JSNA Briefing on Learning Disability





The average life expectancy for women with a learning disability is 18 years shorter than for women in the general population, for men it is 14 years shorter³.

These health inequalities often start early in life and result, to an extent, from barriers people with learning disabilities face in accessing timely, appropriate and effective health care. This can be due to a number of reasons including: lack of transport links, staff not understanding learning disability, failure to recognise a person with learning disability is unwell, inadequate after care or follow-up and not enough involvement allowed from carers³.

There have been a number of government policies developed across several different areas including health, social care, education, employment and criminal justice. An example of the different national policies areas are shown in Figure 1.

Figure 1 Key Policy Areas⁴

NHS England, in conjunction with the government, have established programs to improve treatment and outcomes in relation to health. More specifically, in 2015 a national review programme of premature deaths in people with learning disabilities was commissioned, this is covered in more detail later in this briefing.

There is a commitment to reducing the numbers of people with learning disabilities who are placed in inpatient services and a focus towards developing community based services as a model of care. NHS England and NHS Employers are also implementing a national programme to support NHS organisations to increase the employment of people with learning disabilities within the NHS.

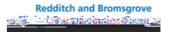
³ Mencap. (2018). Health inequalities. [online] Available at:













Children with Learning Disability

The numbers of children with a learning disability are reported through the National School Census of Special Educational Needs and Disabilities (SEND). Children and young people



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Population Projections

Population projections carried out by Oxford Brookes University and the Institute of Public Care, estimate that overall there will be an increase of individuals with a learning disability from, as shown in Figure 3, 10,900 in 2017 to 11,759 in 2035, which is 859 in total. In the 18-64 year old age group, numbers are expected to fall from 8,183 to 7,970 individuals living in Worcestershire with a Learning Disability. In contrast to this there is projected to be an increase of individuals living with learning disability from 2,717 to 3,789 in the 65+ age group. This trend is also observed when looking at numbers of individuals by type of learning disability, as shown in Table 3.

Figure 3 Total Number of people estimated to have a Learning Disability in Worcestershire (2017-2035)

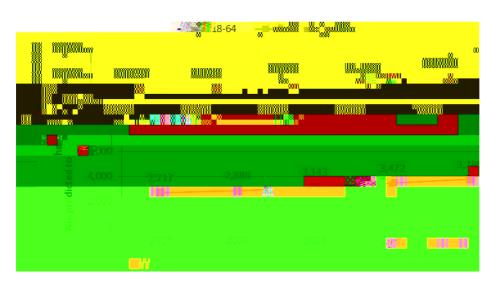


Table 3 Total Number of people estimated to have a Learning Disability by type of Disability and Age Group in Worcestershire (2017-2035)

Type of Learning Disability (18-64, 65+)	2017	2020	2025	2030	2035
Autistic Spectrum Disorders - 18-64	3,360	3,345	3,333	3,302	3,275
Autistic Spectrum Disorders - 65+	1,234	1,310	1,437	1,590	1,723
Downs Syndrome - 18-64	211	210	209	206	204
Downs Syndrome - 65+	5	5	5	6	7
Moderate to Severe - 18-64	1,861	1,851	1,844	1,839	1,830
Moderate to Severe - 65+	369	386	409	447	483
Type of Learning Disability (18-64 only)	2017	2020	2025	2030	2035
Challenging Behaviour - 18-64	152	151	150	149	147
Living with a parent - 18-64	659	648	644	653	660
Severe Learning Disability - 18-64	487	483	483	485	484

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Health of People with Learning Disabilities



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Improving the Health and Care of People with Learning Disabilities

Annual Health Check: An annual health check is offered to all adults and young people (aged 14+) with learning disabilities. This is to ensure that health needs are met and health



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Over Medication: Stopping over medication of people with a learning disability, autism or both (STOMP)11: Individuals with a learning disability or autism or both are more likely to be given psychotropic medication than other people. There has been a national programme to ensure that people with learning disabilities and their families and carers are aware of the types of drugs that they are taking and fully informed about their use. In addition to this health professionals involved in the care of people with learning disabilities and those who prescribe psychotropic medication have signed up to a pledge to stop overmedication of patients.

What is being done in Worcestershire?

Worcestershire County Council spends around £50 million each year on services for people with learning disabilities¹².



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Premature Death and Learning Disability

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD¹³) undertaken between 2010-12, found that 38% of people with a learning disability died from an avoidable cause, primarily relating to the lack of provision of good quality health care, compared to 9% in comparison to the general population³. Research has also shown that people with Learning Disabilities are four times more likely to die of preventable causes when compared with the general population¹⁴.

Table 5 Key Reports and Recommendations into the health and care of people with learning disabilities¹⁵

Year	Report/Recommendation					
2001	learning disabilities. Valuing people white paper 2011 (Department of Health)					
2004						
2006	Identified that people with learning disabilities experienced considerable inequalities in health. Disability Rights Commission review.					
2007	Death by Indifference Mencap. Further call for an formal inquiry to take place into premature deaths of people with learning disabilities					
2008	Independent inquiry into access to healthcare for people with learning disabilities. Recommendation to establish a Learning disabilities Public Health Observatory and a time limited Confidential enquiry into premature deaths of people with a learning disability.					
2010- 2012	Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD). Recommendation to set up a national review body to monitor deaths of people with learning disabilities to learn from experience and use as a driver to reduce inequalities in care.					

A key recommendation of the CIPOLD review resulted in the setup of the Learning Disabilities Mortality Review (LeDeR) programme, which is led by the University of Bristol and Healthcare Quality and Improvement Partnership (HQIP). The LeDeR programme reviews all deaths of people with a learning disability helps to identify common causes of death and to establish, what lessons can be learnt.

The first national report from the LeDeR programme reviewed all deaths reported to the programme between July 2016 to November 2017. There were a total of 1,311 deaths reported. The report identified the following:

There were more deaths in males (57%) in comparison to females (43%).

There were a high proportion of individuals from a White ethnic background (93%). There is a specific piece ofwiorko1(i)5(du)3(a-4(o)-212T1i25347.93 Tm)3()6(r)13((es)E)(o)13(f





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64% of people with Learning Disabilities died in hospital, compared to 47% in the general population.

Compared to the general population, the median age of death is 23 years younger for males and 29 years younger for women.

Most common individual causes of were pneumonia (16%), Sepsis (11%) and Aspiration pneumonia (9%).

The most common underlying causes of death were due to diseases of the respiratory system (31%), circulatory system (16%) and cancer (10%).

Key areas of learning that were identified as part of the review were greater need to inter-agency collaboration including communication, awareness of the needs of people with learning disabilities and greater understanding and application of the Mental Capacity Act (MCA). These issues have been repeatedly identified in previous reviews and enquiries.

In Worcestershire, all deaths for people with Learning Disabilities are reviewed by the local LeDeR team on a quarterly basis.

Accommodation

Arranging where to live poses difficulties for many people with learning disability. Local authority social service departments commonly help here. Accommodation can be divided into settled accommodation, where the person can reasonably expect to stay as long as they want and unsettled accommodation which is either unsatisfactory or, where, like in residential care homes, residents do not have security of tenure.

In Worcestershire, there are a similar proportion of adults with a learning disability who are living in settled accommodation (75.0%) when compared to England (75.2%). There are a significantly higher proportion of working age adults with a learning disability who are living in unsettled accommodation (25.0%) when compared to England (24.7%).

What is being done in Worcestershire¹³?

In the Worcestershire County Council Housing and Support plan there is a commitment to ensuring that people with learning disabilities have a range of different types of housing to choose from.

Improving the Shared Lives Service¹⁶, where people with Learning Disabilities live with a family.

Providing better information for people with learning disabilities and their families about their choices of places to live.

¹⁶ Worcestershire County Council (2018) Shared Lives Scheme, [Online], Available from: <u>http://www.worcestershire.gov.uk/info/20563/shared_lives_scheme</u>, Accessed: 29/06/2018







Social Support & Employment

Paid work 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. Government policy has emphasised the importance of maximising work opportunities for people with learning disabilities since the publication of Valuing People (2001).

Worcestershire has a similar proportion of working age adults with a learning disability who are in paid employment (5.9%) when compared to the England average (5.8%). The gap in employment rate between those with a learning disability and the overall employment rate is 70.1% which is a similar level to the England average at 68.7%. A significantly higher proportion of supported adults with a learning disability were receiving direct payments in Worcestershire (31.8%) when compared to the England average (28.6%).

What is being done in Worcestershire¹³?

Worcestershire County Council carried out a project called Learning Disability Big Conversation and as part of this work identified that having a paid job was important for people with learning disabilities.

Improvements underway in Worcestershire for a more inclusive Supported Employment Service.







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Data Notes

Organisations who carried out the original collection and analysis of the data bear no responsibility for its further analysis or interpretation.

Further Information and Feedback

This briefing has been written by Worcestershire County Council's Public Health Team. We welcome your comments on these briefings and how they could better suit your requirements, please do contact us with your ideas.

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This document can be provided in alternative formats such as Large Print, an audio recording or Braille. Please contact Janette Fulton on telephone number 01905 843359 or by email jfulton@worcestershire.gov.uk.



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Appendix 1: NHS Digital: Learning Disabilities Dataset (2016-17) by Clinical Commissioning Group, Worcestershire

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LDOB014	Patients in the control patient cohort and the most recent BMI assessment classification (or Down's Syndrome BMI centile classification), in the 15 months to Reference Year End Date, is overweight (BMI 25.0 – 29.9).	9.2%	9.8%	10.2%
LDOB015	Patients recorded on their general practice's Learning Disabilities Register and the most recent BMI assessment classification (or Down's Syndrome BMI centile classification), in the 15 months to Reference Year End Date, is obese (BMI >=30.0).	23.8%	25.0%	23.4%
LDOB016	Patients in the control patient cohort and the most recent BMI assessment (or Down's Syndrome BMI centile classification), in the 15 months to Reference Year End Date, is obese (BMI >=30.0).	9.1%	9.2%	10.2%
	Cancer Indicators			
LDOB035	Patients recorded on their general practice's Learning Disabilities Register and who have a diagnosis of cancer, excluding non-melanotic skin cancer, as at Reference Year End Date.	0.7%	0.5%	1.0%
LDOB036	Patients in the control patient cohort and who have a diagnosis of cancer, excluding non- melanotic skin cancer, as at Reference Year End Date.	2.4%	2.8%	3.1%
LDOB019	Patients recorded on their general practice's Learning Disabilities Register and who are eligible for cervical cancer screening being female aged 25 to 64 with no history of hysterectomy, on whom an adequate cervical smear test has been performed in the five years prior to Reference Year End Date.	25.7%	30.3%	30.8%
LDOB020	Patients in the control patient cohort and who are eligible for cervical cancer screening being female aged 25 to 64 with no history of hysterectomy, on whom an adequate cervical smear test has been performed in the five years prior to Reference Year End Date.	77.7%	77.2%	79.5%
LDOB021	Patients recorded on their general practice's Learning Disabilities Register being female aged 50 to 69 who received breast cancer screening in the five years prior to Reference Year End Date.	41.4%	54.5%	61.5%
LDOB022	Patients in the control patient cohort being female aged 50 to 69 who received breast cancer screening in the five years prior to Reference Year End Date.	62.9%	68.9%	74.9%
LDOB023	Patients recorded on their general practice's Learning Disabilities Register and aged 60 to 69 who are eligible for colorectal cancer screening and who have a record of having a colorectal cancer screening result recorded in the five years prior to Reference Year End Date.	65.5%	56.7%	84.5%
LDOB024	Patients in the control patient cohort and aged 60 to 69 who are eligible for colorectal cancer screening and who have a record of having a colorectal cancer screening result recorded in the five years prior to Reference Year End Date.	73.3%	73.2%	88.4%
	Long Term Conditions/Diagnoses			
	Patients recorded on their general practice's			

Patients recorded on their general practice's
Learning Disabilities Register and who have a
diagnosis of gastric oesophageal reflux disease
(GORD), as at the Reference Year End Date.

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LDOB029	Patients recorded on their general practice's Learning Disabilities Register and who have evidence of diagnosis or the treatment of chronic constipation in the five years to Reference Year End Date. Or 2 constipation medications in the last 12 months to the reference date that are dated more than 6 months apart.	16.0%	14.0%	17.7%
LDOB033	Patients recorded on their general practice's Learning Disabilities Register and who have an active diagnosis of asthma, as at Reference Year End Date.	9.3%	8.6%	8.4%
LDOB034	Patients in the control patient cohort and who have an active diagnosis of asthma, as at Reference Year End Date.	6.4%	6.2%	6.9%
LDOB037	Patients recorded on their general practice's Learning Disabilities Register and who have an active diagnosis of chronic kidney disease (CKD) stages 3–5, as at Reference Year End Date.	2.5%	1.9%	3.0%
LDOB038	Patients in the control patient cohort and who have an active diagnosis of chronic kidney disease (CKD) stages 3–5, as at Reference Year End Date.	3.9%	4.5%	4.7%
	Patients recorded on their general practice's			

LDOB039







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LDOB065	Patients recorded on their general practice's Learning Disabilities Register and who have a diagnosis of severe mental illness as defined by QOF v30 (Mental health), as at Reference Year End Date.	6.6%	5.5%	5.4%
LDOB066	Patients in the control patient cohort and who have a diagnosis of severe mental illness (Mental health), as at Reference Year End Date.	0.7%	0.7%	0.7%
LDOB067	Patients recorded on their general practice's Learning Disabilities Register and who have a diagnosis of stroke or transient ischaemic attack (TIA), as at Reference Year End Date.	2.1%	1.5%	1.6%
LDOB068	Patients in the control cohort and who have a diagnosis of stroke or transient ischaemic attack (TIA), as at Reference Year End Date.	2.0%	2.0%	2.7%
LDOB069	Patients recorded on their general practice's Learning Disabilities Register and who have a diagnosis of hypothyroidism, as at Reference Year End Date.	12.1%	9.7%	9.3%
LDOB070	Patients in the control patient cohort and who have a diagnosis of hypothyroidism, as at Reference Year End Date.	4.4%	4.5%	5.3%
LDOB071	Patients recorded on their general practice's Learning Disabilities Register and registered as being in need of palliative care and support as at Reference Year End Date.	0.6%	0.5%	1.6%
LDOB072	Patients in the control patient cohort and registered as being in need of palliative care and support as at Reference Year End Date.	0.4%	0.6%	0.8%
LDOB073	Patients recorded on their general practice's Learning Disabilities Register and newly diagnosed who have angina (diagnosed on or after the reference year start date 1 April 2014), as at Reference Year End Date.	0.0%	0.0%	0.0%
LDOB074	Patients in the control patient cohort and newly diagnosed who have angina (diagnosed on or after the reference year start date 1 April 2014), as at Reference Year End Date.	0.1%	0.0%	0.1%
LDOB075	Patients recorded on their general practice's Learning Disabilities Register newly diagnosed who have angina (diagnosed on or after the reference year start date 1 April 2014) and referred for specialist assessment in the 24 months up to the Reference Year End Date.	0.0%	0.0%	0.0%
LDOB076	Patients in the control patient cohort newly diagnosed who have angina (diagnosed on or after the reference year start date1 April 2014) and referred for specialist assessment in the 24 months up to the Reference Year End Date.	0.0%	0.0%	0.0%
	Diabetes			
LDOB051	Patients recorded on their general practice's Learning Disabilities Register who have an active diagnosis of diabetes mellitus and who have a record of IFCC–HbA1c, a measure of effectiveness of control of blood sugar in diabetes, in the 12 months to Reference Year End Date.	5.5%	7.4%	7.7%
LDOB052	Patients in the control patient cohort who have an active diagnosis of diabetes mellitus and have a record of IFCC–HbA1c in the 12 months to Reference Year End Date.	5.3%	5.4%	6.1%
LDOB053	Patients recorded on their general practice's Learning Disabilities Register who have an active diagnosis of diabetes mellitus and whose latest record of IFCC-HbA1c was 75 mmol/mol or less (satisfactory) in the 12 months to Reference Year End Date.	4.6%	6.0%	6.2%

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LDOB054	Patients in the control patient cohort who have an active diagnosis of diabetes mellitus and whose latest record of IFCC-HbA1c was 75 mmol/mol or less (satisfactory) in the 12 months to Reference Year End Date.	4.7%	4.8%	5.4%
	Epilepsy Indicators			
LDOB055	Patients recorded on their general practice's Learning Disabilities Register, which have an active diagnosis of epilepsy and on drug treatment for epilepsy, as at Reference Year End Date.	18.0%	16.9%	20.0%
LDOB056	Patients in the control patient cohort, who have an active diagnosis of epilepsy and on drug treatment for epilepsy, as at Reference Year End Date.	0.7%	0.7%	0.8%
LDOB057	Patients recorded on their general practice's Learning Disabilities Register who have an active diagnosis of epilepsy, on drug treatment for epilepsy and have a record of seizure frequency in the 12 months to Reference Year End Date.	28.3%	26.4%	32.8%
LDOB058	Patients in the control patient cohort who have an active diagnosis of epilepsy, on drug treatment for epilepsy and have a record of seizure frequency in the 12 months to Reference Year End Date.	12.4%	13.0%	21.1%
LDOB059	Patients recorded on their general practice's Learning Disabilities Register who have an active diagnosis of epilepsy, on drug treatment for epilepsy and have a record of seizure frequency in the 12 months to Reference Year End Date and have been seizure-free in this period.	15.0%	6.4%	2.5%
LDOB060	Patients in the control patient cohort who have an active diagnosis of epilepsy, on drug treatment for epilepsy and have a record of seizure frequency in the 12 months to Reference Year End Date and have been seizure–free in this period.	8.7%	9.5%	16.0%
	Down Syndrome Indicators			

Patients recorded on their general practice's Learning Disabilities Register and who have a diagnosis of Down's Syndrome (DS), as at Reference Year End Date.









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