



**WIRRAL  
INTELLIGENCE  
SERVICE**

# **Learning Disability & Autistic Spectrum Disorder Profile**

**Wirral Intelligence  
Service**

**June 2020**

## **Learning Disability & Autistic Spectrum Disorder Profile**

The Learning Disability Profiles were developed in collaboration with the Cheshire & Merseyside Transforming Care Board. They are intended to support both local and sub-regional decision-making enabling local priority setting but providing a range of data on health and care needs of people with learning disabilities.

### **For further information please contact:**

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# Wirral Learning Disability & Autistic Spectrum Disorder Profile

This profile presents published data on the estimated population as well as those known to services as well as support offered by education, adult social care and health services.

## KEY FINDINGS/RECOMMENDATIONS

- **Prevalence:** There is an increase in the estimated prevalence of children with autism since the 2016 health needs assessment. This predicted the 2019 figure would be 746 but this profile estimates 1,316. Underlying prevalence has not changed significantly so this is likely due to adjustments made by Office for National Statistics (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 (CiN):** LD/A represents a substantial proportion of CiN who have a disability.

- ✿ **Support from Adult Social Care:** Wirral supports less adults with LD per head of population than Cheshire & Merseyside, the North West and England.
- ✿ **The proportion of adults living on their own or with their families** is lower in Wirral than in Cheshire & Merseyside but higher than England. It is consistent with the principles of Transforming Care.
- ✿ **The proportion in paid employment** is lower than both Cheshire & Merseyside and England. Across Cheshire & 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.
- ✿ Although the number of **Safeguarding (Section 42) enquiries** involving people with LD has fallen recently the Wirral rate has been statistically higher than England from 2015/16 to 2018/19.
- ✿ **Mortality Rates:** The death rate across England for people with LD is four-times higher than the general population. The average across Cheshire & Merseyside has been consistently higher than the England average. In Wirral it has consistently been lower, although the rate is statistically similar.
- ✿ **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 Wirral uptake has fallen. At 54.6% it is now higher than Cheshire & Merseyside average but below England.
- ✿ **Obesity:** The rate of obesity for people with LD is considerably higher in all Cheshire and Merseyside CCGs compared to 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. Wirral has performed consistently worse than Cheshire & Merseyside and England. At 39.5% uptake, it falls some way short of 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 prevalence for epilepsy, severe mental illness, dementia, non-type 1 diabetes and asthma. Prevalence of depression is also high, at a similar level to those without LD.

# Estimated Numbers of People

(sources on page 12 & 13)

## Learning Disabilities (LD)



1,980 under 18 estimated to have LD



575 18-24 year olds estimated to have LD



3,891 adults aged 25-64 estimated to have LD



1,476 older people aged 65 and over estimated to have LD



**TOTAL 7,922** Estimated people with LD living in Wirral

## Autistic Spectrum Disorder (ASD)

1,316 under 18 estimated to have ASD

220 18-24 year olds estimated to have ASD

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

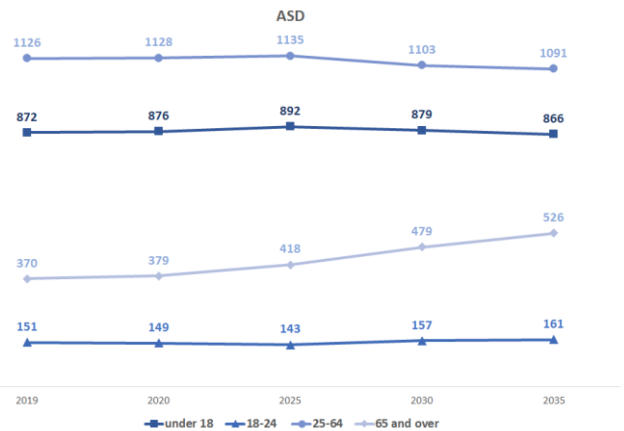
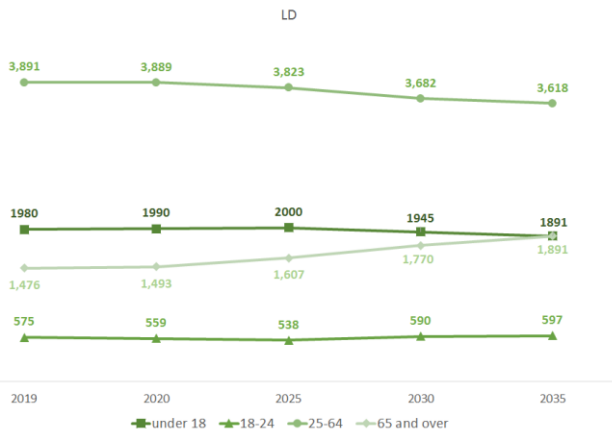
650 older people aged 65 and over estimated to have ASD

**TOTAL 3,772** Estimated people with ASD living in Wirral

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 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:



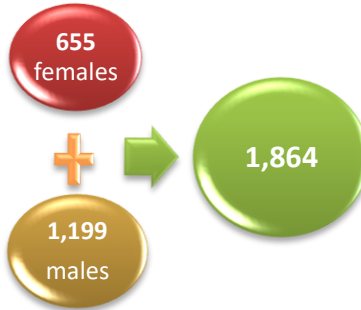
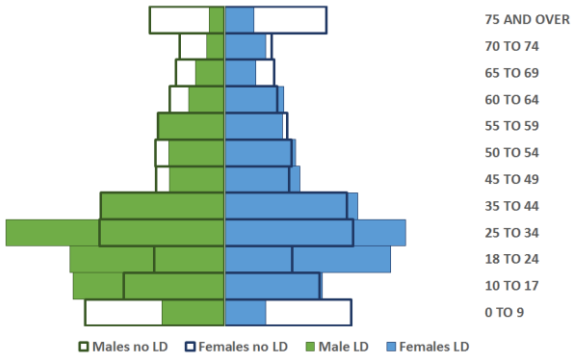
Most significant projected change is the increase in numbers aged 65 and over. This driven by population changes and assumes prevalence remains static. Dementia, including earlier onset dementia, and frailty will be particular challenges. This reflects the general population but will need approaches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

# Numbers known to services

(sources on page 12 & 13)

## Those with LD identified in Primary Care

Population distribution by age and gender: those with LD and those without



Based on **NHS Digital 2018/19** dataset  
Included **79%** of GP population data across NHS Wirral CCG

**QOF 2018/19** showed **2,414** 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 (2019) primary need:

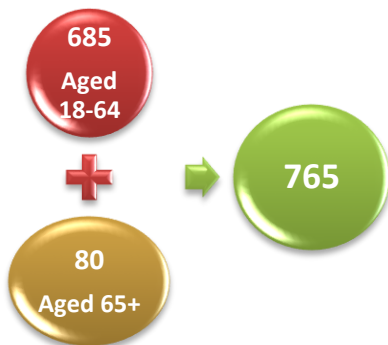
- Moderate learning difficulty
- Severe learning difficulty
- Profound & Multiple learning difficulty
- ASD



## By Adult Social Care

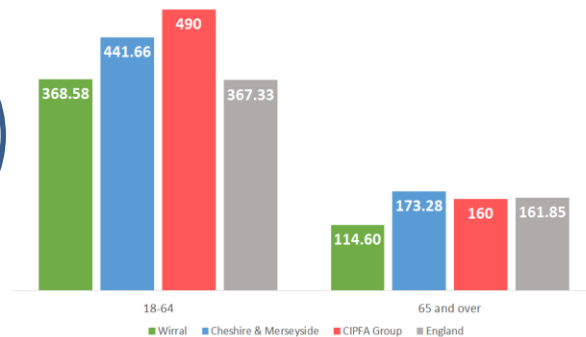
Receiving long term support (2018/19)

### Numbers



**25.8%** registered carers support someone with LD (C&M 21.5%, England 21%)

Rate per 100,000 population



# Children with LD and ASD (sources on page 12 & 13)

## 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*	723	16.4%	619	19.0%	894	77.2%
Moderate Learning Difficulty**	468	10.6%	306	9.4%	116	10.0%
Pupils with Severe Learning Difficulty**	9	0.2%	<5	<1%	409	35.4%
SEN due to: Profound & Multiple Learning Difficulty**	<5	<1%	0	0.0%	41	3.5%
Autistic Spectrum Disorder**	245	5.6%	311	9.5%	328	28.3%

\* percentage denominator is all pupils with SEN

\*\* percentage denominator is all pupils with SEN due to LD/ASD

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).

Wirral  
estimate  
158

### 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	Learning Disability
Wirral	2,830	329	26.7	45.6
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

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

11.6% (n=329) of Children in Need (CIN) in Wirral have a disability, higher than the 10.4% in both Cheshire & Merseyside (C&M) and North West (NW) who have a disability. It is lower than the 1 in 8 (12.4%) for England as a whole. Of those CiN, almost 5 out of 10 (150 of 329)\* have LD and 1 in 4 (88 of 329)\* have Autism/Asperger Syndrome (\*Note – underpinning data only provides percentages for the % CIN with a disability by type of disability recorded. The numbers are estimates based on those % so subject to a level of inaccuracy).

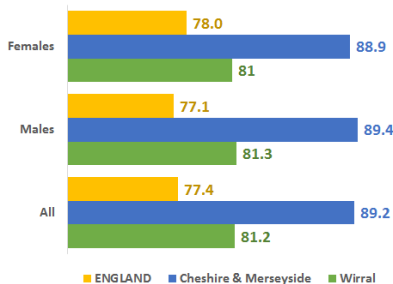
# Adults with LD and ASD (sources on page 12 & 13)

## 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
Wirral	685	368.58	80	114.60
Cheshire & Merseyside	6,570	441.66	850	173.28
CIPFA Group	n/a	490	n/a	160
North West	18,380	419.22	2,230	164.62
England	124,315	367.33	16,475	161.85

*CIPFA is a statistical neighbours grouping*

### ASCOF 1G: Proportion of adults with LD living on own or with family (2018/19)



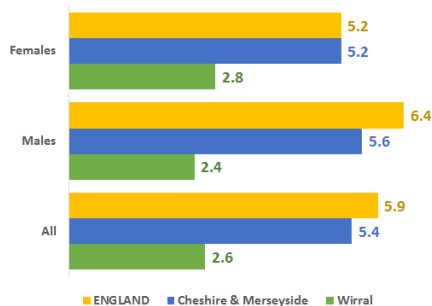
Lower proportion of Wirral people with LD living in the community than for Cheshire & Merseyside but higher than England (2018/19).

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 (2018/19)

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

Lower proportion with LD in paid employment in Wirral than Cheshire & Merseyside and England as a whole.



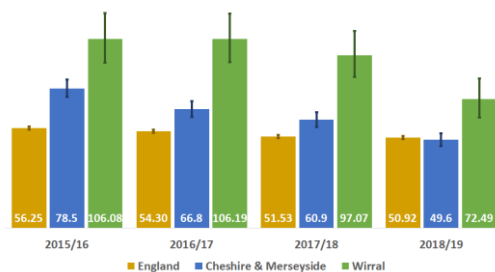
### Safeguarding: Individuals with LD involved in Section 42 safeguarding enquiries (2018/19)

Wirral rate statistically higher than England 2015/16-2018/19

#### Numbers each year

2015/16	225
2016/17	235
2017/18	225
2018/19	175

Rate per 1,000 on GP LD register

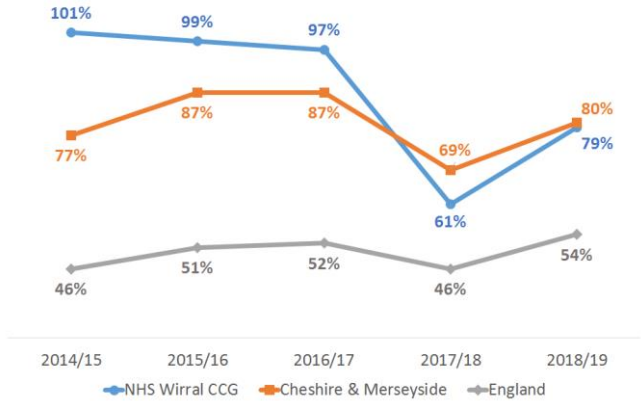
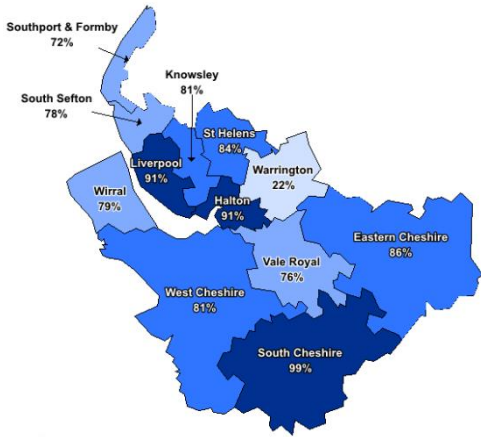




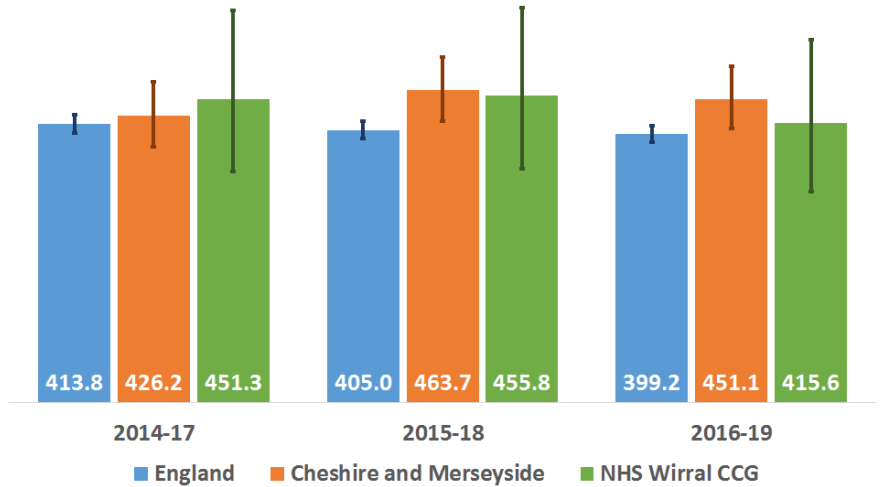
# Health of people with LD (sources on page 12 & 13)

Every year since 2014/15 NHS Digital collects 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 of GP practices in NHS Wirral CCG was higher than both Cheshire & Merseyside and England 2014/15 to 2016/17. It has remained higher than England but was lower than Cheshire & Merseyside 2017/18 and 2018/19.

## COVERAGE: percentage of patients included in data



People with learning disabilities have a death rate on average 4 times higher than the general population (if assuming All Population is 100). Whilst the average across Cheshire & Merseyside has been consistently higher than the England average, in Wirral it has consistently been lower, although the rate is statistically similar.

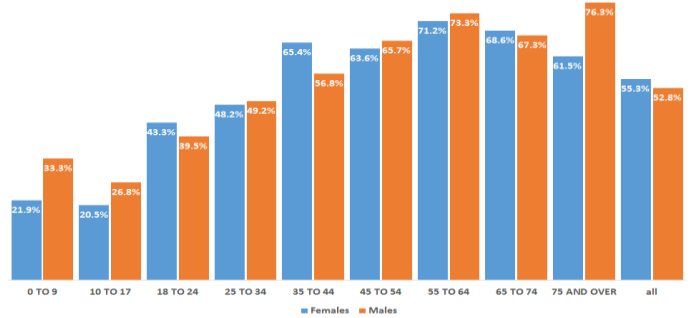
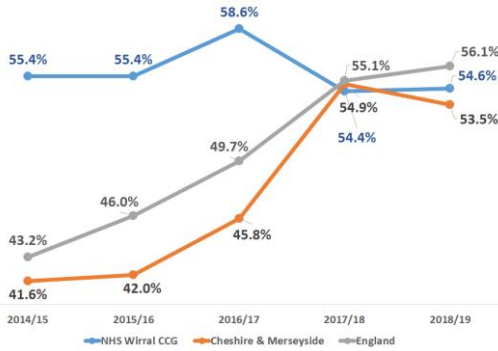


# Health of people with LD (sources on page 12 & 13)

## Health Promotion: Health Checks, BMI and Seasonal Influenza Immunisations (2018/19)

### Annual Health Checks

Wirral has performed steadily and for the most part better than Cheshire & Merseyside (C&M) and England. Improvements across England now mean it outperforms Wirral. The percentage receiving annual health checks generally increases with age, peaking at 55-64 for women and 75 and over for men



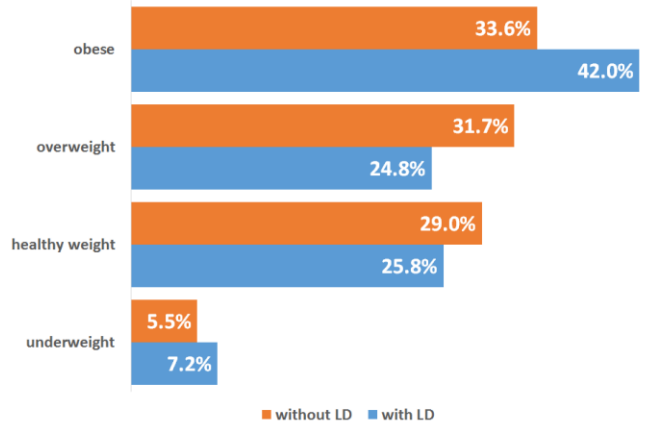
### Weight

60.7% of people in Wirral with LD have a Body Mass Index (BMI) recorded in last 15 months:

- 66.6% women
- 57.4% men

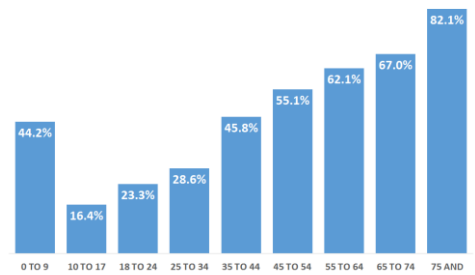
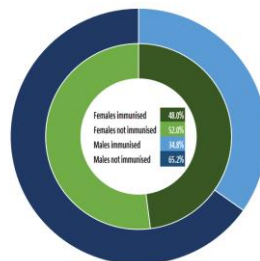
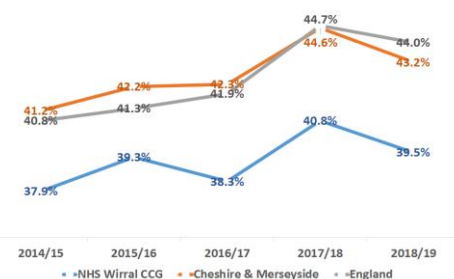
More people with LD obese compared to those without LD

This compares to 28.1% of those without LD



### Flu vaccination uptake

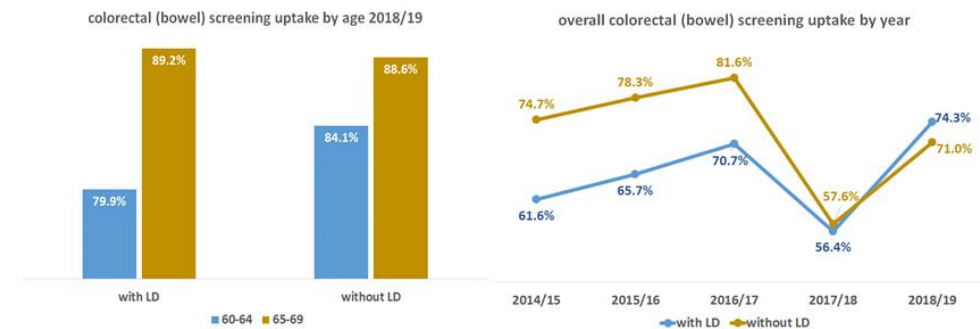
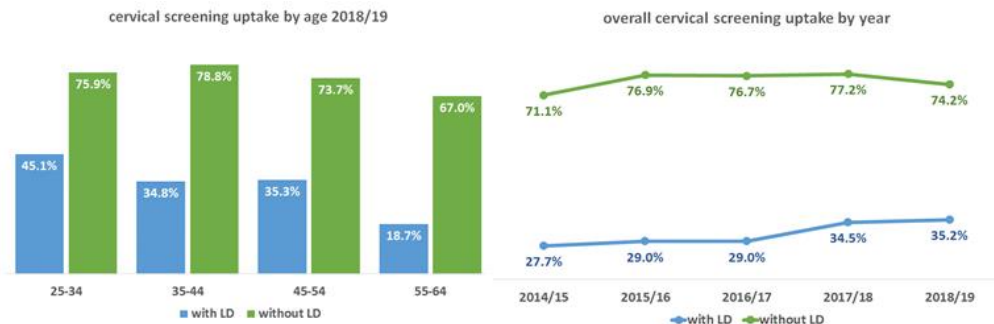
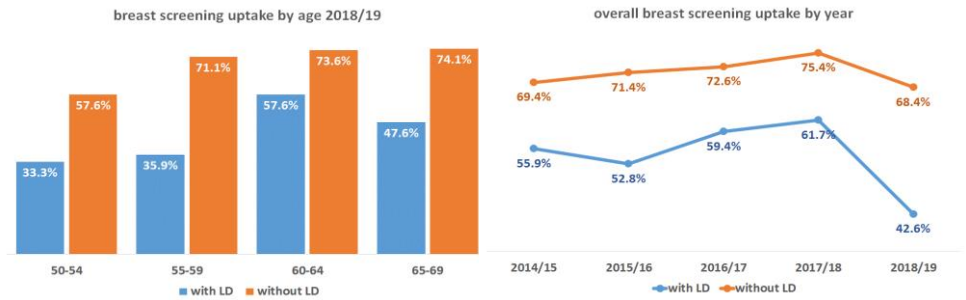
The percentage being immunised against seasonal influenza (flu) has fallen recently, both nationally and across C&M. This has also happened in Wirral, despite uptake rates having been consistently lower than C&M and England. More women than men in Wirral are immunised. This is the same as the national and C&M picture. Immunisation levels increase with age.



# Health of people with LD (sources on page 12 & 13)

## Cancer

Cancer prevalence lower in those with LD, 1.3%, compared to those without LD, 3.2%. When factoring the difference in age profile, the rate amongst people with LD is 25% LOWER than people without LD (Standardised prevalence ratio 0.75). These 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 (3<sup>rd</sup> Annual LeDeR report)



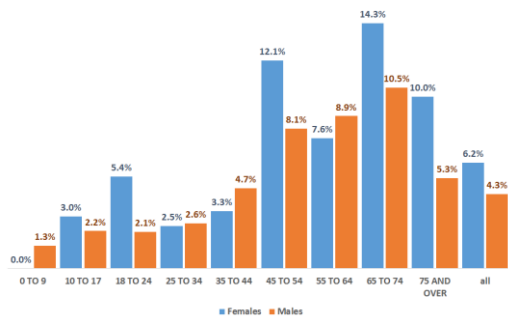
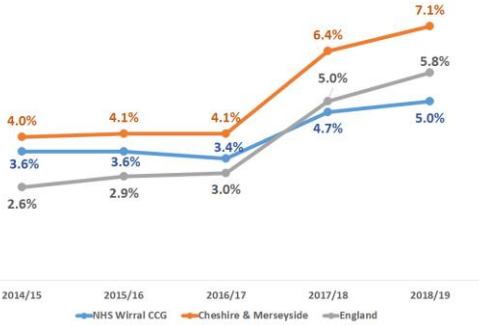
2018/19 data suggests the biggest area for improvement is in cervical screening. Similar trends in uptake seen for those with LD and those without LD.

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 (sources on page 12 & 13)

## Long Term Conditions

Dysphagia is a term used to describe swallowing problems. Rates in Wirral are now lower than both Cheshire & Merseyside and England. Affects more than 1 in 8 people with LD aged 55 and over. Generally dysphagia is more prevalent in older people. It is also more prevalent in women.



In terms of prevalence in populations, then for people with LD it is epilepsy, severe mental illness (psychosis) and asthma that are much higher than for people with no LD. Also the vast majority of long-term chronic conditions, except for Cancer, CHD and High BP, are more prevalent in people with LD when age differences factored in (standardised prevalence ratio) (2018/19 data)

**Example:**  
 SPR = 0.5 - the condition is half as common as expected in people with learning disabilities.  
 SPR = 2 - the condition is twice as common as expected in people with learning disabilities

	Prevalence in population		Standardised Prevalence Ratio		
	LD	No LD	expected	observed	ratio
epilepsy	15.5%	0.7%	12	289	24.50
severe mental illness	7.5%	1.0%	17	140	8.45
dementia	0.9%	1.0%	5	17	3.47
palliative care	0.6%	0.6%	3	12	3.54
hyperthyroidism	7.7%	4.3%	48	143	3.00
heart failure	1.4%	1.3%	10	26	2.67
CKD	2.4%	3.5%	27	45	1.70
T1 diabetes	0.9%	0.4%	8	16	1.98
non T1 diabetes	5.6%	4.6%	64	104	1.61
asthma	10.6%	6.7%	104	197	1.90
stroke/TIA	1.0%	2.0%	17	19	1.12
depression	17.3%	18.0%	219	323	1.48
COPD	1.3%	2.4%	21	24	1.13
hypertension	8.2%	13.8%	160	152	0.95
cancer	1.3%	3.2%	33	25	0.75
CHD	1.3%	3.4%	32	24	0.76

	with LD	without LD
BP check in last 5 years	82.7%	32.1%
Hypertension prevalence	8.2%	6.9%
Epilepsy prevalence on drug treatment	15.5%	0.4%
Epileptic on drug treatment with seizure frequency known	21.8%	7.2%
Epileptic on drug treatment seizure free in last 12 months	55.6%	54.0%
Type 1 diabetes prevalence	0.9%	0.2%
non Type 1 diabetes prevalence	5.6%	2.3%
1FCC - HbA1c recorded	90.8%	91.8%
1FCC - HbA1c 75 mmol/mol or less (satisfactory)	75.2%	85.2%

- Greater % LD patients have blood pressure (BP) checked
- Greater % of epileptics with LD on drug treatment and also seizure free in last 12 months
- Recording of HbA1c higher amongst those with LD but satisfactory management is lower compared to those without LD
- All (2018/19 data)

1 in 10 Wirral patients with LD suffer from Gastric Reflux (GORD) and even greater numbers visit the GP due to constipation (2018/19 data)

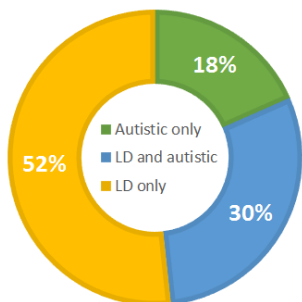
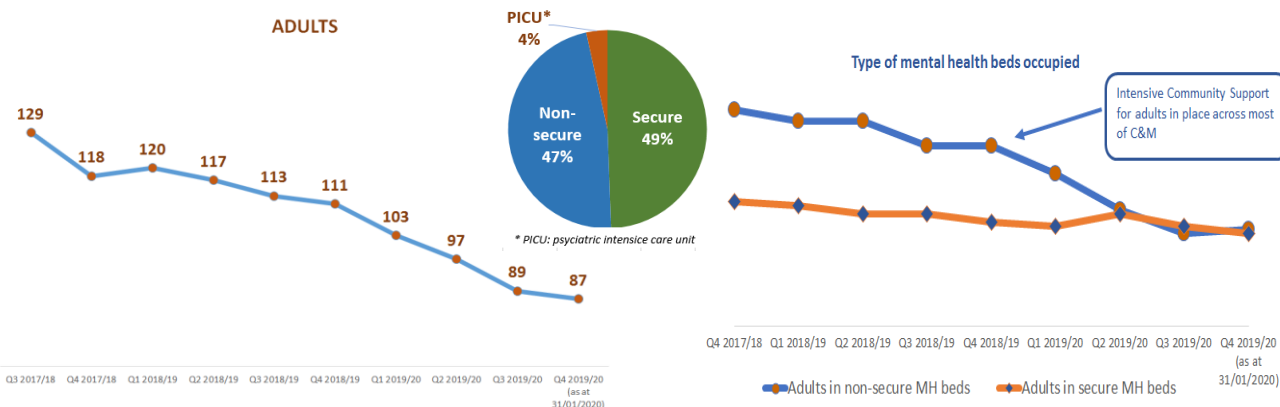
### Learning Disability - Long Term Conditions (Wirral CCG) (2018/19)

GORD	10.7%
Dysphagia	5.0%
Constipation	13.6%
Down's Syndrome	8.0%
Down's Syndrome with hyperthyroidism	2.7%
Down's Syndrome with dementia	0.3%

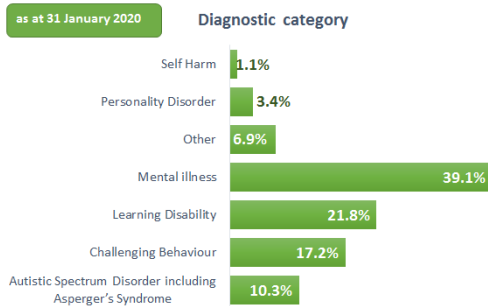
# Health of people with LD (sources on page 12 & 13)

## Mental Health Inpatients in Cheshire & Merseyside

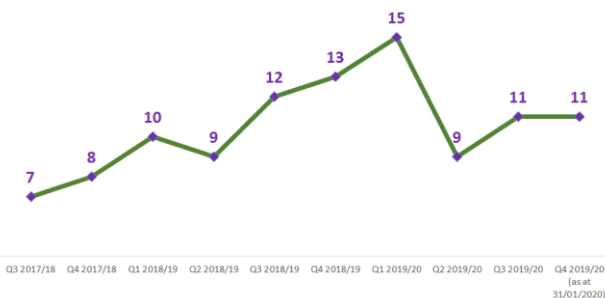
Recent trends show that whilst there has been a steady decrease quarter by quarter for the number of adults with LD who are mental health inpatients. In the past there were many more people with LD in non-secure mental health beds, intensive community support has reduced this substantially and the two 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.



### CHILDREN & YOUNG PEOPLE



Most **children admitted as inpatients** 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 from Greater Manchester and Lancashire and South Cumbria combined. At the end of December 2019, the number of CYP inpatients across Cheshire and Merseyside was higher than the total number of inpatients from the other North West areas.

# 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., Hastings 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-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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## Page 4

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-](https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities)

[information/publications/statistical/health-and-care-of-people-with-learning-disabilities](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>

## Page 5

Children with SEN due to LD & ASD: Department for Education:

<https://www.gov.uk/government/statistics/statements-of-sen-and-ehc-plans-england-2019>

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