NHS England and NHS Improvement

Champs Public Health Collaborative

Working together to improve health and wellbeing in Cheshire and Merseyside

Halton
Learning Disability & Autistic Spectrum Disorder Profile

This profile presents published data on the estimated and known to services as well as support offered by education, adult social care and health services. Please note the data source and geographic area as some data sources may be at CCG or LA, and some may only be C&M.

KEY FINDINGS

- **Prevalence:** There has been an increase in the estimated prevalence of children with autism since the 2016 health needs assessment. This predicted the 2019 figure would be 308 but this profile estimates 549. Underlying prevalence has not changed significantly so this is likely due to adjustments made by ONS to population projections.

- **Projected Trends:** The key trend to note is the increase in the number of older people with Learning Disability and Autism (LD/A), and how this might impact on local service provision particularly around earlier onset dementia and frailty. There will be a greater need to develop skills around LD/A in health and social care organisations who provide care for older people.

- **Numbers known to services:** There is a significant discrepancy between the estimated population with LD/A and the numbers recorded on GP registers. This means that a high volume of people **may** not be receiving reasonable adjustments or support in order to access primary and secondary care services.

- **Support from Schools and Children's Services:** Of particular note is the number of children presenting with Autism Spectrum Disorder (ASD) in both secondary and special schools. Analysis of the children and young people (aged under 18) who access inpatient mental health beds in Cheshire and Merseyside shows that the majority (c.90%) have an autism only diagnosis. Improving the skill mix to support children with autism in education should be considered, given the increased prevalence.

- **Children in Need:** LD/A represents a substantial proportion of CIN who have a disability.

- **Support from Adult Social Care:** Halton supports more adults with LD per head of population than Cheshire and Merseyside, the North West and England.

- The proportion of adults **living on their own or with their families** is lower in Halton compared to Cheshire and Merseyside but higher than England. This continues the trend from previous reports. It is consistent with the principles of Transforming Care.

- Although the proportion of Halton females with **LD in paid employment** is better than in Cheshire and Merseyside and England the proportion for men is lower. Across Cheshire and Merseyside there are a number of initiatives to encourage young people into paid work, through Supported Internships primarily. There is a real need to increase the pace and consistency of this work across the footprint.

- There has been a fall in the rate of **safeguarding (Section 42) enquiries** involving people with LD. The rate was statistically higher than Cheshire & Merseyside and England 2015/16-2017/18 but , although higher, was statistically similar for 2018/19.

- **Mortality Rates:** The death rate for Halton people with LD is 5.4 times higher than the general population. This is higher than the rate for England and Cheshire & Merseyside.

- **Screening/ Annual Health Checks:** It should be noted that Health Checks are not offered to children under 14, or to people with Autism-only at present. This remains an area of significant challenge for Cheshire and Merseyside. In Halton, despite improvements, only just over half the LD population receiving an annual health check.

- **Obesity:** The rate of obesity for people with LD is higher than those without LD. Work to address this would significantly improve life expectancy and co-morbidity. Areas should consider targeted work around the STOMP/ STAMP initiatives and physical health and exercise.

- **Flu vaccination rate** is low and has fallen 2018/19 compared to 2017/18. At 47.3% it is below the minimum 55% target and a significant way off the World Health Organization 75% ambition (those under age 65 in a clinical 'at risk' group)

- **Cancer:** The low screening uptake for cervical and breast screening for people with Learning Disabilities is considerable. Previous co-produced work has been undertaken by the Transforming Care Partnership in relation to identifying Cancer Red Flags and Looking After Your Lungs. A targeted campaign to improve screening could be considered.

- **Long-term conditions:** Commissioners should consider carefully the higher numbers around epilepsy, severe mental illness, depression, dementia and diabetes shown in the figures.

Estimated Numbers of People

Learning Disabilities (LD)

827 under 18 estimated to have LD

257 18-24 year olds estimated to have LD

1,586 adults aged 25-64 estimated to have LD

496 older people aged 65 and over estimated to have LD

TOTAL 3,166 estimated people with LD living in Halton

Autistic Spectrum Disorder (ASD)

549 under 18 estimated to have ASD

96 18-24 year olds estimated to have ASD

643 adults aged 25-64 estimated to have ASD

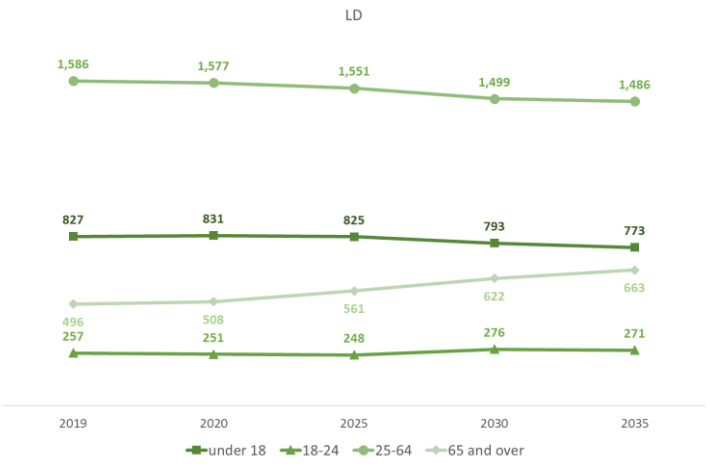
225 older people aged 65 and over estimated to have ASD

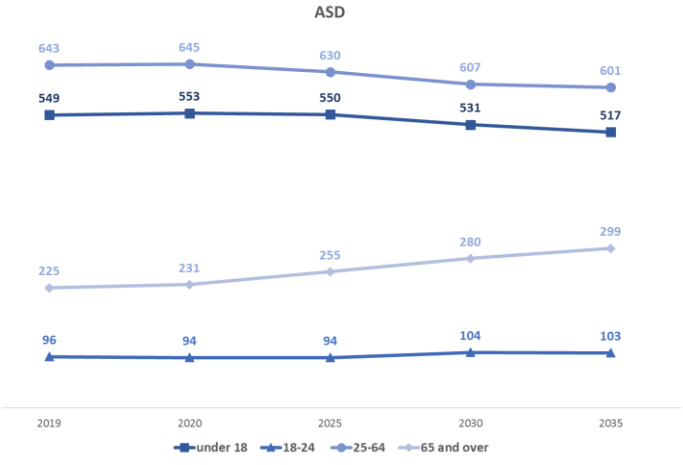
TOTAL 1,513 estimated people with ASD living in Halton

Estimates based on updated research since 2016 C&M health needs assessment - Adult Psychiatric Morbidity Survey 2014, Emerson et al 2014 and Rydzewska et al 2019 (children). This is likely to impact on any direct comparisons, especially under 18 estimates.

Projected trends

Using these current prevalence rates, applying them to population projections shows different patterns for each age group:



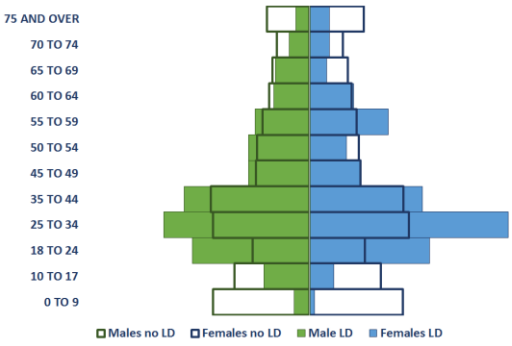


Most significant projected change is the increase in numbers aged 65 and over. This driven by population changes and assumes prevalence remains static. Dementia, including earlier onset dementia, and frailty will be particular challenges. This reflects the general population but will need approaches that take LD in to account.

Numbers known to services

Those with LD identified in Primary Care

Population distribution by age and gender



306 females + 422 males = 728 persons

Based on **NHS Digital 2018/19** dataset
Included **91%** of GP population data in Halton CCG

QOF 2018/19 showed **819** but no age and gender breakdown available

Numbers known to services much smaller than estimates.
Estimates will include people with mild LD.
However, likely that a significant number of people who would benefit from reasonable adjustments are not getting them as they are not identified as being in need

By Education

Children with SEN primary need:

- **Moderate learning difficulty**
- **Severe learning difficulty**
- **Profound & Multiple learning difficulty**
- **ASD**

1,803 primary + 1,169 secondary + 357 special = 3,449 all pupils

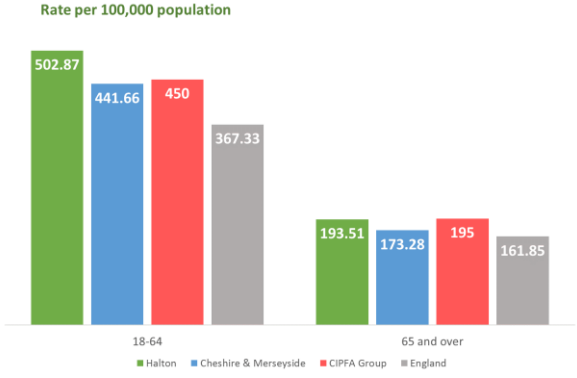
By Adult Social Care

Receiving long term support

Numbers

385 Aged 18-64 + 45 Aged 65+ = 430

24% registered carers support someone with LD (more than NW and England)



Children with LD and ASD

Support from Schools and Children's Services, as at 31 March 2019

Special Education Need (SEN)

		Primary		Secondary		Special	
		Number	Percentage	Number	Percentage	Number	Percentage
Total number of pupils with SEN whose primary need is LD or ASD		12,155	5.8%	5,731	3.9%	4,608	70.9%
Pupils with SEN due to:	Moderate Learning Difficulty	455	25.2%	322	27.5%	11	3.1%
	Severe Learning Difficulty	6	0.3%	2	0.2%	60	16.8%
	Profound & Multiple Learning Difficulty	3	0.2%	1	0.1%	22	6.2%
	Autistic Spectrum Disorder	33	1.8%	81	6.9%	151	42.3%

Emerson et al (2014) estimate that about 1 in 8 (11.7%) of children with LD also show behaviours that challenge. They assert that this is likely to be a conservative estimate due to the failure of the Strengths & Difficulties Questionnaire (SDQ) to identify behaviours that challenge that are more specific to (and not uncommon among) children with learning disabilities (e.g., severe self-injury).

Halton est. 103

Children in Need

	Number of children in need at 31 March 2019	Number of children in need with a disability recorded	Percentage of children in need with a disability recorded due to ASD/AS or LD: *Autism/ Asperger Syndrome*	Percentage of children in need with a disability recorded due to ASD/AS or LD: *Learning Disability*
England	399,510	49,630	34.5	43.2
North West	60,460	6,300	33.4	42.3
Cheshire and Merseyside*	18,504	1,932	36.9	42.2
Halton	931	125	24.0	20.0

* note Cheshire & Merseyside figures calculated using 9 local authority statistics

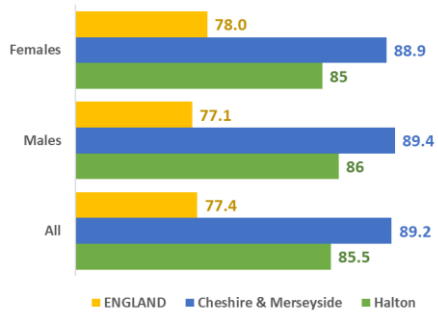
1 in 13 Children in Need (CIN) in Halton, C&M and NW have a disability. Lower than the 1 in 8 for England as a whole. Of those, over 1 in 5 have a LD and 1 in 4 have ASD/Asperger Syndrome (possible some have both LD and ASD/Aspergers)

Adults with LD and ASD

Support from Adult Social Care - Primary Support Reason (PSR) being LD

	18-64		65 and over	
	Number	Rate per 100,000	Number	Rate per 100,000
Halton	385	502.87	45	193.51
Cheshire & Merseyside	6,815	441.66	880	173.28
North West	18,430	419.22	2,225	164.62
England	124,035	367.33	14,965	161.85

ASCOF 1G: Proportion of adults with LD living on own or with family



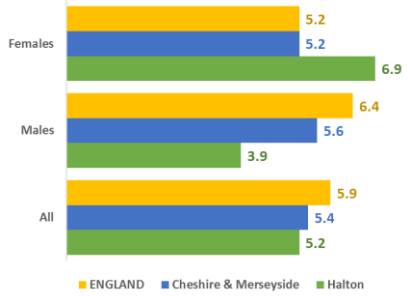
Higher proportion of people with LD living in Halton than nationally, but lower than in C&M as a whole.

Research shows those living in social housing most likely to have ASD. Especially so for men. 8% men living in social housing ID as having ASD

ASCOF 1E: Proportion of adults with LD in paid employment

ASD associated with lower educational attainment; prevalence 0.2% in those with degree to 2.1% in those with no qualifications

Higher proportion of people with LD in paid employment in Halton than across Cheshire & Merseyside as a whole and seen nationally.



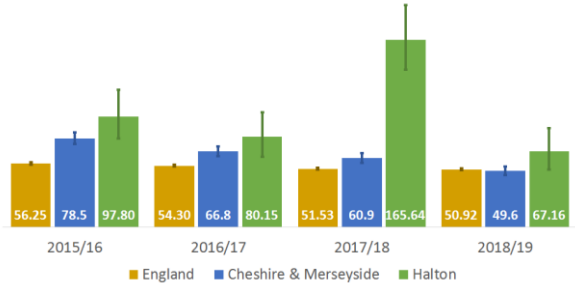
Safeguarding: Individuals with LD involved in Section 42 safeguarding enquiries

Halton rate statistically higher than England until 2018/19. Now statistically similar.

Numbers each year

2015/16	80
2016/17	65
2017/18	135
2018/19	55

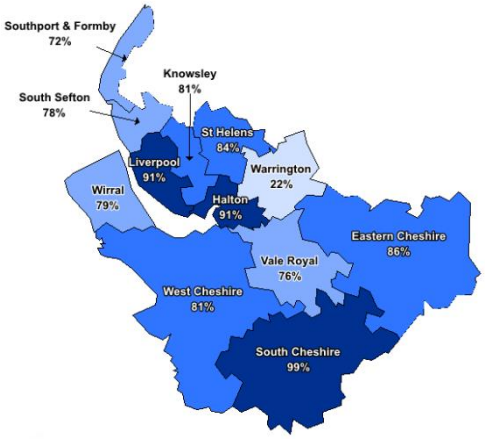
Rate per 1,000 on GP LD register

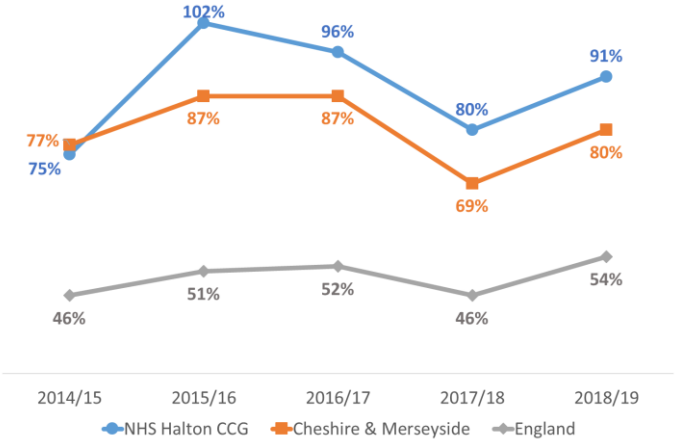


Health of people with LD

Each year since 2014/15, NHS Digital has collected data from GP practices on a range of health issues and compares the status of people identified as having a learning disability with those that do not. Data is published at a CCG level. Coverage in NHS Halton CCG has been higher than Cheshire & Merseyside and England.

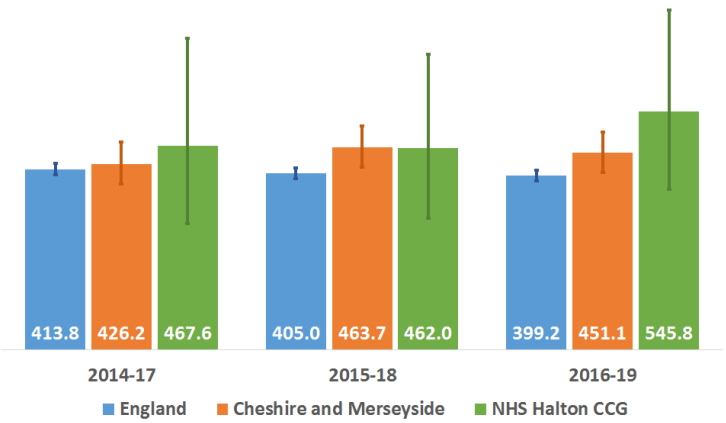
COVERAGE: percentage of patients included in data





People with learning disabilities have a death rate on average 4 times higher than the general population

Rates are higher in Halton CCG compared to Cheshire & Merseyside and England. They are 5.5 times higher than those in Halton who did not have LD. Despite an increase each year rates are not statistically different to either area



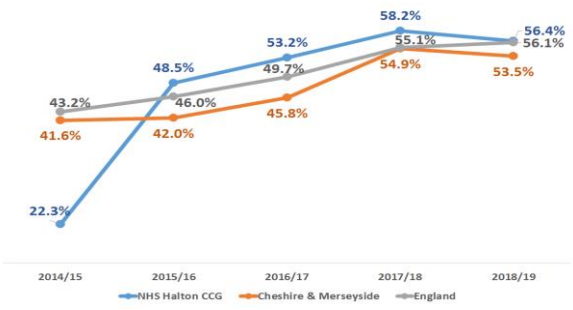
Produced by Sharon McAteer, Public Health Halton on behalf of Champs

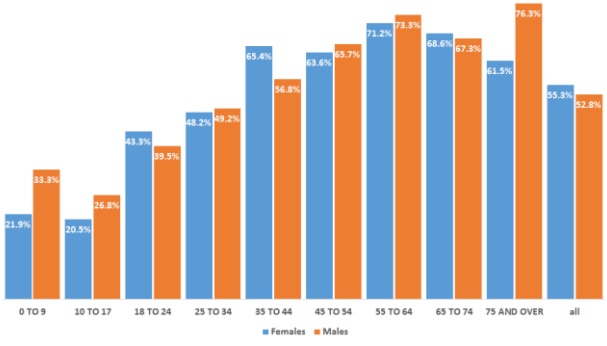
Health of people with LD

Health Promotion: Health Checks, BMI and Seasonal Influenza Immunisations

Annual Health Checks

Halton CCG has been improvements in performance in the uptake of annual health checks for people with LD. From a low of 22.3% in 2015/16, this has more than doubled to a rate that is now above Cheshire & Merseyside and England levels. The percentage receiving annual health checks generally increases with age, peaking at 55-64 for women and 75+ for men





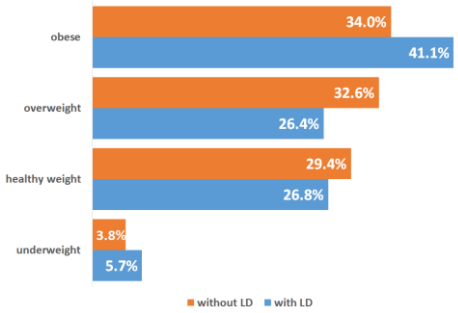
Weight

66.9% of people in Halton CCG with LD have a Body Mass Index (BMI) recorded in last 15 months:

- 71.7% women
- 63.5% men

This compares to 30.3% of those without LD

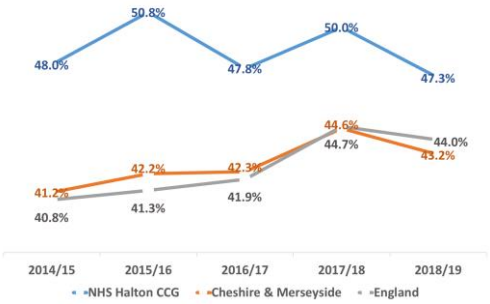
More people with LD obese compared to those without LD

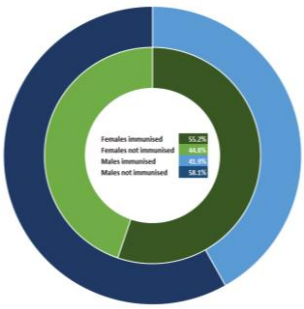


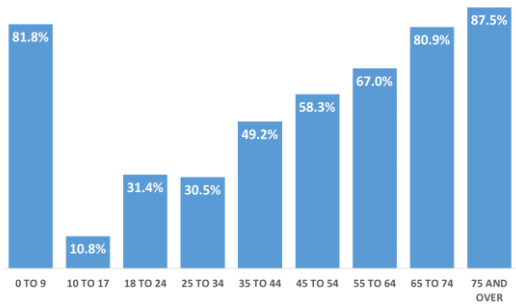
Flu vaccination uptake

The percentage being immunised against seasonal influenza (flu) has fallen both nationally and across Cheshire & Merseyside. Halton CCG has followed this patterns although it's uptake rate have been and remain higher than both. More women than men in Halton CCG are immunised. This is the same as the national picture. Immunisation levels increase with age. There is an anomaly with the 0-9 age group but this is probably due to small numbers in that group.

Target: At least 55% in all clinical risk groups…. Ultimately the aim is to achieve at least a 75% uptake in these groups given their increased risk of morbidity and mortality from flu.



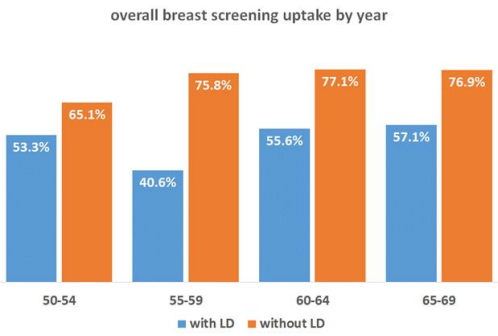


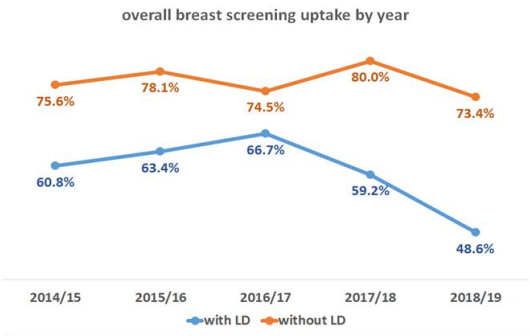


Health of people with LD

Cancer

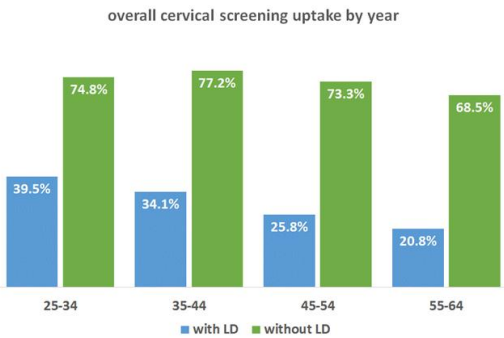
Cancer prevalence is lower in those with LD (1.9%) compared to those without LD (3.2%). However, the difference is less marked when the difference in age profile is taken into account (Standardised prevalence ratio 0.90).
Nevertheless, lower prevalence rates are consistent with the findings of the LeDeR programme which found a lower proportion of people with LD died from cancer compared to the general population (3rd Annual LeDeR report)

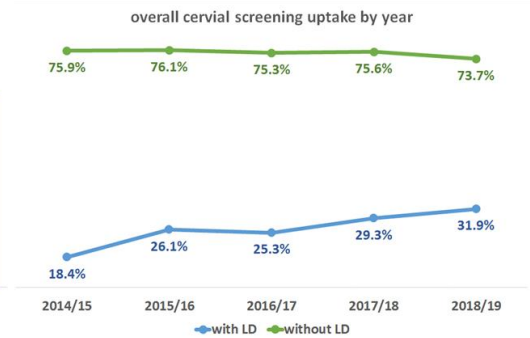


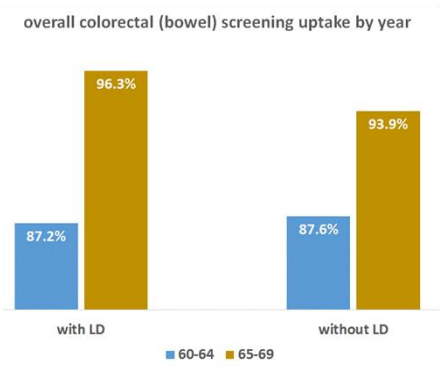


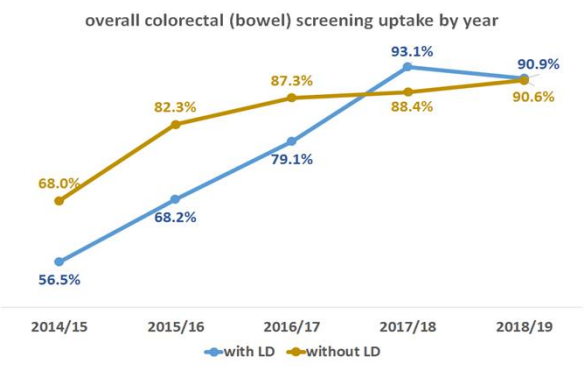
Biggest area for improvement is in cervical screening. Similar trends in uptake seen for those with LD and those without LD.

Gaps in service provision that may have contributed to the death of a person were reported in 7% of LeDeR reviews. This included access to cancer screening,





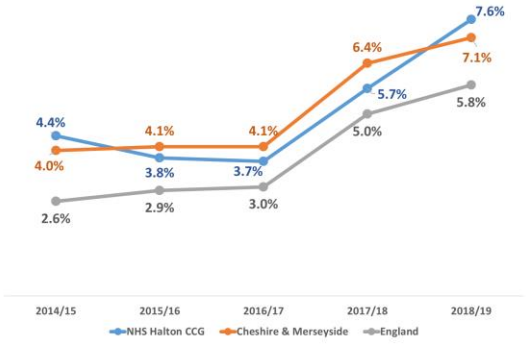


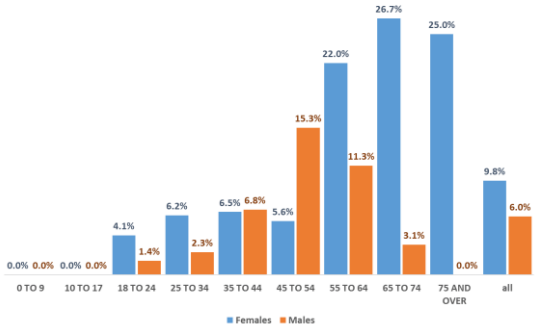


Health of people with LD

Long term conditions

Dysphagia is a term used to describe swallowing problems. It is more prevalent in LD patients in C&M than England, and even more so patients in Halton CCG. Affects more than 1 in 8 people with LD aged 55 and over. Generally dysphagia is more prevalent in older people.





Epilepsy, severe mental illness (psychosis) and dementia prevalence all much higher than for people with no LD. Most long-term chronic conditions are more prevalent in people with LD when age differences factored in (standardised prevalence ratio)

Long-Term Conditions: LD population compared to non-LD population

	Prevalence		Standardised Prevalence Ratio		
	LD	No LD	ratio	expected	observed
Epilepsy	16.5%	0.7%	23.84	5	20
Severe mental illness	7.0%	0.8%	6.75	8	51
Dementia	1.8%	0.7%	6.26	2	13
Palliative care	1.0%	0.5%	4.65	2	7
Hyperthroidism	7.3%	3.4%	2.41	22	53
Heart failure	2.1%	1.5%	3.38	4	15
CKD	3.3%	2.9%	2.04	12	24
T1 diabetes	0.6%	0.5%	1.20	3	4
Non-T1 diabetes	6.5%	5.6%	1.55	30	47
Asthma	10.5%	6.8%	1.83	42	76
Stroke/TIA	2.1%	1.8%	1.94	8	15
Depression	14.3%	16.8%	1.02	102	104
COPD	1.4%	2.7%	1.02	10	10
Hypertension	11.1%	14.4%	1.09	74	81
Cancer	1.8%	3.0%	0.85	15	13
CHD	1.8%	3.8%	0.88	15	13

	with LD	*without LD*
BP check in last 5 years	90.1%	32.1%
Hypertension prevalence	11.1%	7.2%
Epilepsy prevalence on drug treatment	16.5%	0.3%
Epileptic on drug trestment with seizure frequency known	39.2%	17.7%
Epileptic on drug trestment seizure free in last 12 months	51.1%	44.9%
Type 1 diabetes prevalence	0.6%	0.2%
non Type 1 diabetes prevalence	6.5%	2.8%
1FCC - HbA1c recorded	98.0%	92.9%
1FCC - HbA1c 75 mmol/mol or leass (satisfactory)	80.0%	83.7%

- Greater % LD patients have blood pressure (BP) checked, but a higher prevalence of hypertension
- Greater % of epileptics with LD on drug and seizure free in the last 12 months
- Recording of HbA1c is higher for people with LD; lower satisfactory management among LD compared to non-LD

1 in 7 patients with LD suffer from Gastric Reflux (GORD) and even greater numbers visit the GP due to constipation

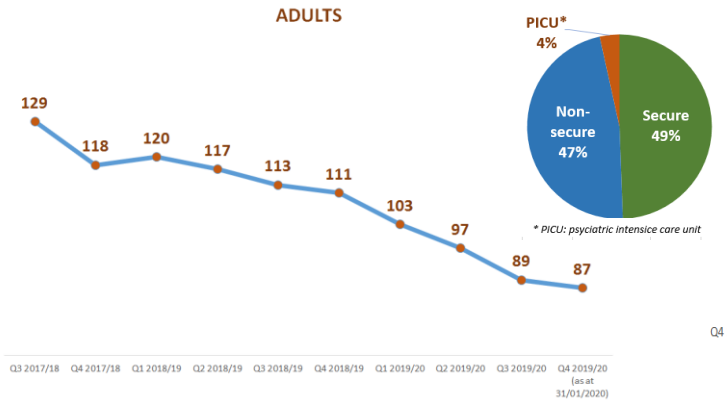
Conditions in LD population only

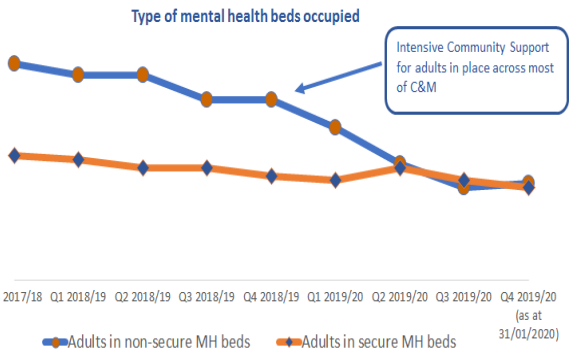
GORD	13.5%
Dysphagia	7.6%
Constipation	13.3%
Down's Syndrome	9.8%
Down's Syndrome with hyperthyroidism	2.5%
Down's Syndrome with dementia	0.8%

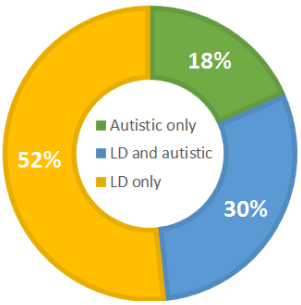
Health of people with LD

Mental Health Inpatients

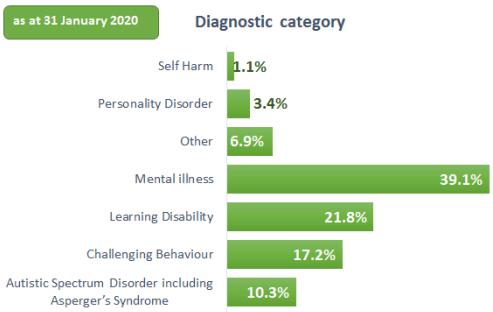
Recent trends show that whilst there has been a steady decrease quarter by quarter for the number of adults with LD who are mental health inpatients. Whilst the used to be many more people with LD in non-secure mental health beds, intensive community support has reduced this substantially and the two main types of beds are now roughly equal. PICU accounts for just 4%.

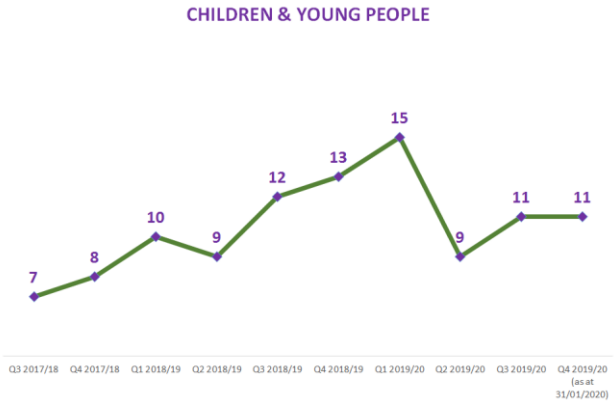






Over half of adults in mental health beds have LD only. Mental illness accounts for 1 in 3 of all patients, with LD and challenging behaviour also being important features.





Most children admitted have an autism only diagnosis rather than a dual LD & ASD diagnosis. Although the number of Children and Young People with LD/A in inpatient CAMHS beds looks low, Cheshire and Merseyside uses a higher number of inpatient CAMHS beds than the other North West areas. At the end of December 2019, the number of CYP inpatients across Cheshire and Merseyside was higher than the total number of inpatients from Greater Manchester and Lancashire and South Cumbria combined.

Technical Specification: Data Sources and Methodologies

All data in this profile is sourced from non-restricted published datasets (apart from page 11). Over time local areas may choose to add any non-published data they have access to.

Page 3:Population Estimates methodology and data sources

Both Learning Disabilities (LD) and Autistic Spectrum Disorder (ASD) use national surveys and research as a way of determining total population prevalence. This is done because relying on only those that are known to services is likely to be an under-estimate; not all those with the conditions will have had a diagnosis and/or have chosen to approach services for support.

Learning Disabilities:

Under 18s: *Emerson* E., H*astings* R.P., *McGill P,* Pinney A., Shurlock J. (*2014*) *Estimating the number of children in England with learning disabilities* and whose behaviours challenge

Adults (18 and over): figures for each LA taken from PANSI (covers age 18-64) and POPPI (covers 65plus). These require registration which is free

https://www.pansi.org.uk/index.php and https://www.poppi.org.uk/index.php

Autistic Spectrum Disorder:

Under 18s: Rydzewska E, Hughes-McCormack LA, Gillberg C, *et al*. Age at identification, prevalence and general health of children with autism: observational study of a whole country population. *BMJ Open* 2019;9:e025904. doi:10.1136/bmjopen-2018-025904

Adults (18 and over): *Adult Psychiatric Morbidity Survey* 2014, NHS Digital

https://digital.nhs.uk/data-and-information/publications/statistical/adult-psychiatric-morbidity-survey/adult-psychiatric-morbidity-survey-survey-of-mental-health-and-wellbeing-england-2014

Population projections:

Local population estimates determined by applying prevalence rates in the above reports to population projections from the Office for National Statistics (ONS) subnational population projections by persons, males and females, by single year of age. The latest subnational population projections available for England, published 24 May 2018 Accessed via Nomis website **https://www.nomisweb.co.uk/datasets/ppsyoala**

Technical Specification: Data Sources and Methodologies

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Population pyramid and gender breakdown: from data in the Health and Care of People with Learning Disabilities data series, NHS Digital **https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities**

QOF, NHS Digital: **https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2018-19-pas**

Children with SEN due to LD & ASD: Department for Education:**https://www.gov.uk/government/statistics/statements-of-sen-and-ehc-plans-england-2019**

Adult social care: Adult Social Care Activity and Finance Report, England - 2018-19 References tables dataset **https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2018-19**

Carers: Personal Social Services Survey of Adult Carers in England 2018-19 **https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19**

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Children with SEN due to LD & ASD: Department for Education: **https://www.gov.uk/government/statistics/statements-of-sen-and-ehc-plans-england-2019**

Children in Need who have a disability: **https://www.gov.uk/government/statistics/characteristics-of-children-in-need-2018-to-2019**

Estimating numbers with challenging behaviour: *Emerson* E., H*astings* R.P., *McGill P,* Pinney A., Shurlock J. (*2014*) *Estimating the number of children in England with learning disabilities* and whose behaviours challenge

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Long term support, Primary Support reason table: from Tables T36 and T37, Adult Social Care Activity and Finance Report, England - 2018-19 References tables dataset **https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2018-19**

Measures from the Adult Social Care Outcomes Framework (ASCOF), England, 2018-19: indicators 1E and 1G:**https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof/upcoming**

Education attainment and social housing statistics: **https://www.mentalhealth.org.uk/learning-disabilities/help-information/statistics/learning-disability-statistics-/187690**

Adult Safeguarding**: https://digital.nhs.uk/data-and-information/publications/statistical/safeguarding-adults/annual-report-2018-19-england**

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All data from Health and Care of People with Learning Disabilities, Experimental Statistics: 2018 to 2019, NHS Digital **https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2018-to-2019**

Flu vaccination target: **https://www.england.nhs.uk/wp-content/uploads/2019/03/annual-national-flu-programme-2019-to-2020-1.pdf**

Reference to LeDeR and page 9 regarding cancer: The Learning Disabilities Mortality Review – Annual Report 2018, Published: 21 May 2019

https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2018/#.XkKCLvnxKUk

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Unpublished data from Cheshire & Merseyside Transforming Care Programme Board