

Worcestershire Health and Wellbeing Board JSNA Briefing on Learning Disabilities

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Summary

- In Worcestershire it is estimated that in 2020 there were 8,316 individuals aged 18-64 years¹ and 2,889 individuals aged 65 and over who have a learning disability². This means that in the County, there are approximately 11,205 individuals overall aged 18+ who are thought to have a learning disability.
- There are a total of 3,684 children and young people aged 4-19 identified as having a learning disability.
- People with learning disabilities have more healthcare needs than the general population. Approximately 50% of people with learning disabilities will have at least one significant health problem.
- Around 1.5 million people in the UK have a learning disability. Of these, it is estimated that up to 350,000 people have a severe learning disability. This figure is increasing³.
- People with learning disabilities experience significant socio-economic inequality and are less likely to be in employment. The wider socio-economic inequalities in this group of individuals can also be significant.
- Nationally, 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 shorter.
- The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD⁴) 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 population.
- The current CHC forecast spend on LD packages for 21/22 is £25.14 million, this is the split as follows: Herefordshire £6.908 million and Worcestershire £18.106 million.

1 Oxford Brookes University (2018) Projecting Adult Needs and Service Information (PANSI), Available from: <http://www.pansi.org.uk/> , Accessed: 20/09/2021

2 Oxford Brookes University (2018) Projecting Older People Population Information (POPPI), Available from: <http://www.poppi.org.uk/> , Accessed: 20/09/2021

³ [Learning disabilities - NHS \(www.nhs.uk\)](http://www.nhs.uk)

⁴ Heslop, P., Blair, P., Fleming, P., Houghton, M., Marriott, A. and Russ, L. (2013). The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). [online] Bristol: Norah Fry Research Centre, pp.1-128. Available at: <https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf> [Accessed 4 Jun. 2018].

Background

“A learning disability needs to be viewed as a complex way of being”⁵

A learning disability⁶, not to be confused with a learning difficulty such as Dyslexia or Dyspraxia, is a name given to a group of conditions that are present before the age of 18 which affect the way a person understands information and how they communicate. This means they can have difficulty in:

- Understanding simple or complex information
- Learning new skills
- Coping independently

The term covers a range of disabilities, including Downs Syndrome and chromosomal disorders, but does not include specific 'learning difficulties' such as Dyslexia. Many people with a learning disability have additional health, sensory and mobility problems, and a number have additional mental health problems. Causes of learning disabilities can be categorised as outlined in Table 1.^{7,8}

Table 1 Examples of Learning Disability and related conditions

Prenatal	Perinatal	Postnatal
Chromosome & Genetic abnormalities: Downs syndrome, Rhett syndrome	Precipitated or prolonged labour: Cerebral palsy	Infection: Meningitis, Measles, Encephalitis
Maternal Infections: Rubella	Prematurity, Environmental i.e., abuse/neglect: Global Developmental Delay	Injury: Abuse, accidents
Environmental/Societal: Foetal alcohol syndrome		Chromosome & Genetic abnormalities: Batten Disease, Tay-Sacs Disease
Prenatal cause: Cerebral palsy		

People with learning disabilities have poorer health than the general population and experience health inequalities in several different ways.

⁵ Gates (2001) Valuing People [\(PDF\) Gates, B \(2001\) Valuing people: Long awaited strategy for people with learning disabilities for the 21st Century in England, UK. Journal of Learning Disabilities. 5\(3\). 203-207. \(researchgate.net\)](#)

⁶ [Learning disabilities: applying All Our Health - GOV.UK \(www.gov.uk\)](#)

⁷ [Learning disabilities: applying All Our Health - GOV.UK \(www.gov.uk\)](#)

⁸ [Learning disabilities - NHS \(www.nhs.uk\)](#)

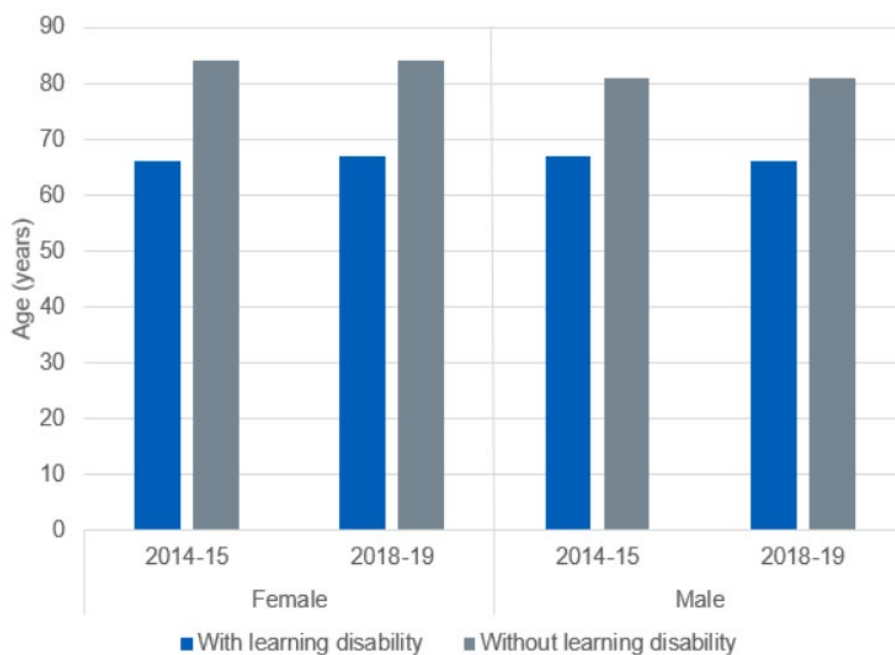
A study undertaken by Public Health England⁹ found that people with learning disabilities were more likely to experience poorer self-rated health, psychological distress, arthritis, diabetes, epilepsy, or multiple morbidity.

Several risk factors for poor health were more common for people with learning disabilities including obesity, lower grip strength, and poor lung function. Behavioural risk factors were also more common such as poor diet, low levels of physical activity, smoking, alcohol use and hospital admission for a newly diagnosed condition. Further information can be found at I.H.A.L the Learning, Health and Disabilities Observatory¹⁰. The observatory monitors the health of people with learning disabilities.

The study also found that people with learning disabilities experience significant socio-economic inequality and are less likely to be in employment, have financial stability and to have two or more friends when compared with those without learning disabilities. The wider socio-economic inequalities in this group of individuals can be significant.

Based on 2018/19 NHS data for England as a whole, males with a learning disability have a life expectancy of 66 years. This is 14 years lower than for males in the general population. Based on 2018-19 data, females with a learning disability have a life expectancy of 67 years. This is 17 years lower than for females in the general population. There has been no statistically significant change in life expectancy for patients with a learning disability between 2014-15 and 2018-19.¹¹

Figure 1 Life expectancy for males and females with and without a learning disability, for 2014-15 and 2018-19.



⁹ Public Health England (2017) Health inequalities and the 'hidden majority' of adults with learning disabilities, [Online], Available at: <https://publichealthmatters.blog.gov.uk/2016/10/04/health-inequalities-and-the-hidden-majority-of-adults-with-learning-disabilities/> [Accessed: 5 Jun. 2018]

¹⁰ [Improving Health & Lives - Learning Disabilities Observatory | Advisory group of self-advocates and family carers \(improvinghealthandlives.org.uk\)](https://www.improvinghealthandlives.org.uk/)

¹¹ [Condition Prevalence - NHS Digital](https://www.nhs.uk/digital)

Source: NHS Digital

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 carers.

Government Policies

There have been a number of government policies developed across different areas including health, social care, education, employment and criminal justice. An example of the different national policies areas is shown in Figure 2.

Figure 2 Key Policy Areas¹²

Figure 3 - National Priorities



NHS England, in conjunction with the government, have established programmes to improve treatment and outcomes for people with learning disabilities in relation to health. More

¹² Parkin, E (2016), Briefing Paper: Number 07058 26 April 2016 Learning Disability – overview of policy and services, [Online], Available from: <http://researchbriefings.files.parliament.uk/documents/SN07058/SN07058.pdf> , Accessed: 27/06/2018

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. The most recent target¹³, as set out in the NHS Long Term Plan, is for a reduction in inpatient provision of 50% (as compared to 2015 levels) by 2023/24.

In February 2020, the Equalities and Human Rights Commission launched a legal challenge against the Secretary of State and Social Care over the failure to move people with learning disabilities and autism into appropriate accommodation.¹⁴ There were longstanding concerns about the rights of more than 2,000 people with learning disabilities and autism being detained in secure hospitals, often far away from home and for many years.

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.

Population Trends

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 are recorded on the census according to Primary and Secondary need.

Three types of special educational needs when combined are approximately equivalent to learning disabilities: moderate learning difficulty (MLD), severe learning difficulty (SLD) and profound multiple learning difficulty (PMLD). Table 2 shows the number and rate of pupils for whom moderate, severe, or profound and multiple learning difficulty was recorded as the primary SEN support reason.

Table 2 Number and proportion per 1,000 population of school aged children with Learning Disabilities by type (2020)

Type of Learning Disability	No.	Worcestershire	England
Moderate Learning Difficulty	2,302	28.5	29.1
Profound + Multiple Learning Difficulties	55	0.68	1.29
Severe Learning Difficulty	373	4.6	4.0
Total with Learning Disability	2,730	33.8	34.4

Source: Public Health England, Learning Disability Profiles. Available [here](#).

This corresponds to 2.9% of school age children¹⁵

Adults with Learning Disability

¹³ [SN07058.pdf \(parliament.uk\)](#)

¹⁴ [Health Secretary faces legal challenge for failing patients with learning disabilities and autism | Equality and Human Rights Commission \(equalityhumanrights.com\)](#)

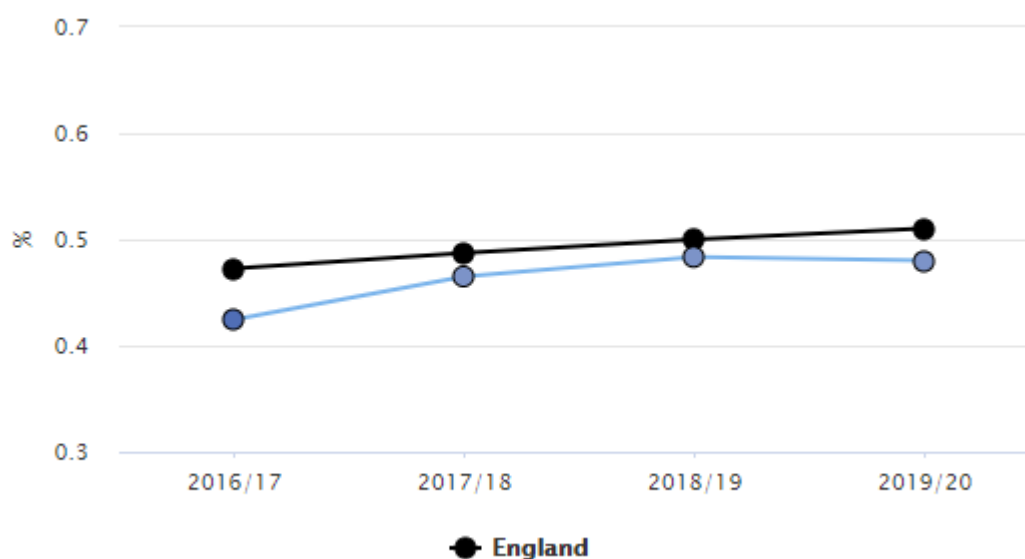
¹⁵ The School Census covers all pupils enrolled in state funded primary, secondary or special schools

It is estimated that in 2020 there were 8,316 individuals aged 18-64 years¹⁶ and 2,889 individuals aged 65 and over who have a learning disability¹⁷. This means that in the County, there are approximately 11,205 individuals overall aged 18+ who are thought to have a learning disability. However; it is important to note that that these figures are modelled estimates based on population prevalence (see Data Notes on p34)

In 2019/20, there were 2,947 individuals (all ages) recorded as having a Learning Disability at their GP Practice in Worcestershire. This equates to 0.5% of all registered patients, which is similar to the England average of 0.5%.

The difference between these figures suggests that many people with a learning disability do not have this recorded by their GP.

Figure 4 Learning Disability: QOF Prevalence (All Ages) - Worcestershire



Source: Public Health England, Learning Disability Profiles

Population Projections

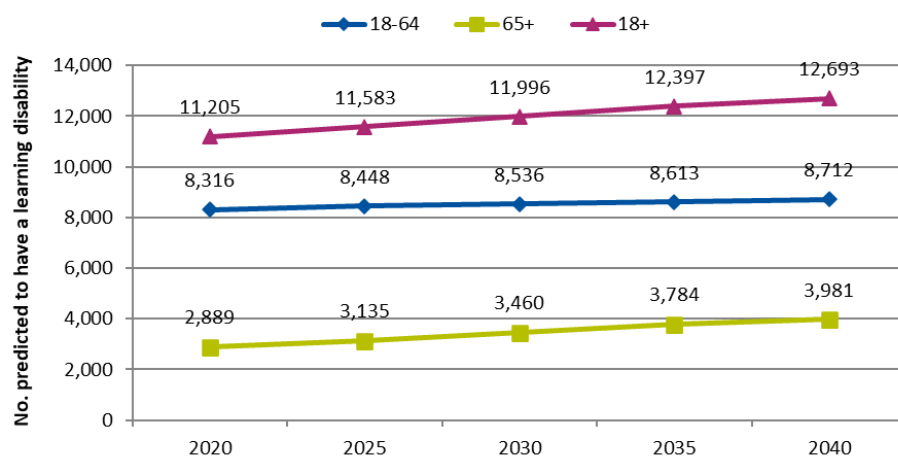
Population projections carried out by Oxford Brookes University and the Institute of Public Care, estimate that overall, there will be an increase of individuals with a learning disability in Worcestershire from 11,205 in 2020 to 12,693 in 2040, which is 1,488 (+13%) in total (as shown in Figure 3).

In the 18-64 year old age group, numbers are expected to increase from 8,316 to 8,712 (+5%) individuals living in Worcestershire with a learning disability. In contrast to this there is projected to be a more significant increase of individuals living with learning disability in the 65+ age group - from 2,889 to 3,981 (+1,092 or an increase of 38%). This trend is also observed when looking at numbers of individuals by type of learning disability, (as shown in Table 3).

16 Oxford Brookes University (2018) Projecting Adult Needs and Service Information (PANSI), Available from: <http://www.pansi.org.uk/> , Accessed: 20/09/2021

17 Oxford Brookes University (2018) Projecting Older People Population Information (POPPI), Available from: <http://www.poppi.org.uk/> , Accessed: 20/09/2021

Figure 5 Total Number of people estimated to have a Learning Disability in Worcestershire (2020-2040)



Source: PANSI/POPPI 2020

Table 3 Total Number of people estimated to have a Learning Disability or Autistic Spectrum Disorder by Type and Age Group in Worcestershire (2020-2040)

Type of Learning Disability (18-64, 65+)	2020	2025	2030	2935	2040
Autistic Spectrum Disorders - 18-64	3,406	3,460	3,492	3,520	3,564
Autistic Spectrum Disorders - 65+	1,305	1,424	1,572	1,703	1,782
Type of Learning Disability	2020	2025	2030	2935	2040
Moderate to Severe - 18-64	1,892	1,926	1,956	1,978	2,004
Moderate to Severe - 65+	387	411	452	492	507
Challenging Behaviour - 18-64	154	157	158	159	160
Living with a parent - 18-64	661	669	690	706	712
Total number of individuals with a Learning Disability	2020	2025	2030	2935	2040
18-64	8316	8448	8536	8613	8712
65+	2889	3135	3460	3784	3981
Total	11205	11583	11996	12397	12693
Autistic Spectrum Disorders	2020	2025	2030	2935	2040
Autistic Spectrum Disorders - 18-64	3,406	3,460	3,492	3,520	3,564
Autistic Spectrum Disorders - 65+	1,305	1,424	1,572	1,703	1,782

Source: POPPI/PANSI 2020

Learning Disability and Autism

Autism ¹⁸is a lifelong developmental disability that affects how people perceive, communicate and interact with others, although it is important to recognise that there are differing opinions on this and not all autistic people see themselves as autistic. There are an estimated 700,000 autistic adults and children in the UK which is approximately 1% of the whole population. Autism varies widely and is often referred to as a spectrum condition, because of the range of ways it can impact on people and the different level of support they

¹⁸ [The national strategy for autistic children, young people and adults: 2021 to 2026 \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/91221/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf)

may need across their lives. While autism is not a learning disability, around 4 in 10 autistic people have a learning disability¹⁹.

Autistic people²⁰ may:

- find it hard to communicate and interact with other people
- find it hard to understand how other people think or feel
- find things like bright lights or loud noises overwhelming, stressful or uncomfortable
- get anxious or upset about unfamiliar situations and social events
- take longer to understand information
- do or think the same things over and over

Roughly one in 100 people are estimated to have the Autistic Spectrum Disorder. The rate is higher amongst males (2%) than females (0.3%).²¹

The autism spectrum is very wide, ranging from people with limited self-help, independence, academic, or verbal skills through to those who are fully independent but have significant social difficulties.

Although there is overlap, not all people with a learning disability have autism and not all people with autism have a learning disability. A study by NHS Digital found that the rate of autism was highest amongst people with the most severe intellectual disability.

NHS Digital found among adults with learning disabilities living in private households whose learning disability was sufficiently severe that they could not have taken part in the APMS 2007, the prevalence of autism was 35.4 per cent. Among adults with mild or severe learning disabilities living in communal care establishments, the prevalence of autism was 31.0 per cent.²²

A 2006 report 'Prevalence of Disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)' found that 55% of those with ASD had an IQ below 70%.²³

Currently, there is no register or count of adults with autism in Worcestershire. Therefore, the number of people with autism in the community can only be estimated using prevalence rates derived from survey data.

In 2020, it was estimated that in Worcestershire there were 4,711 adults with ASD (3,406 people aged between 18-64 years and 1,305 people aged 65+ years).²⁴ 988 children with autism were known to schools. This is a rate of 12.2 per 1,000 children which is lower than the national rate of 18.0 per 1,000 children.²⁵

¹⁹ [Learning disability - Autism | Autistica | Autistica](#)

²⁰ [What is autism? - NHS \(www.nhs.uk\)](#)

²¹ NHS Digital. Estimating the Prevalence of Autism Spectrum Conditions in Adults - Extending the 2007 Adult Psychiatric Morbidity Survey. January 2012. Available online [here](#).

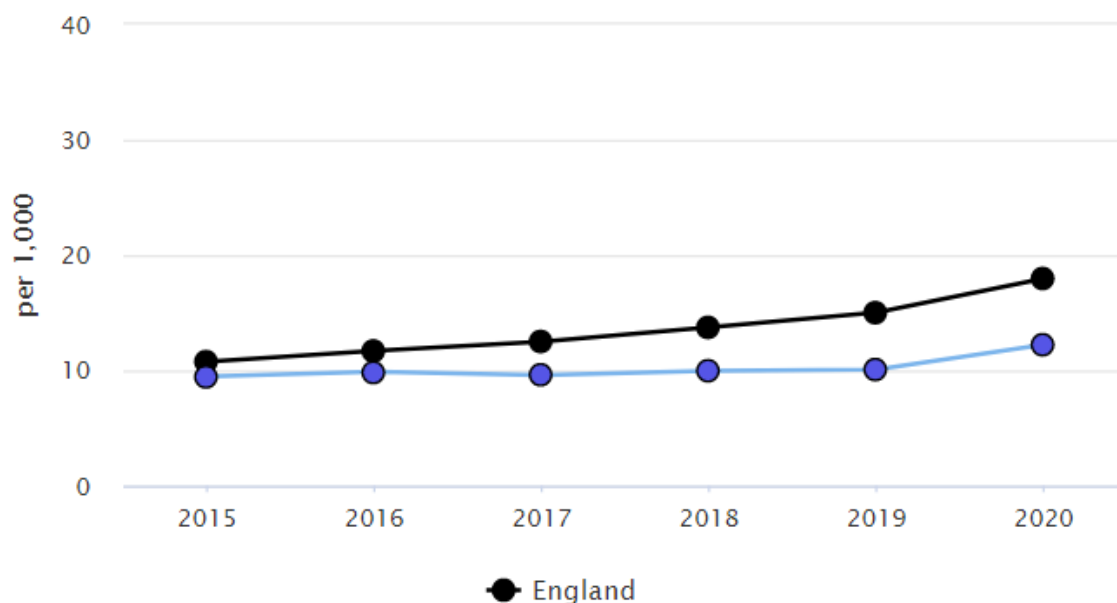
²² NHS Digital. Estimating the Prevalence of Autism Spectrum Conditions in Adults - Extending the 2007 Adult Psychiatric Morbidity Survey. January 2012. Available online [here](#)

²³ Baird, G. et al, The Lancet, 368 (9531), pp. 210-215, 2006

²⁴ Oxford Brookes University and Institute of Public Care. Projecting Adult Needs and Service Information. PANSI. Autistic spectrum disorders. Available online [here](#).

²⁵ Public Health England, Learning Disability Profiles. Available online [here](#).

Figure 6 Children with Autism known to schools in Worcestershire



Source: Fingertips.phe.org.uk

Impact of COVID-19 on People with Learning Disabilities

In June 2020, the Care Quality Commission (CQC) published data on deaths of people with a learning disability. The figures included deaths reported by services who provide care for people with a learning disability and/or autism. This includes adult social care, independent hospitals and community care. Between 10 April and 15 May 2020, 386 people who were receiving care from learning disability and/or autism services died. In the same period last year 165 people died. This represents a 134% increase.²⁶

In November 2020, Public Health England published the report 'Deaths of people identified as having learning disabilities with Covid-19 in England in the Spring of 2020'. This found 451 per 100,000 people registered as having a learning disability died with COVID-19

²⁶ [*SN07058.pdf \(parliament.uk\)](#)

between 21 March and 5 June, a death rate which was 4.1 times higher than the general population after adjusting for other factors such as age and sex.

But as not all deaths in people with learning difficulties are registered on these databases, researchers estimated the real rate may have been as high as 692 per 100,000 or 6.3 times higher than the general population.

Deaths were also spread much more widely across the age spectrum among people with learning disabilities, with far greater mortality rates in younger adults, compared to the general population. The death rate for people aged 18 to 34 with learning disabilities was 30 times higher than the rate in the same age group without disabilities the researchers found.

Among people with learning disabilities, the rate of COVID-19 deaths for adults in residential care was higher than the rates of COVID-19 deaths of adults with learning disabilities generally. This difference is likely in part to reflect the greater age and disability in people in residential care.

People with learning disabilities are more likely to have other physical health problems such as obesity and diabetes, and certain kinds of learning disability, such as Down's syndrome, can make people more vulnerable to respiratory infections, which can increase their risk of dying from COVID-19.

The most recent Speakeasy Now People's Parliament debate in March 2021 discussed four key issues highlighted by the pandemic.

Issue 1

Raising awareness about why people with learning disabilities are vulnerable and making sure that people with learning disabilities receive the same priority as other vulnerable groups.

The Government placed all people registered with their GP as having a learning disability into Group 6 priority for the COVID-19 vaccination programme.

Issue 2

To ensure all information is accessible and easy to understand. Helping people with learning disabilities to access online information.

Members stated that often information is not easy to understand and requested all information should be in Easy Read format, often forms are too complicated and hard to fill in. Many people also stated that they could not use computers or know how to get information from the internet.

Issue 3

Getting informal support from local communities. Improving access for people with learning disabilities to local community support groups.

The 'Lives Through Friends' organisation helped people to be involved in their local communities. However, more should be done to improve the inclusivity of people with learning disabilities into community groups.

Issue 4

Helping people with learning disabilities reduce health risks such as obesity and Type – 2 Diabetes.

Members stated that during the initial stages of the pandemic, many people missed their Annual Health Checks and others had their check done over the telephone. People also experienced longer waiting times. People were not supported to via Healthy eating clubs and exercise classes.

Many people with learning disabilities along with their social workers are not aware of the local physical activities' provision.

Impact of COVID-19 for people with Autism, during lockdowns in Worcestershire :

- There was a spike in safeguarding concerns for families and carers of people with autism (e.g., violence expressed by young people on their carers and siblings)
- Autistic people were disproportionately affected by loss of routine
- Loss of employment may have been harder for people with Asperger's (as employment harder to find in the first place).
- Heightened fear of Coronavirus because of the lifting of restrictions
- Coronavirus becoming an obsession and people with autism developing compulsions (OCD) e.g., about handwashing
- Young people with autism possibly more susceptible to misinformation as they might find it harder to distinguish what is true and false.
- Communication is a challenge for this group and some found it harder to communicate online
- School closure and loss of access to support having a big impact on parent carers of people with autism (possibly belongs in carers section)
- Some people with autism did express relief over less pressure to interact socially (+ve). But should be noted many felt the opposite and very much missed face to face support/support groups
- Range of access to services increased and for some the online/webinar format has been more convenient/well received (+ve)
- Parents reported problems with the diagnosis and support pathway due to school closures (schools are crucial in this process).

Deaths of adults with learning disabilities from Covid-19

In July 2020, the Learning Disabilities Mortality Review (LeDeR) programme published a short report describing key information relating to the first 50 completed LeDeR reviews of deaths of people with learning disabilities whose deaths had been attributed to COVID-19.

This was followed by a report published in November 2020 of more detailed analysis (undertaken in September 2020) of the circumstances leading to death for a representative sample of 206 adults with learning disabilities who died from suspected or confirmed COVID-19.

Key Findings (National)

There was a significant increase in the number of deaths at the peak of the COVID-19 pandemic from March to May 2020. The peak month for deaths from Covid-19 was April 2020.²⁷

- In each region, the proportion of deaths of people with learning disabilities from Covid-19 notified to the LeDeR programme was greater than the proportion of deaths from Covid-19 in the general population (24% vs 13%).
- A greater proportion of males than females with learning disabilities died from Covid-19, more so than in the general population.
- Younger people with learning disabilities died more in relation to older people. 4% of people with learning disabilities were aged 85 or over, compared to 42% in the general population.
- A significantly larger proportion of people who died from Covid-19 had Down's Syndrome (21%) than those who died from other causes.
- Demographic variables significantly associated with a greater likelihood of dying from COVID-19 were being of Asian/Asian British ethnicity, or living in a nursing home, supported living setting or a residential home.
- Adults who died from COVID-19 were more likely to be obese compared to adults who died from other causes.
- 83% of adults with learning disabilities with who died from Covid-19 died in hospital. This is higher than that of adults (aged 20 years and over) in the general population who died from Covid-19 in hospital (68%).
- Of the completed reviews of deaths of people who died from Covid-19, 17% noted problems that a person had in accessing timely and appropriate healthcare.
- Care received by 3% of those who died from Covid-19 was reported to have fallen so far short of good practice it had a significant impact on the person's health and wellbeing or contributed to their death. Such poor-quality care was most frequently due to delays in the diagnosis and treatment of illness.
- People from white British background more frequently received care graded as meeting or exceeding good practice (54%), compared to people from minority ethnic groups (48%).

²⁷ [Deaths of people with learning disabilities from COVID-19.pdf \(bristol.ac.uk\)](#)

Key Findings (Local)²⁸

The pandemic had an unusual impact on the pattern of reported notifications. Only one death was notified to LeDeR during quarter three. Between May 2020 and March 2021, but particularly between October 2020 and March 2021, death notifications were below expected levels.

The characteristics and health needs of individuals who had died from confirmed or suspected COVID-19 were subject to an initial Rapid Review to enable the extraction of key learning points in a timely manner. Where a completed review confirmed the cause of death as COVID-19 further analysis of associated factors was undertaken.

Learning from COVID as a cause of death is detailed in the annual report on page 29

(below relates to wider local findings and are not specific to COVID)

During 2020/21 the COVID-19 pandemic brought into sharp focus and in many ways compounded the health inequalities experienced by people with a learning disability. Underlying health conditions that had not previously featured as a significant contributory theme for premature mortality were brought to people's attention. Information and learning gathered from the completion of LeDeR Reviews this year contributed to the wealth of information that we have collectively generated now that we have been undertaking learning from LeDeR Reviews for three full annual reporting year cycles.

From the themed learning generated up to and during 2020/21 and the feedback of people with lived experience a number of priorities were felt to be of greatest importance.

- Supporting people's emotional and mental health needs
- Supporting people with learning disability or autism and their loved ones to make and influence choices about their care when they are very unwell or when they are dying
- Recognising and responding to health need through Annual Health Checks
- Increasing protection from respiratory conditions
- Taking a zero tolerance to avoidable deaths related to poor management of constipation or bowel impaction
- Prevent a deterioration of health needs by recognising and supporting people to understand the impact of obesity

The agreed areas of focus outlined will be a key feature of the milestones within our 3 Year Learning Disability and Autism Plan and in the Herefordshire and Worcestershire LeDeR Three Year Strategy that will be developed during 2021.

²⁸ [LeDeR Programme – Annual Report 2020/2021 \(herefordshireandworcestershireccg.nhs.uk\)](https://www.herefordshireandworcestershireccg.nhs.uk)

National Strategies and Plans

The NHS Long Term Plan

The NHS has a crucial role to play in helping people with a learning disability, autism or both lead longer, happier and healthier lives.

The NHS Long-term Plan aims to improve people's health by making sure they receive timely and appropriate health checks, while improving the level of awareness and understanding across the NHS of how best to support them as patients.

The plan also aims to enable people with complex needs to be supported to live fulfilling lives at home rather than in hospital, offer more a personal budget, to give them choice over the type of support they receive.

The objectives of the NHS Long term plan:²⁹

- To **Improve community- based support** so that people can lead lives of their choosing in homes not hospitals. This will help to reduce the reliance on specialist hospitals and address the inappropriateness of this provision and the long term repeated record of systematic abuse within them.
- **Develop a clearer and more widespread focus on the needs of autistic people and their families**, starting with autistic children with the most complex needs.
- Make sure that all NHS commissioned services are providing **good quality health, care and treatment** to people with a learning disability and autistic people and their families. NHS staff will be supported to make changes needed (reasonable adjustments) to make sure people with a learning disability and autistic people get equal access to, and experience of and outcomes from care and treatment.
- **Reduce waiting times for specialist services.** Children and young people with suspected autism have to wait for long periods before being provided with a diagnostic assessment. Over the next three years, autism diagnosis will be included alongside work with children and young people's mental health services to reduce waiting times. By 2023/24 children and young people with a learning disability, autism or both with the most complex needs will have a designated keyworker. initially, keyworker support will be provided to children and young people who are inpatients or at risk of being admitted to hospital. Keyworker support will also be extended to the most vulnerable children with a learning disability and/or autism, including those who face multiple vulnerabilities such as looked after and adopted children, and children and young people in transition between services.
- **Reduce health inequalities**, improving uptake of annual health checks, reducing over medication through Stopping The Over-Medication of children and young people with a learning disability, autism or both (STOMP) and Supporting Treatment and Appropriate Medication in Paediatrics (STAMP) programmes and taking action to prevent avoidable deaths through learning from deaths reviews (LeDeR). To

²⁹<https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/a-strong-start-in-life-for-children-and-young-people/learning-disability-and-autism/>

continue funding the LeDeR programme. To enable more care to move to the community, the NHS will support local systems to take greater control of budgets to reduce avoidable admissions, enable shorter lengths of stay and end out of area placements. Where possible people with a learning disability, autism or both will be enabled to have a Personal Health Budget.

- Increased investment in intensive, crisis and forensic community support to enable more people to receive personalised care in the community closer to home and reduce preventable admissions to inpatient services.
- Continue to **champion the insight and strengths of people with lived experience and their families in all the NHS services.**
- Ensure that the NHS has a **continually improved awareness of the needs of people with a learning disability and autistic people**, working together to improve the way it cares, supports, listens to, works with and improves the health and wellbeing of them and their families.
- **Action to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people.** The NHS will improve the uptake of the existing annual health check in primary care for people aged over 14 years with a learning disability, so that at least 75% of those eligible have a health check each year.
- **Focus on improving the quality of inpatient care across the NHS and independent sector.** By 2023/24, all care commissioned by the NHS will need to meet the Learning Disability Improvement Standards.

The Long Term Plan confirmed that all parts of England would be served by an Integrated Care System. ICS are new partnerships between the organisations to meet health and care needs across an area, to coordinate services and to plan in a way that improves population health and reduces inequalities between different groups.

National Autism Strategy

The Government released a new National Autism Strategy in July 2021. This has the following priorities:

- Improving understanding and acceptance of autism within society
- Improving autistic children and young people's access to education, and supporting positive transitions into adulthood
- Supporting more autistic people into employment
- Tackling health and care inequalities for autistic people
- Building the right support in the community and supporting people in inpatient care
- Improving support within the criminal and youth justice systems

Work has now commenced to plan for a new Worcestershire Strategy to meet these priorities.

Local Strategies and Plans

Herefordshire and Worcestershire ICS Learning Disability and Autism Three Year Plan 2021–24

The Herefordshire and Worcestershire ICS Learning Disability and Autism Three Year Plan 2021–24 comprises three workstreams:

- Reduce health inequalities
- Avoid admission to locked hospitals
- More support in the community for autistic people

The plan aims to reduce health inequalities by:

- Continuing to embed learning from LeDeR reviews to address health inequalities. (100% of LeDeR reviews within 6 months with action plan to reduce avoidable deaths).
- Increasing annual health checks to at least 85%
- Increasing the uptake of the flu vaccine and coronavirus vaccines
- Improving training for staff
- Improving access to personalisation clinics (Autism friendly)
- Sustaining and improving on AHCs for LD with a focus on increasing the number of people registered specifically those who are aged 14-25 year and people from Ethnic Minorities.
- Continually assessing and reviewing quality and impact

Avoid admission to locked hospitals by:

- Expanding enhanced and consistent Care Service
- Commencing Community Forensic mental health services as part of the community learning disability service
- Encouraging more supported living.

Enhance support for autistic people in the community by:

- Securing sufficient timely diagnostic capacity. Striving to reduce the waiting times for an assessment for autism
- Putting in place post-diagnostic support for autistic adults based on best-practice models
- Providing training for all health and social care staff

- Providing a new Autism Service for young adolescents transitioning to adulthood from 2022.

It is important to note that some of these milestones relate to the 21/22 aspect of the 3 plan. More details on the plan can be found [here](#).

A 3 year LeDeR delivery plan will be agreed by March 2022.

Learning Disability Strategy for Worcestershire 2019-2022

There is also a **Learning Disability Strategy for Worcestershire 2019-2022 – “Better Outcomes for People with a Learning Disability and their Families”**. The Strategy includes seven main aims:

- Staying Healthy
- Living Well
- Having a Place to Live
- Having a Job
- Staying Safe
- The Right Support for Carers
- Preparing for Adulthood

More details on the strategy can be found [here](#).

Health of People with Learning Disabilities

People with learning disabilities have more healthcare needs than the general population. Approximately 50% of people with learning disabilities will have at least one significant health problem. Rates of epilepsy are over 20 times higher in comparison to the general population. Rates of dementia are higher (22%) than for the general population (6%). People with learning disabilities are also more likely to have difficulties with eating, drinking and swallowing (dysphagia) and, those with dysphagia, are more likely to experience respiratory infections.

In Worcestershire, (this is counted by GP registration not by place of residence), 2020/21, 85% of people aged 14 years and over, with a Learning Disability underwent an annual Health Check, with their GP or family doctor, this is significantly higher than the England rate (48.9%).

The most recent annual report on the health and care of people with learning disabilities (2018-19) produced by NHS Digital, showed that:

In Worcestershire, a higher proportion of people on the Learning Disability register:

- Had a **blood pressure measurement** in the last 5 years when compared to the control cohort (of patients not on the Learning Disability Register).
- Had a **BMI assessment** in the last 5 years when compared to the control cohort.

- were **Underweight or overweight/obese** when compared to the control cohort.
- Had an active diagnosis of **asthma** when compared to the control cohort.
- Had a diagnosis of **dementia** when compared to the control cohort.
- Had a diagnosis of **severe mental illness** when compared to the control cohort.
- Had a diagnosis of **hypothyroidism** when compared to the control cohort.
- Had an active diagnosis of **diabetes** when compared to the control cohort.
- Had an active diagnosis of **epilepsy** when compared to the control cohort.

In Worcestershire, a lower proportion of people on the Learning Disability register:

- Had received a **flu vaccination** when compared to the control cohort.
- Had a diagnosis of **cancer** when compared to the control cohort.
- Had a **cervical cancer screen** when compared to the control cohort.
- Had a **breast cancer screen** when compared to the control cohort.
- Had a **colorectal cancer screen** when compared to the control cohort.
- Had an active diagnosis of **chronic kidney disease** when compared to the control cohort.
- Had an active diagnosis of **COPD, Coronary Heart Disease, Hypertension, Stroke** when compared to the control cohort.

Full breakdown of results for Worcestershire is available in Appendix 1.

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 conditions are identified and managed at the earliest possible stage.³⁰ In Worcestershire in 2018/19, there is a lower proportion of eligible adults with a learning disability who have had an annual health check (56.5%) when compared to England (59.3%).

Annual Health Checks are part of the national strategy to improve access to better health care for people with a learning disability and more latterly Autistic people.

1. Outcomes from the **LD mortality review (LeDeR)** identified that annual health checks are key to ensure people with an LD's health is monitored and they are taking opportunities for health screening to **reduce health inequalities** for people with a learning disability and autistic people.
2. It is recognised that people with a Learning disability have poorer physical and mental health than other people, they are also more likely to die younger.

In 2020/21 85% of Annual Health Checks were completed across Herefordshire and Worcestershire, becoming a leader of good practice regionally. The national target is 70%.

There is a continued aim to complete 85% of Annual Health Checks over the next 3 years as part of the LDA long term plan. This will enable our local system to build on our established collaborative approach to improve the quality of the AHC. There is a programme of work to review and refresh GP registers to align them to the reviewed NHS England guidance. These trajectories are inclusive of 14-25 year olds and people from black, Asian and other ethnic minority background.

Personalised clinics are being developed so people can have a positive and reasonably adjusted experience of health checks across our system.

To support the relaunch of AHC and to improve the quality and consistency we have developed with partners a range of accessible information guides and self-assessment tools to support individuals and their families to access and to increase awareness of AHC. This information is accessible and is now available on the CCG website:

<https://herefordshireandworcestershireccg.nhs.uk/our-work/learning-disabilites-and-autism/annual-health-checks>

Herefordshire and Worcestershire CCG will be running a 'learning disability and health' training programme for all health staff across the system, with a focus on improving quality of service delivery.

³⁰ NHS Choices (2018) Annual Health Checks, [Online], Available from: <https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks> , Accessed: 27/06/2018

Speakeasy NOW

Speakeasy NOW is a user-led charity based in Worcestershire.³¹ The services the charity provides include:

- Self- advocacy groups – meet once a month to talk about disability issues as well as offering friendships. Groups run in Worcester, Malvern, Bromsgrove, Redditch, Evesham, and Droitwich.
- Expert Members are active participants on Worcestershire’s Learning Disability Partnership Board. Some Expert Members are Co-chairs and work with Commissioners from Worcestershire County Council. Expert Members represent people with learning disabilities. Also work with Children’s Services to help plan better Transitions for young people with learning disabilities.
- Health Checkers teamwork with the three Worcestershire Clinical Commissioning groups and with the Staying Healthy group of Worcestershire’s Learning Disability Partnership Board. The Health Checkers are people with learning disabilities who care strongly about the quality of Health Services in Worcestershire.³² Health Checkers meet every 2 months to plan and discuss their work and to meet with different Health Professionals and providers.

A recent Worcestershire review of the Annual Health Check Programme carried out by the Worcestershire Speak Easy organisation, reported that many individuals found that they enjoyed the experience and had a good relationship with their GP. Issues raised included not understanding information that was given, sometimes during a consultation, conversations were continued with carer/parent or family member rather than the individual themselves. There was some concern about the quality of the annual health check and whether it was as thorough as it should be.³³

National Initiatives

Best Practice

Nationally, there are a number of programmes of work seeking to address the health inequalities faced by people with learning disabilities including development of best practice approaches for commissioning in collaboration with the NHS Right Care Team called Right Care Pathways. Recent areas of work relating to people with learning disabilities include diabetes, sepsis and constipation including reasonable adjustments for each specific pathway.

³¹ [People’s Parliament – SpeakEasy NOW](#)

³² <http://www.speakeasynow.org.uk/our-work/health-checkers>

³³ Speak Easy N.O.W (2018) Health Checkers, [Online], Available from: <http://www.speakeasynow.org.uk/our-work/health-checkers/> Accessed: 27/06/2018

Reasonable Adjustment

The Equality Act 2010 stipulates that discrimination on the grounds of disability³⁴ is unlawful³⁵. Reasonable adjustments for disabled people are sometimes required to make it easier for disabled people to receive accessible health and care services³⁶. Examples include:

- providing literature in Easy Read
- provision of extra equipment, and
- providing additional guidance and support.

A digital reasonable adjustment programme is underway, which aims to have a digital flag on a patient's healthcare record (Summary Care Record) to show that they require a reasonable adjustment. This is to improve awareness amongst health professionals and to ensure people are getting the level of support that they require.

Herefordshire and Worcestershire CCG is one of 12 national learning pilots for the introduction of a 'reasonable adjustment flag' on the Summary Care Record.

Flu Vaccination

Children and adults with learning disabilities are clearly identified as a clinically 'at risk' group, eligible for a free flu vaccine as part of the national flu vaccine programme, Public Health England are coordinating their efforts with local stakeholders to improve vaccination uptake in this group of individuals, who have lower rates of vaccination in comparison to the overall Worcestershire average for under 65s at risk as outlined in Table 4. This includes the administration of flu vaccination via nasal spray, particularly for individuals with needle phobias.

Table 4 Flu Vaccination Uptake by Clinical Commissioning Group (CCG) in 2018-19

Indicator	Redditch & Bromsgrove CCG	South Worcestershire CCG	Wyre Forest CCG	Worcestershire Uptake (U65's At Risk)
Patients with Learning Disability receiving a seasonal influenza vaccination	41.8%	47.1%	43.5%	53.7%

Over Medication

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. More details of this

³⁴ [Equality Act 2010: guidance - GOV.UK \(www.gov.uk\)](http://www.gov.uk)

³⁵ <https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf> [Accessed 4 Jun. 2018].

³⁶ NHS England (2018) Reasonable Adjustments, [Online], Available from: <https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/> Accessed: 22/06/2018

national project are available from the NHS England website, Stopping over medication of people with a learning disability, autism, or both (STOMP).³⁷

³⁷ NHS England (2018) Stopping Overmedication of People with Learning Disabilities (STOMP), [Online], Available: <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/> Accessed: 25/06/2018.

What is being done in Worcestershire?

Worcestershire County Council spends around £72 million each year on adult social care services for people with learning disabilities.³⁸

The Learning Disability Strategy for Worcestershire 2019-2022 – “Better Outcomes for People with a Learning Disability and their Families” – has seven “big aims” to support people with learning disabilities, their families and carers:

- “Staying Healthy” – implementing Worcestershire’s Learning Disability and Autism 3 Year Plan to improve health and provide safe and sustainable care, reducing early deaths and health inequalities of people with learning disabilities and reduce the number of people in inpatient services.
- “Living Well” – ensuring people with learning disabilities can live as independently as possible, making sure people can have and keep good relationships, know where to go for support, and have worthwhile things to do and be part of their local communities
- “Having a Place to Live” – developing the right sort of housing and support for people with learning disabilities, improving information and communications about housing and making sure that housing and support are safe.
- “Having a Job” – making sure people with learning disabilities who want to work find jobs, through employment support, working with partners, businesses and communities and publicising the good things about paid work.
- “Staying Safe” – being safe whilst out in the community, raising awareness of and reducing Hate and Hate Crime and making sure support services for people with learning disabilities are good quality.
- “The Right Support for Carers” – finding new ways to involve carers, enabling and supporting carers to plan for the future as they and their family member with a learning disability grow older, and ensuring carers are well-supported with quality care and support when they are ill or need a break.
- “Preparing for Adulthood” – improving the journey into adulthood for young people and their families through earlier and better joined-up planning, developing education, social care and health provision to meet young people’s needs as they grow up and involving children, young people and families in planning and service design.

People with learning disabilities and their families are also supported by health and social care partners across the system in the following ways:

- Worcestershire County Council Learning Disability team and Herefordshire and Worcestershire Health and Care Trust Learning Disabilities team work closely together to provide, better outcomes for people with learning disabilities.
- Learning Disability Nurses work closely with people with learning disabilities and their families to keep them healthy. They are involved in making reasonable adjustments for individuals to make sure they can use and access services properly.

³⁸ Worcestershire County Council budget 2021/22 (gross budget).

- All people with learning disabilities are offered an annual health check each year by their family doctor. In addition to this there is a Primary Care Liaison Nurse who ensures that family doctors give a good service to people with learning disabilities.
- A specialist commissioning team ensures that people with learning disabilities and complex needs are not admitted into inpatient settings unless absolutely necessary and, when they are, ensures that they are admitted for the shortest amount of time possible and assisted when returning home. Specialist health commissioners work in partnership with social care commissioners to develop services in the community to support people with complex needs.
- All partners are working to improve access to universal services and community groups to ensure that people with learning disabilities can use these services in the same ways other people are able to.

Premature Death and Learning Disability

63% of people with learning disabilities die before reaching the age of 65, compared to 15% in the general population.³⁹

The Confidential Inquiry into Premature Deaths of People with learning disabilities (CIPOLD) 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% of the general population.⁴⁰ Research has also shown that people with learning disabilities are four times more likely to die of preventable causes when compared with the general population.⁴¹

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 in order to identify common causes of death and to establish, what lessons can be learnt. The programme supports local areas to implement a consistent format for these reviews. The LeDeR programme is commissioned on behalf of NHS England (NHSE) and during 2020/2021 continued to be hosted by the University of Bristol.

The phased roll-out of the LeDeR Programme reached Herefordshire and Worcestershire in 2017. The initial introduction of the programme coincided with the introduction of the Learning from Deaths guidance which made clear the expectation that the LeDeR methodology would be the preferred format for reviewing deaths for people with a learning disability.

Table 5 Key Reports and Recommendations into the health and care of people with learning disabilities⁴²

Year	Report/Recommendation
2001	Recommendation for Confidential Inquiry into premature deaths of people with learning disabilities. Valuing people white paper 2011 (Department of Health)
2004	Recommendation for inquiry into deaths of people with learning disabilities following Mencap 'Treat me Right' report.
2006	Identified that people with learning disabilities experienced considerable inequalities in health. Disability Rights Commission review.
2007	Death by Indifference Mencap. Further call for a formal inquiry to take place into premature deaths of people with learning disabilities

³⁹ [2021: LeDeR Annual Report 2020 | School for Policy Studies | University of Bristol](#)

⁴⁰ Heslop, P., Blair, P., Fleming, P., Houghton, M., Marriott, A. and Russ, L. (2013). The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). [online] Bristol: Norah Fry Research Centre, pp.1-128. Available at: <https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf> [Accessed 4 Jun. 2018].

⁴¹ Disability Rights Commission (2006), Equal Treatment: Closing the Gap, [Online], Available from: <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/DRC-Health-FI-main.pdf> , Accessed: 25/06/2018

⁴² University of Bristol (2018) Why a Confidential Inquiry is necessary, [Online], Available from: <http://www.bristol.ac.uk/cipold/confidential-inquiry/why/> , Accessed: 25/06/2018

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.

The Government response to the third annual Learning Disabilities Mortality Review (LeDeR) recommended that:⁴³

- It is essential to have focussed leadership within the health and care sectors to ensure the LeDeR programme is successful and well embedded across the system. It should be implemented on a national level in NHS England and NHS Improvement. The NHS Long Term Plan⁴⁴ set out the NHS's commitment to accelerate the LeDeR initiative and continue to fund the LeDeR programme.
- NHS England and local authority social care should maintain the specific LeDeR approach to reviewing deaths, ensure the quality of completed reviews, and translate learning into action.
- NHS England should continue to support Clinical Commissioning Groups (CCGs) to complete mortality reviews to the recognised standard. This is essential to ensure that learning from deaths are captured and acted upon.
- CCGs are now expected to publish annual local LeDeR reports
- NHS England will publish data, as part of a forthcoming learning disability and autism dashboard, on the progress of LeDeR reviews to maximise transparency.

⁴³ [The Government response to the third annual Learning Disabilities Mortality Review \(LeDeR\) Programme report \(publishing.service.gov.uk\)](#)

⁴⁴ [NHS Long Term Plan v1.2 August 2019](#)

Learning Disabilities Mortality Review (LeDeR) Annual Report 2020 (National)

Deaths occurring between 2018 and 2020⁴⁵

The latest national report from the LeDeR Programme compares data from the deaths of 9,110 people who died in the three-year period 2018-20.

Between 2018-2020 the number of deaths fluctuated between 200-300 each month with a larger number of deaths reported during winter months.

There was a significant increase in the number of deaths at the peak of the Covid-19 pandemic from March–May 2020.

Demographic information about people who died:

- Males accounted for 57% in 2018 and 61% in 2020.
- 91% were of White British ethnicity in 2018, 90% in 2019 and 89% in 2020. Fewer than 5% of adults who died were of Asian/Asian British ethnicity (3% of those in 2018, 3% in 2019 and 4% in 2020. (The number of deaths from different minority ethnic groups is too small for analysis by individual ethnicities.
- Adults with profound and learning disabilities - 9% of those who died in 2018, 8% in 2019 and 7% in 2020.
- The lowest median age at death of adults, at 33 years, was for males from ethnic minority groups and with severe, profound and multiple learning disabilities. Their median age at death had increased from 30 in 2018 to 32 in 2019 and 42 years in 2020.
- Almost half (46%) of adults had 7 to 10 long-term health conditions when they died. A small proportion of adults (3%) had three or fewer long-term health conditions.
- Underlying cause of death related to respiratory system and circulatory system were more frequent in those aged 65 and over, or in people with severe or profound or multiple learning disabilities.
- Underlying causes of death related to the nervous system were more frequent in the youngest age group (15-49 years), people in minority ethnic groups, or people with severe or profound and multiple learning disabilities.
- Underlying causes of death related to congenital and chromosomal conditions were most frequent in people aged 50-64 years, or in white British people.
- Underlying conditions related to COVID-19 were more frequently reported in people from minority ethnic groups.

Learning Disability Annual Health Check

Information about whether the person had received an annual health check was reported for 5,850 deaths of adults for whom a review of their death had been completed.

⁴⁵ [LeDeR programme annual report 13.05.2021 FINAL.pdf \(bristol.ac.uk\)](#)

- Overall, approximately three-quarters of adults had had a learning disability annual health check in the year before they died.
- Those who had not received an annual health check were more likely to be in the 18-24 years age group or to have mild learning disabilities.

Recommendations (National)

Recommendation 1

LeDeR reviews to be undertaken through the lens of greater racial awareness. (Audience: NHS England).

Recommendation 2

Local Authorities to ensure that Joint Strategic Needs Assessments (JSNA) collect and publish local data on the health needs of children and adults with learning disabilities, capturing any characteristics that relate to specific ethnic groups. Integrated Care Systems (ICS),¹⁴ and their commissioned Primary Care Networks to take actions to reduce any disparities between people from different ethnic groups when planning local services for people with learning disabilities and their families.

Recommendation 3

A nationally endorsed standard resource is required, with local flexibility, that provides information for people with learning disabilities and their families about legal rights and entitlements, national services and how to access them, and local sources of support. Mechanisms must be in place for its effective distribution, particularly to people from minority ethnic groups. (Audience: NHS England).

Recommendation 4

Strategically planned, long-term, targeted, joint investment is needed to strengthen partnerships with local communities and provide support for peer-to-peer networks, to build on and future-proof existing contacts and structures within local communities and increase trusted word-of-mouth communication and information sharing. (Audience: Local Authorities, ICSs, Primary Care Networks).

Recommendation 5

Local systems, including commissioning, to be responsive and develop strategic plans that address the longstanding needs of people with learning disabilities and their families that the COVID-19 pandemic has illuminated, including the availability of specialist learning disability teams in acute, primary and community care. (Audience: ICSs).

Recommendation 6

From the outset of any future public health emergency, the needs and circumstances of people with learning disabilities must be considered and built into 15 national policy and guidance by the National Institute for Health Protection and the Department of Health and Social Care. A data collection tool should be established to capture emerging evidence relating to people with learning disabilities, which would trigger adjustments to policy, guidance, systems and processes as required. (Audience: National Institute for Health Protection, Department of Health and Social Care; NHS England).

Recommendation 7

Commissioning guidance for NHS111 services to include a requirement for the provision of specifically tailored training to NHS111 staff about how to respond appropriately to calls about people with a learning disability or from people with a learning disability and their families. (Audience: NHS England/NHS Improvement).

Recommendation 8

A LeDeR representative should routinely and as of right be involved with the child death review meeting/process for children with learning disabilities, in order to ensure that necessary information is collected and transferred into the wider LeDeR programme. (Audience: NHS England).

Recommendation 9

NHS England to collect and collate evidence about the needs and circumstances of people who have been subject to mental health or criminal justice restrictions and use this to inform appropriate, personalised service provision for this group of people. While waiting for this evidence, robust after-care support (as required by S117 of the Mental Health Act) must be provided. (Audience: NHS England, Local Authorities).

Recommendation 10

Previous recommendations about minimising the risk of aspiration pneumonia in people with learning disabilities need to be addressed. (Audience: NICE, Department of Health and Social Care, NHS England).

Herefordshire and Worcestershire Learning Disabilities Mortality Review (LeDeR) Annual Report 2020/21⁴⁶

The phased roll-out of the LeDeR programme reached Herefordshire and Worcestershire in 2017. The initial introduction of the programme coincided with the introduction of the Learning from Deaths guidance which made clear the expectation that the LeDeR methodology would be the preferred format for reviewing deaths for people with a learning disability. The LeDeR programme is commissioned on behalf of NHS England (NHSE) and during 2020/2021 continued to be hosted by the University of Bristol.

During 2020/2021 all deaths continued to receive an Initial Review. Where there are areas of concern in relation to the care of the person who has died, or if it is felt that further learning could be gained, a more detailed Multi-Agency Review (MAR) of the person's life and death is facilitated. LeDeR does not replace other statutory formats and processes for reviewing a person's death where concerns exist.

In Worcestershire, all deaths for people with Learning Disabilities are reviewed by the local LeDeR team on a quarterly basis. The annual report provides an update on the progress and impact made across Herefordshire and Worcestershire during the period covering 1st April 2020 to 31st March 2021, the third full year of programme implementation. This includes the initial and subsequent peaks in the number of cases of the COVID-19 pandemic and some of the consequential implications of 'lockdown'.

Figure 7 Number of notifications received by the LeDeR programme (Worcestershire)

Financial Year	Number of notifications received
2018/19	32
2019/20	23
2020/21	36

⁴⁶ Herefordshire and Worcestershire Integrated Care System. Learning Disabilities Mortality Review (LeDeR) Programme (Herefordshire and Worcestershire). Annual Report 2020/21. June 2021. Available [here](#).

- During the first quarter of 2020-21 the pandemic impacted mortality across the UK and the number of notifications for Worcestershire was almost equal to the total number of notifications for the whole of the preceding year.
- The median age of deaths notified to the LeDeR programme in Worcestershire between 2017 and 2020 was 61 years for women and 60 years for men.
- In Worcestershire, since the LeDeR programme began in 2017, 55% of notifications have been male deaths.
- In Worcestershire, since the LeDeR programme began in 2017, 58% of deaths notified to the programme occurred in hospital, 37% of deaths in the usual place of residence, 4% of deaths in a residential/nursing home and 1% in another place (other).
- No completed reviews have identified that acute care was required but was not accessed or the decision to not convey to hospital was found to be contributory to death in any way.
- Recommendations predominantly support that more people could achieve a different or preferred place of death if the timeliness of the identification of irretrievable deteriorating health or processes for planning and coordinating end of life care, were different. This includes examples where a return to home or an alternative care setting is considered
- Across the whole programme (Herefordshire and Worcestershire combined) Respiratory conditions continue to be the most prominent cause listed on death certification.
- Deaths due to aspiration pneumonia make up 35% of deaths for all respiratory causes.
- A Priority Action Group continues to focus on the modifiable factors that can contribute toward aspiration pneumonia
- Very low numbers of deaths are recorded as being due to sepsis. The ICS has also seen very low numbers of deaths reported due to Sudden Death in Epilepsy (SUDEP) or epilepsy related.
- Bowel related deaths have significantly reduced since the first year of the programme (overall less than 2% compared to 6% of all England LeDeR notifications). A review of interventions across both counties is the focus of a Priority Action Group and may identify additional learning to further embed good practice.
- Deaths where the cause is listed as due to cancer remain fairly static and reflect a broad range of primary sites. Late stage diagnosis is not uncommon. Death due to cancer appears to be reflected less often for people with a learning disability than for the general population. We do not know how many people may be dying from undiagnosed cancer. Further analysis of screening access is underway and equity of uptake will be a key priority over the next 2-3 years.
- Deaths where the cause of death is listed as due to cardio-vascular disease also remain static however all deaths were exclusively compatible with individuals who had a recorded high Body Mass Index.

Figure 8. Themes for most frequently reported cause of death for people with a learning disability

Cause of death	Bowel related	Respiratory and Pneumonia	Dementia	Cancer	Cardio-vascular	Epilepsy	Sepsis	Other	COVID-19
Hfd & Worcs Whole Programme	7	73	9	20	21	3	3	15	
Hfd & Worcs April 19 – March 20	2	17	2	5	6	1	1	4	
Hfd & Worcs April 20 – March 21	1	16	5	4	4	1	1	7	8

Locally, themes have emerged over the course of the LeDeR Programme. The frequency with which a recommendation type is made, and the seriousness of the potential outcome, supported a Steering Group to agree key priority areas for improvement and the development of Priority Action Groups to take forward each area of required improvement.

During 2019/20 there were 5 Priority Action Groups:

- Bowel Health (linked to a key theme of deaths with an underlying factor of chronic mis-management of faecal impaction)
- Respiratory Conditions (linked to the most frequent cause of death and the factors that might influence modifiable factors)
- Annual Health Checks (including a theme in review learning for variability in the uptake and quality of checks)
- Support during an Acute Hospital admission
- Experience of the end of life (including themes relating to ReSPECT and DNACPR decisions and documentation)Summary

The pandemic has meant that there was an urgent need to review the areas of focus. Some priority action groups were paused or merged. For example, the 'Support during a Hospital Stay' and 'Experience at end of life' groups merged and the focus shifted to respond to growing concerns about the perception of inappropriate use of ReSPECT forms in acute hospitals and community settings and the Priority Action Group for Respiratory Conditions rapidly evolved to focus almost solely on COVID-19.

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, whereas 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%).

In Worcestershire, the Supported Living Strategy, availability schemes, and changes in practice have led to a significant increase in usage of Supported Living services across the board. There has been an increase from 333 individuals with a learning disability in supported living on 31st March 2017 to 466 individuals on 31st October 2020.

What is being done in Worcestershire?³⁸

In the Worcestershire Having a Place to Live Strategy there is a commitment to ensuring that people with learning disabilities have a range of different types of housing to choose from.

A Supporting Living Needs Assessment was completed in December 2020 and commissioning plans developed to create additional supported living required to meet demand. This will have a particular focus on young people transitioning to Adult Social Care, People with Complex Needs and Vulnerable Adults.

Social Support and 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%.

What is being done in Worcestershire?

Worcestershire County Council Supported Employment Service was set up in April 2016 and replaced historic work-related schemes for people with Learning Disabilities.

The team was set up to offer employment related support to people with Learning Disabilities in receipt of Adult Social Care and works to support individuals into work and maintain work. A service to support people to access work activity and employment that also works to positively impact Indicator results:

- The Public Health Indicator: 1.08 Employment for those with long-term health conditions including adults with a learning disability.
- The Adult Social Care indicator: 1E Proportion of adults with a primary support reason of learning disability support in paid employment

Associated Documents and Best Practice

[Public Health England - Learning Disability applying All Our Health](#)

[The Learning Disabilities Mortality Review \(LeDeR\) Programme - Annual Report 2017](#)

[Worcestershire's Adult Learning Disability Strategy 2016-2018: Better outcomes for people with a Learning Disability and their families](#)

[NICE Guideline \[NG111\] - Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges](#)

[NICE Guideline \[NG93\]: Learning disabilities and behaviour that challenges: service design and delivery](#)

[NICE Guideline \[NG54\]: Mental health problems in people with learning disabilities: prevention, assessment and management](#)

[NICE Guideline \[NG96\]: Care and support of people growing older with learning disabilities](#)

Related JSNA Publications

Worcestershire County Council (2017) 2017 Briefing on Learning Disabilities, [Online]
Available from:

http://www.worcestershire.gov.uk/info/20122/joint_strategic_needs_assessment/1499/jsna_briefings Accessed: 22/10/2018

Data Notes

POPPI and PANSI estimates and predictions are based on prevalence rates in a report by Eric Emerson and Chris Hatton of the Institute for Health Research, Lancaster University, entitled Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England, June 2004. The authors take the prevalence base rates and adjust these rates to take account of ethnicity (i.e., the increased prevalence of learning disabilities in South Asian communities) and of mortality (i.e., both increased survival rates of young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities). Therefore, figures are based on an estimate of prevalence across the national population; locally this will produce an over-estimate in communities with a low South Asian community, and an under-estimate in communities with a high South Asian community.

No definitive data is available for the number of adults with Autism in Worcestershire. The definition of autism has changed over the decades and potentially could change in future years. This poses as a challenge for meaningful analysis.

Data is available for children with Autism known to schools.

The latest data from NHS Digital is for 2018-19. Stakeholders have suggested that the learning disabilities landscape has shifted dramatically since this time and this data set does not yet capture the effects of the COVID-19 pandemic.

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 Matthew Fung on telephone number 01905 845040 or by email mfung@worcestershire.gov.uk

Appendix 1: NHS Digital: Learning Disabilities Dataset (2018-19) by Clinical Commissioning Group, Worcestershire⁴⁷

Prevalence key

	Higher than Control
	Lower than Control

Indicator Number	Indicator Description	Redditch & Bromsgrove CCG	South Worcestershire CCG	Wyre Forest CCG
LDOB003a	Patients recorded on their general practice's Learning Disabilities Register, as per the current QOF definition, as at Reference Year End Date	0.4%	0.4%	0.7%

Indicator Number	Routine Health Checks Indicators Indicator Description	Redditch & Bromsgrove CCG	South Worcestershire CCG	Wyre Forest CCG
LDOB005	Learning Disability Health Check in the last 12 months	58.7%	56.5%	54.3%
LDOB025	On Learning Disability register: Blood pressure measurement in the last five years.	85.9%	81.9%	84.6%
LDOB026	Control cohort: blood pressure measurement in the five years	64.9%	66.8%	68.6%
LDOB006	Patients recorded on their general practice's Learning Disabilities Register who had an immunisation against seasonal influenza in the period 1 September to 31 March in the 12 months to the Reference Year End Date.	41.8%	47.1%	43.5%
LDOB007	Patients recorded on their general practice's Learning Disabilities Register who had a BMI assessment in the 15 months to Reference Year End Date.	64.1%	64.8%	66.2%
LDOB008	Patients in the control patient cohort who had a BMI assessment in the 15 months to Reference Year End Date.	28.4%	28.9%	32.4%
LDOB009	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 underweight (BMI <= 18.4).	4.9%	4.6%	4.2%
LDOB010	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 underweight (BMI <= 18.4).	1.2%	1.2%	1.1%

⁴⁷ This is the latest data with this breakdown, The 2019-20 dataset is the latest data available but it only has Herefordshire and Worcestershire CCG

LDOB011	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 healthy weight (BMI 18.5 – 24.9).	19.1%	19.3%	17.9%
LDOB012	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 healthy weight (BMI 18.5 – 24.9).	8.4%	8.1%	9.7%
LDOB013	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 overweight (BMI 25.0 – 29.9).	20.4%	16.8%	20.2%
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%

Indicator Number	Cancer Indicators Indicator Description	Redditch & Bromsgrove CCG	South Worcestershire CCG	Wyre Forest CCG
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%

Indicator Number	Long Term Conditions/Diagnoses Indicator Description	Redditch & Bromsgrove CCG	South Worcestershire CCG	Wyre Forest CCG
LDOB027	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.	9.5%	9.2%	10.8%
LDOB028	Patients recorded on their general practice's Learning Disabilities Register and who have a diagnosis of dysphagia, as at Reference Year End Date.	2.9%	4.6%	4.4%
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.	14.5%	14.6%	15.0%
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.	10.4%	8.6%	8.9%
LDOB034	Patients in the control patient cohort and who have an active diagnosis of asthma, as at Reference Year End Date.	6.3%	6.1%	7.0%
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.	2.1%	1.9%	3.5%
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.	3.4%	4.1%	4.7%
LDOB039	Patients recorded on their general practice's Learning Disabilities Register and who have a diagnosis of chronic obstructive pulmonary disease (COPD), as at Reference Year End Date.	0.3%	0.7%	0.9%
LDOB040	Patients in the control patient cohort and who have a diagnosis of chronic obstructive pulmonary disease (COPD), as at Reference Year End Date.	1.7%	1.7%	2.2%
LDOB041	Patients recorded on their general practice's Learning Disabilities Register and who have a diagnosis of coronary heart disease (CHD), as at Reference Year End Date.	0.8%	0.3%	0.9%
LDOB042	Patients in the control patient cohort and who have a diagnosis of coronary heart disease (CHD), as at Reference Year End Date.	2.9%	2.9%	3.4%

LDOB043	Patients recorded on their general practice's Learning Disabilities Register and who have a diagnosis of dementia, as at Reference Year End Date.	3.1%	1.3%	1.9%
LDOB044	Patients in the control patient cohort and who have a diagnosis of dementia, as at Reference Year End Date.	0.8%	0.8%	0.9%
LDOB045	Patients recorded on their general practice's Learning Disabilities Register and who have an active diagnosis of depression, as at Reference Year End Date.	15.5%	14.6%	18.0%
LDOB046	Patients in the control patient cohort and who have an active diagnosis of depression, as at Reference Year End Date.	14.4%	13.3%	19.1%
LDOB061	Patients recorded on their general practice's Learning Disabilities Register and who have a diagnosis of heart failure, as at Reference Year End Date.	0.9%	1.3%	1.4%
LDOB062	Patients in the control patient cohort and who have a diagnosis of heart failure, as at Reference Year End Date.	1.2%	1.2%	1.4%
LDOB063	Patients recorded on their general practice's Learning Disabilities Register and who have an active diagnosis of hypertension, as at Reference Year End Date.	6.4%	7.3%	9.0%
LDOB064	Patients in the control cohort and who have an active diagnosis of hypertension, as at Reference Year End Date.	13.0%	14.3%	16.2%
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.	6.5%	6.5%	4.2%
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.	1.6%	1.7%	1.5%
LDOB068	Patients in the control cohort and who have a diagnosis of stroke or transient ischaemic attack (TIA), as at Reference Year End Date.	1.8%	1.9%	2.5%
LDOB069	Patients recorded on their general practice's Learning Disabilities Register and who have a diagnosis of hypothyroidism, as at Reference Year End Date.	11.1%	9.9%	8.9%
LDOB070	Patients in the control patient cohort and who have a diagnosis of hypothyroidism, as at Reference Year End Date.	4.3%	4.4%	5.4%
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.	1.1%	0.7%	6.2%
LDOB072	Patients in the control patient cohort and registered as being in need of palliative care and support as at Reference Year End Date.	0.5%	0.6%	1.0%
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.	0.2%	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%	0.2%

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.	0.1%	0.1%	0.1%
LDOB076	Patients in the control patient cohort 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.	0.1%	0.1%	0.1%

Indicator Number	Diabetes Indicator Description	Redditch & Bromsgrove CCG	South Worcestershire CCG	Wyre Forest CCG
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.	4.6%	6.5%	7.8%
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.	4.7%	4.7%	5.8%
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.	4.1%	5.3%	6.8%
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.	4.1%	4.2%	5.1%

Indicator Number	Epilepsy Indicators Indicator Description	Redditch & Bromsgrove CCG	South Worcestershire CCG	Wyre Forest CCG
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.	14.4%	17.5%	17.6%
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.	0.6%	0.6%	0.7%
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.	28.4%	34.8%	43.6%
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.	12.7%	9.6%	33.1%

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.	19.3%	9.3%	12.0%
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.	10.5%	7.8%	22.4%