

InformGloucestershire

Adults with Learning Disabilities in Gloucestershire Prevalence of Needs

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Key points

- In the 10-year period to 2018, Gloucestershire's **adult population** (aged 18+) saw an increase of nearly 40,300 people, with the over-65s accounting for nearly three-quarters of the growth. Long-term projections suggest that the majority of growth of adult population in Gloucestershire will continue to be driven by older people.
- **Learning Disability** is a type of disability. A person with a learning disability finds it harder than others to learn, understand new or complex information and communicate. The key components of learning disability are a reduced intellectual ability that affects someone for their whole life, and may vary from one person to another in severity.
- People with learning disabilities have **poorer health outcome** than the general population, much of which is avoidable.
- **Modelled data estimates** that currently nearly 12,000 adults in Gloucestershire have a learning disability in Gloucestershire, with those aged between 18 and 64 accounting for three-quarters of the total. However, the rate of increase in the next 10 years is predicted to be most steep in the older age groups as life expectancy improves.
- People with **severe or moderate learning disability** are more likely to have social care need than those with mild conditions. Modelling suggest that in Gloucestershire, one in five adults who have a learning disability have a moderate or severe form of the condition, with the majority being under the age of 65.
- Patient Register records show that the number of **diagnosed cases** for a learning disability of all ages in Gloucestershire rose by 15.8% between 2014/15 and 2018/19, from 3,403 to 3,941 people.
- As of May 2019, a total of 3,163 people aged 16 or over in Gloucestershire were claiming a benefit for a learning disability condition. Nearly all of them (98%) were assessed as having a **care or support need**. Data shows that the majority of these (66.9%) were receiving the high or enhanced rate of the benefit, suggesting considerable, long-term personal care and support needs.
- **Autistic Spectrum Disorder (ASD)** is not a learning disability, but around half of people with autism may have a learning disability. Modelled data and calculations suggest that in Gloucestershire, around 3,200 adults currently have a learning disability as a result of ASD. The number is expected to rise to 3,500 in 2030.

Key points (continued)

- A person with **Down's syndrome** will have some degree of learning disability, but the level varies between individuals. Modelling suggests that in Gloucestershire, Down's syndrome affects around 255 adults aged 18 and over in 2020, and the majority are under the age of 65.
- **Challenging behaviour** is not a learning disability, but people with a learning disability are more likely to show challenging behaviour, partly due to communication problems. Modelled estimates suggest that challenging behaviour affects around 170 adults aged 18-64 in 2020 in Gloucestershire, with the number projected to remain stable in the next 10 years.
- Many people with learning disabilities have **complex need**, as they are likely to also develop other long-term health conditions, such as speech impairment, vision impairment, and hearing loss.
- People with learning disabilities are also at an increased risk of developing **dementia** as they age, and they generally develop it at a younger age than the general population. This is particularly the case for people with Down's syndrome. Studies found that people with learning disabilities are less likely to receive a correct or early diagnosis of dementia.
- National survey of carers suggests that compared to other groups of carers, **carers providing learning disability support** were more likely to provide 100 or more hour of care each week, and more likely to have a learning disability themselves
- The same survey also suggests that **quality of life most adversely impacted on by caring for people with a learning disability** was around worries about personal safety, lack of encouragement and support, social isolation, and self-neglect.

Introduction

- This document provides a broad outline of needs of adults with learning disabilities in Gloucestershire that might impact on future demand for social care. The aim is to bring together key evidence to support Gloucestershire County Council and our partner organisations in their understanding of potential social care needs of our most vulnerable adults in the County.
- Since the introduction of the Care Act 2014, as well as identifying need, local authorities are required to identify individuals' strengths – personal, community and social networks – and to maximise those strengths. This will enable people to achieve better outcomes, meeting their needs and improving or maintaining their wellbeing. [Strengths-based analysis](#) on Inform Gloucestershire further provides a baseline understanding of the strengths of the local adult population as well as adult social care service users in Gloucestershire. The [Community](#) theme on Inform Gloucestershire also looks at other characteristics within the population such as social capital and community assets that may mitigate any needs.

Current Adult Population in Gloucestershire

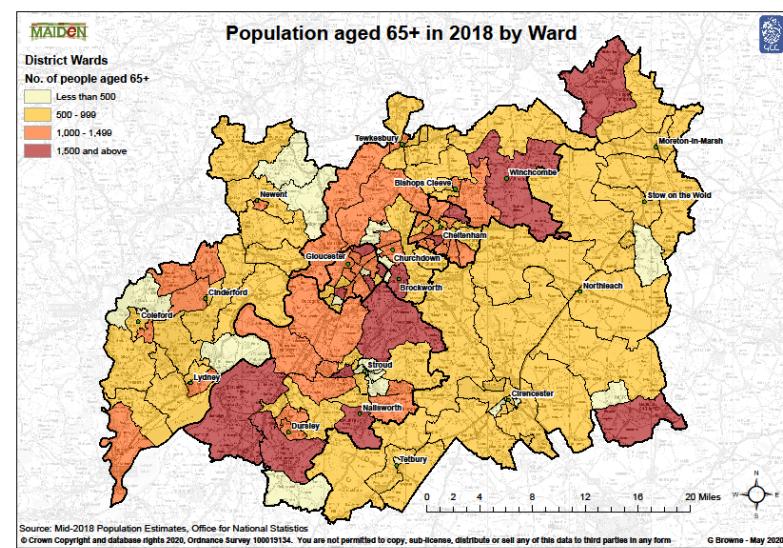
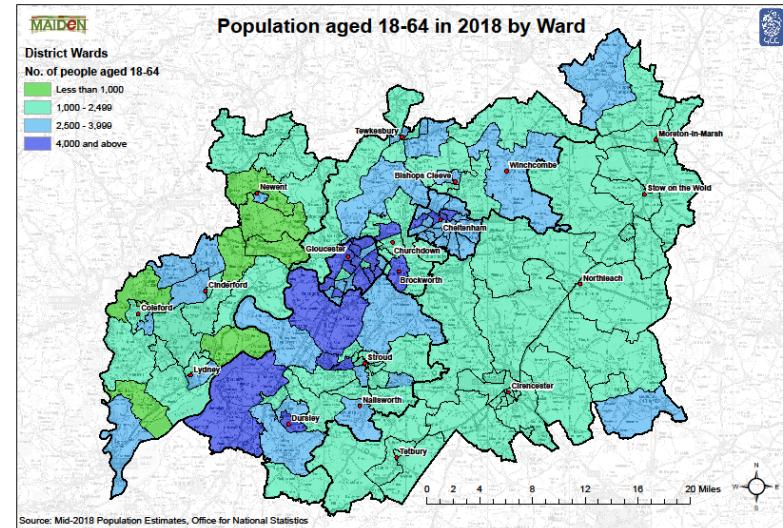
- In the 10-year period to 2018, Gloucestershire's adult population (aged 18+) saw an increase of nearly 40,300 people, with the over-65s accounting for nearly three-quarters of the growth.
- By 2018, a total of 505,400 people aged 18 or over were living in Gloucestershire. Across the County, just over a quarter (26.7%, 135,000 people) of the adult population were over-65s.
- Currently, Gloucester City had the largest adult population in the County (100,300 people), driven by a large number of 18-64 year olds. Stroud district had the largest number of the older population (26,600 people) in the County.

Adult Population in Gloucestershire Districts, Mid-2018				
	Adult population			District share of adult population Aged 18+
	Aged 18-64	Aged 65+	Aged 18+	
Gloucestershire	370,449	134,973	505,422	100.0%
Cheltenham	71,291	22,519	93,810	18.6%
Cotswold	49,933	22,760	72,693	14.4%
Forest of Dean	49,133	21,034	70,167	13.9%
Gloucester	78,727	21,570	100,297	19.8%
Stroud	68,391	26,618	95,009	18.8%
Tewkesbury	52,974	20,472	73,446	14.5%
% by Age Gloucestershire	73.3%	26.7%	100.0%	

Source: Mid-2018 Population Estimates, Office for National Statistics

Current Distribution of Adult Population by Ward

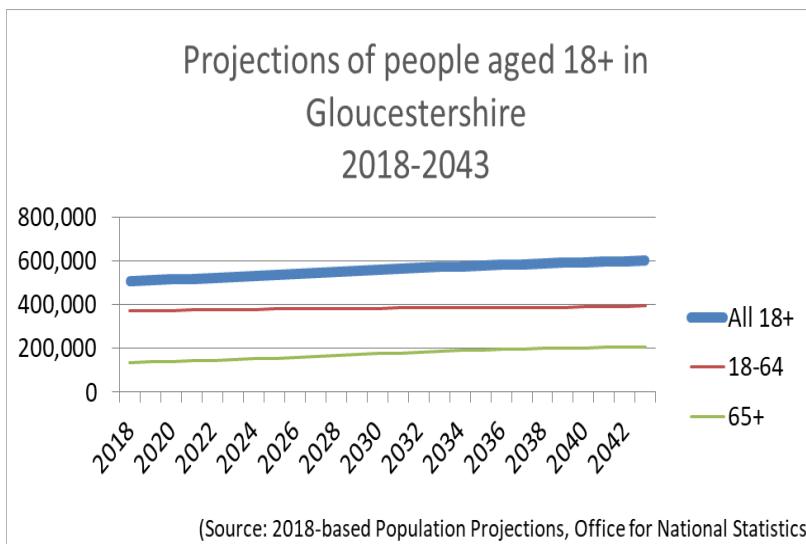
- In 2018, there were 22 council wards that had more than 4,000 residents who were aged 18 or over. Most of the areas with the highest numbers of adults were in Gloucester City. The top 10 areas were Barton and Tredworth, Moreland, Matson and Robinswood, Barnwood, Abbeydale, Abbeymead, Longlevens, Westgate, St Paul's and St Peter's.
- In the same year, there were 15 council wards that had at least 1,500 residents aged over-65. These were Hucclecote (Gloucester), Longlevens, Campden & Vale, Winchcombe, Prestbury, Abbeydale, Wotton-under-Edge, Grange, Painswick and Upton, Lechlade, Kempsford & Fairford South, Berkeley Vale, Park, Caincross, Brockworth and Nailsworth.



(Source: Annual Small Area Population Estimates 2018, Office for National Statistics)

Projected Adult Population for Gloucestershire

- Latest projections suggest that adult population in Gloucestershire will rise between 2018 and 2043, but different age groups are forecast to grow at different rates.
- The 18-64 year-olds are projected to rise moderately, by 6.6% in the 25-year period and reach 394,900 people by 2043, while older people aged 65+ are expected to increase by 52.5% and reach an estimated 205,900 people in the same period.
- The projections are equivalent to an average annual increase of 980 people aged 18-64, and 2,800 people aged 65+ over the 25-year period.



Projections of people aged 18+ in Gloucestershire by age group

	2018	2030	2043	change 2018-43	% change 2018-43
All 18+	505,422	559,200	600,799	95,377	18.9%
18-64	370,449	383,835	394,934	24,485	6.6%
65+	134,973	175,365	205,865	70,892	52.5%

Source: 2018-based Population Projections, Office for National Statistics

Projected Adult Population for Districts

- At a district level, Tewkesbury Borough is projected to have the greatest increase in population aged 18-64 in the County between 2018 and 2043, rising by 21.3% and by 11,300 people.
- At the same time, Cotswold is projected to have the greatest increase in the older population aged 65+ between 2018 and 2043, rising by 65.1% and by 14,800 people.

Projections of adult population in Gloucestershire Districts, by broad age group										
	2018		2030		2043		No. change 2018-2043		% change 2018-2043	
	Age 18-64	Age 65+	Age 18-64	Age 65+	Age 18-64	Age 65+	Age 18-64	Age 65+	Age 18-64	Age 65+
Gloucestershire	370,449	134,973	383,835	175,365	394,934	205,865	24,485	70,892	6.6%	52.5%
Cheltenham	71,291	22,519	69,534	28,374	69,594	32,759	-1,697	10,240	-2.4%	45.5%
Cotswold	49,933	22,760	54,018	31,074	55,971	37,571	6,038	14,811	12.1%	65.1%
Forest	49,133	21,034	50,203	26,888	51,700	30,675	2,567	9,641	5.2%	45.8%
Gloucester	78,727	21,570	79,784	28,191	81,491	32,958	2,764	11,388	3.5%	52.8%
Stroud	68,391	26,618	70,315	33,704	71,896	39,295	3,505	12,677	5.1%	47.6%
Tewkesbury	52,974	20,472	59,981	27,134	64,282	32,607	11,308	12,135	21.3%	59.3%

Source: 2018-based Population Projections, Office for National Statistics

What is Learning Disability

- The NHS defines Learning Disability (LD) as a type of disability.
- A person with a learning disability finds it harder than others to learn, understand new or complex information and communicate.
- This includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood with a lasting effect on development.
- The document 'Valuing People - A New Strategy for Learning Disability for the 21st Century' by the Department of Health and Social Care defines someone as having a learning disability if they function at a level of intellectual ability significantly lower than their chronological age, usually considered as having an IQ of seventy or less.
- It also suggests that mild learning disability is broadly comparable to the educational term 'moderate learning difficulty', and moderate-to-profound learning disability is comparable to the educational term 'severe learning difficulty'.
- The key components of learning disability are therefore a reduced intellectual ability that affects someone for their whole life, and may vary from one person to another in severity.

Learning Disability and Health Inequalities

- People with learning disabilities have poorer health outcome than the general population, much of which is avoidable.
- These health inequalities often start early in life and result, to an extent, from barriers they face in accessing timely, appropriate and effective health care.
- The impact of these health inequalities is serious; as well as having a poorer quality of life, people with learning disabilities die at a younger age than their non-disabled peers.
- The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found that men with learning disabilities died on average 13 years younger than men in the general population and women 20 years younger.
- CIPOLD data also shows that people with learning disabilities are three times as likely as people in the general population to have a death classified as potentially avoidable through the provision of good quality healthcare.

Modelled Prevalence and Projections of Learning Disability

- PANSI and POPPI models estimate that in 2020, nearly 12,000 adults in Gloucestershire have a learning disability, with those aged between 18 and 64 accounting for 75.4% (8,990 people) of the total.
- However, the rate of increase between 2020 and 2030 is predicted to be most steep in the older age groups as life expectancy improves, rising by 47.2% for those aged 85 and over and 34.7% for those aged 75-84.
- PANSI and POPPI project that by 2030 there will be 9,020 people aged 18-64 and 3,690 people aged 65 and over who have a learning disability condition in Gloucestershire.

People aged 18 and over predicted to have a learning disability in Gloucestershire				
	2020	2025	2030	% change 2020-2030
Aged 18-24	1,250	1,240	1,380	10.4%
Aged 25-34	1,790	1,750	1,670	-6.7%
Aged 35-44	1,840	1,950	1,980	7.6%
Aged 45-54	2,110	1,920	1,900	-10.0%
Aged 55-64	2,000	2,160	2,090	4.5%
Total Aged 18-64	8,990	9,020	9,020	0.3%
Aged 65-74	1,630	1,660	1,880	15.3%
Aged 75-84	950	1,180	1,280	34.7%
Aged 85 and over	360	420	530	47.2%
Total Aged 65+	2,940	3,260	3,690	25.5%
Total Aged 18 and over	11,930	12,280	12,710	6.5%

(Source: PANSI and POPPI Version 13 - 2016-based projections. Numbers rounded)

Modelled Prevalence and Projections of Moderate or Severe Learning Disability

- People with severe or moderate learning disability are more likely to have social care need than those with mild conditions. PANSI and POPPI data suggest that in Gloucestershire, one in five adults who have a learning disability have a moderate or severe form of the condition.
- In 2020, an estimated 2,400 adults in Gloucestershire have a moderate or severe learning disability in Gloucestershire, with the majority (83.9%) being under the age of 65.
- However, the rate of increase is predicted to rise rapidly in the older age groups, by 30.0% for those aged 75-84 and 66.7% for those aged 85 and over between 2020 and 2030.

People aged 18 and over predicted to have a moderate or severe learning disability Gloucestershire				
	2020	2025	2030	% change 2020-2030
Aged 18-24	290	290	330	13.8%
Aged 25-34	380	380	360	-5.3%
Aged 35-44	460	490	500	8.7%
Aged 45-54	470	430	430	-8.5%
Aged 55-64	430	470	450	4.7%
Total Aged 18-64	2,030	2,060	2,070	2.0%
Aged 65-74	260	270	310	19.2%
Aged 75-84	100	120	130	30.0%
Aged 85 and over	30	40	50	66.7%
Total Aged 65+	390	430	490	25.6%
Total Aged 18 and over	2,420	2,490	2,560	5.8%

(Source: PANSI and POPPI Version 13 - 2016-based projections. Numbers rounded)

People Diagnosed with a Learning Disability Condition

- The Patient Register records the number of people of all ages diagnosed with learning disabilities in Gloucestershire.
- Recorded diagnosed cases rose between 2014/15 and 2018/19 from 3,403 to 3,941. This represents an increase of 538 people (i.e. 15.8%) over the 4-year period.

People (all ages) diagnosed with a learning disability in Gloucestershire			
	Number of patients diagnosed with learning disabilities	% of patients diagnosed with learning disabilities*	
	Gloucestershire	Gloucestershire	England
2014/15	3,403	0.5	0.4
2015/16	3,464	0.5	0.5
2016/17	3,549	0.6	0.5
2017/18	3,623	0.6	0.5
2018/19	3,941	0.6	0.5

*Numerator: The total number of patients with learning disabilities as recorded on practice disease register. Denominator: All registered patients

Source: Fingertips, Public Health England

Current Benefit Claims for a Learning Disability Condition

- As of May 2019, a total of 3,163 people aged 16 or over in Gloucestershire were claiming a benefit for a learning disability condition. This represents a decrease of 2-3% on the previous three years.
- The latest benefit claim number was comparable with POPPI and PANSI estimated prevalence of adults with a moderate or severe learning disability in Gloucestershire (2,420 people in 2020) which excluded the 16 and 17 year-olds.

Benefit claims for people aged 16+ with learning difficulties in Gloucestershire						
	May 2014	May 2015	May 2016	May 2017	May 2018	May 2019
DLA (Learning Disability) Aged 16+	2,806	2,871	2,730	2,042	1,596	1,163
DLA (Severely Mentally Impaired) Aged 16+	118	127	125	87	76	60
AA (Learning Disability) Aged 65+	19	23	19	17	12	11
AA (Severely Mentally Impaired) Aged 65+	-	-	-	-	-	-
PIP (Learning Disability) Aged 16+	12	44	207	763	1,105	1,350
PIP (Autistic Spectrum Disorders) Aged 16+	10	46	156	365	475	579
Total	2,965	3,111	3,237	3,274	3,264	3,163

DLA: Disability Living Allowance; AA: Attendance Allowance; PIP (Personal Independence Payment). Figures include both care and mobility components for DLA and PIP and all award rates for AA (For details see Notes)

Source: Stat-Xplore, Department for Work and Pensions

Care and Support Need

- Out of a total of 3,163 people aged 16 and over receiving benefits for a learning disability in Gloucestershire (see previous slide), 98% (3,107 people) were assessed as having a care or support need.
- Of these, 66.9% (i.e. 2,080 people) were receiving the high or enhanced rate of the benefit, suggesting that for the majority of claimants, there were considerable, long-term personal care and support need. The proportion awarded high or enhanced rate was also increasing fast: the percentage was 25.4% in 2014.

People aged 16+ with learning difficulties awarded care or daily living components of disability benefits in Gloucestershire							
		May 2014	May 2015	May 2016	May 2017	May 2018	May 2019
Total people aged 16+ awarded care or daily living components		2,903	3,055	3,174	3,227	3,224	3,107
Number receiving high or enhanced rate:							
DLA (Learning Disability) Aged 16+	High	589	621	611	452	364	270
DLA (Severely Mentally Impaired) Aged 16+	High	116	122	125	86	78	60
AA (Learning Disability) Aged 65+	High	10	10	8	7	5	5
PIP (Learning Disability) Aged 16+	Enhanced	12	40	178	718	1,045	1,280
PIP (Autistic Spectrum Disorders) Aged 16+	Enhanced	10	33	112	294	379	465
Total number receiving high or enhanced rate		737	826	1,034	1,557	1,871	2,080
% receiving high or enhanced rate		25.4%	27.0%	32.6%	48.2%	58.0%	66.9%

DLA: Disability Living Allowance; AA: Attendance Allowance; PIP (Personal Independence Payment). Figures include both care and mobility components for DLA and PIP and all award rates for AA (For details see Notes)

Source: Stat-Xplore, Department for Work and Pensions

Autistic Spectrum Disorder

- Autism is not a learning disability, but around half of people with autism may have a learning disability, which will affect the level of support they need in their life.
- Projections from PANSI and POPPI suggest that in Gloucestershire, there are around 6,300 adults with Autistic Spectrum Disorder (ASD) in 2020, and the number is projected to rise to nearly 7,000 in 2030.
- This can be translated into a total of 3,200 adults in Gloucestershire who have a learning disability as a result of ASD as of 2020. The number is expected to rise to 3,500 in 2030.

People aged 18 and over predicted to have Autistic Spectrum Disorders Gloucestershire				
	2020	2025	2030	% change 2020-2030
Aged 18-24	470	470	520	10.6%
Aged 25-34	710	700	670	-5.6%
Aged 35-44	740	770	780	5.4%
Aged 45-54	890	810	790	-11.2%
Aged 55-64	860	940	910	5.8%
Total Aged 18-64	3,670	3,690	3,670	0.0%
Aged 65-74	720	740	840	16.7%
Aged 75-84	590	730	820	39.0%
Aged 85 and over	1,310	1,470	1,660	26.7%
Total Aged 65+	2,620	2,940	3,320	26.7%
Total Aged 18 and over	6,290	6,630	6,990	11.1%

(Source: PANSI and POPPI Version 13 - 2016-based projections. Numbers rounded)

Down's Syndrome

- A person with Down's syndrome will have some degree of learning disability, but the level of ability varies between individuals.
- POPPI and PANSI estimate that in Gloucestershire, Down's syndrome affects around 255 adults aged 18 and over in 2020, and the number is projected to reduce slightly to 240 by 2030.
- The majority are under the age of 65.

People aged 18 and over predicted to have Down's Syndrome in Gloucestershire				
	2020	2025	2030	% change 2020-2030
Aged 18-24	30	30	30	0.0%
Aged 25-34	50	40	40	-20.0%
Aged 35-44	50	50	50	0.0%
Aged 45-54	60	50	50	-16.7%
Aged 55-64	60	60	60	0.0%
Age 65+	5	6	6	20.0%
Total Aged 18 and over	255	236	236	-7.5%

(Source: PANSI and POPPI Version 13 - 2016-based projections. Numbers rounded)

Challenging Behaviour

- Challenging behaviour is not a learning disability, but people with a learning disability are more likely to show challenging behaviour. This can be due to people having difficulty communicating and expressing frustrations.
- PANSI and POPPI estimate that challenging behaviour affects around 170 adults aged 18-64 in 2020 in Gloucestershire, with the number projected to remain stable in the next 10 years.

People aged 18-64 with a learning disability, predicted to display challenging behaviour, by age			
Gloucestershire			
	2020	2025	2030
Age 18-24	21	21	23
Age 25-34	32	32	30
Age 35-44	34	35	36
Age 45-54	40	37	36
Age 55-64	40	43	41
Total Age 18-64	167	167	167

(Source: PANSI and POPPI Version 13 - 2016-based projections. Numbers rounded)

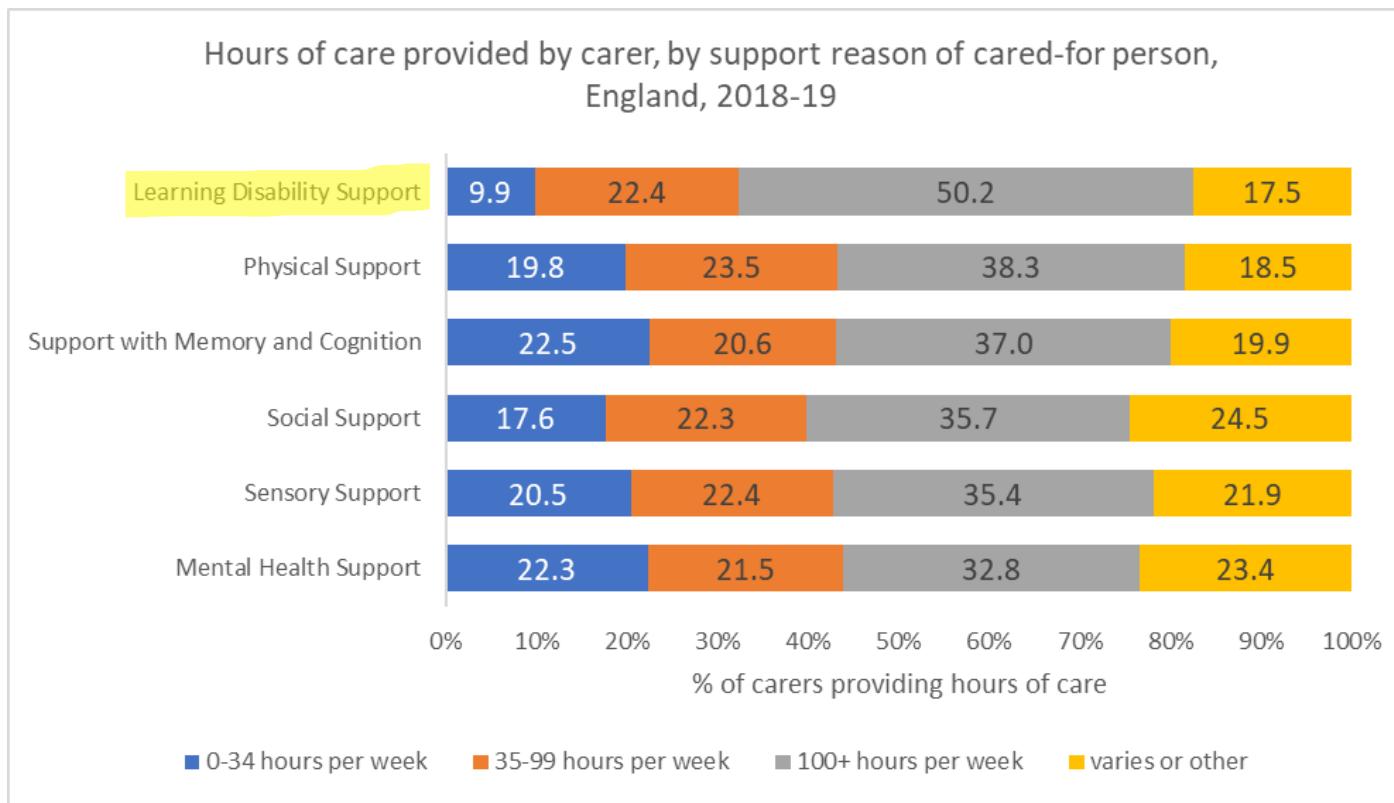
Complex Need

- Nationally, it was estimated that 1.2m people with learning disabilities and 0.6m people with autistic spectrum disorder have speech impairment¹.
- Adults with learning disabilities are ten times more likely to be blind or partially sighted than the general population. People with Down's syndrome are at particularly high risk of developing vision impairment².
- 40% of people with learning disabilities have a hearing impairment, with those with Down's syndrome at a particularly high risk of developing hearing loss³.
- People with learning disabilities are at an increased risk of developing dementia as they age: about 1 in 5 people with a learning disability who are over the age of 65 will develop dementia⁴.
- People with learning disabilities who develop dementia generally do so at a younger age. This is particularly the case for people with Down's syndrome: a third of people with Down's syndrome develop dementia in their 50s⁵.
- People with a learning disability often show different symptoms in the early stages of dementia, are less likely to receive a correct or early diagnosis of dementia, and may not be able to understand the diagnosis⁶.

(Source:: See Notes)

Caring for People who have a Learning Disability: Hours of Care

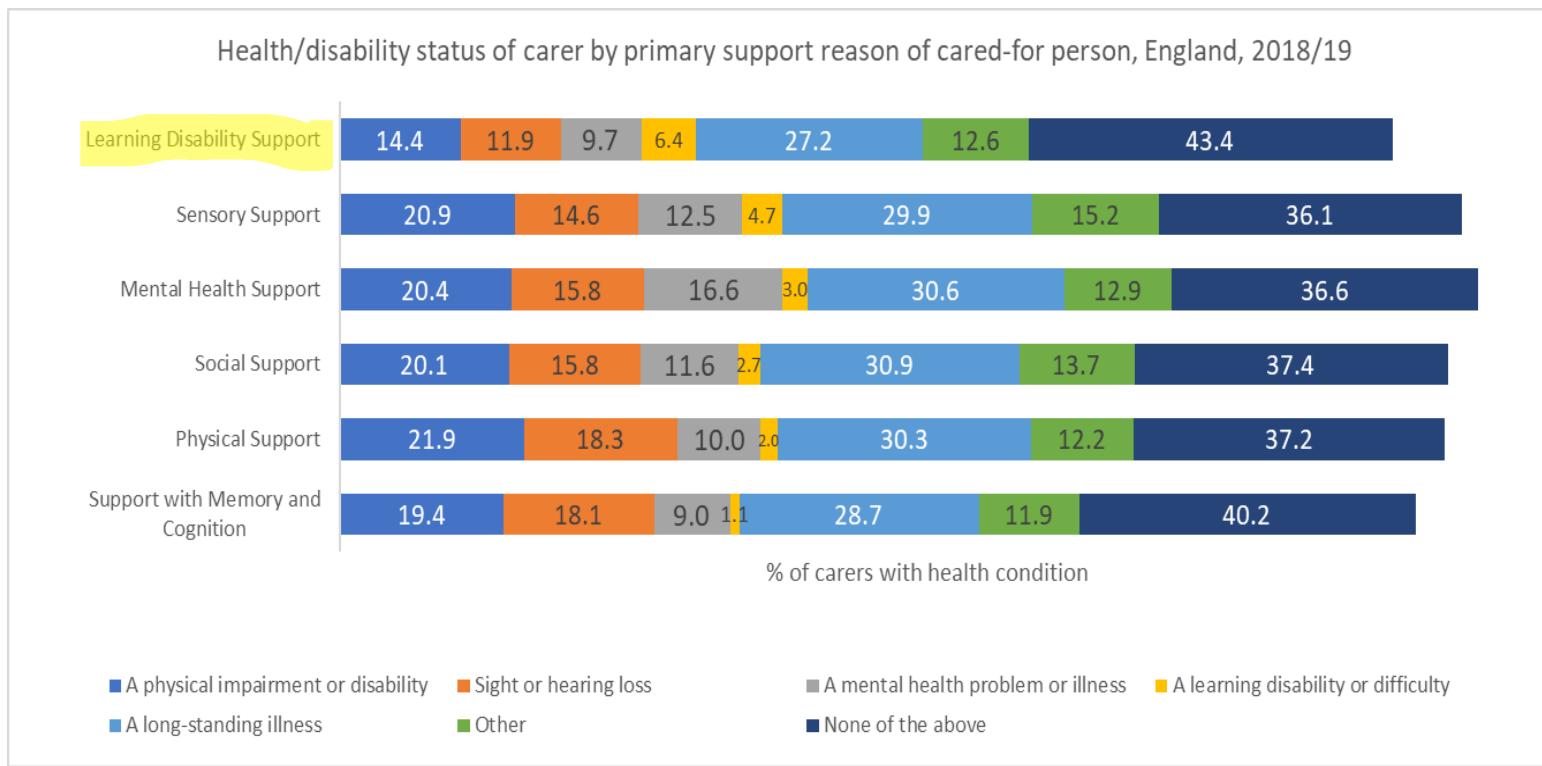
- The latest Carer Survey for England suggests that half of informal carers (50.2%) providing learning disability support provided care for 100 hours or more per week. This was the highest proportion of all carer groups.
- In total, 72.4% of carers providing learning disability support provided care for 35 hours or more per week.



(Source: Survey of Adult Carers 2018/19, England)

Caring for People who have a Learning Disability: Health/Disability of Carer

- Carer Survey for England also found that carers providing learning disability support were less likely to have a disability or health condition than other groups of carers (56.6%).
- However, they were more likely than the other groups of carers to have a learning disability themselves (6.4% of carers providing learning disability support).



(Source: Survey of Adult Carers 2018/19, England)

Caring for People who have a Learning Disability: Impact on Quality of Life

Personal Safety

- 21.8% of carers providing learning disability support had some worries or were extremely worried about their personal safety. They were one of the groups of carers most likely to have worries about their personal safety.

Looking after myself

- Carers providing learning disability support were one of the groups of carers most likely to say they looked after themselves. However, 16.0% felt they were neglecting themselves, and 31.6% said they were not able to look after themselves well enough.

Encouragement and support

- 19.6% of carers providing learning disability support said they had no encouragement and support, and 45.9% said they had some encouragement or support but not enough.

Social Contact

- 16.6% of carers providing learning disability support said they had little social contact and felt socially isolated, and 48.2% said they had some social contact but not enough.

Control over daily life

- 13.2% of carers providing learning disability support said they had no control over their daily life, and a further 61.7% said they did not have enough control.

Doing things with my time

- 13.0% of carers providing learning disability support said they didn't do anything they valued or enjoyed with their time, and 66.1% said they were not able to do enough things they valued or enjoyed.

Notes

Disability Benefits (Slides 12 and 13)

Attendance Allowance (AA) is a benefit for people over state pension age who have care needs as a result of a disability or long term health condition. It is paid at two rates depending on the level of need, and does not cover mobility needs.

Disability Living Allowance (DLA) is a non-means tested benefit for disabled people who need help with mobility or care and who are aged under 65 when they make the claim; if their mobility and care needs continue after they turn 65 they will continue to receive DLA. It provides a non-contributory, non means-tested and tax-free contribution towards the disability-related extra costs of severely disabled people who claim help with those costs before the age of 65.

Personal Independence Payment (PIP) is a benefit for people aged 16 or over who have not reached state pension age when they make the claim. From April 2013, PIP started replacing Disability Living Allowance (DLA) for people of working age. If people are awarded PIP before they are of state pension age, they will continue to receive it after.

Source (Slide 17)

1. Mapping Disability: Accompanying Notes, Sport England, 2016
2. Eye health data summary report, February 2014, RNIB
3. Carvill S. Review: Sensory impairments, intellectual disability and psychiatry. *Journal of Intellectual Disability Research* 2001;45:467-83
4. Factsheet 430LP Alzheimer's Society, March 2015
5. Ibid
6. Ibid