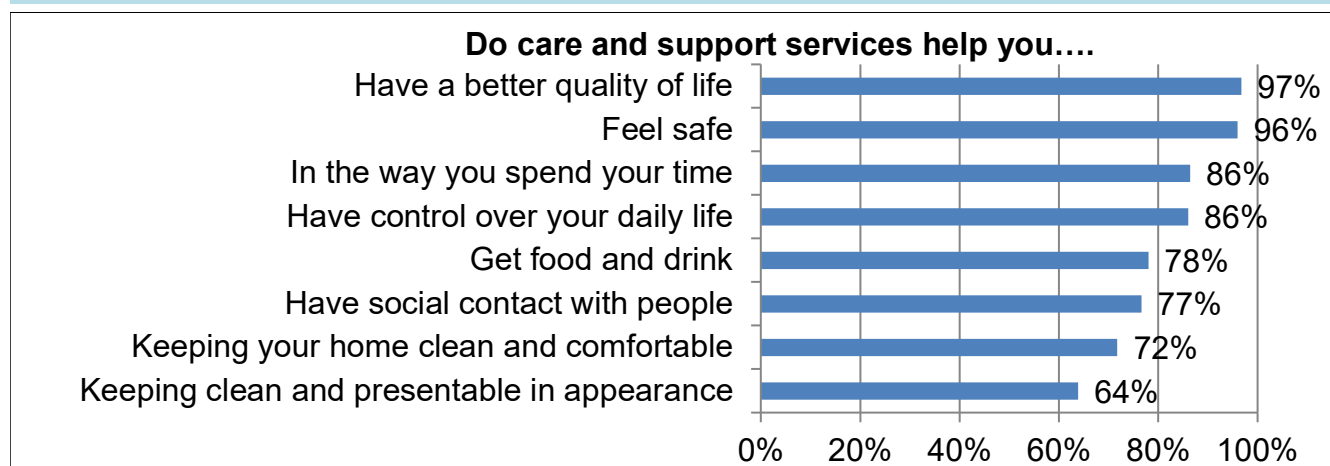


Source: Chart 21 Responses to the Adult Social Care Survey from the LD cohort, Adult Social Care Survey 2018-19, Cheshire West and Chester Council

The indicator 'I have as much control over my life as I want' achieved the lowest satisfaction score. We can see that although 43% said they did have as much control as they would like, a further 53% said that they do have adequate control over their life. This should be an area of focus for care and support services along with ensuring information and advice about support, services and benefits is easy to find for service users and their care givers.



Almost all LD adult social care users felt that care and support services helped them have a better quality of life and feel safe. A lower proportion of LD service users felt that care and support services helped them to keep clean and presentable in appearance.



Source: Chart 22 'Yes' responses to the Adult Social Care Survey from the LD cohort 'Do care and support services help you...', Adult Social Care Survey 2018-19, Cheshire West and Chester Council

Table 33 compares the last three years of responses to a series of statements in the Adult Social Care Survey from LD service users. There has been an increase in service users saying 'I have as much social contact as I want with people that I like', and from 2017-18 to 2018-19, an increase in service users saying 'I am satisfied with the care and support service I receive'. Decreases have been seen in the individual saying 'I feel clean and able to present myself the way they I like'

Over the last three years responses to the Adult Social Care survey have fluctuated slightly but 'I have as much control over my daily life as I want' has consistently received the lowest percentage of service users agreeing with this statement.

Percentage of respondents who...	2016-17	2017-18	2018-19	Trend line
I am satisfied with the care and support services I receive	96%	88%	93%	
I have a good quality of life	84%	84%	85%	
My home is as clean and comfortable as I want	80%	89%	85%	
I feel as safe as I want	86%	88%	84%	
I have as much social contact as I want with people I like	59%	64%	76%	
I feel clean and am able to present myself the way I like	81%	83%	74%	
I get all the food and drink I like when I want it	73%	77%	73%	
I'm able to spend my time as I want doing things I value or enjoy	73%	68%	71%	
I have easily found information and advice about support, services or benefits	65%	62%	69%	
I have as much control over my daily life as I want	41%	50%	43%	



Source: Table 34 Comparing the last three years Adult Social Care Survey responses from the LD cohort, Adult Social Care Survey 2016-17, 2017-18, 2018-19, Cheshire West and Chester Council

Table 35 shows the last three years of respondents answering 'yes' to a series of statements querying if care and support services help them. There has been a decrease in LD respondents saying that care and support services help them in 'keeping clean and presentable in appearance'.

In addition there were also larger decreases in the proportion of LD service users saying that care and support services help them in the way they spend their time, having control over their daily life, and keeping their home clean and comfortable.

Over the last three years, there has been in a decrease in the proportion of LD respondents saying 'yes' – "care and support services help me" in all of the indicators except feeling safe which has remained the same.

Do care and support services help you....	2016-17	2017-18	2018-19	Trend line
Have a better quality of life	97%	98%	97%	
Feel safe	96%	96%	96%	
In the way you spend your time	97%	91%	86%	
Have control over your daily life	93%	92%	86%	
Get food and drink	92%	79%	78%	
Have social contact with people	85%	77%	77%	
Keeping your home clean and comfortable	86%	78%	72%	
Keeping clean and presentable in appearance	86%	77%	64%	

Source: Table 35 Comparing the last three years Adult Social Care Survey responses from the LD cohort, Adult Social Care Survey 2016-17, 2017-18, 2018-19, Cheshire West and Chester Council

Respondents were also asked if they "can get to the places in their local area that they want to go?" 63% said they were able to get to all the places that they want with 22% finding it difficult and 15% being unable to or not able to leave their home.

There has been an increase in the LD cohort finding it difficult to, or being unable to, get to all the places in their local area that they would like.

LD respondents who said...	2016/17	2017/18	2018/19
I can get to all the places in my local area that I want	68%	74%	63%
At times I find it difficult to get to all the places in my local area that I want	21%	16%	22%
I am unable to get to all the places in my local area that I want	8%	9%	10%
I do not leave my home	3%	2%	5%

Source: Table 36 Comparing the last three years Adult Social Care Survey responses from the LD cohort, Adult Social Care Survey 2016-17, 2017-18, 2018-19, Cheshire West and Chester Council



11) Key Issues

One of the key issues in producing this JSNA has been data availability; as without informed datasets that have been collected over a period of time, an accurate assessment of need cannot be reached. This could lead to unmet needs for people with LD.

Unmet Needs

11.1) Children and young people transitioning

National data from Public Health England 2019 state that since 2010, the number of children with a learning disability receiving statements of SEN and EHC plans has decreased by 10% - but the proportion of children with a learning disability who have statements/EHC plans being educated in mainstream schools has decreased from 36% to 26% (Public Health England, 2019).

Note: More information on this for children in CW&C can be reviewed in the CW&C SEND JSNA. The number of young people with an LD with an EHCP in CW&C can be viewed in section seven of this JSNA.

In addition, Public Health England also states that children and young people with a disability are more likely to live in poverty than those without a disability. However, rates are much higher again for children with a learning disability:

- among children with a moderate learning disability 27.5% at SEN support and 36.2% with statements/EHC plans were eligible for and claiming free school meals
- among children with a severe learning disability 29.1% at SEN support and 34.1% with statements/EHC plans were eligible for and claiming free school meals
- and among children with profound and multiple learning disabilities 22.0% at SEN support and 28.3% with statements/EHC plans were eligible for and claiming free school meals.

Unfortunately, data available for young people with an LD aged 14 plus in CW&C, doesn't currently allow us to build a bigger picture of individual care, support or services accessed; as much of this is wrapped up in SEND information. Therefore it is difficult to gain an evidenced insight into the specific needs of young people with an LD transitioning in CW&C to view how this compares nationally.

At the moment we can only estimate that around 270 young people aged 14 to 17 with LD are going through transition; with around 70 of these young people expected to have a severe LD.

Work is currently underway through the work of the Preparation for Adulthood Group within the Local Authority to identify the information, data and outcomes currently collected for young people going through transition in order to plan for improvement in this area.

However, whilst an accurate local picture isn't available at the moment, the national data above; does imply that young people with an LD, including those approaching transition; are likely to come from poorer backgrounds and may not have been educated in mainstream schooling.



11.2) Unmet health needs

Unfortunately, for the purposes of the JSNA we were unable to obtain data regarding the number of admissions, discharges or re-admissions into acute hospitals across CW&C for people with LD and the type of health services they access.

However, national data tells us that people with a learning disability have worse physical and mental health than people without a learning disability.

On average, the life expectancy of women with a learning disability is 18 years shorter than for women in the general population; and the life expectancy of men with a learning disability is 14 years shorter than for men in the general population (NHS Digital 2017).

As discussed previously in analysis of Cheshire and Merseyside Review of LD deaths data, some deaths within the LD population can be avoided.

Data from University of Bristol Disability Study 2019 shows the median age of death for different levels of learning disability severity.

Median age of death for different levels of impairment



Source: University of Bristol Norah Fry Centre for Disability Studies, 2019

In reference to this, national data also shows that:

- 55.1% of patients with a learning disability received an annual health check in 2017-18 (NHS digital 2019)
- 44.9% of patients with a learning disability received flu immunisations in 2017/18 (NHS Digital 2019)
- People with a learning disability are more likely to get dementia (mencap.org.uk)
- Phipps (2013) also notes “there is a link between the genetic basis of Down’s Syndrome and dementia. Chromosome 21, which is duplicated in people with Down’s syndrome and is linked to the production of a type of proteins called amyloid. A build-up of this protein is one of the key features of dementia.”



Cancer screening

2019-20 data on screening is available from NHS England to understand the proportion of the eligible population who in the previous five years had:

- Cervical screening (female aged 25-64 years)
- Breast screening (female aged 50-69 years)
- Colorectal screening (male and female aged 60-69 years).

Screening data for LD highlights that cervical screening for females aged 25-64 has a significantly lower uptake for females with an LD than those without and LD.

If eligible, proportion who:	CW&C: LD cohort	CW&C: Non LD cohort
Had cervical screening in last 5 years	60.3%	78.3%
Had breast screening in last 5 years	61.8%	73.2%
Had colorectal screening in last 5 years	92.4%	89.8%

Source: Table 37 Health and care of people with learning disabilities, Cheshire CCG Business Intelligence, November 2020

Note: Data is classed as experimental as it is still considered in its testing phase due to poor coverage across CCGs in England, poor data quality, and undergoing evaluation. Users should be aware of the status and constraints of the data but it is published and considered valid to use. West Cheshire CCG and Vale Royal CCG are participating CCGs.

Whilst cervical screening for woman with LD is in line with the national average, this needs to be a significant area of focus for the borough due to the 44.5 % difference between rates for women with an LD compared to women without an LD. Breast screening and colorectal screening is higher in CW&C than the England average, considerably so for breast screening. Colorectal screening is also in line with the non LD cohort.

Flu Vaccinations, BMI assessment and blood pressure checks

Intelligence also tells us that those with an LD are at greater risk of a number of conditions and illnesses. Blood pressure checks and Body Mass Indicator Measures (BMI) undertaken in primary care can be a useful tool to highlight those at risk and ensure preventative measures are put in place.

The Cheshire and Merseyside Learning Disabilities Mortality Review (LeDeR), as discussed in the Outcomes section of this JSNA, also shows that respiratory problems are a major cause of death for people with LD. This highlights the importance of those with an LD receiving their annual free flu vaccination.



Although Cheshire West and Chester have a marginally better uptake of patients with LD having a flu jab, BMI assessment, and blood pressure check than the national average, it should be highlighted that less than half of patients eligible for a free flu jab are receiving

	CW&C: LD cohort 18+	CW&C: LD cohort all age	England: LD cohort all age
Had a flu jab in last 12 months	48.2%	45.5%	44%
Had a BMI assessment in last 15 months	69.4%	64.9%	62.8%
Had a blood pressure measure in last 12 months	90.4%	82.5%	83.2%

Source: Table 38 Health and care of people with learning disabilities, experimental statistics, 2018-19, NHS digital

To improve life expectancy for people with an LD and to reduce avoidable deaths, it is recommended that services across health and social care are better aligned to ensure appropriate information can be shared in a timely manner to improve the treatment and care being delivered to the LD community. Developments underway in 2019 towards reviewing deaths should continue to ensure there is a structured review process of deaths in the local area. There should also be an increased focus on providing health checks in primary care to reach the 75% target, as well as increasing the number of people with LD who attend cancer screening checks and receive an annual flu jab.

11.3) Friendships and Social Isolation

Being physically present in a community does not necessarily mean people with an LD feel integrated within the community or accepted by their peers. Therefore being able to feel included, build friendships and have a chance to participate in groups, sports and leisure activities are key needs that should be taken into consideration for this community.

National research shows that teenagers with a learning disability partake in fewer activities and participate less frequently than their peers without a learning disability. They also tend to have fewer friends (mencap.org.uk). People with a disability also take part in fewer leisure activities than people without a disability (mencap.org.uk).

Those with profound and multiple learning disabilities (PMLD) have smaller social networks, which consist mainly of family members.

Providing community services that cater for social integration, inclusion and activity based exercises to support the health and wellbeing of people with an LD should be a priority.

11.4) Sexuality and Relationships

Mencap.org.uk acknowledges that information and support to help people with a learning disability to understand their sexuality and have relationships is lacking within many learning disability services.



It is important to recognise that people with a learning disability can be lesbian, gay, bisexual and/or transgender plus (LGBT+) and that appropriate support is given by support workers to help people with a LD express their sexuality and develop personal relationships in a safe environment with appropriate safeguards in place.

Providing Relationship Sex Education (RSE) to the LD community is an appropriate and accessible way of supporting the development of relationships whilst keeping people safe.

Research also shows that people with an LD are often willing to take part in RSE with positive outcomes achieved showing increasing self-esteem, positive feelings about sex and improved knowledge of sexuality issues.

11.5) Discrimination

Under the Equality Act 2010, having a disability, including a learning disability, is a protected characteristic in law. Therefore all employers and organisations across CW&C have a duty to make 'reasonable adjustments' to ensure people with an LD can access jobs, education and services as easily as non-disabled people.

Support services across both health and social care should look to make reasonable adjustments to their practice to provide adequate support or care provisions for a person with an LD.

Information and support should also be available across CW&C to support businesses and organisations to make reasonable adjustments for people who may be employed with a learning disability.

11.6) Learning disabilities in Black, Asian and Minority Ethnic community (BAME)

It is also acknowledged that both nationally and locally more work is required to understand the differing needs of people with LD in the BAME community.

The "Reaching Out" report, notes the findings of the "Reaching out to families project" commissioned by the Department of Health in 2012 to review the current state of play for BAME families in the UK who had a family member with a learning disability.

This report found that:

- "People with learning disabilities and their families from Black, Asian and Minority Ethnic (BAME) communities continue to experience inequalities in health and social care despite various efforts to improve engagement".
- "Having information and knowledge about local Black, Asian and Minority Ethnic communities is crucial to understanding the needs and aspirations of people with learning disabilities from these communities"
- "Where identification and engagement with the different BME communities in an area worked well it was led on a corporate, local authority wide basis i.e. not just within Learning Disability or Adult Care Services"



Sourcing the appropriate data to fully explore the types of people with a learning disability and their differing need levels in Cheshire West, as well as the care services they access was a challenge for this JSNA.

In CW&C, approximately 5% of the population is BAME (non-White British), if we apply this 5% to estimates of the LD population, we would expect approximately 200 BAME adults aged 18 plus with a disability of some sort of whom around a quarter might need support from health and social care.

Of those with an LD aged 18 plus receiving support from Adult Social Care at November 2019, ethnicity had been captured for almost all clients (98.5%). There were 34 clients known to services who were non-white British; 3% of the cohort. The majority of these BAME clients were White but not British (this would include but is not limited to, those who identify as Irish, Eastern European, and Western European for example).

The above would suggest that whilst CW&C is good at noting ethnicity for those that come forward, it is likely, according to estimates based on population, that there are a number of people from LD BAME communities who have not come forward to access care and support from health or social care services and are therefore not known to the authorities.

12) National recommendations and best practice

In the 2015 report “Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition”, jointly commissioned by Association of Directors for Adult Social Services (ADASS), NHS England (NHSE) and the Local Government Association (LGA), a recommended service model for learning disabilities care and provision is provided.

The report also acknowledged that;

“Children, young people and adults with a learning disability and / or autism who display behaviour that challenges, including those with a mental health condition, have the right to the same opportunities as anyone else to live satisfying and valued lives and to be treated with the same dignity and respect.”

To achieve the above successfully, the report recommends that commissioning for the ideal care model should not be conducted in isolation, e.g. by the learning disability commissioner alone, but by utilising a system wide approach that incorporates both health and social care and the full span of commissioning activity including, strategic, operational and individual / micro commissioning. Diagram two provides a visual of this process.



Source: Diagram 2 Commissioning for the ideal care model, Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.

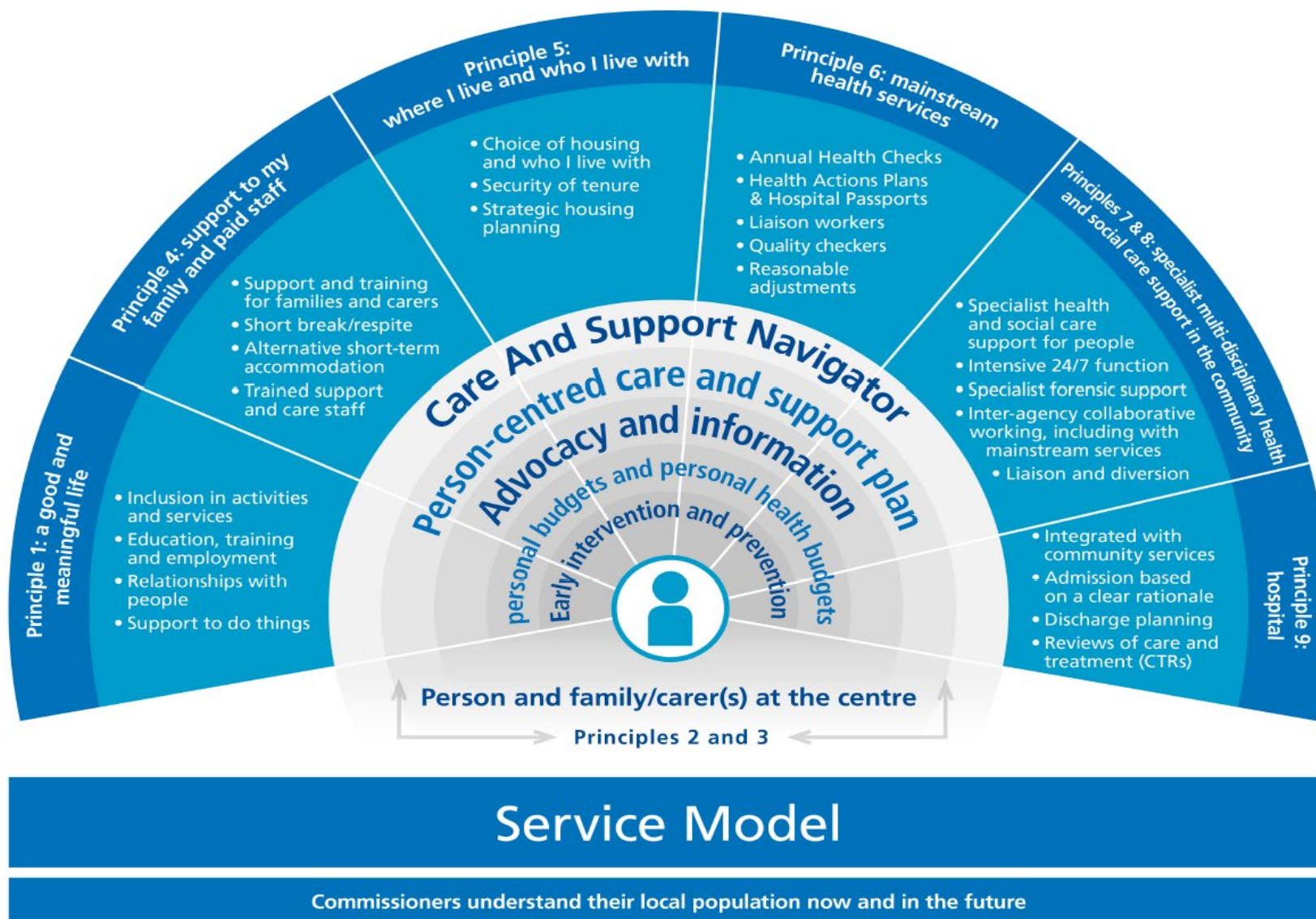
The report also states that good services for people with LD and autism should follow nine main principles that can be underpinned by the following:

- I have a good and meaningful everyday life
- My care and support is person centred, planned, proactive and co-ordinated
- I have choice and control for how my health and care needs are met
- My family and paid care and support staff get the help they need to support me to live in the community
- I have a choice about where I live and who I live with
- I get good care and support from mainstream health services

A visual of the reports recommended service model is provided in diagram three.



Learning Disability JSNA





Source: Diagram 3 Main principles underpinning an ideal service model, Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.



To support this further, NICE Guidance 2018, “Learning disabilities and behaviour that challenges: Service design and delivery” further recommends that;

“Children, young people and adults with a learning disability ... are likely to use both health and care services throughout their lives ... a lack of integration across services, including childrens’ and adults’ can impact on quality of care. Local authorities working together with clinical commissioning groups, can provide a more joined up and person-centred approach.”

13) Future developments in Cheshire West

Future development across CW&C looks to take note of national guidance and best practice.

13.1) Future commissions

Within social care, a re-commission of the Local Authority’s Learning Disabilities Framework will begin in 2020. This will look to ensure social care services provided for people with LD cover the span of needs within our community. To do this, the progression model will be used to define this commission.

This model breaks down support requirements into one of four categories reflecting the varying levels of complexity of our service users. These are as follows:

1. Support for people who are self-managing
2. Low level community support
3. Specialist community support
4. Accommodation based support

Through this recommission the local authority will look to commission services that are:

- **Community based support to those who are self-managing** – this will enable people with an LD to live a fulfilling life, enable them to feel part of the community and include services that offer information and advice to support.
- **Low level support** – this will include services, typically of a non-specialist nature, that support people with relatively low support needs. The support may be delivered in someone’s home or to help people access the community. Examples of low-level support might include domiciliary care and some forms of housing related support.
- **Specialist support in the community** - This will include support to people with more complex needs that requires delivery by staff with more specialist training or experience. Care may also be delivered by a team of people working together in a co-ordinated way. Specialist support in the community may include different models of supported living, particularly (but not exclusively) where groups of people are sharing support. The support may address maintenance needs to support disabilities or risks that cannot be easily changed, but also developmental needs, where the person can increase their independence.



- **Accommodation-based support** - This category will look to commission models of care and support where accommodation and support are inextricably linked, for example, registered models such as hospitals, residential and nursing care. Also included are supported living models where support and accommodation are provided by the same provider organisation. Accommodation based models are typically relatively inflexible: it is difficult to reduce support when a person's needs decrease and increasing dependency often triggers a requirement for the person to relocate or be provided with additional one to one support.

Working well, the "progression" model will ensure that the best possible matching of services to a person's individual requirements, thereby facilitating highly individualised, person-centred support. It will also help to move away from institutional models of support as people gain skills and confidence.

13.2 Partnership working

Continuing the collaborative work taking place across both health and social care through the Transforming Care programme, activity in 2020 will focus on the following initiatives;

- Reducing the number of patients with a learning disability, autism or both inappropriately in inpatient beds across the Cheshire West and Chester footprint. Initiatives, such as step-up and step-down models will be developed across health and social care to support more patients in the community and to be discharged from hospital inpatient care so that patients can live fulfilling lives in the community with appropriate support.
- Work is underway across all primary care networks to look at how we can ensure more people with a learning disability access their yearly GP health check, delivered to a high quality standard.
- Work on the STOMP programme will continue.
- As the number of LeDeR reviews increases locally it will allow statistically relevant data to be reported for individuals with LD in Cheshire. Further work is being undertaken by local Cheshire CCGs on the outcome of the LeDeR reviews of deaths in the learning disability population to obtain a more informed local picture by the end of 2020.

13.3 Young People and Transition

In order to better understand the number of young people accessing care services and their needs, including the number of young people with an LD going through transition, a Preparation for Adulthood Group has been established within the Local Authority.

It is envisaged this group's purpose will help the system better understand needs of young people and young people in transition. Currently the group is undertaking a preparation for adulthood audit to highlight current delivery and the steps needed to improve service provision for young people. From conducting this audit, a better understanding of the needs of young people with LD across CW&C will be gained and the planned development of clear quality driven datasets will allow assessment of current outcomes being achieved.



This will furthermore enable identification of service provision gaps to help plan for improvement.

13.4 Employment Support

Sub-regional Local Authorities were recently successful in securing a bid award of £5.4m from the European Social Fund to support cohorts of complex adults and young people at risk of exclusion, including those with learning disabilities, into positive destinations including employment. This programme will co-locate employment support specialists alongside referring teams such as the Adult Social Care team. The programme titled Journey First is due to start registering beneficiaries in June 2020 and will run for 3 years.

14) Strengths in Cheshire West and Chester

Key strengths within CW&C are as follows:

- **Housing and Employment**

In 2018/19, 6.4% of people with an LD aged 18-64 were in paid employment, an improvement from 5.7% the previous year and higher than the 5.9% England average.

Moreover, in the last two years, the proportion of adult social care clients with an LD living in their own home or with family has remained stable at around 88%, and has been consistently higher than the England average.

This shows that within CW&C consistent improvement and achievement is being maintained across the borough to ensure that people with an LD can enter employment and be in an appropriate care setting for their needs.

CW&C also have a very active Employment sub-group of the Learning Disabilities Partnership Board now working on its year two activity plan. Through this group and the council's links with the Department for Work and Pensions Disability and Employment Engagement Officers, key links with local employers and broker opportunities can be achieved to help more people with an LD into work.

- **Participation in Further Education or Training**

The number of young people with LD continuing into further education or participating in some form of training is high in CW&C. At March 2019, 91% of 16-17 year olds with an EHCP were in education and training. Work being undertaken by Not in Education, Employment or Training Panel (NEET) has been a major part of this achievement as through this group young people have been given the opportunity to receive a bespoke plan of support tailored to their needs to aid development, education and training opportunities.

- **Adult Social Care Survey**

Feedback from the annual Adult Social Care Survey for CW&C tells us that overall 93% of people with an LD stated "I am satisfied with the care and support services I receive." Moreover a further 85% felt they had a good quality of life.



To continue to achieve these positive outcomes, further consideration now needs to be given as to how people with LD can feel they have greater choice and control over their lives. As 43% said they did have as much control as they would like.

- **Preventive work in smoking**

Smoking during pregnancy is a key area of development both nationally and within CW&C. West Cheshire is currently reducing smoking in pregnancy rates in line with the National England average which is commendable. Conversely, further improvement work is required for residents in Vale Royal.

However, credit is to be given to the partnership work being undertaken by the Cheshire CCGs and Public Health to improve rates locally. Smoking in pregnancy is one of the targeted work streams at the Women, Children, Young People and Families Group that incorporates the Vale Royal footprint, and a priority area of improvement for West Cheshire CCG's Maternity Network.

This has led to significant action being taken to ensure:

- All pregnant women who are smokers are referred to smoking cessation advisors
- Mid Cheshire Hospital has a smoking cessation midwife who attends a weekly antenatal clinic.

15) Key areas for improvement

- **Complications during birth**

Almost two thirds of births at the Countess of Chester Hospital during 2018/19 had complications and complicated births have been increasing by around 2% each year.

As mentioned in the risk section of this JSNA, complications in birth can increase the risk of associated causes of developing a learning disability. There is a need to understand reasons for the increasing number of a complicated births taking place in the Countess of Chester.

- **Accidental injury**

Injury, especially head injury, can result in development of an LD. CW&C are currently significantly higher than the England average for injury in under 5's and 0-14 year olds. As a result, there is an Unintentional Injuries Partnership Group established to understand this further.

- **Young people, SEND and transitions**

At the present time, our understanding of young peoples' aspirations and achievements are grouped together under the wider banner of SEND. More understanding is needed of young peoples' individual needs and the services they are accessing, especially those approaching transition with a learning disability.



- **Data quality**

Unfortunately data available from social care systems meant it wasn't possible to look at the numbers of people with an LD accessing specific social care services and there are cases where data has not been recorded. For example out of 1,254 users of adult social care only 303 had their employment status completed.

Therefore revision of the data captured during social care reviews, emphasising the importance of accurate data reporting to practitioners, and changes to the input methods available on current systems, would enable more informed service specific data to be collected.

- **Health care data**

For the purposes of the JSNA, data was not available to help understand the number of admissions, discharges or re-admissions into acute hospitals across CW&C. This is because the national data set currently does not stipulate the reporting of whether the individual has an LD diagnosis. Further work needs to be undertaken by health partners to consider how this information could be collected to enable a full assessment of need for future JSNA and learning performance developments.

- **Uptake of GP Health Checks, Screening and Flu immunisations**

Within this JSNA it has been highlighted that only:

- 57% of those aged 14+ eligible for an annual GP health check received a flu jab and under 25's were less likely to have an health check
- 35% of people with an LD eligible for cervical screening attended compared to 80% of the non LD population
- 46% of all people on the LD GP register received a flu jab
- 46% of registered people with an LD are obese.

This would suggest that more work needs to be done within primary care and with GPs to increase the uptake of preventive measures such as annual health checks, screening and flu immunisation. Further validation of the data received by clinical commissioning groups from primary care could also be considered to gain a valid picture of health needs and activity.

- **Maintaining positive mental health and wellbeing**

Within the JSNA, 18% of those with LD aged 18 and over had depression and 10% had a severe mental illness. The importance of mental health was also highlighted in the Adult Social Care User Survey 2018-19 where 57% of respondents with LD reported they were anxious or depressed.

Future developments should explore how mental health and wellbeing needs are provided for in the community in conjunction with providing care and support for physical needs.

Comparing this to how general wellbeing can also be affected for people with LD by unmet needs as described within the JSNA will also be important.



• An ageing population

Through the development of this JSNA, it was not clear what developments are taking place to ensure supported living and residential accommodation is fit for purpose as we move towards an increasing ageing population of people with LD in CW&C.

Future planning should consider how supported living and residential accommodation will meet the needs of an increasing ageing population who may have less informal care networks able to provide support.

The commissioning of bespoke accommodation may be required to meet the needs of this population as well as exploring how new technologies can be utilised to support care workers and clients with increasing care demand.

16) Recommendations

a) Life expectancy/ health outcomes

- To improve life expectancy for people with an LD and to reduce avoidable deaths, it is recommended that services across health and social care are better aligned to ensure appropriate information can be shared in a timely manner to improve the treatment and care being delivered to the LD community.
- Developments underway in 2019 towards reviewing deaths should continue to ensure there is a structured review process of deaths in the local area.
- There should also be an increased focus on providing health checks in primary care to reach the 75% target, as well as increasing the number of people with LD who attend cancer screening checks and receive an annual flu jab.

b) Young people and transitions

- During the course of the production of this JSNA, great difficulty was had in sourcing information on the specific needs of young people aged 14+ who have a learning disability and who are at the age of transition. As a result, this JSNA does not discuss the local outcomes being achieved or the level of needs identified for young people with an LD and going through transition.
- From exploration with transition teams and early help and prevention leads, it is clear that whilst the local authority has a transitions team, a SEND team, education department, young peoples' services and childrens social care teams, much of our current understanding of young peoples' aspirations and achievements are grouped together under the wider banner of SEND.
- However, this JSNA acknowledges that the abilities and experiences of young people within this group are largely different, as is the support needed to ensure they reach their potential – particularly those with an LD.
- To support the development of this area, it is recommended that the newly established Preparation for Adulthood Group work with collective decision makers across the council to pull together all data held on young people and transitions to establish what data streams are available. This will build a picture of the current performance for young people and transitions. From this, a method or streamlined system of data reporting should be agreed to enable regular performance reporting against young people and transition outcomes to enable a plan for improvement.



- For young people with learning disabilities, it is recommended that key outcome measures planned and reported on include type / level of learning disabilities and the amount of support given around education, training, developing relationships, health needs, employment and career development.
- Review of these outcomes and level of need will then allow commissioners to effectively plan the development of services across the borough that can cater for the needs of young people and young people in transition with a learning disability. This will be particularly important as forecasts projected within this JSNA show a 9% increase predicted for young people with an LD under 18 between 2018 and 2028.

c) Developing community opportunities

- People with learning disabilities have the right to live a full, happy and active life as those without any form of disability. It is recommended that everyone in the LD community has the opportunity to build friendships, be engaged in decision making linked to their own their care, and have access to services that allow them the time and space to build personal relationships and to take part in sports and leisure activities.
- Local Authorities should consider the range of services they have commissioned to meet these needs, not only to provide this provision but to give people a greater choice of the groups they join.
- Ensuring easy access to transport as well as developing city centre and community space to support the development of LD group meetings and activity venues could also be beneficial to community development. Consideration should also be given as to how personal relationships for people with LD can be developed in a safe environment, perhaps through the commissioning of Relationship Sex Education.
- There should also be a range of information and support services available across the borough that can advise communities, employers and educational settings on how to make reasonable adjustments for people with an LD.

d) Future planning for an ageing population

- It is clear from population forecasts that over the next 20 years an 18% increase in the number of people with an LD over 65 is expected.
- It is recommended that future commissioning intentions begin to consider how current services provided can be shaped to adequately provide for an ageing LD population, particularly services related to supported living, residential and nursing accommodation.
- When developing these plans, thought should be given to the evidence that people with learning disabilities (as discussed in the unmet needs section of this JSNA) are more likely to develop dementia and to the models of care described in the national best practice section of this document and the recommendations issued by NICE 2018.
- To meet the needs of the ageing LD population successfully, greater aligned working between NHS and social care teams will need to be implemented, with consideration given to joint commissioned arrangements and/or the development of specialist multidisciplinary teams.
- Training and skills of care staff should also be developed.
- It is also suggested that future commissioning intentions should also focus on the development of bespoke property that can cater for an ageing population with likely mental health needs that can be maintained within their local communities. This will ensure best practice principles of independent supported living- at the centre of the community, with adequate access to multidisciplinary care at a chosen place of residence is achieved



- Initiatives that focus on delivering new technologies in social care settings to the benefit of clients and care staff should also be part of future planning.

e) Data development for learning disabilities

- Unfortunately data availability and the quality of data across both health and social care was lacking for the production of this JSNA.
- Social care data available; due to the timing of the report, meant it wasn't possible to look at the numbers of people accessing specific services over a year meaning the JSNA can only focus at a point in time.
- Furthermore, no data could be sourced to understand the number of acute admissions and discharges for people with an LD or the services they accessed. This did not allow a full assessment of need to be established.
- It is therefore recommended that a review of the type of information inputted into social care systems is undertaken. This would ensure system process methods and practitioner inputs together enable the adequate recording and reporting of care and support provisions being accessed. Operational teams, commissioners and system information officers will need to approach this review in partnership.
- In addition, NHS partners in Clinical Commissioning Groups are also asked to consider the contracting opportunities available to them to enable data to be collected on the number and type of services being accessed by people with Learning Disabilities 14+, including admissions and discharges to acute hospital.



17) Appendix

17.1) Data tables

The data tables for charts in this report that do not have data labels included can be seen below.

Table A. Estimated prevalence of learning disability in Cheshire West and Chester by severity, associated chart 1.

Age group	Moderate LD	Severe LD
14 to 17	200	70
18 to 24	380	120
25 to 34	550	170
35 to 44	560	180
45 to 54	710	230
55 to 64	640	210

Source: Prevalence calculated from SEN2 January 2019 for learning disability types Moderate, Severe, Autism (age 8-15) and Profound and Multiple (age 5-15). Numbers rounded to nearest 10. Applied to 2018 Mid-Year Population Estimates, Office for National Statistics.

Table B. Estimated prevalence of LD by Care Community, associated chart 2.

Care community	Moderate LD	Severe LD
Chester Central	210	70
Chester East	550	180
Chester South	370	120
Ellesmere Port	690	220
Frodsham and Helsby	270	90
Neston and Willaston	240	80
Northwich	820	260
Rural Alliance	350	110
Winsford	370	120

Source: Prevalence calculated from SEN2 January 2019 for learning disability types Moderate, Severe, Autism (age 8-15) and Profound and Multiple (age 5-15). Numbers rounded to nearest 10. Applied to 2018 Mid-Year Population Estimates, Office for National Statistics.

Table C. Percentage of mothers smoking at time of delivery, associated chart 5.

	2011/1 2	2012/1 3	2013/1 4	2014/1 5	2015/1 6	2016/1 7	2017/1 8	2018/1 9
CW&C	12.7%	12.2%	13.0%	11.5%	10.0%	11.7%	12.3%	10.6%
England	13.3%	12.8%	12.2%	11.7%	11.0%	10.7%	10.8%	10.6%

Source: Calculated by PHE from the NHS Digital return on Smoking Status at Time of Delivery (SATOD).



Table D. Countess of Chester Hospital Antenatal, Birth and Postnatal Data, associated chart 6

Birth stage	Category	Percentage of births
Antenatal	Standard	50%
	Intermediate	35%
	Intensive	15%
Birth	Complication	65%
	Non complication	35%
Post-natal	Standard	40%
	Intermediate	56%
	Intensive	4%

Source: Countess of Chester Hospital Antenatal, Birth and Postnatal Data, 2018/19, Countess of Chester Hospital (Mid Cheshire Hospital data is not available).

Table E. Week of pregnancy at which maternity services were accessed, associated chart 7

	10 weeks or under	11-12 weeks	13-14 weeks	15-19 weeks	20-24 weeks	25-29 weeks	30-34 weeks	35-39 weeks	40+ weeks
Countess of Chester Hospital	73.3%	13.1%	4.1%	2.7%	1.8%	1.4%	1.4%	1.2%	1.0%
Mid Cheshire Hospital	73.5%	11.9%	3.1%	3.3%	2.6%	1.8%	1.8%	1.5%	0.4%
England average	57.8%	20.3%	7.5%	5.1%	2.2%	2.1%	1.9%	2.2%	0.8%

Source: Week of pregnancy at which maternity services were accessed, 2017-18, NHS Maternity Statistic

Table F. Rate per 10,000 hospital admissions for under 15's, associated chart 8

	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19
CW&C	153.3	128.2	124.8	116.3	128.6	131.1	114.5	121.2
England	118.3	103.9	112.2	109.6	104.2	101.5	96.4	96.1

Source: Rate per 10,000 hospital admissions for under 15's, Hospital Episode Statistics

Table G. Rate per 10,000 hospital admissions for 15-24 year olds, associated chart 9

	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19
CW&C	155.2	119.8	127.4	127.9	131.8	143.5	147.4	140.1
England	145.6	131.5	137.7	132.6	134.1	129.2	132.7	136.9

Source: Rate per 10,000 hospital admissions for 15-24s, Hospital Episode Statistics

Table H. Rate per 10,000 hospital admissions for under 5's, associated chart 10

	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19
CW&C	230.2	185.5	170.2	165.8	173.6	164.4	147.6	153.5
England	148.3	134.8	140.9	137.5	129.6	126.3	121.2	123.1



Source: Rate per 10,000 hospital admissions for under 5's, Hospital Episode Statistics

Table I. Rate per 100,000 hospital admissions for under-fives, associated chart 11

	2008-10	2009-11	2010-12	2011-13	2012-14	2013-15	2014-16	2015-17
CW&C	28.8	24.3	19.5	21.8	21.2	19.4	15.3	14.6
England	23.6	22.1	20.7	19.1	17.9	17	17.1	17.4

Source: Rate per 100,000 hospital admissions for under-fives, Hospital Episode Statistics

Table J. Rate of EHCPs for young people per 1,000, associated chart 14

	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
CW&C	32.5	30.1	29.7	29.9	30.9	31.3	31.4	31.5	31.0	33.6
England	27.7	27.6	27.7	27.8	27.9	28	27.7	27.9	29.0	30.8

Source: Rate per 1,000 young people with an EHCP, SEN2

Table K. Responses to How is your health in general? On the Adult Social Care User Survey 2018-19, associated chart 15

How is your health in general?	Very good	Good	Fair	Bad	Very bad
% of reponses	43%	27%	23%	6%	1%

Source: Adult Social Care User Survey 2018-19, Insight and Intelligence, Cheshire West and Chester Council

Table L. Pupils with an EHCP going to EET from KS4 by school associated chart 16 and 17

% of pupils with an EHCP going to EET from KS4	2015/16:	2016/17	2017/18
CW&C schools	86%	90%	84%
England schools	90%	90%	91%
CW&C special schools	88%	88%	84%
England special schools	88%	89%	90%

Source: Pupils with an EHCP going to Education, Employment or Training (EET) from KS4 by school, from Destinations at KS4, Department for Education