

**Adults with Learning Disabilities
Health and Wellbeing Needs Assessment
2024**

Executive Summary

Adults with learning disabilities have a higher risk of morbidity and premature mortality compared with the general population, demonstrating the significant health inequalities they face. Improving the lives of adults with learning disabilities is a national priority. There have been national reviews to identify common themes in mortality and gaps in care provision. This health needs assessment builds on this approach at a local level, bringing together a range of intelligence on the health of people with a learning disability and the particular risk factors they experience.

It reviews the health and care of adults with learning disabilities in both Hampshire and the Isle of Wight. The objectives are to:

- set out the prevalence of learning disability in Hampshire and Isle of Wight
- define the risk factors that contribute to premature death
- understand the access to care and support for adults with learning disabilities

The data used in this report where possible will be at the lowest geographical area. For most of the report the data is only available at Integrated Care Board (ICB) level, through an experimental dataset. This means only a sample of patient data is available.

Key findings from the Needs Assessment

Overall, the data suggest 0.49% of Hampshire's population have a learning disability recorded in primary care registers (7010 people). The highest prevalence is recorded in the New Forest at 0.62% and the lowest in Hart at 0.34%. On the Isle of Wight 0.73% of the population have a learning disability recorded (1066 people). However, this is estimated to represent only 26.9% and 38.4% respectively of those who are living with a learning disability. The recorded prevalence is higher in males than females for both Hampshire and Isle of Wight (HIOW) and Frimley ICBs. The highest prevalence is recorded in the 18-24 year old age band for both sexes.

There is clear evidence that people living with learning disabilities live shorter lives than the general population. Reduced life expectancy is evident in the ICB population pyramids which show sharp reductions in numbers of people with a learning disability after age 65, and more populous younger age groups under 34 years. The [LeDeR Learning from Lives and Deaths - people with a learning disability and autistic people 2022](#) report showed an improvement in length of life for people who had LeDeR reviews, with a median age of death at 62.9 years in 2022, an increase from 61.8 years in 2018. However this is still over 20 years shorter than for people in the general population. In 2022 diseases of the circulatory system (16.7%) were the most common cause of death followed by cancers (14.6%) and diseases of the respiratory system (14.5%).

People with a learning disability are more likely to be overweight (twice as likely), obese (three times as likely) and underweight (four times as likely) than the rest of the

population. Prevalence of overweight and obese body mass index (BMI) is persistently high within all age bands, particularly in teenage years and young adulthood and shows an overall rising trend. People with learning disabilities are 20.3 percentage points higher levels of inactivity compared with those without learning disability.

People with learning disabilities have been identified as a high-risk group under the seasonal influenza vaccination programme. Overall, 63.7% of the HIOW ICB and 59.2% of the Frimley ICB population with learning disabilities received an influenza immunisation in 2022/23, above the England average of 56.0%.

All three adult cancer screening programmes have significantly lower uptake in the population with learning disabilities than those without, (breast and colorectal approximately 20 percentage points lower and cervical over 40 percentage points lower). This population also has higher rates of colorectal cancers than those without learning disabilities.

The data suggest that gastrointestinal disorders such as dysphagia and constipation are far more common among people with learning disability, with dysphagia showing a rising trend, likely reflecting better recognition of the condition. Higher standardised prevalence ratios (SPR) show a greater prevalence of many health conditions than expected in people with learning disabilities including heart failure, stroke, severe mental illness (SMI), dementia and epilepsy. Local data suggests that rates of depression are similar compared to the general population. Health conditions present at much earlier ages in people with a learning disability compared to those without learning disabilities across the ICBs, contributing to the higher level of premature deaths in individuals with learning disabilities. Greater inequalities emerge within specific age groups.

While the majority of people with learning disabilities received a learning disability annual health check in 2022/23 (79.8% national benchmark, HIOW ICB 79.4%, Frimley ICB 84.7%), very few of these reviews had an annual health plan recorded.

Apart from having poorer health, people with learning disabilities also face greater risks of exposure to the social determinants of poorer health such as poverty, inappropriate accommodation and unemployment. They are disproportionately affected by poverty and more likely to experience deprivation. Hampshire's disability employment gap at 72.7 percentage points is wide and tracks significantly above England figures, whereas on the Isle of Wight access to employment is higher, with a narrower gap of 57.8 percentage points, tracking below and significantly better than England. Around 78.7% of Hampshire service users with a learning disability were living in their own home or with family in 2022/23, similar to South East (78.3%) but below England (80.5%) figures, but at 69.9% Isle of Wight proportions are lower.

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1. Introduction

People with learning disabilities face vulnerabilities from health inequalities and social exclusion. Improving their lives with a focus on health inequalities is a national and local priority. In addition to increased health risks associated with their biological conditions, they can have unidentified or untreated health conditions, due to inequalities in access or suitable care provision which leads to premature mortality.

Recent national reviews of the health and lives of people with learning disabilities demonstrate significant disparities compared to people without a learning disability. There have been improvements in the care of individuals with learning disabilities and as a result, life expectancy of this population has gradually increased. However, there are still significant differences between the life expectancies of adults with learning disabilities and the general population. This is most likely due to increased health needs, poor accessibility of services and fewer opportunities to benefit from the wider determinants of health.

This health needs assessment explores national and local data to enable a better understanding of the health needs of people with learning disabilities; it brings together a range of intelligence on the health of people with a learning disability and the particular risk factors that they experience.

1.1 Scope and purpose

The needs assessment investigates the health, wellbeing and causes of mortality in adults with learning disabilities in Hampshire and Isle of Wight. It focuses on adults with learning disabilities (aged 18 and over) who are resident or registered with a GP within Hampshire. Individuals may be living in the community or in residential care (run by the local authority and other providers).

This report also sets out information on the need and demand for health and social care services for people with learning disabilities to ensure that they can live long, healthy and independent lives.

The objectives of the health needs assessment are to:

- understand the prevalence of learning disability in adults in Hampshire,
- consider the access to care and support for adults with learning disabilities, including the wider determinants of health,
- investigate the risk factors that contribute to premature death,

The needs assessment does not include learning difficulties, as described in the 'Definition of Learning Disability' section. Additionally, it does not cover people with autism without a learning disability, although there may be some similarities in the inequalities identified.

1.2 Definition of Learning Disability

The [NHS](#) provides an overview on the causes of learning disability stating that ‘Sometimes it is because a person's brain development is affected, either before they are born, during their birth or in early childhood.’ This can be caused by genetic factors or chromosomal conditions (such as Down’s syndrome), illness during early childhood or complications during pregnancy or birth. Sometimes there is no known cause.

Whilst there are several definitions of learning disability, there is no universally accepted definition across health and social care.

The NHS and the national [Valuing People](#) strategy of 2001 stated a learning disability includes the presence of:

- “a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development”.

However, the [Valuing People Now](#) strategy of 2009 also included people with more ‘complex needs’, a term used to describe a range of multiple and additional needs that people with learning disabilities may have.

[Mencap](#), the learning disability charity, defines learning disability as “a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people”.

It describes different types of learning disability:

- Mild
- Moderate
- Severe
- Profound or multiple learning disabilities.

People with severe or profound learning disabilities are likely to need care and support with daily life, such as in mobility, personal care and communication. This may also affect some people with moderate learning disabilities, but not all. Some people with learning disabilities may also have physical disabilities.

In the context of social care, the Local Authority’s Learning Disabilities team, determines an assessment of learning disability need and eligibility for support based on the [Care Act 2014](#). Therefore, there may be differences in those that are registered with their GP as having a learning disability, and those who receive social care. This is explored further in the next section.

Within education services, learning difficulty is a broader term which includes conditions such as dyslexia and dyscalculia. Whilst the terms learning disability and learning difficulty are sometimes used interchangeably, this needs assessment does not cover learning difficulties.

2. Demography

2.1 Prevalence

Inconsistencies in the definitions of a learning disability and the challenge of integration of data systems, mean there is no central register of people with a learning disability across health and social care making it difficult for service commissioners to understand the level of need in their population. The GP Learning Disability register within the Quality Outcome Framework (QOF) is widely acknowledged despite the fact it represents an underestimate of the actual numbers of people with learning disabilities¹. Those on the QOF learning disability register may not be known to social care, and vice versa. There is also a proportion of people who are not known to NHS or social care services who have a self-reported learning disability, though likely to have a lower level of need.

Overall, according to the 2022/23 QOF indicator for learning disability, an estimated 0.54% of the population living in the NHS Hampshire and Isle of Wight (HIOW) integrated care board (ICB) (D9Y0V²) area were recorded by their GP as having a learning disability, equating to an estimated 10,400 people across the ICB. This is significantly lower than the England ICB learning disability prevalence of 0.56% but similar to the South East average of 0.53%. There has been a rise in the recorded prevalence of learning disability across the ICB over the past five years from 0.46% in 2018/19 to 0.54% at the end of March 2023, an increase of 0.08 percentage points. In NHS Frimley ICB, prevalence is 0.42%, which means an estimated 3,496 people across the ICB. The ICB learning disability prevalence is significantly lower than the England (0.56%) and South East (0.53%) prevalence, ranking it the 2nd lowest in the country. However, the ICB has experienced a rise in the recorded prevalence of learning disability over the past five years of 0.08 percentage points, from 0.34% in 2018/19 to 0.42% at the end of March 2023.

At a local authority level, there are an estimated 7,010 people (all ages) registered with a learning disability on GP disease practice registers in Hampshire, a prevalence of 0.49% in 2022/23, and an increase from 0.39% in 2016/17. However, this [Office for Health Improvement \(OHID\)](#) prevalence within the QOF is estimated to account for just 26.9% of adults with a learning disability, against [Projecting Older People Population Information System](#) baseline estimates of people with a learning disability, missing around 77% of this population (see section 2.2)³.

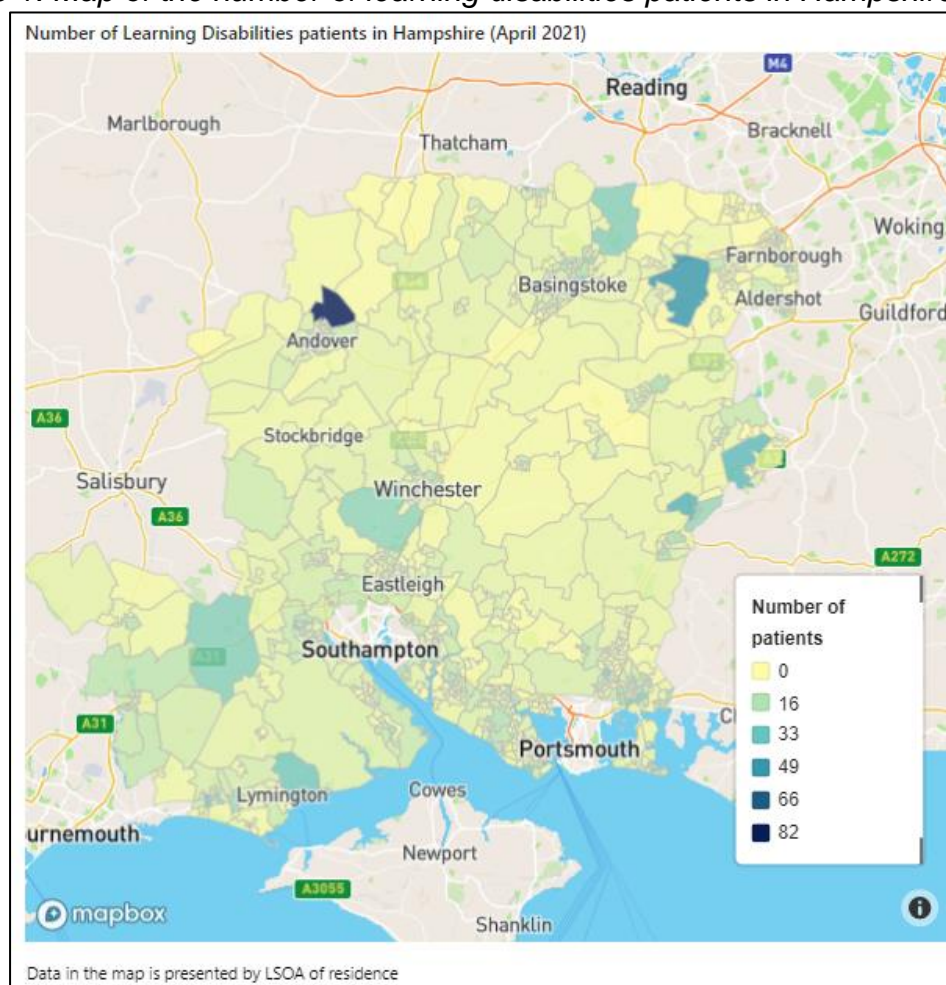
Both Table 1 and Figure 1 show variation in the prevalence of learning disability across the districts. The highest prevalence is evident in the New Forest where 0.63% of the population have learning disabilities recorded on practice disease registers. The lowest prevalence is in Hart at 0.32%.

¹ [Improving Health & Lives - Learning Disabilities Observatory | Advisory group of self-advocates and family carers \(improvinghealthandlives.org.uk\)](#)

² In this report Hampshire and Isle of Wight (HIOW) ICB refers to the sublocation of HIOW ICB D9Y0V

³ [Microsoft Power BI](#) – percentage calculated based on the difference between the predicted people to have a learning disability and the number of people registered with a learning disability

Figure 1: Map of the number of learning disabilities patients in Hampshire, April 2021



Source: [Hampshire JSNA](#)

Table 1: Prevalence of learning disability (all ages) recorded on the practice disease registers in Hampshire by district, 2022/23

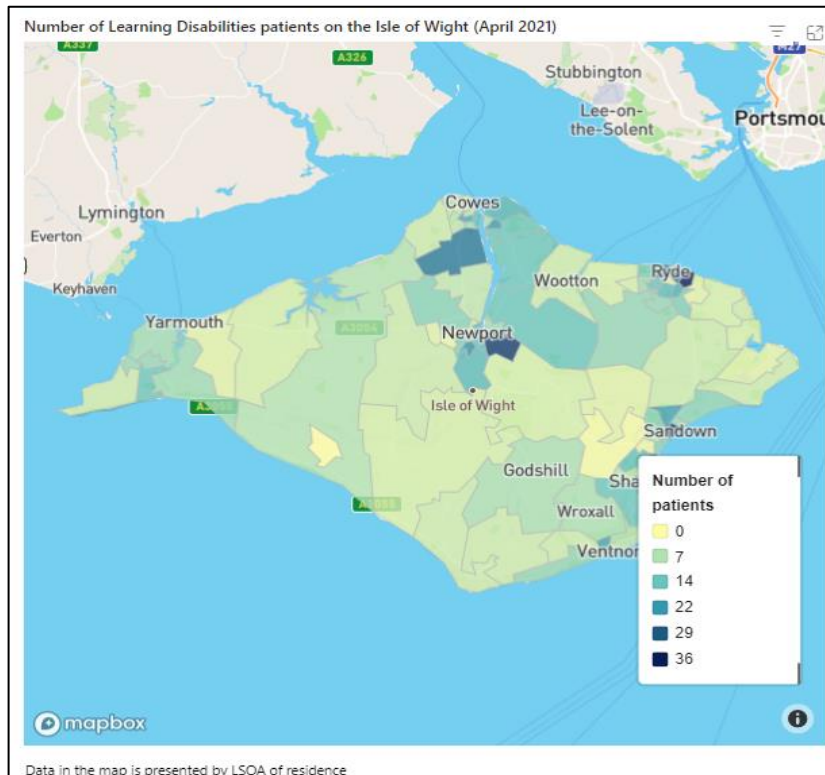
District	Prevalence	Number of people registered
Basingstoke and Deane	0.49%	915
East Hampshire	0.45%	556
Eastleigh	0.47%	610
Fareham	0.47%	575
Gosport	0.49%	411
Hart	0.34%	366
Havant	0.61%	798
New Forest	0.62%	1,170
Rushmoor	0.44%	488
Test Valley	0.51%	595
Winchester	0.40%	526

Source: [Hampshire JSNA. NHS Digital Quality and Outcomes Framework \(QOF\) 2022/23](#)

On the Isle of Wight in 2022/23, there were 1,066 people (all ages) living with a learning disability recorded on the disease register, a prevalence of 0.73% which has not significantly changed in recent years. This is the highest prevalence of all counties

and unitary authorities in the South East Region. However, this prevalence accounts for only 38.4% of adults with a learning disability estimated to be identified on GP registers.⁴ Figure 2 shows the variation in prevalence across the Island.

Figure 2: Map of the number of learning disabilities patients on the Isle of Wight, April 2021



Source: [Isle of Wight JSNA](#)

NHS Digital's *Health and Care of People with Learning Disabilities*⁵ presents information about the key differences in healthcare between people with a learning disability and those without. The data are aggregated from GP practice learning disability registrations to Sub-ICB Location, and ICB level, and are not available at smaller geographies. These series are experimental statistics due to limitations in practice coverage as the data extracts are dependent on system suppliers using only EMIS and Cegedim Healthcare Systems (formerly Vision) and lacks data provided by The Phoenix Partnership (TPP) which accounts for around 40% of practices, and thus a gap in coverage nationally. In 2022/23 the total learning disability patient coverage was 69.4% for HIOW ICB, similar to that in 2021/22. Coverage at 96.5%, was much higher and more representative for Frimley ICB, and an increase on 2021/22 (93.9%). The difference in coverage reflects the variation in system suppliers. Another potential gap arises because practice participation in the data collection is voluntary, meaning practices must participate to give consent for data to be collected. Coverage across HIOW and Frimley ICBs relative to England and the South East region is shown in Table 2.

⁴ [Microsoft Power BI](#) – percentage calculated based on the difference between the predicted people to have a learning disability and the number of people registered with a learning disability

⁵ [NHS Digital. Health and Care of People with Learning Disabilities](#)

Table 2: Health and Care of People with Learning Disabilities practice coverage for 2021/22 and 2022/23

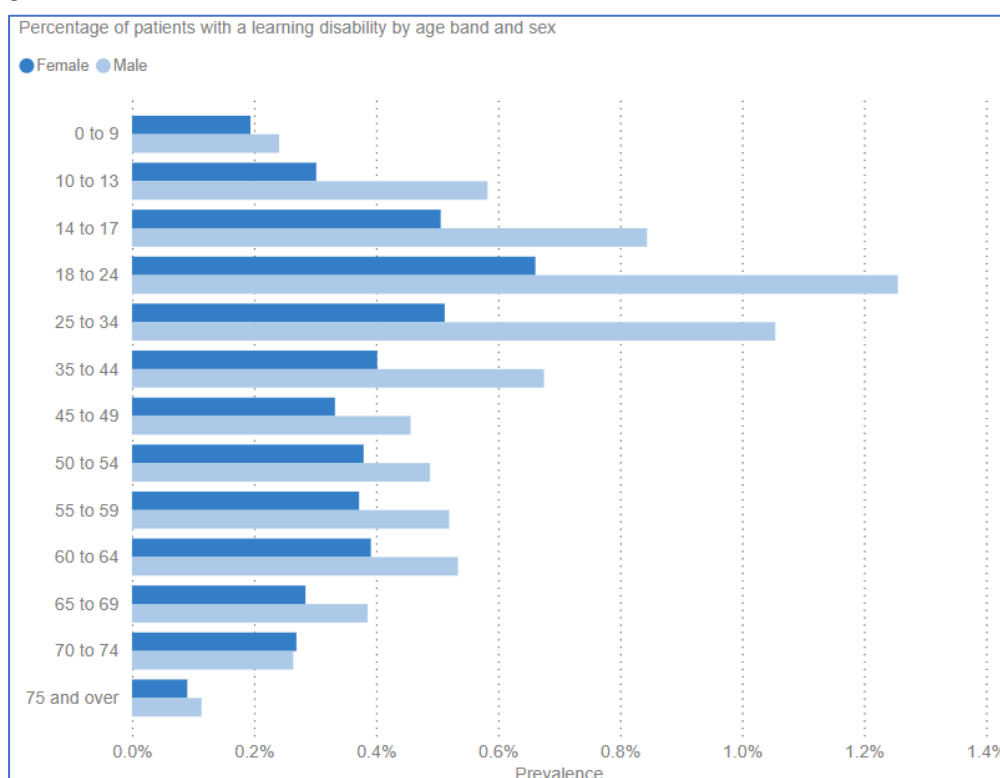
Geographical area	2021/22	2022/23
HIOW ICB	69.5%	69.4%
Frimley ICB	93.9%	96.5%
South East region	76.3%	76.4%
England	55.7%	55.1%

Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

These data series are used in this needs assessment because they provide a comparable dataset that facilitates discussions about the differences in the healthcare of people with learning disabilities and without, aiming to highlight health inequalities that could lead to differences in mortality rates and health outcomes. However, constraints of this data including coverage limitations must be taken into account when interpreting findings.

Using this dataset Figure 3 shows the estimated prevalence of people with learning disabilities in HIOW ICB, by age band and sex.

Figure 3: Prevalence of learning disabilities in HIOW ICB, by age band and sex, 2022/23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

It shows that prevalence varies with sex and age. More young people have learning disabilities than older people. The highest percentage of the population with a learning disability is the 18–24 year age group for both sexes. Prevalence is very low in the youngest age, with gradual increases in each band up until the 18–24-year-old age group. Most likely this is an underestimate as learning disabilities are often not identified in many children until after they start school and may not be recorded in

practice records until substantially later than this. Prevalence falls sharply over the age of 65 as a result of relatively early deaths.

The prevalence in males is higher than females across every age band. Males aged 18 to 24 have the highest recorded prevalence.

Key differences in the age and sex structure between people with a learning disability and those without were looked at using 2022/23 data of patients recorded by their GP as having a learning disability, and comparative control group not recorded as having a learning disability. Figure 4 shows that the population pyramid for people with a learning disability has a different age and sex structure to that of the general population. The shape of the pyramid for people with learning disabilities is more populous in younger age groups under 34 years compared to the general population. Reduced life expectancy is evident for people with learning disabilities, with sharp reduction in numbers after age 65. Low numbers for those aged under nine reflect incomplete recognition of learning disabilities in that age band. The population pyramid also shows that more men than women have learning disabilities.

Figure 4: Age and sex population distribution of adults with learning disabilities compared to the total population in HIOW ICB, by age band and sex, 2022/23

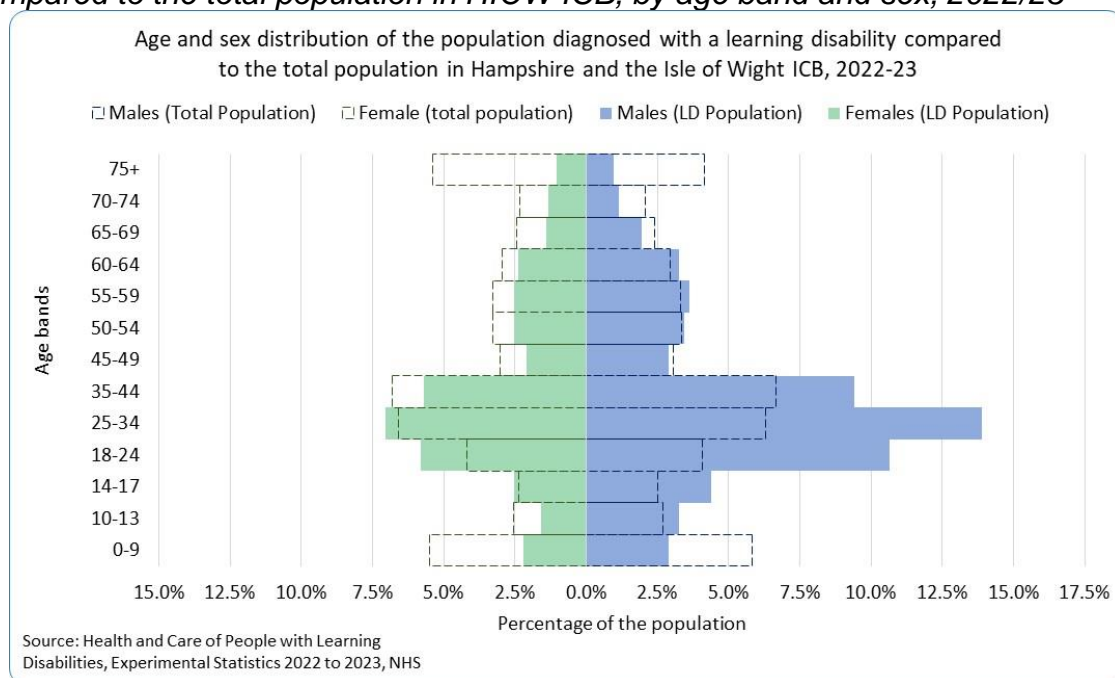
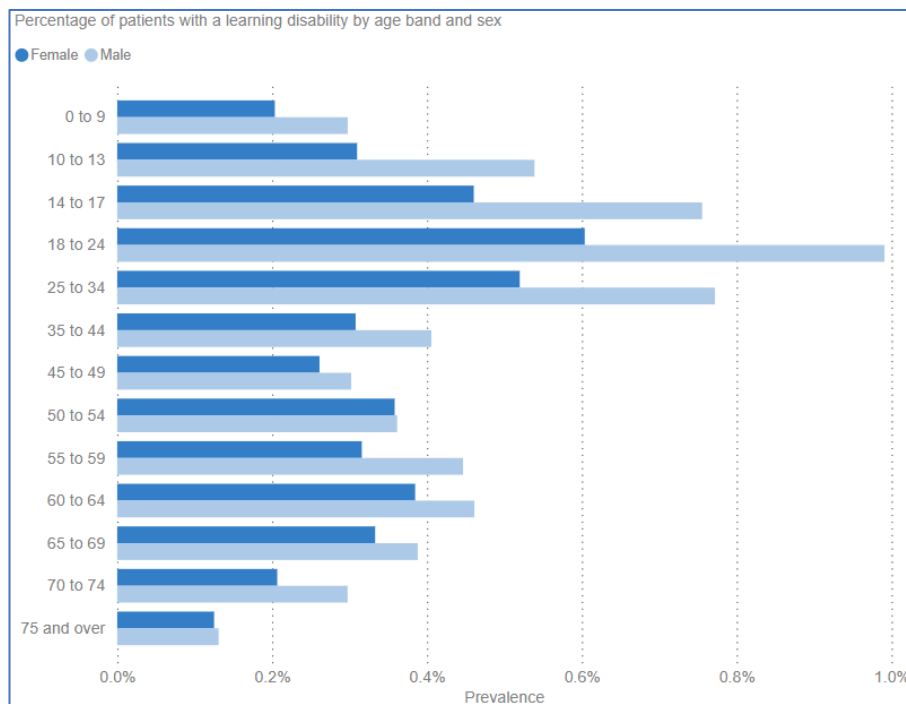


Figure 5 displays the estimated prevalence of people with learning disabilities in the Frimley ICB, by age band and sex. It shows a very similar pattern to that observed in HIOW ICB, that the highest percentage of the population with a learning disability is in the 18–24-year age group for both sexes.

The prevalence in males is also higher than females in every age group. As for the HIOW ICB, there is very low prevalence in the youngest age group, with gradual increases in each band up until the 18–24-year-old age group, probably due to similar reasons.

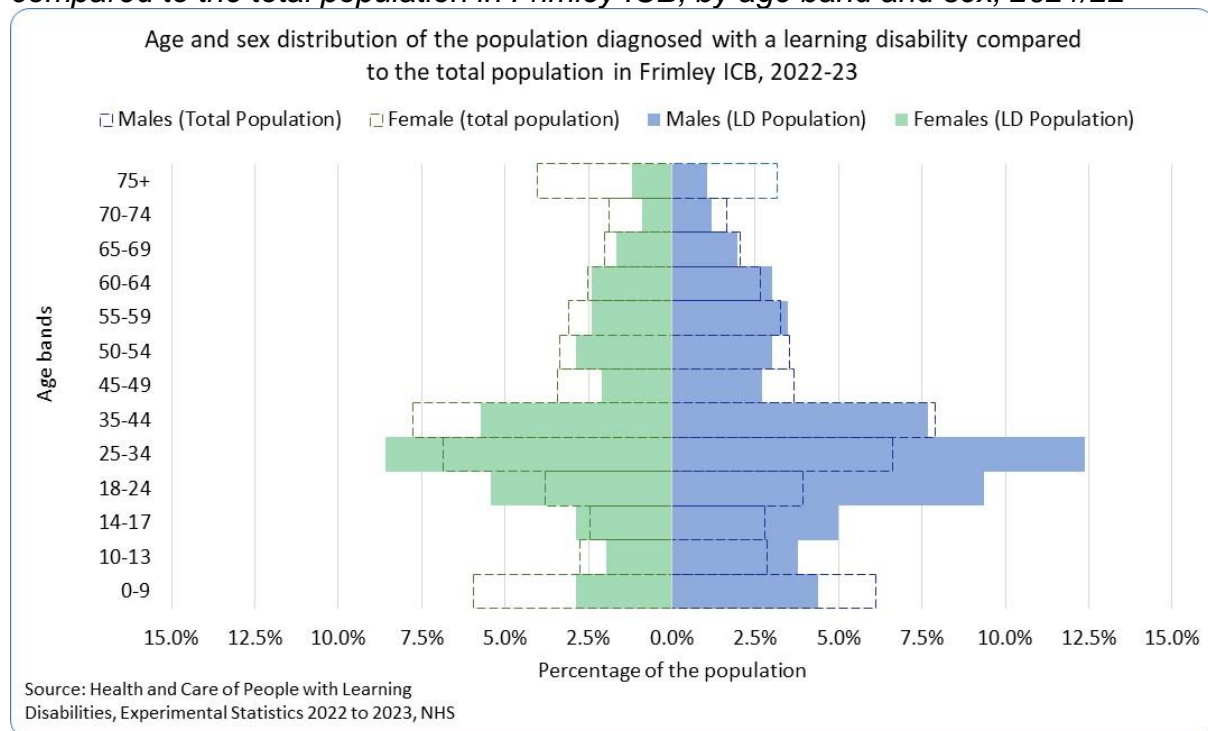
Figure 5: Prevalence of learning disabilities in Frimley ICB, by age band and sex, 2022/23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Similar to HIOW ICB, the population pyramid in Figure 6 demonstrates the larger proportion of younger adults under 34 years, and reduced life expectancy represented for people with learning disabilities compared to the total general population who are older and live longer. The national age and sex profile is similar to that of the ICBs.

Figure 6: Age and sex population distribution of adults with learning disabilities compared to the total population in Frimley ICB, by age band and sex, 2021/22



Source: Health and Care of People with Learning Disabilities, Experimental Statistics 2022 to 2023, NHS

2.2 Population projections

Both Hampshire and the Isle of Wight's populations are increasing and ageing. The population with learning disabilities is also likely to increase too. Population projections up to 2040 for people with learning disabilities have been calculated using ONS population figures and applying prevalence rates of learning disability reported by Emerson *et al*⁶. The rates are adjusted to take account of ethnicity and mortality and are significantly higher than GP practice-based QOF prevalence registrations discussed in section 2.1, as the estimates also include unregistered people with a learning disability. The predicted increase of older people (75 and over) in Hampshire and the Isle of Wight overall has also been reflected in adults with learning disabilities, shown in Figures 7-10.

In Hampshire, it is predicted that the number of people living with a learning disability (18+) will increase from 26,028 in 2023 to 27,760 by 2040. Figure 7 presents the data for people with any learning disability by age band and shows that the 75+ age group is predicted to increase the most, with the population increasing by 42%, an increase of 1,422 people.

Figure 7: Predicted prevalence of people with learning disabilities in Hampshire by age band

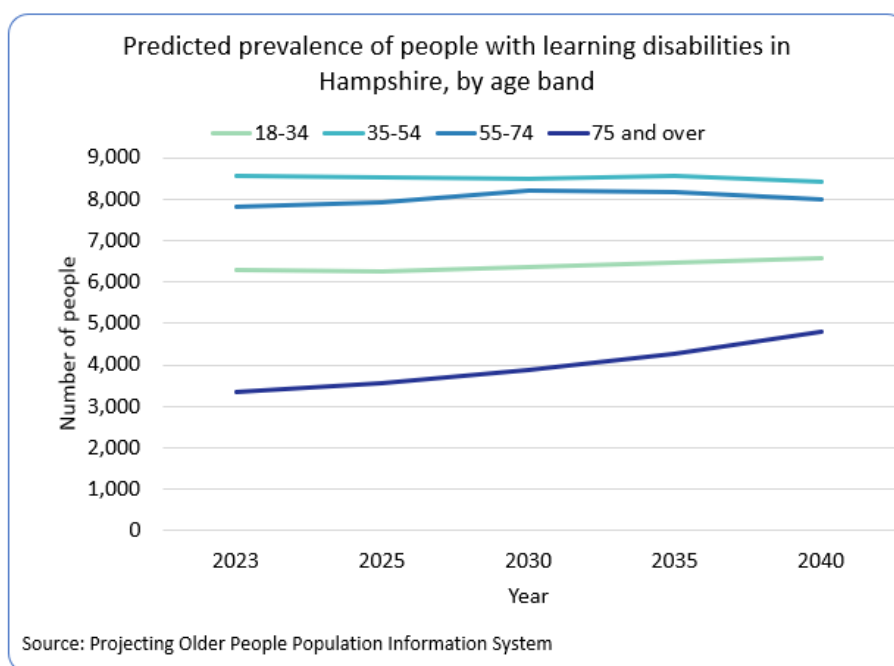
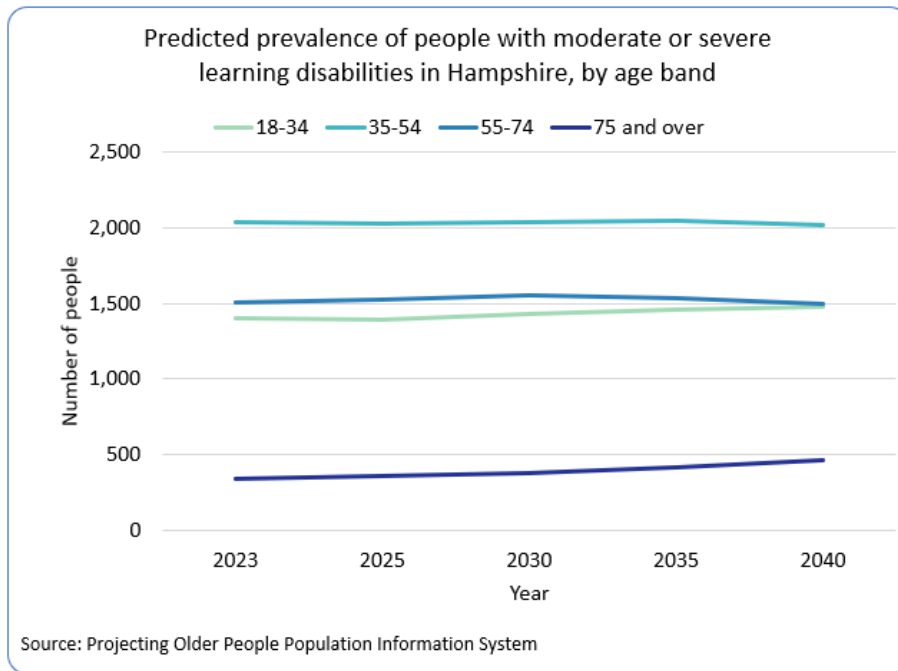


Figure 8 presents data for the population with a moderate severe learning disability, who are more likely to require higher levels of health and social care. The number of people with a moderate or severe learning disability aged 75 and over is again estimated to increase the most.

⁶ Emerson, E and Hatton, C. Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England. Institute for Health Research, Lancaster University: Lancaster, 2004.

Figure 8: Predicted prevalence of people with moderate or severe learning disabilities in Hampshire, by age band



For the Isle of Wight likewise, the number of people living with a learning disability (18+) is predicted to increase from 2,774 to 3,036 by 2040. Figure 9 presents the data for people with any learning disability. The number of people with a learning disability aged 75 and over is estimated to increase the most from 443 to 673, a 52% increase.

Figure 9: Predicted prevalence of people with learning disabilities on the Isle of Wight, by age band

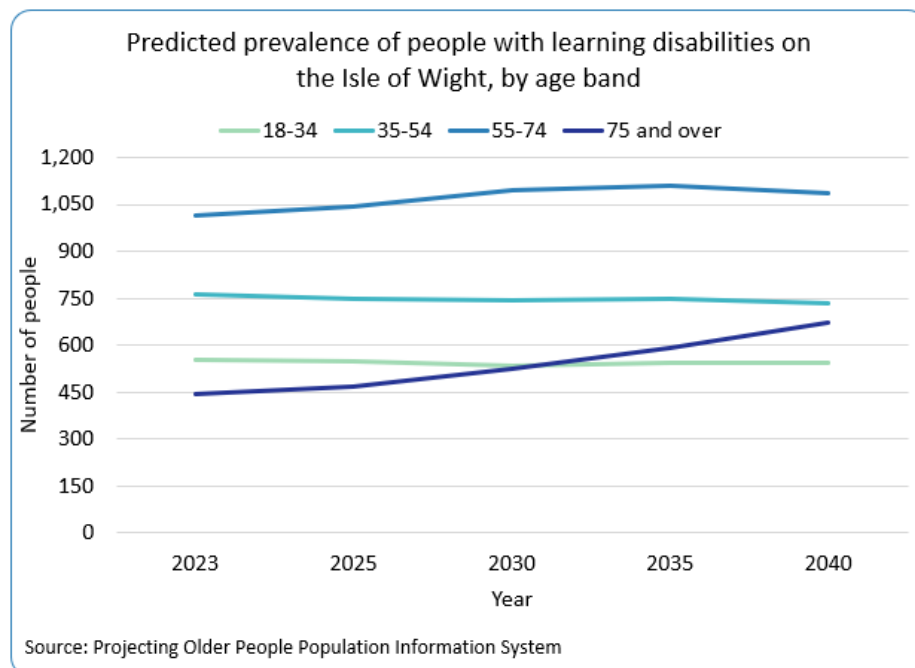
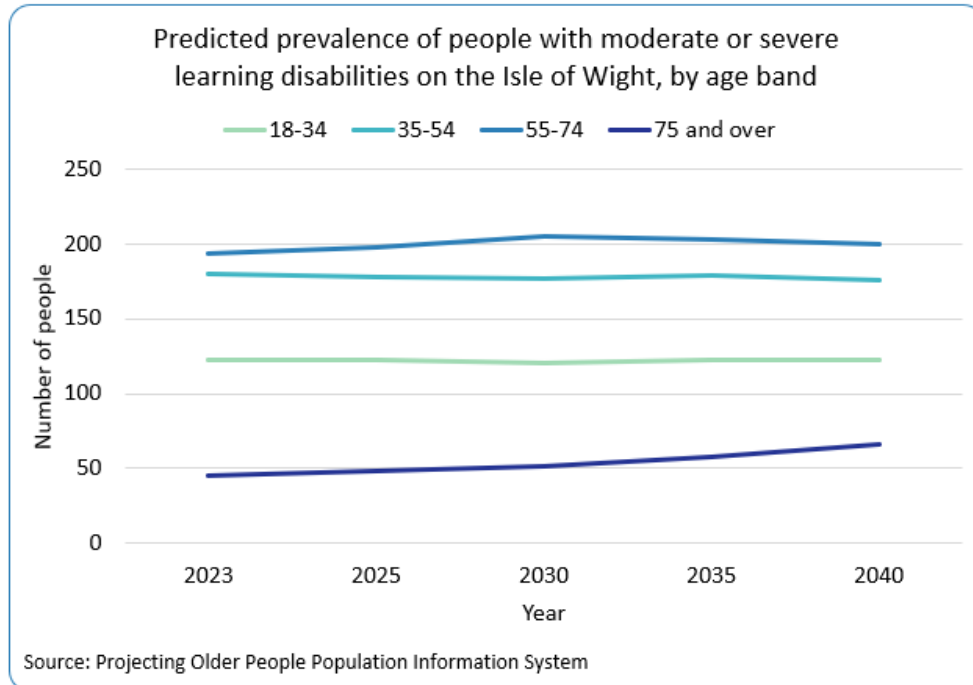


Figure 10 presents data for the population with a moderate severe learning disability, and also shows that the number of people with a moderate or severe learning disability aged 75 and over is estimated to increase the most.

Figure 10: Predicted prevalence of people with moderate or severe learning disabilities on the Isle of Wight, by age band



2.3 Ethnicity

A national cross-sectional survey in 2010⁷ of intellectual and developmental disabilities in children aged 7 to 15 years found that marginalised ethnic communities generally had a lower rate of a diagnosed learning disability, with two exceptions. The study showed rates of mild intellectual disability were higher in Gypsy/Romany and Traveller children and rates of severe learning disabilities were higher in children of South Asian origin.

The reasons for the difference in prevalence are yet to be confirmed but researchers have hypothesised it could be due to a range of factors including:

- Inequalities in access to maternal healthcare
- Higher rates of genetic or environmental risk factors
- Increased levels of material and social deprivation⁸.

The study was based on children that would have been identified as having a learning disability by education services. Therefore, one of the main limitations of the study is the unknown validity of special educational needs ascertainment and coding.

There can be specific difficulties for people with learning disabilities from ethnic minority groups, particularly in more rural areas where small numbers could make them less visible to services and even more vulnerable to social isolation⁹. Access to accurate information on the number of people with learning disabilities from different ethnicities is vital to ensure that sufficient and appropriate services can be planned, commissioned and provided.

The majority of Hampshire (93%) and the Isle of Wight (97%) population are white British, however ethnic diversity is increasing and varies between districts within Hampshire. For example, Rushmoor has a significantly lower proportion of the population who are White (77%). Table 3 highlights the ethnic minority groups across Hampshire and the districts, the Isle of Wight, England and the South East. Using 2021 census data allows for identification of the districts with a higher proportion of the population from certain ethnic groups that are likely to be associated with an increased risk of learning disabilities.

The proportion of people from each ethnic group, that is associated with a higher risk of learning disability, varies. Hampshire and the Isle of Wight have a lower proportion of populations from almost every ethnic group (Table 2), compared to England and the South East. An exception to this is within the Gypsy or Irish Traveller ethnic group which has a larger proportion of the population in Hampshire compared to England, but slightly lower than the South East.

⁷ Emerson, E., Deprivation, ethnicity and the prevalence of intellectual and developmental disabilities. *Journal of Epidemiology and Community Health*, 2010.

⁸ Mir, G., Nocon, A., Ahmad, W., et al (2001) *Learning Difficulties and Ethnicity*. London: Department of Health.

⁹ *Learning Difficulties and Ethnicity: Updating a Framework for Action*. Foundation for People with Learning Disabilities and Department of Health: London (2012)

Table 3: Percentage of residents from ethnic minority groups associated with higher prevalence of learning disabilities by area

Area name	Bangladeshi	Indian	Pakistani	Other Asian	Gypsy or Irish Traveller
Hampshire	0.19%	1.20%	0.25%	1.64%	0.17%
Basingstoke and Deane	0.26%	2.56%	0.38%	2.15%	0.12%
East Hampshire	0.16%	0.49%	0.18%	0.77%	0.22%
Eastleigh	0.27%	1.93%	0.27%	0.75%	0.15%
Fareham	0.12%	0.73%	0.11%	0.40%	0.10%
Gosport	0.11%	0.41%	0.03%	0.49%	0.05%
Hart	0.16%	1.33%	0.22%	1.39%	0.25%
Havant	0.15%	0.73%	0.06%	0.42%	0.05%
New Forest	0.10%	0.33%	0.04%	0.48%	0.27%
Rushmoor	0.30%	2.11%	1.23%	10.55%	0.19%
Test Valley	0.19%	1.28%	0.26%	1.04%	0.13%
Winchester	0.22%	0.86%	0.16%	1.21%	0.29%
Isle of Wight	0.11%	0.23%	0.07%	0.60%	0.05%
England	1.11%	3.26%	2.78%	1.69%	0.11%
South East	0.43%	2.60%	1.57%	1.72%	0.18%

Source: Census 2021 - [Nomis - Official Census and Labour Market Statistics \(nomisweb.co.uk\)](https://www.nomisweb.co.uk)

Data from the latest *Health and Care of People with Learning Disabilities* release presents the ethnicity profile of the population with learning disabilities in both ICBs, illustrated in Figures 11-12. The data show that prevalence of learning disability varies by ethnic group. Of all the ethnic groups, the White ethnic group had the highest recorded prevalence across both ICBs, reflecting the background ethnic profile of the populations. As a result, in the HIOW ICB, prevalence of learning disability is lower in Black, African, Caribbean or Black British, Asian or Asian British and mixed or multiple ethnic groups, as is the case in the Frimley ICB, apart from mixed or multiple ethnic groups where prevalence is slightly higher. However, it may be that people with a learning disability from Black, African, Caribbean or Black British, Asian or Asian British and mixed or multiple ethnic groups are underrepresented in the healthcare system because they may also not be identified on learning disability registers. The higher proportions of Asian or Asian British in the Frimley ICB are evident from the data.

Figure 11: Ethnicity profile of patients with and without a diagnosis of learning disability as of 31st March 2023 in Hampshire and the Isle of Wight ICB

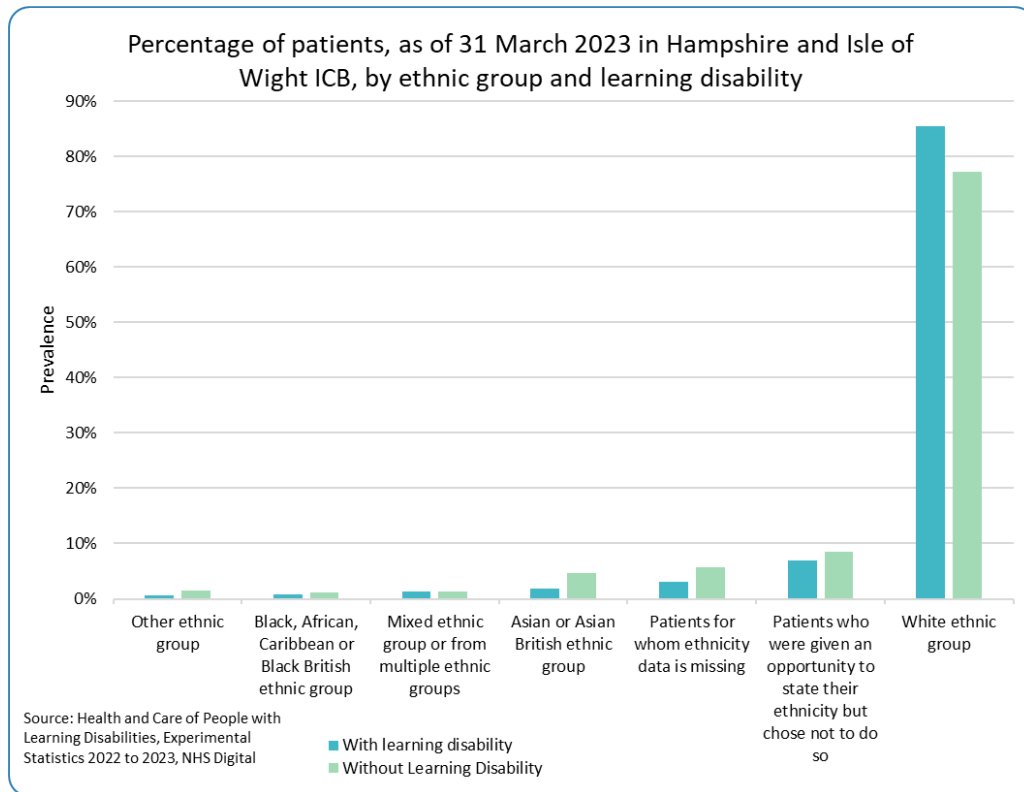
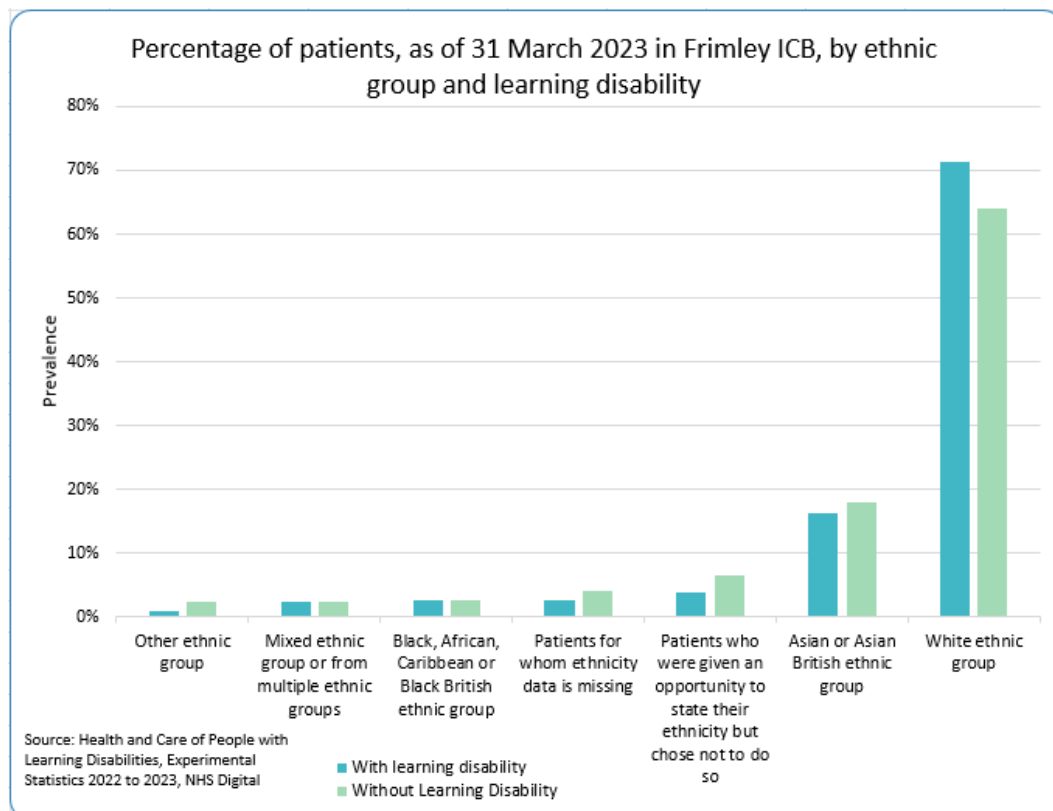


Figure 12: Ethnicity profile of patients with and without a diagnosis of learning disability as of 31st March 2023 in Frimley ICB



2.4 Mortality and Life Expectancy

Mortality –The greater tendency to experience certain health conditions, some being preventable, as well as poorer healthcare access have a bearing on the higher rates of premature and avoidable deaths observed in people with learning disability, yet quantifying mortality amongst people with a learning disability is challenging. In 2010/13, the [Confidential Inquiry into Premature Deaths of People with Learning Disabilities \(CIPOLD\)](#) was set up to review the reasons for the earlier and avoidable mortality in people with a learning disability and concluded that of 247 deaths of people with learning disabilities, “42% of deaths were considered to be premature”. Information in the 2018/19 [Health and Care of People with Learning Disabilities](#) publication reported, the national standardised mortality ratio as 399, with a lower confidence limit of 387 and an upper confidence limit of 411 for the 2016-2019 period. This means that, given uncertainty, people with a learning disability aged 0 to 74 years were between 3.87 and 4.11 times more likely to die in the period than would be expected for people in the general population in the same age and sex group. Approximately 450,000-500,000 deaths among the general population are reported each year in England and it is expected that around 3,000 of these deaths would be people whose GP identifies them as having a learning disability. However, only approximately 1,000 death certificates indicated a learning disability in 2014/15¹⁰. For some it is clearly stated, but for others it could be identified from a diagnosis such as Down’s syndrome. Additionally, the overall numbers of people, and therefore the numbers of deaths, are comparatively small making local monitoring of death rates for people with learning disabilities difficult.

LeDeR - The LeDeR programme is a ‘learning disabilities mortality review’ that reviews deaths of all people with learning disabilities aged 4 years and over notified to the programme and summarises the findings in annual reports. In June 2021 the programme changed to *Learning from Life and Death Reviews* and now includes deaths of adults who have a diagnosis of autism but no learning disability in the process. All people from minority ethnic communities will now also get a focussed review due to significant under reporting of deaths from these communities to LeDeR. The [LeDeR Learning from lives and deaths – People with a learning disability and autistic people 2021](#) report indicated that in 2020, on average 61% of the population with learning disabilities died before age 65, compared to 15% of the general population. The reasons for this are explored more in section 3. Of the deaths reviewed, the leading cause of death was COVID-19 and will be discussed in the next section. In 2021 the second leading cause of death was diseases of the circulatory system (14.3%) and the third diseases of the respiratory system (12%). The report concluded that approximately half of the deaths of people with learning disabilities were deemed to have been avoidable, compared to less than a quarter (22%) for people for the general population¹¹.

More positively, the [LeDeR Learning from Lives and Deaths - people with a learning disability and autistic people 2022](#) report showed an improvement in length of life for

¹⁰ [People with learning disabilities in England 2015: Main report \(publishing.service.gov.uk\)](#)

¹¹ General population based on data from 2018-2020

people who had LeDeR reviews. The report findings show that the median age at death for people with a learning disability was 62.9 years in 2022, an increase from 61.8 years in 2018. This increase was seen despite the COVID-19 pandemic. Though there has been an increase in the median age of death for people with a learning disability, this is still over 20 years shorter than for people in the general population. Diseases of the circulatory system caused a slightly higher percentage of deaths (16.7%) in 2022 and was the most common cause of death followed by cancers (14.6%) and diseases of the respiratory system 14.5%. Although the percentage of deaths caused by COVID-19 was lower in 2022 (5.7%) in comparison to the combined percentage from 2020 and 2021 (21.4%), at 5.7% it was still higher in people with a learning disability in comparison to the general population (3.9%).

Findings from the [HIOW LeDeR Annual Report 2021/22](#) were similar to the national report with a median age at death of 62 years for males and 61 years for females. However, of the 61 deaths reviewed, the most common cause of death was pneumonia (28%) followed by cardiovascular, cancer, kidney disease and COVID-19.

Life expectancy - Life expectancy for the learning disabilities population is shorter than that of the general population and this has been highlighted in earlier annual reports of the *Health and Care of People with Learning Disabilities* series. In the 2018/19 report, males with a learning disability had a life expectancy at birth of 66 years. This is 14 years lower than for males in the general population¹². Similarly, females with a learning disability had a life expectancy of 67 years, which is 17 years lower than the females in the general population¹³.

3. Health and Wellbeing

The following sections investigate the causes of death and ill health in more detail.

3.1 Cardiovascular disease

Circulatory system (also called cardiovascular system) disease is an umbrella term to describe diseases affecting the heart and connecting blood vessels¹⁴. The [LeDeR 2022](#) reported that 16.7% of all deaths were due to diseases of the circulatory system, making it the most common cause of death in people with a learning disability.

Glover et. al. reported that 'epidemiological research on age-related rates of cardiovascular disease in people with [intellectual disabilities] is scarce and inconclusive,' but that myocardial infarction and chronic ischaemic heart disease caused the most deaths. After adjusting for age and gender, death rates for these conditions in people with learning disabilities were double those in the general population. Specific standardised mortality rates include ischaemic heart disease (SMR 2.2) and Cerebrovascular Disease (SMR 3.3).¹⁵

¹² [Condition Prevalence - NDRS \(digital.nhs.uk\)](#)

¹³ [Condition Prevalence - NDRS \(digital.nhs.uk\)](#)

¹⁴ [Circulatory disease | definition of circulatory disease by Medical dictionary \(thefreedictionary.com\)](#)

¹⁵ [Mortality in people with Intellectual Disabilities](#)

A 2018 Public Health England (PHE), now OHID, report [Health inequalities: Cardiovascular disease](#) looked at the recorded prevalence of these conditions through primary care records of nearly 15,000 adults with learning disabilities in England. It showed that the prevalence of ischemic heart disease among adults with a learning disability is lower than in the general population (prevalence ratio 0.65), but rates of heart failure are higher (prevalence ratio 2.26) as are rates of stroke and transient ischemic attack (TIA) (prevalence ratio 1.74). Congenital heart defects are also substantially more common in people with learning disabilities.

Data suggest overall diagnosed hypertension prevalence is lower among people with a learning disability compared to the general population in both ICBs. Whilst the prevalence of stroke or TIA in the HIOW ICB is similar in both population groups, it appears to be slightly higher among the Frimley ICB population with learning disabilities than the general population. This is also true for heart failure prevalence, being marginally increased in the Frimley ICB population with learning disabilities, whereas the prevalence of heart failure is somewhat lower in the HIOW ICB population of people with a learning disability. The latest *Health and Care of People with Learning Disabilities* prevalence figures for these conditions are presented in Table 4.

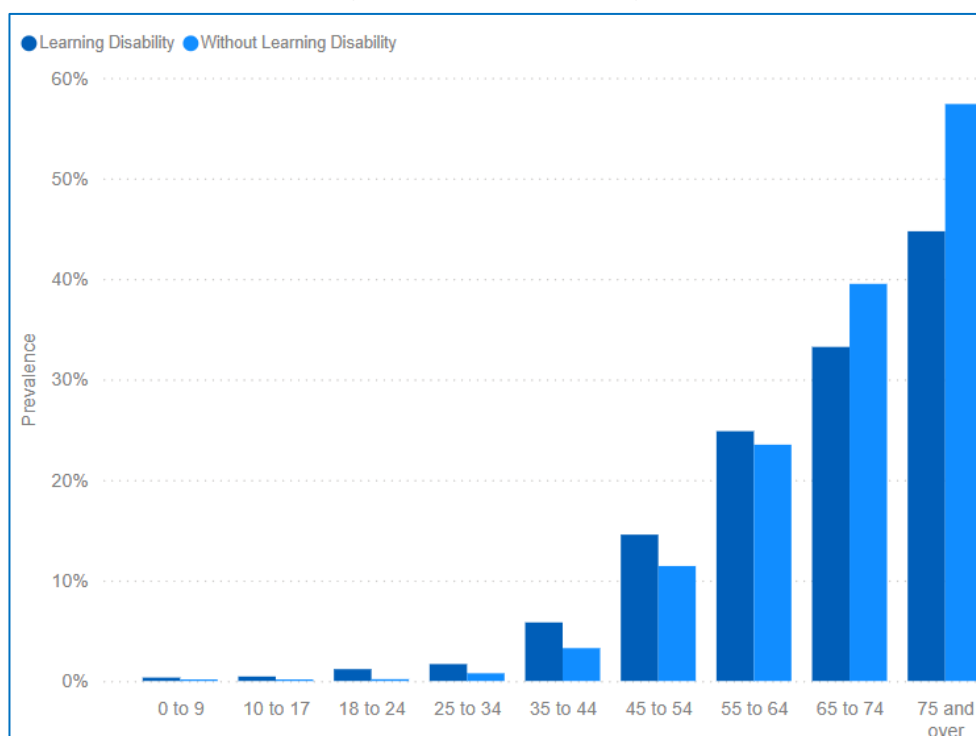
Table 4: Percentage of patients in HIOW ICB and Frimley ICB with a circulatory disease by disease type, 2022/23

Type of circulatory disease	HIOW ICB		Frimley ICB	
	With learning disability	Without learning disability	With learning disability	Without learning disability
Hypertension	8.9%	14.1%	10.4%	12.9%
Coronary heart disease	0.8%	2.8%	1.1%	2.4%
Stroke or TIA	1.9%	1.9%	1.5%	1.4%
Heart Failure	1.0%	1.2%	1.1%	0.9%

Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

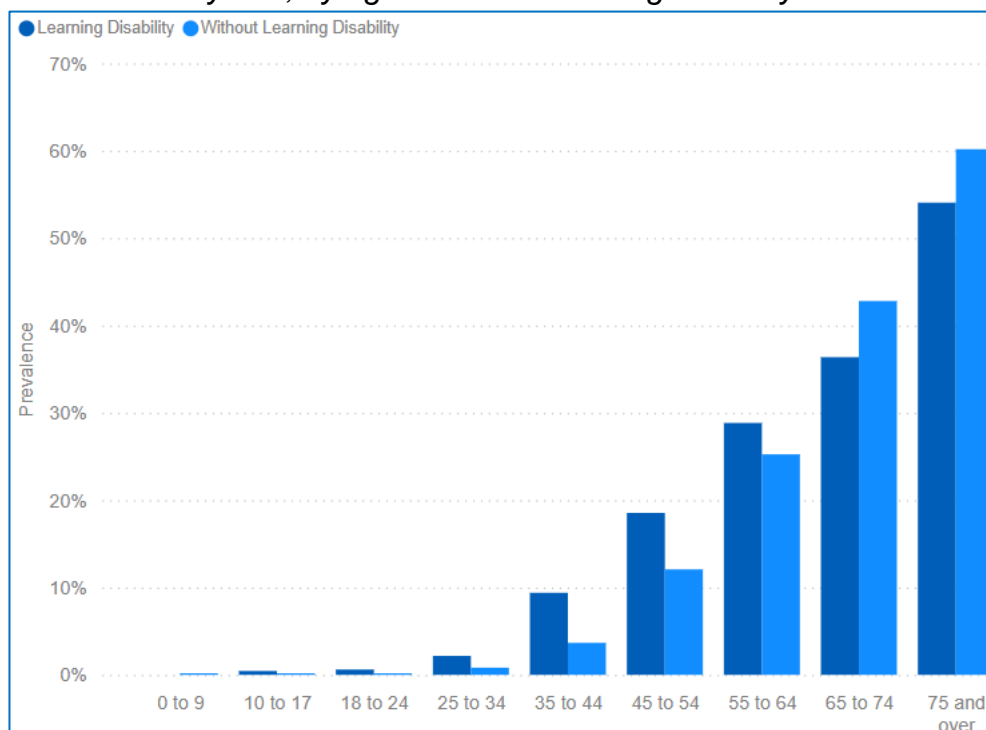
However, Figures 13 and 14 illustrate these conditions presenting in people with a learning disability at much earlier ages compared to those without learning disabilities across the HIOW and the Frimley ICBs, contributing to the higher level of premature deaths in individuals with learning disabilities. There are very small differences in the active diagnosis of hypertension prevalence in ages 0-24, with prevalence of less than 1% for both populations. But after this, between 25 and 55 years, the higher prevalence in patients with learning disabilities compared to the general population is more pronounced. This trend reverses in ages 65 and over and may reflect greater interaction with health services in younger adults with a learning disability, and/or under diagnosis among older adults with learning disability, but most likely a reflection of the lower life expectancy in people with a learning disability (impacting prevalence within relatively wide age strata).

Figure 13: Percentage patients with an active diagnosis of hypertension as of 31st March 2023 in HIOW ICB, by age band and learning disability



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Figure 14: Percentage patients with an active diagnosis of hypertension as of 31st March 2023 in Frimley ICB, by age band and learning disability



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Standardised prevalence ratios (SPR) from the 2022/23 *Health and Care of People with Learning Disabilities* are also presented in Table 5 and show that heart failure and stroke or TIA are about twice as common in people with learning disabilities, whereas

coronary heart disease is less prevalent in patients with learning disabilities than in those without.

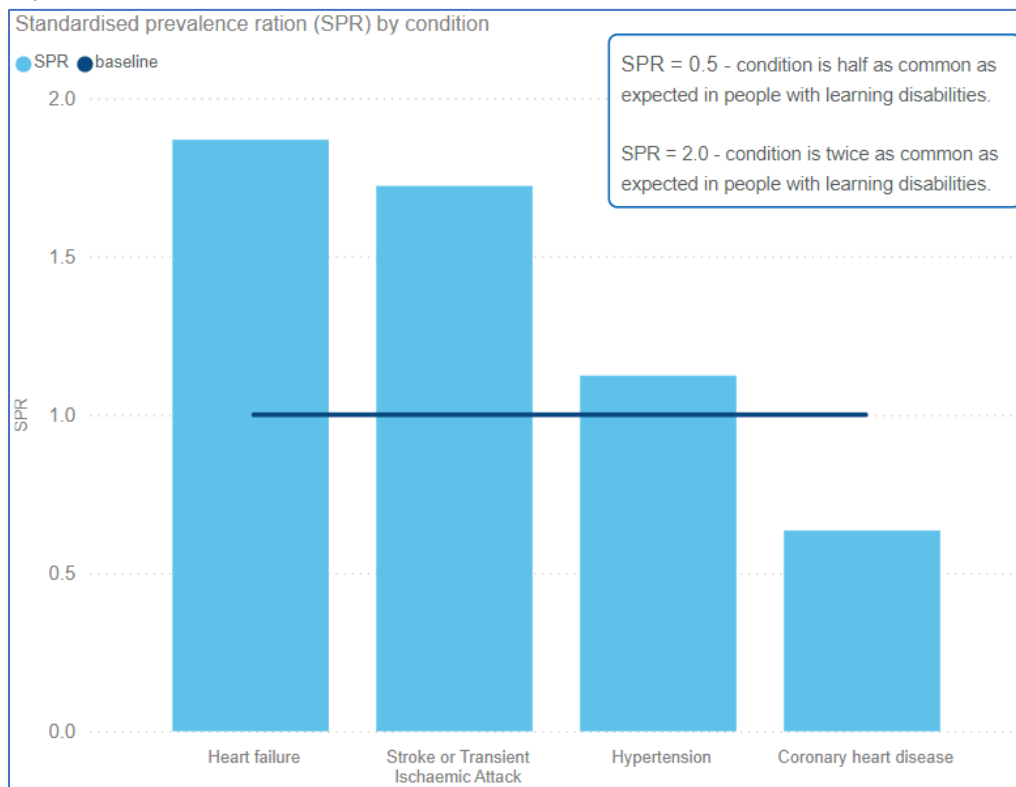
Table 5: Standardised prevalence ratios for circulatory disease by disease type, 2022/23

Type of Circulatory disease	HIOW ICB	Frimley ICB	England
Hypertension	1.1	1.2	1.1
Coronary heart disease	0.6	0.7	0.6
Heart Failure	1.9	2.3	1.9
Stroke or TIA	2.1	1.9	1.7

Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

For both the ICBs, SPRs are broadly comparable to the England figures which is illustrated in Figure 15.

Figure 15: Standardised prevalence ratios for circulatory disease by disease type for England, 2022/23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

3.2 Respiratory disease

Respiratory disease is a major cause of premature death in people with learning disabilities and according to the [LeDeR 2022](#) report, was the second most common cause of death (14.6%). The [2013 CIPOLD](#) report identified that a respiratory disorder was the most prevalent immediate cause of death in people with learning disabilities, followed by heart and circulatory disorders. People with learning disabilities are more likely to experience certain health conditions which can increase their risk of morbidity and mortality of respiratory diseases. For example, obesity can lead to obstructive sleep apnoea. This is a particular concern in people with Down's syndrome who may also have narrowed upper airways¹⁶ and so preventing avoidable risk factors, such as obesity, may reduce morbidity and mortality.

There are many respiratory conditions and associated abnormalities that contribute to premature mortality in people with learning disabilities. It is difficult to identify which condition is responsible for the greatest burden in mortality due to the uncertainty in prevalence and issues in recording data in deaths. The following conditions are considered to be major causes of mortality in people with learning disabilities:

- Chronic Obstructive Pulmonary Disease (COPD)
- Influenza
- Dysphagia, Aspiration Pneumonia and Pneumonia
- COVID-19

3.2.1 Chronic Obstructive Pulmonary Disease (COPD)

COPD is a term for chronic lung conditions that affect a person's ability to breathe normally. It causes breathlessness and a productive cough. As it worsens, particularly when exacerbated by acute respiratory infections, it can cause respiratory failure.

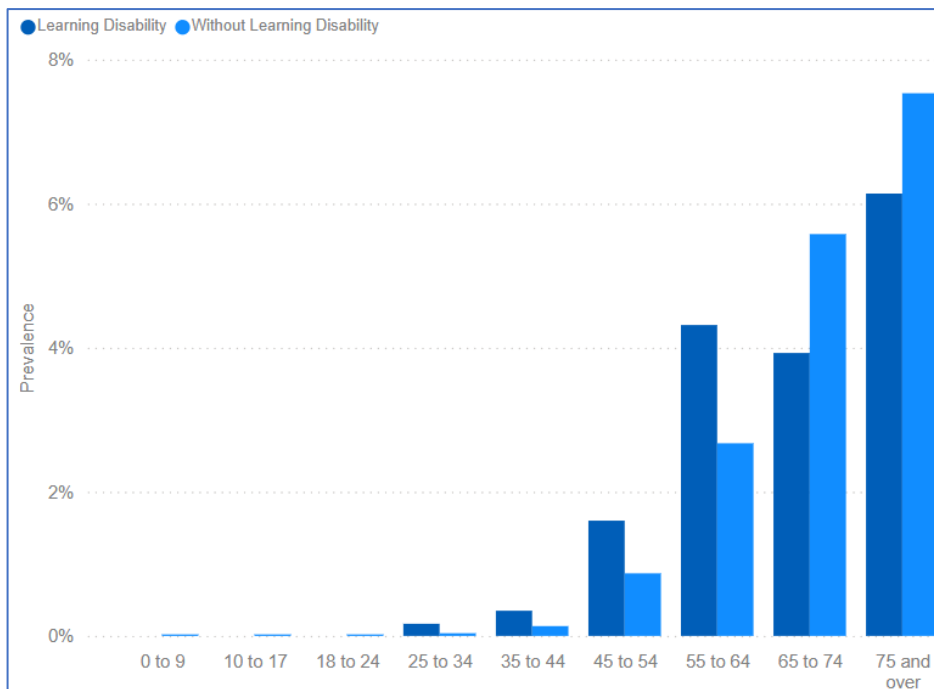
Although respiratory diseases are a common cause of death in people with learning disabilities, there has been little research into the co-morbid patterns of people with learning disabilities and COPD¹⁷. Overall, COPD is less prevalent in the population with learning disabilities with 1.1% of people having received a diagnosis, compared to 1.7% in the population without learning disabilities in the HLOW ICB¹⁸. However, *Health and Care of People with Learning Disabilities 2022/23* data suggests that between the ages of 25 to 64, the prevalence of COPD in people with learning disabilities is more common than in the general population, but not so above the age of 65 as shown in Figure 16.

¹⁶ <http://www.bristol.ac.uk/media-library/sites/sps/leder/28.%20Nutrition%20and%20diet.pdf>

¹⁷ [IHAL-2013-02_Hospital_admissions_that_should_not_happen_ii.pdf \(ndti.org.uk\)](#)

¹⁸ [Microsoft Power BI](#)

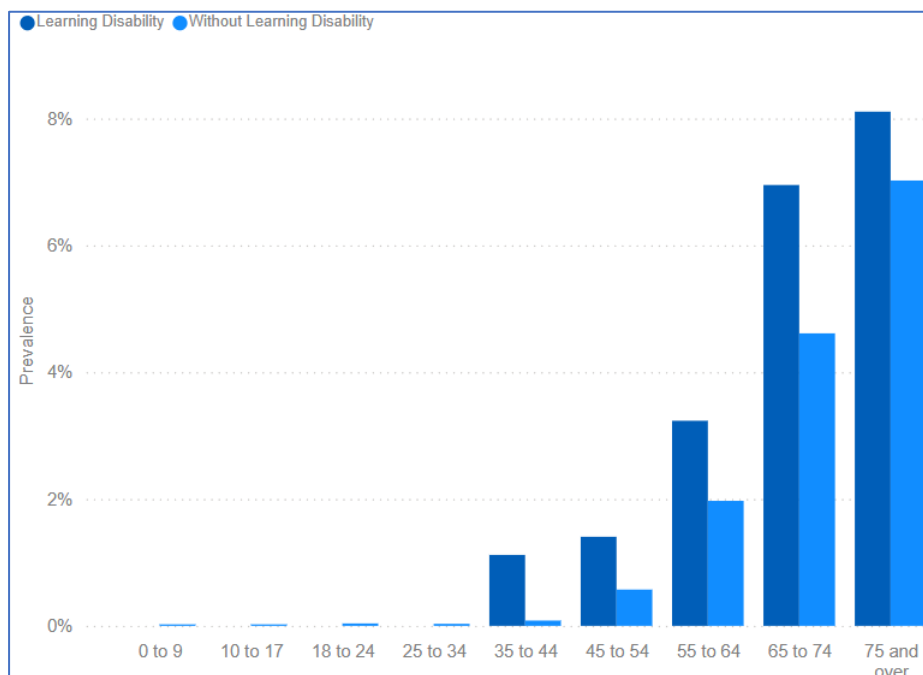
Figure 16: Percentage of patients who had received a diagnosis of chronic obstructive pulmonary disease in HIOW ICB by age band, 2022-23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Figure 17 shows a different pattern for Frimley ICB compared to HIOW ICB, with a higher prevalence of COPD in patients with a learning disability than without a learning disability across all age groups.

Figure 17: Percentage of patients who had received a diagnosis of chronic obstructive pulmonary disease in Frimley ICB by age band, 2022-23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

3.2.2 Influenza

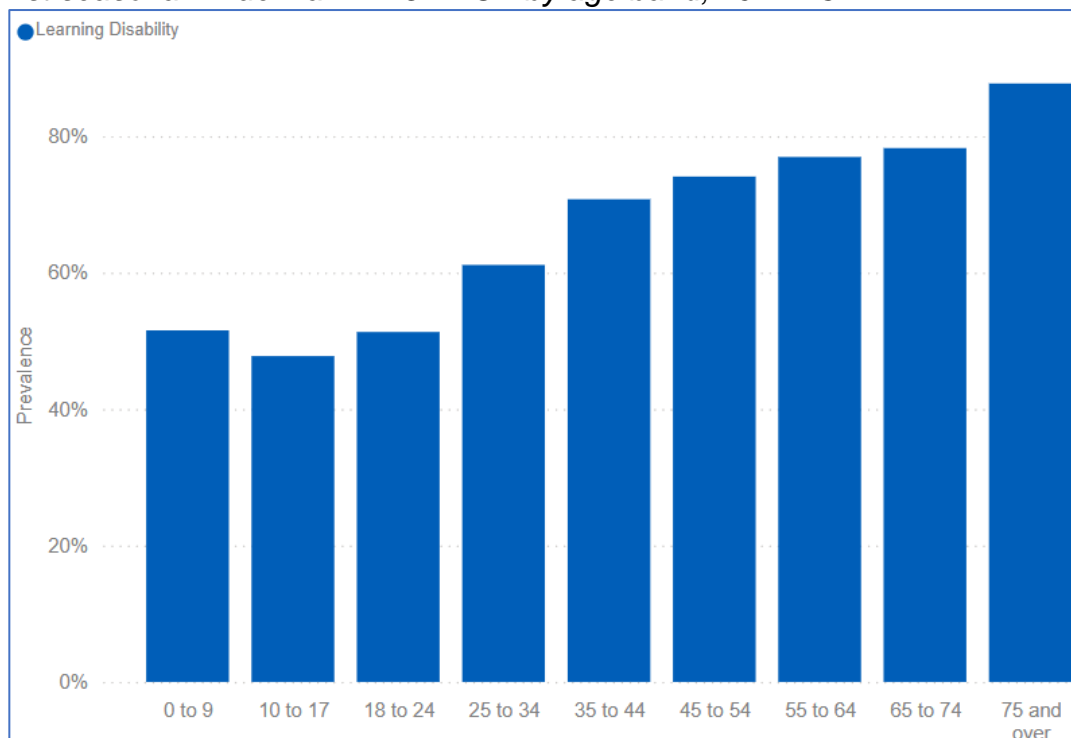
Influenza is a common cause of potentially avoidable hospital admission. The [LeDeR 2022](#) report found that at 9.5% it was the second leading cause of death among people aged over 65. Following the [2013 CIPOLD](#) report highlighting that adults with learning disabilities be considered a high-risk group for deaths from respiratory problems, a recommendation was made to make the influenza vaccination available to all adults with a learning disability. This was implemented in 2014/15 and in the 2020/21 season eligibility was extended to those with wider learning disabilities not just those with severe learning disability. There has been progress in overall uptake which increased between 2017/18 and 2021/22 but has fallen in 2022/23 as shown in Table 6. People with a learning disability in the ICBs have a better uptake than the England average. Uptake is greatest in the population aged 75 and over and the lowest in 10-17 year olds. Figure 18 shows a large variation in vaccination uptake in the HIOW ICB, with a general trend of vaccine uptake increasing with age. This is also the case for the Frimley ICB (Figure 19)

Table 6: Influenza vaccination uptake in people with learning disabilities in HIOW and Frimley ICBs, 2017/18 - 2022/23

	2018/19	2019/20	2020/21	2021/22	2022/23
HIOW ICB	33.5%	51.3%	67.9%	69.2%	63.7%
Frimley ICB	27.9%	47.2%	60.1%	63.0%	59.2%
England	19.8%	43.2%	56.4%	59.5%	56.0%

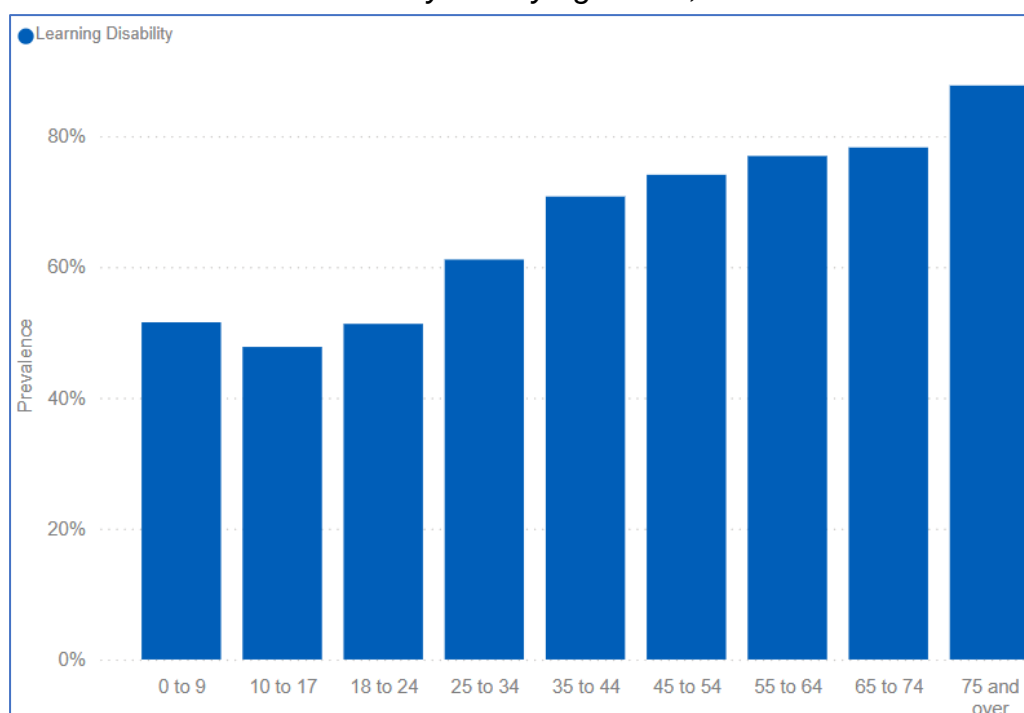
Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Figure 18: Percentage of patients with a learning disability who had an immunisation against seasonal influenza in HIOW ICB by age band, 2022-23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Figure 19: Percentage of patients with a learning disability who had an immunisation against seasonal influenza in Frimley ICB by age band, 2022-23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Influenza vaccination uptake needs to be encouraged to protect people with a learning disability who are most at risk of serious illness or death should they develop influenza. Increasing the registration of people with a learning disability on GP learning disability registers would help to increase flu vaccination uptake as registration ensures they get invited for flu vaccination. Discussion at their annual health check and reasonable adjustments to enable people with learning disabilities have their flu vaccination which could be easy read flu invite letters and information, extra time, or an accompanying friend. As a means of making the programme more accessible, those that are frightened of needles can be offered the nasal spray vaccine¹⁹. It is also important for carers (whether professional or not) to have an influenza vaccination as this can prevent the onward transmission of the virus.

3.2.3 Dysphagia, Aspiration Pneumonia and Pneumonia

Dysphagia is a term used to describe problems with swallowing. Some people with dysphagia have trouble swallowing whereas others may not be able to swallow at all. It is usually caused by another health condition such as stroke, dementia and gastro-oesophageal reflux disease, as well as poor oral health²⁰. Figures show that 40% of people with learning disabilities and dysphagia experience recurrent respiratory tract infections caused by inhalation of foods or liquids²¹, and are at a higher risk of choking.

¹⁹ [Health information :: Southern Health NHS Foundation Trust](#)

²⁰ [Dysphagia \(swallowing problems\) | NHS inform](#)

²¹ [Dysphagia in people with learning difficulties: reasonable adjustments guidance - GOV.UK \(www.gov.uk\)](#)

Estimates of dysphagia in people with learning disabilities have ranged from 36% (based on speech and language therapy caseloads) to over 70% (based on inpatient populations). However, those with mild dysphagia are less likely to report this or ask for help from services, so it is predicated that this figure is likely to be an underrepresentation.

Data for HIOW and Frimley ICBs, presented in Table 7, shows that the percentage of people diagnosed with dysphagia is increasing, though Frimley ICB rates are lower than the HIOW and England figures. The higher rates may be due to better recognition of the condition and better understanding of the impact it has on poor health outcomes.

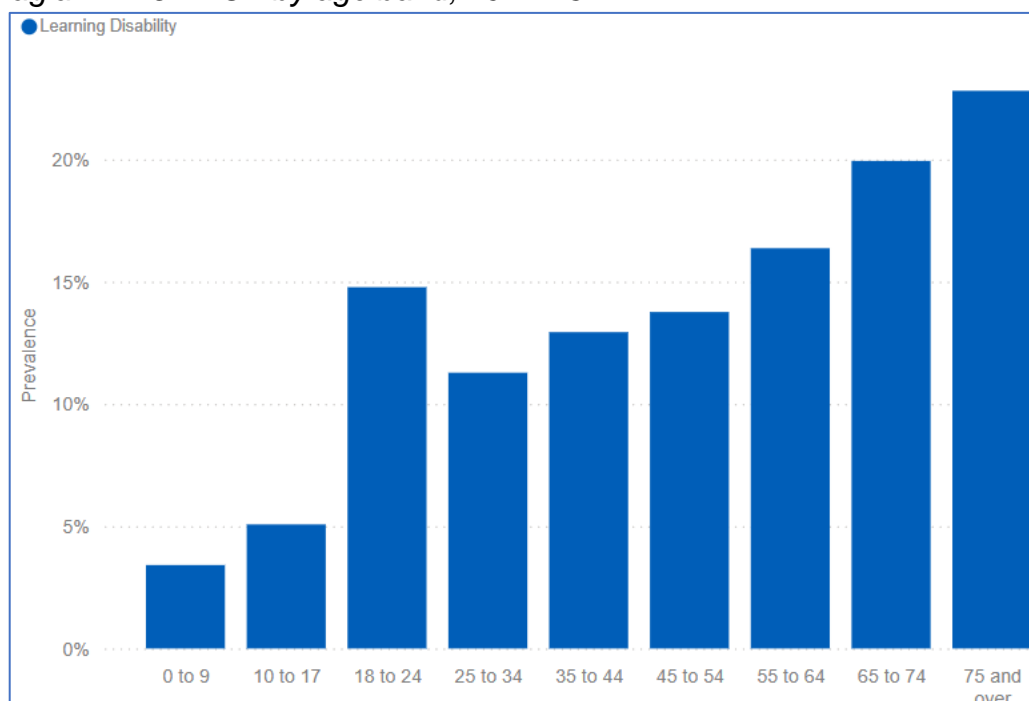
Table 7: Percentage of patients with a learning disability with a diagnosis of dysphagia in HIOW and Frimley ICBs

	2018/19	2019/20	2020/21	2021/22	2022/23
HIOW ICB	5.8%	6.7%	8.7%	10.6%	12.6%
Frimley ICB	4.9%	5.5%	5.4%	7.3%	9.3%
England	5.8%	6.6%	7.8%	9.2%	10.8%

Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Dysphagia prevalence rises with age and ICB rates presented in Figures 20 and 21 evidence this. In HIOW ICB 3.4% of 0-9 year olds have a diagnosis of dysphagia, compared to 22.8% of 75 year olds and over. Higher rates in 18-24 year olds (14.8%) suggest better identification in this age band.

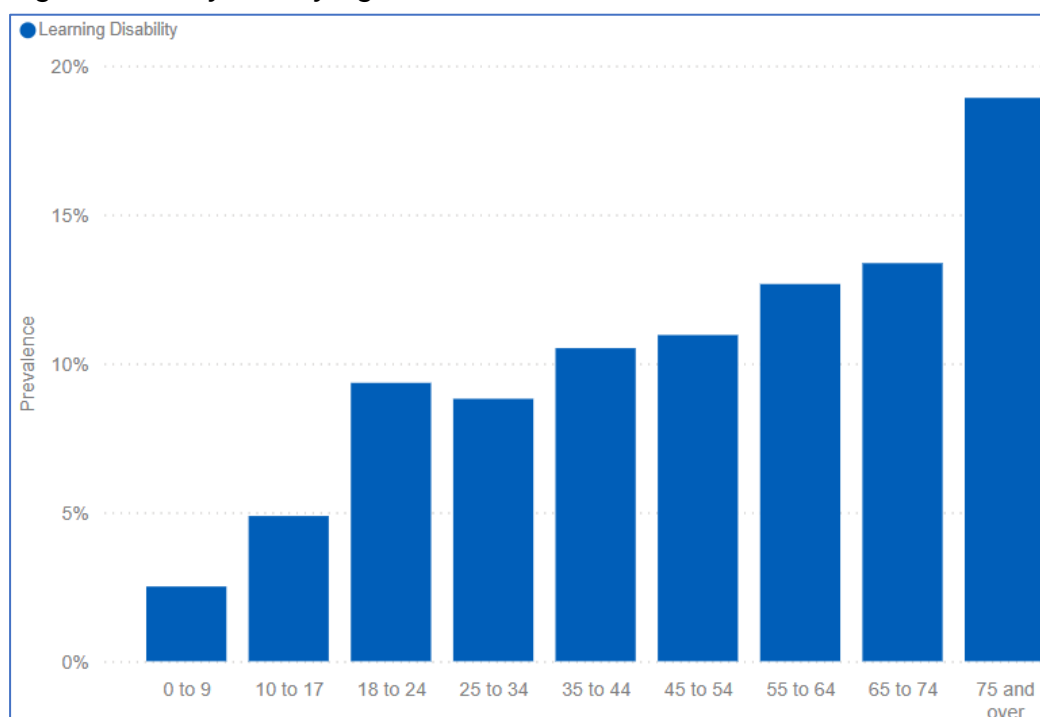
Figure 20: Percentage of patients with a learning disability with a diagnosis of dysphagia in HIOW ICB by age band, 2022-23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

This pattern is similar in Frimley ICB, with 2.5% of 0-9 year olds having a diagnosis of dysphagia, compared to 18.9% of 75 year olds and over, and 9.3% of 18-24 year olds (Figure 21).

Figure 21: Percentage of patients with a learning disability with a diagnosis of dysphagia in Frimley ICB by age band, 2022-23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

The National Patient Safety Agency highlighted that dysphagia is a significant health risk and can lead to aspiration pneumonia. In the [2013 CIPOLD](#) report aspiration pneumonia was identified as a significant cause of death. The [NHS](#) defines aspiration pneumonia is a chest infection that can develop after accidentally inhaling something, such as a small piece of food. It causes irritation in the lungs which may cause bacterial infection or respiratory failure. Aspiration pneumonia can be more common in people with learning disabilities due to increased risk of dysphagia, seizures and COPD. The [LeDeR 2022](#) report highlighted that 8.4% of respiratory related deaths were from aspiration pneumonia.

The risk of choking should be identified early in people with learning disabilities to ensure appropriate feeding practices as this can prevent future death. In Hampshire, between 2005 and 2010, there were five deaths as a result of choking incidents in people with learning disabilities. After identifying common themes in these deaths, data were submitted to the Hampshire Safeguarding Adults Board and a multi-agency steering group was formed to identify areas for improvement and prevent future deaths²². This has remained on the agenda for the Hampshire Safeguarding Adults Board, with development of [guidance on managing choking risk](#), updated in 2023. The guidance provides best practice for Adults' Health and Care, and health care staff, those who commission care and carers, on how to identify, assess and manage an adult who presents with a choking risk.

There was a notable decline in the deaths from pneumonia recorded by the [LeDeR 2021](#), this is likely to be partly due to the effect of COVID-19 social distancing and

²² [Choking Incidents print.indd \(hants.gov.uk\)](#)

other preventative infection control measures. It could also be that some pneumonia deaths were being classified as COVID-19. The [LeDeR 2021](#) found that 21% of respiratory deaths were caused by pneumonia, compared to 52% in 2018. Although the [LeDeR 2022](#) reported an uptick in people dying of pneumonia (35.3%), rates remained lower than before the COVID-19 pandemic, suggesting improved management and prevention of this avoidable cause of death.

It is not known locally what proportion of deaths were associated with pneumonia. Identifying the early signs of illness is essential and therefore carers should be aware of the symptoms of pneumonia. It is important to access timely medical care when the symptoms arise.

3.2.4 COVID-19

COVID-19 was the leading cause of death (21.4%) listed in the [LeDeR 2021](#) report, based on death certificates, for people with learning disabilities and caused 62% of respiratory deaths. The estimated excess deaths during that year and the previous year, compared to pre-pandemic years, are double that of the general population. In 2020, there was an excess of 34.3% of deaths for people with a learning disability compared to 14.5% in the general population. In 2021, this decreased to 21.5% of deaths in people with a learning disability compared to 10.4% in the general population.

Early in the pandemic, excess deaths for people with a learning disability were very high approximated at 178.7% in April 2020. This compares to 101.6% in the general population. Excess death rates in people with learning disabilities were fairly similar regardless of sex in 2020 and 2021. Whereas, in the general population excess death rates were higher for males in England. Excess deaths by ethnicity showed that those from minority ethnic groups had significantly higher excess death in 2020 – 58.2% compared to 31.3% in the population of white ethnicity.

Looking specifically at the 18 to 64-year-old population, COVID-19 remained the leading cause of death in 2020 and 2021 for people with a learning disability; 21% of deaths in 2020 and 19% of deaths in 2021. In the general population the leading cause was ischaemic heart disease followed by COVID-19, which caused 8.9% of deaths in 20- to 64-year-olds.

There are limited data on vaccination status for those included in the [LeDeR 2021](#) report. Of all the deaths of people with learning disabilities analysed during 2021, only 304 (11.1%) had data on vaccination status. Overall, 154 (50.7%) people who had vaccination status recorded were unvaccinated, and 150 (49.3%) were fully vaccinated. Data shows that of those with a learning disability who were unvaccinated, 28% died of COVID-19, while only 3.5% of deaths of people who were vaccinated were due to COVID-19. This means that those who were unvaccinated were 8 times more likely to die of COVID-19 than another cause compared to those who were vaccinated.

From the beginning of the COVID-19 pandemic, there were concerns that 'do not attempt cardiopulmonary resuscitation' (DNACPR) decisions were being made without

involving people, or their families and/or carers if so wished, and were being applied to groups of people, rather than taking into account each person's individual circumstances. The [Care Quality Commission's Protect, respect, connect – decisions about living and dying well during COVID-19](#) review found a large variation in practice, where in some cases, people were not always aware that a DNACPR decision was in place. While most providers included in the review were unaware of DNACPR decisions being applied to groups of people, there was evidence from people, their families and carers that there had been 'blanket' DNACPR decisions in place.

The [LeDeR 2022](#) reported COVID-19 as the sixth most common cause of death in people with a learning disability, accounting for 5.7% of deaths. It listed COVID-19 as the second most common respiratory cause of death, causing 28% of respiratory deaths. Though there has been a marked reduction on 2020 and 2021 figures, the percentage of deaths caused by COVID-19 was still higher in people with a learning disability in comparison to the general population (5.7% of deaths that occurred in 2022 in people with a learning disability; 3.9% of deaths that occurred in 2022 for the general population). People with a learning disability should continue to be prioritised for vaccination against COVID-19 by increasing GP learning disability registrations to help reduce the continued impact of COVID-19.

3.3 Cancer

The risk for an individual of developing a type of cancer can be influenced by their level of exposure to different causal agents. These can be genetic or through personal, environmental and lifestyle factors. For example, obesity, alcohol consumption, lack of exercise, exposure to tobacco smoke and some infections from sexually transmitted diseases are associated with common types of cancer.

Early diagnosis and prompt treatment are important to cancer survival. People with learning disabilities may need further assistance to achieve this through support to recognise and act on the warning signs and to navigate through the health system²³. This can be hindered further through organisational barriers, which is discussed in more detail in the sections below.

According to the [LeDeR 2022](#) report, cancers were the third most common cause of death in adults with a learning disability (14.5%) of deaths, and at 11.8% the leading cause of death among older adults aged 65 and over. Bowel cancer accounted for 15.8% of cancer deaths, slightly higher in comparison to the proportion reported in [LeDeR 2021](#) (13.6%). Cancer of the oesophagus accounted for 5.4% of deaths, lower than that reported in [LeDeR 2021](#) (6.6% of deaths). The average age of death for people that died of bowel cancer reported to LeDeR between 2018 and 2022 was 63.1 years.

The types of cancer that result in mortality differ slightly between adults with learning disabilities and the general population. Findings from the [LeDeR 2022](#) report were that

²³ Trétarre B and others. Breast cancer and screening in persons with an intellectual disability living in institutions in France. *Journal of Intellectual Disability Research*, 2017. 61(3): p. 266- 278

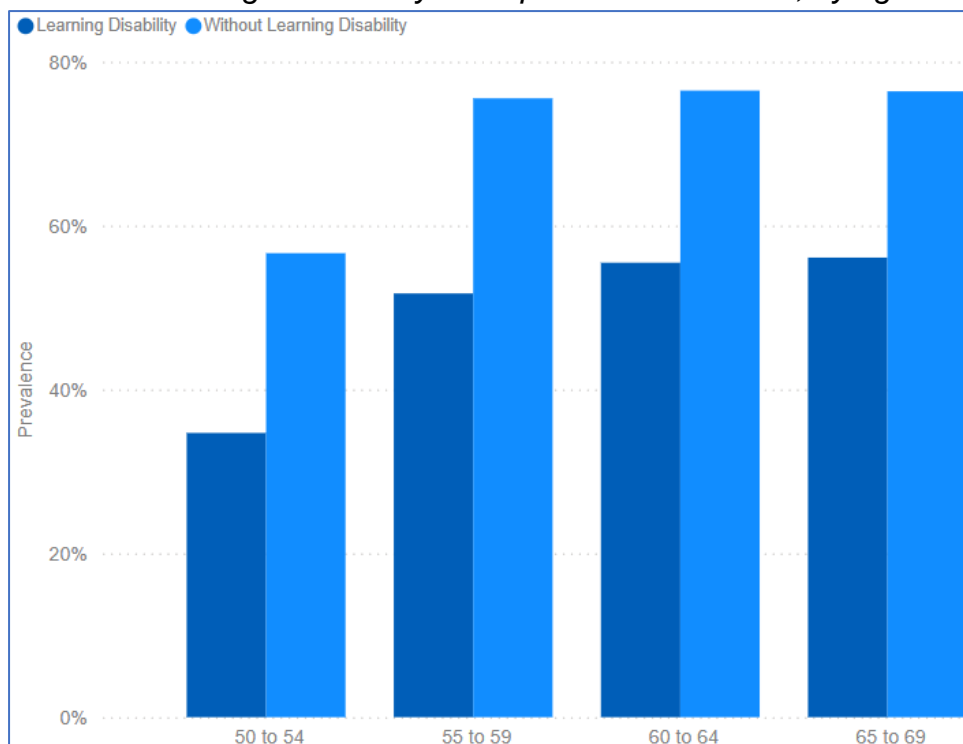
bowel cancer accounted for a higher percentage of cancer deaths in people with a learning disability between 2017 and 2019, compared to the UK general population. Whereas lung cancer and prostate cancer caused a higher percentage of cancer deaths in the UK general population, compared to those with a learning disability.

Cancer screening is available for breast, cervical and bowel cancer. In all three types of cancer, screening uptake is lower in people with learning disabilities than the general population.

3.3.1 Breast screening

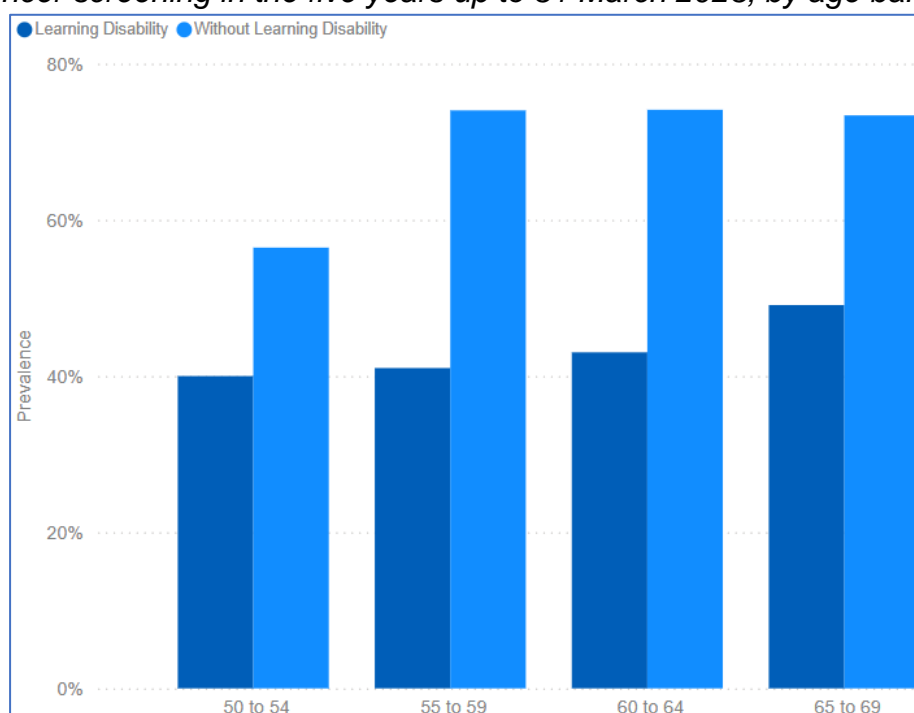
In 2022–23, 48.5% women with a learning disability underwent breast cancer screening in HIOW ICB, compared with 70.8% of women without a learning disability, a 22.3 percentage point difference. Similarly, in Frimley ICB 42.7% of eligible women with a learning disability had a breast cancer screen, compared with 68.6% of those without a learning disability, with a slightly bigger 25.9 percentage point difference. Figures 22 and 23 illustrate the lower level of participation in breast cancer screening programmes among of women with a learning disability than those without a learning disability in both ICBs. Uptake of breast screening increases with age.

Figure 22: Percentage of female patients aged 50-69 in HIOW ICB who received breast cancer screening in the five years up to 31 March 2023, by age band



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Figure 23: Percentage of female patients aged 50-69 in Frimley ICB who received breast cancer screening in the five years up to 31 March 2023, by age band



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Table 8: Trend in the percentage of female patients aged 50-69 with learning disabilities who received breast cancer screening in the two ICBs and England

	2018/19	2019/20	2020/21	2021/22	2022/23
HIOW ICB	50.0%	50.1%	48.0%	48.7%	48.5%
Frimley ICB	57.4%	52.9%	49.3%	47.8%	42.7%
England	49.5%	50.5%	48.1%	47.2%	46.8%

Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Table 8 shows that in the HIOW ICB, the take up of breast cancer screening has remained stable since 2018/19 but has faltered since a decline in 2020/21. However, in the Frimley ICB there has been a downward trend in uptake. The ICBs breast screening uptake is higher than the England average.

Research has indicated that women with learning disabilities may be at increased risk of breast cancer due to being less likely to have children²⁴.

Barriers to accessing screening can include:

- practical barriers, such as mobility issues and difficulty using appointment systems
- communication barriers with health professionals
- lack of family/ carers to support attendance at screening and local support services
- stress and anxiety
- a lack of knowledge about screening

²⁴ [Health Inequalities: Breast Cancer](#)

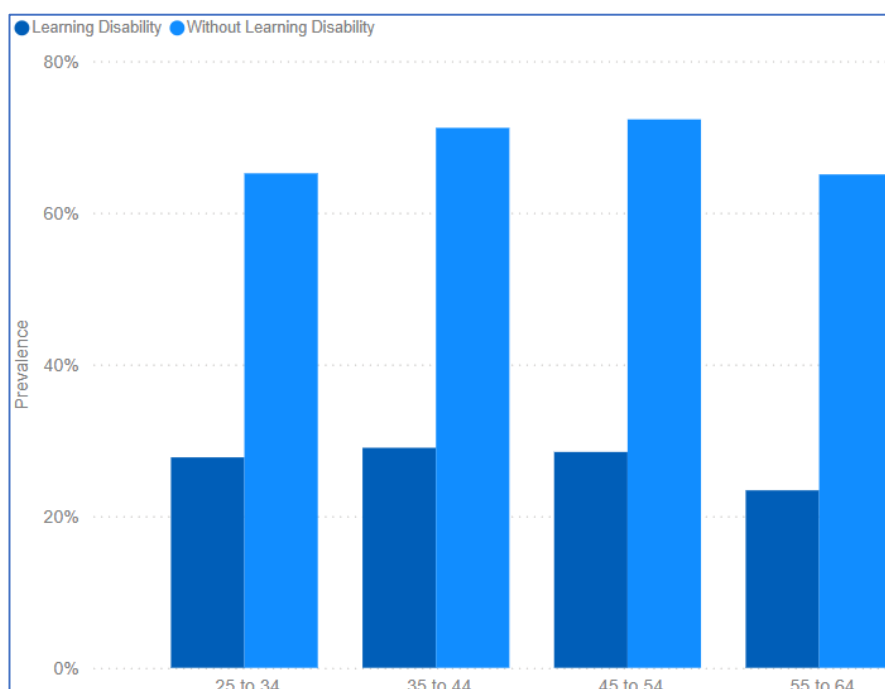
- a lack of knowledge among health professionals of the needs of people with a learning disability
- a lack of awareness among screening staff about reasonable adjustments, accessible information and other resources to support people with a learning disability²⁵
- fear and embarrassment.

The NHS has published an easy guide on the breast screening service to help women with learning disabilities make an informed choice on accessing the service²⁶.

3.3.2 Cervical screening

As regards cervical cancer screening uptake, the gap was even larger than for breast cancer screening. In 2022/23 an estimated 27.3% of women with a learning disability had an adequate cervical cancer screen in HIOW ICB, compared with 68.5% of women without a learning disability, a 41.2 percentage point difference. Likewise, in Frimley ICB 27.3% of eligible women with a learning disability had an adequate cervical cancer screen, compared with 69.1% of those without a learning disability, a similar 41.8 percentage point difference. Figures 24 and 25 graphically present the larger gap in cervical cancer screening among people with a learning disability compared to those without a learning disability in both ICBs.

Figure 24: Percentage of people aged 25-64 in HIOW ICB who had an adequate cervical smear test in the three years and six months up to 31 March 2023 by age band

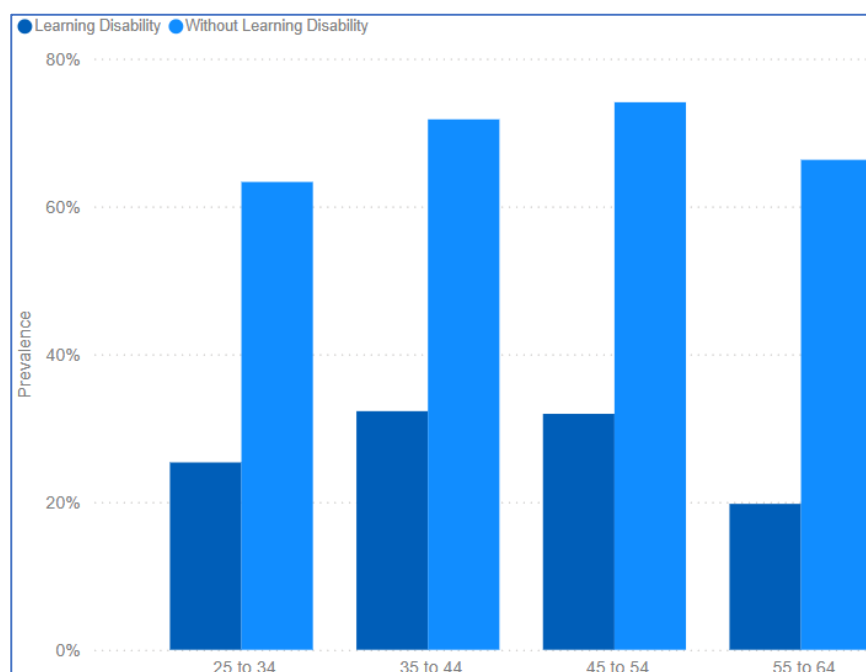


Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

²⁵ [Population screening: reducing inequalities for people with a learning disability, autism or both - GOV.UK \(www.gov.uk\)](https://www.gov.uk)

²⁶ [Easy guide to breast screening.pdf \(publishing.service.gov.uk\)](https://publishing.service.gov.uk)

Figure 25: Percentage of people aged 25-64 in Frimley ICB who had an adequate cervical smear test in the three years and six months up to 31 March 2023 by age band



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Table 9 presents data from both ICBs, and England, on the eligible population of people with learning disabilities who had an adequate cervical smear test in the correct time period²⁷ up to 31 March 2023. In both ICBs, the uptake among people with learning disabilities was persistently lower than the England average. Programme monitoring statistics for the ICBs show fluctuations in cervical cancer screening uptake and a general lack of progress. For HIOW ICB, after a brief rise in 2019/20, cervical cancer screening uptake went down again. There has been a declining trend in cervical cancer screening uptake for Frimley ICB, with a slight rise after 2021/22.

Table 9: Trend in cervical screening uptake in people with learning disabilities in the two ICBs and England

	2018/19	2019/20	2020/21	2021/22	2022/23
HIOW ICB	26.1%	28.7%	28.3%	26.4%	27.3%
Frimley ICB	26.8%	26.0%	24.5%	26.2%	27.3%
England	31.5%	32.4%	30.5%	31.0%	31.2%

Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

The [2013 CIPOLD](#) report found evidence of barriers for women with learning disabilities to access cervical screening because of presumptions being made about their sexual history or current sexual activity. This can be by both health and social

²⁷ 3 years and 6 months for patients aged 25-49, and 5 years and 6 months for patients aged 50- 64.

care professionals, as well as an individual's family carer²⁸. Other difficulties involve understanding the process of a smear test and the ability to give appropriate consent²⁹.

Every person who has a cervix and is within the screening age range (25-64) is eligible for NHS cervical screening regardless of their gender identity. People with learning disabilities can often understand and consent to screening with adequate support and preparation. Learning disability alone is not a valid reason for ceasing to offer the opportunity.

In 2022/23 Southern Health Foundation Trust and the Wessex Cancer Alliance led a working group to develop and deliver training for cervical screening sample takers. The sample takers training is designed to give nurses and GPs a greater understanding of reasonable adjustments for people with learning disabilities to help them attend their screening appointment, quashing myths around how people acquire Human papillomavirus (HPV) and the suitability of people with learning disabilities to have cervical screening, including when to cease or defer patients from the cervical screening programme. In addition to this a [Toolkit to increase uptake of Cervical Screening in people with a learning disability](#) was developed to help practitioners. Over the last year, approximately 175 sample takers from Hampshire and IOW ICB area have been trained. The evaluation showed sample takers have been putting into practice their learning by:

- ensuring the person had access to easy read literature,
- phoning and talking through any queries,
- letting the person look at the equipment beforehand,
- making the room safe and secure.

The reason for the increased confidence was the resources, understanding, ideas of how and what to communicate. In addition to this, practitioners were able to offer more time to work with people.

3.3.3 Bowel Cancer Screening

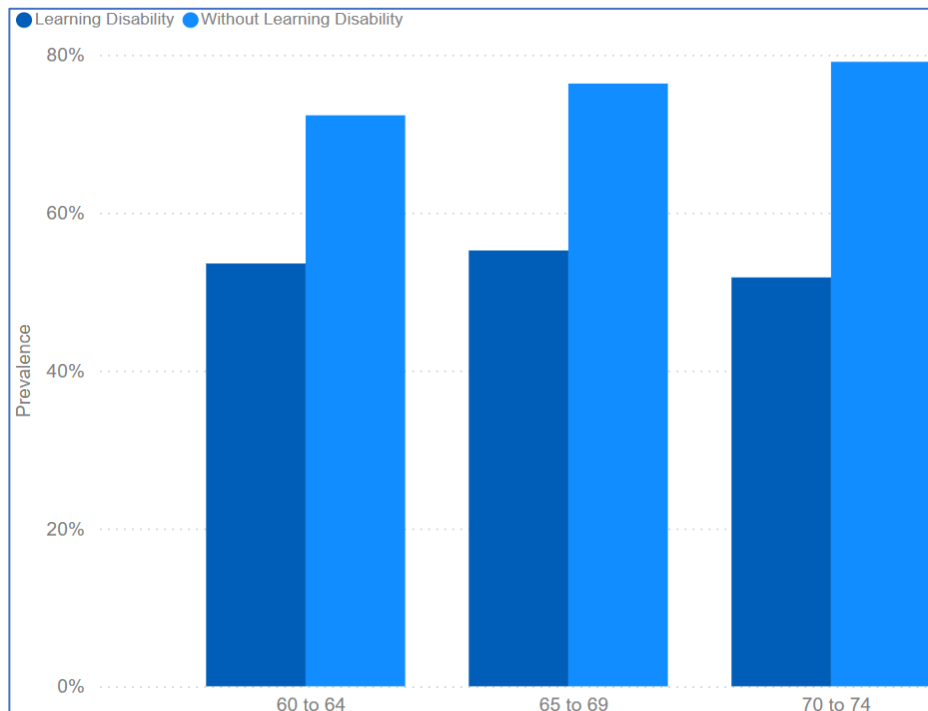
The National bowel cancer screening programme is offered to everyone aged 54 to 74 every 2 years, and is expanding to those aged 50 to 53 years by April 2025.

An estimated 53.7% of people with a learning disability had a bowel cancer screen in the two years and six months leading up to March 2023 in HIOW ICB, compared with 75.6% of people without a learning disability, a 21.9 percentage point difference. In Frimley ICB, 53.3% of people with a learning disability had an adequate bowel cancer screen, relative to 71.4% of those without a learning disability, an 18.1 percentage point difference. Figures 26 and 27 demonstrate the disparity in uptake between those with and those without a learning disability, with higher uptake in adults without a learning disability.

²⁸ [Cervical Screening When You Have a Learning Disability | Jo's Cervical Cancer Trust \(jostrust.org.uk\)](https://www.jostrust.org.uk/cervical-screening-when-you-have-a-learning-disability)

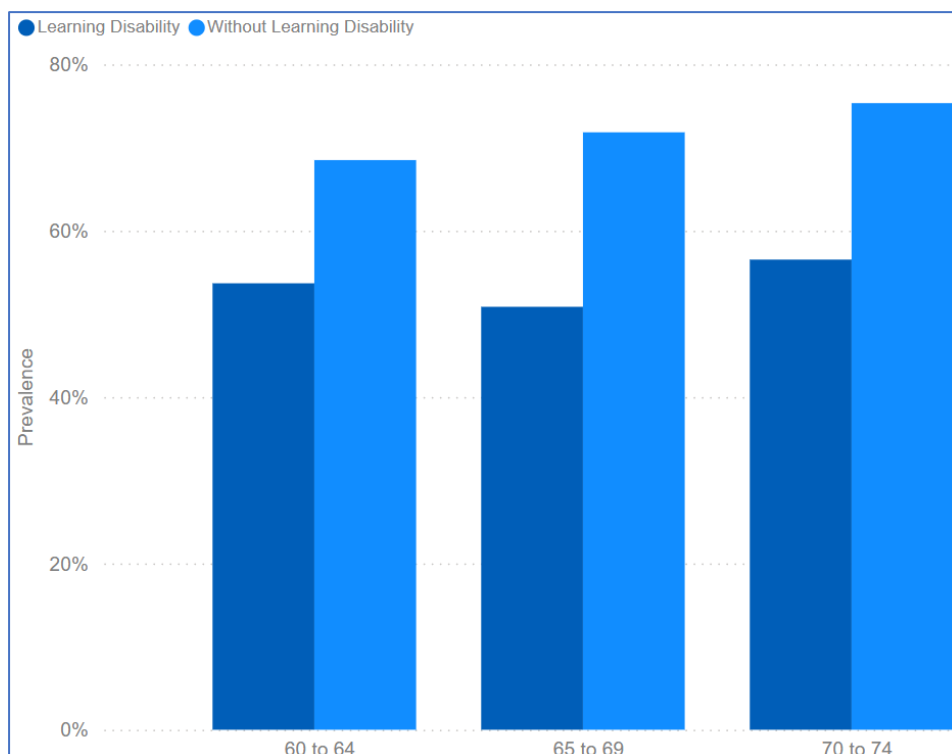
²⁹ [Health matters: making cervical screening more accessible - GOV.UK \(www.gov.uk\)](https://www.gov.uk/health-matters/making-cervical-screening-more-accessible)

Figure 26: Percentage of the eligible population aged 60-74 in HIOW ICB who had a bowel cancer screening result (indicating an adequate sample) in the previous two years and six months leading up to 31 March 2023, by age band.



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Figure 27: Percentage of the eligible population aged 60-74 in Frimley ICB who had a bowel cancer screening result (indicating an adequate sample) in the previous two years and six months leading up to 31 March 2023, by age band



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

More positively Table 10 shows that uptake is increasing in people with a learning disability in both ICBs and across England.

Table 10: Trend in bowel cancer screening uptake in people with learning disabilities in the two ICBs and England

	2020/21	2021/22	2022/23
HIOW ICB	46.2%	53.4%	53.7%
Frimley ICB	40.7%	52.0%	53.3%
England	43.3%	50.3%	52.7%

Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Since the introduction of home testing faecal immunochemical test (FIT) kits, bowel cancer screening uptake has increased across the UK. However, people with a learning disability may need help and support to encourage them to complete the test. Improving the likelihood of completing the test can help reduce health inequalities and ensure that people with learning disabilities can access bowel cancer screening.

3.4 Constipation

Constipation is a frequently reported issue in people with learning disabilities. A diet low in fibre, inadequate hydration, lack of exercise and side effects of antipsychotic medication are contributory to this problem. In people with learning disabilities constipation can be a cause of behavioural problems identified by carers and care staff as challenging. It has also been identified as a common cause of avoidable emergency hospitalisations, can disguise cancer and can have a significant negative impact on quality of life. We know that a change in bowel habits, including increased constipation³⁰ is a common symptom of bowel cancer and that based on the [LeDeR 2022](#) report, bowel cancer accounted for a higher percentage of cancer deaths in people with a learning disability than the general population.

In 2022/23 16.3% of patients with learning disabilities also had constipation in HIOW ICB and 13.0% in Frimley ICB, against the England average of 13.5%. Prevalence has been relatively static with minor fluctuations over the past five years in both ICBs and England (see Table 11).

Table 11: Trend in the prevalence of constipation people with learning disabilities in the two ICBs and England

	2018/19	2019/20	2020/21	2021/22	2022/23
HIOW ICB	16.8%	16.1%	16.1%	16.3%	16.7%
Frimley ICB	11.9%	12.9%	12.1%	12.9%	13.0%
England	13.3%	13.5%	13.2%	13.1%	13.5%

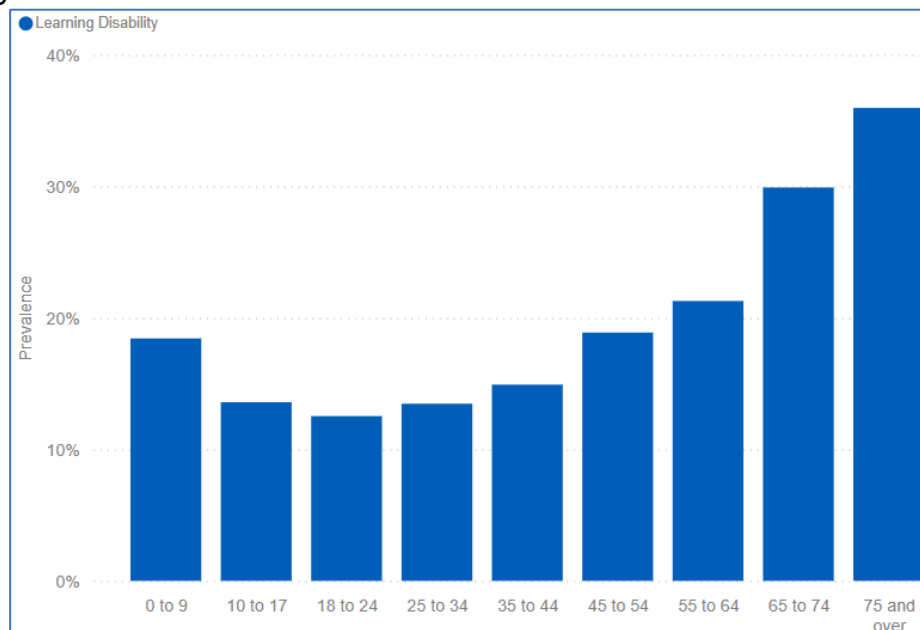
Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Constipation prevalence data were only collected for people with learning disabilities so no comparison of rates with those for people without learning disabilities is possible. Figures 28 and 29 show that the rate of constipation rose with age through adult life. In the HIOW ICB the rate rises from 18 to 24 years onwards, with the highest

³⁰ [Colorectal cancer | The Royal Marsden](#)

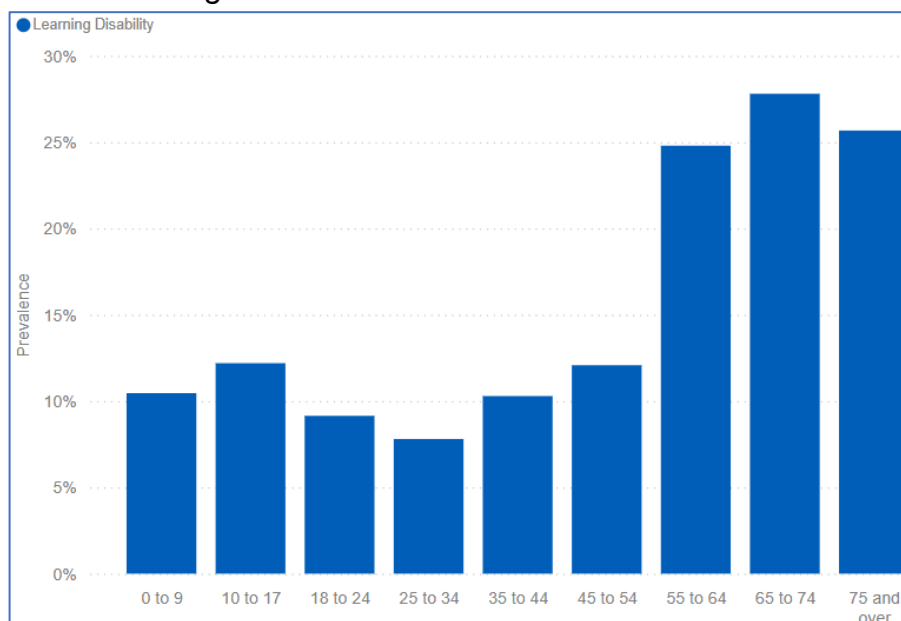
prevalence recorded in adults aged 75 and over at 36.0%. However, for the Frimley ICB, the prevalence of constipation increases from 25 to 34 years, significantly so in ages 55 and over, peaking at 27.8% in patients aged 65 to 74.

Figure 28: Percentage of patients with a learning disability in HLOW ICB with evidence of diagnosis or treatment of chronic constipation in the five years or two constipation medications in the last 12 months that are dated more than 6 months apart, up to and including 31 March 2023



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Figure 29: Percentage of patients with a learning disability in Frimley ICB with evidence of diagnosis or treatment of chronic constipation in the five years or two constipation medications in the last 12 months that are dated more than 6 months apart, up to and including 31 March 2023



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

3.5 Weight

A learning disability can make it difficult to maintain a healthy weight. Women, people with Down's Syndrome, Prader-Willi, Cohen or Bardet-Biedl Syndromes are at particular risk of obesity³¹, including those on certain medications. Excess weight predisposes them to major conditions, including cardiovascular disease (heart failure and stroke), diabetes, cancer and respiratory disease (obstructive sleep apnoea). Therefore, it is important to ensure that adequate and individualised support is available to enable people with learning disabilities to make healthy food choices and engage in regular physical activity, recognising that weight management is more complex than for the general population. The specific type of learning disability an individual has may make weight control difficult and should also be taken into account. Yet being underweight is more prevalent in individuals with severe or profound learning disabilities compared with the general population due to factors such as poor feeding and dysphagia³². Being underweight is an important health issue as this can lead to a compromised immune system, tiredness, low energy levels and reduced respiratory function.³³

3.5.1 Overweight

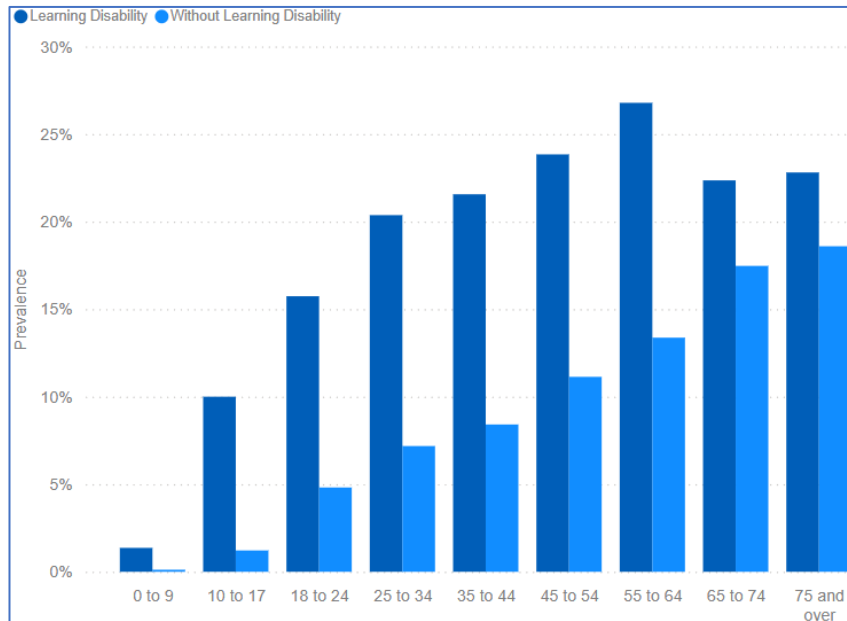
Health and Care of People with Learning Disabilities 2022/23 data show an overweight BMI being more common in patients with a learning disability than those without. In HIOW ICB 18.9% people with a learning disability were classed with an overweight BMI compared to 9.1% without a learning disability. For people with a learning disability in HIOW ICB, prevalence of an overweight BMI rose steadily from 10 to 17, peaking in ages 55 to 64 at 26.8%, and then dropping (see Figure 30).

³¹ [IHAL 2010-03. Health Inequalities & People with Learning Disabilities in the UK: 2010](#)

³² [Managing weight with a learning disability - NHS \(www.nhs.uk\)](#)

³³ [Learning Disabilities Mortality Review \(LeDeR\) Programme: Fact Sheet 28 Nutrition and diet, 2019](#)

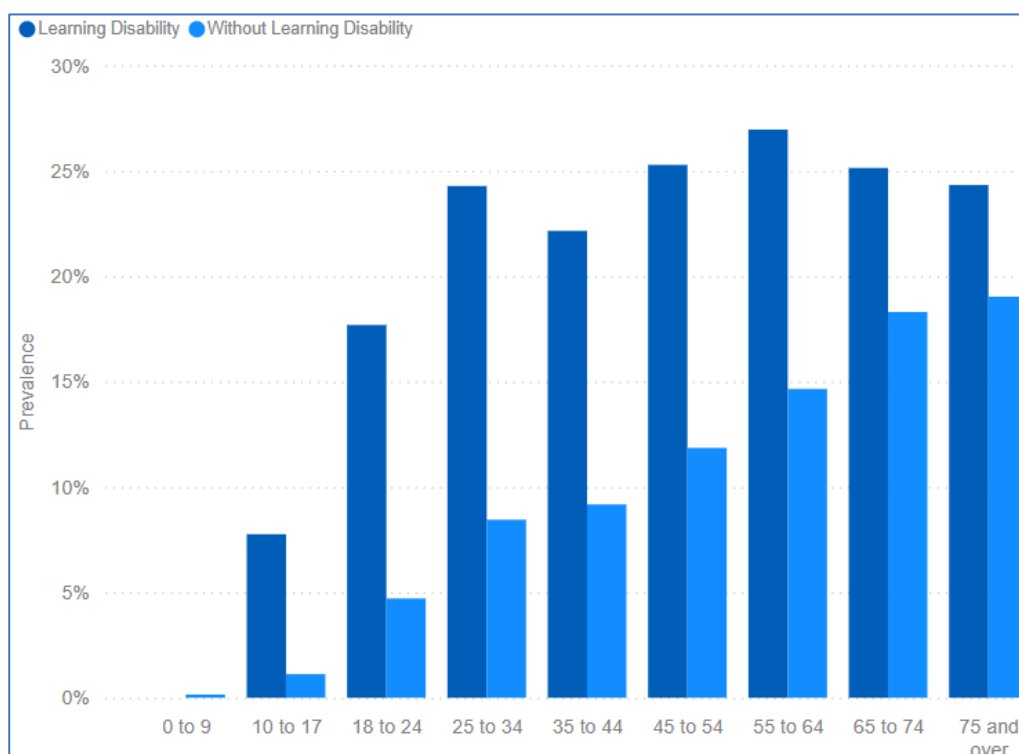
Figure 30: Percentage of patients in H10W ICB whose most recent BMI assessment classification (or Down's syndrome BMI centile classification) is overweight (BMI 25.0 -29.9) in the 15 months up to 31 March 2023, by age band



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

In Frimley ICB 19.5% people with a learning disability had an overweight BMI relative to 9.2% without a learning disability. Figure 31 shows that in Frimley ICB, an overweight BMI rose steadily from 10 to 17 years, dipped slightly in 35 to 44, peaking in ages 55 to 64 at 27.0%, and then dropping. Though a rise in an overweight BMI is evident across all age bands in those without a learning disability in both ICBs, the prevalence in people with a learning disability is persistently high within all age bands.

Figure 31: Percentage of patients in Frimley ICB whose most recent BMI assessment classification (or Down's syndrome BMI centile classification) is overweight (BMI 25.0 -29.9) in the 15 months up to 31 March 2023, by age band



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Data in Table 11 shows trends in overweight BMI; the large increase in 2022/23 could be due to factors such as improved recording in primary care as well as a true rise in overweight BMI prevalence.

Table 12: Trend in the prevalence of overweight people with learning disabilities in the two ICBs and England

	2018/19	2019/20	2020/21	2021/22	2022/23
HIOW ICB	17.4%	17.8%	17.3%	17.3%	18.9%
Frimley ICB	17.2%	15.2%	16.2%	17.0%	19.5%
England	16.5%	17.0%	15.9%	17.4%	18.6%

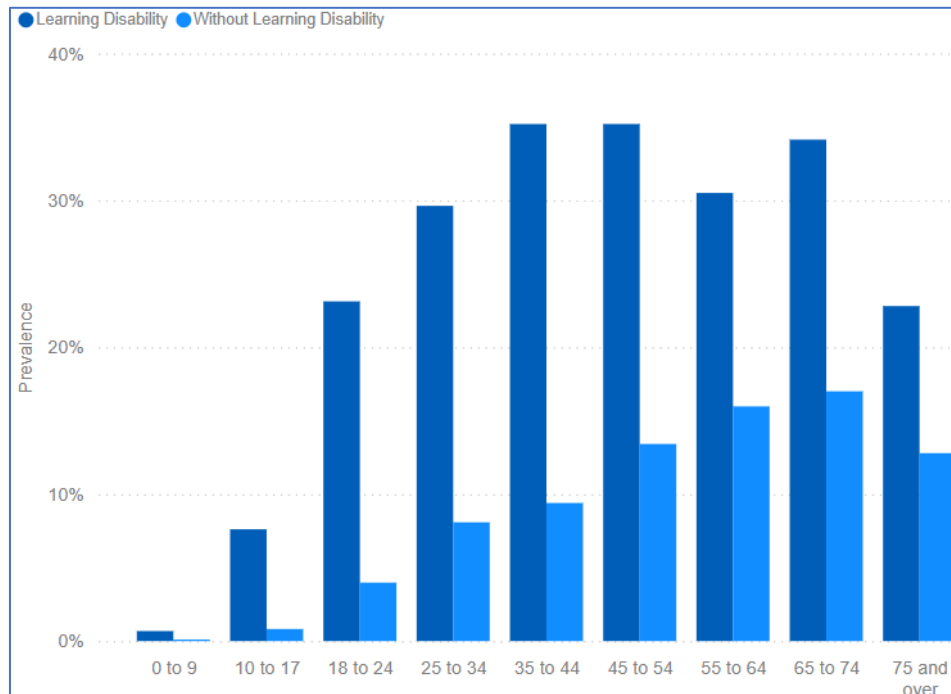
Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

3.5.2 Obesity

Based on *Health and Care of People with Learning Disabilities 2022/23* data, 26.2% of the HIOW and 26.7% Frimley ICB people with learning disabilities had a BMI classified as obese (30 and over), just under the England average of 27.0%. This is much higher than for people without a learning disability at 9.2% for HIOW ICB, 8.5% for Frimley ICB and 9.1% nationally. Figure 32 shows that within the HIOW ICB, in

people with a learning disability after 10 to 17 years there is a sharp rise in recorded obesity peaking in the 35 to 44 and 45 to 54 age bands at 35.2%.

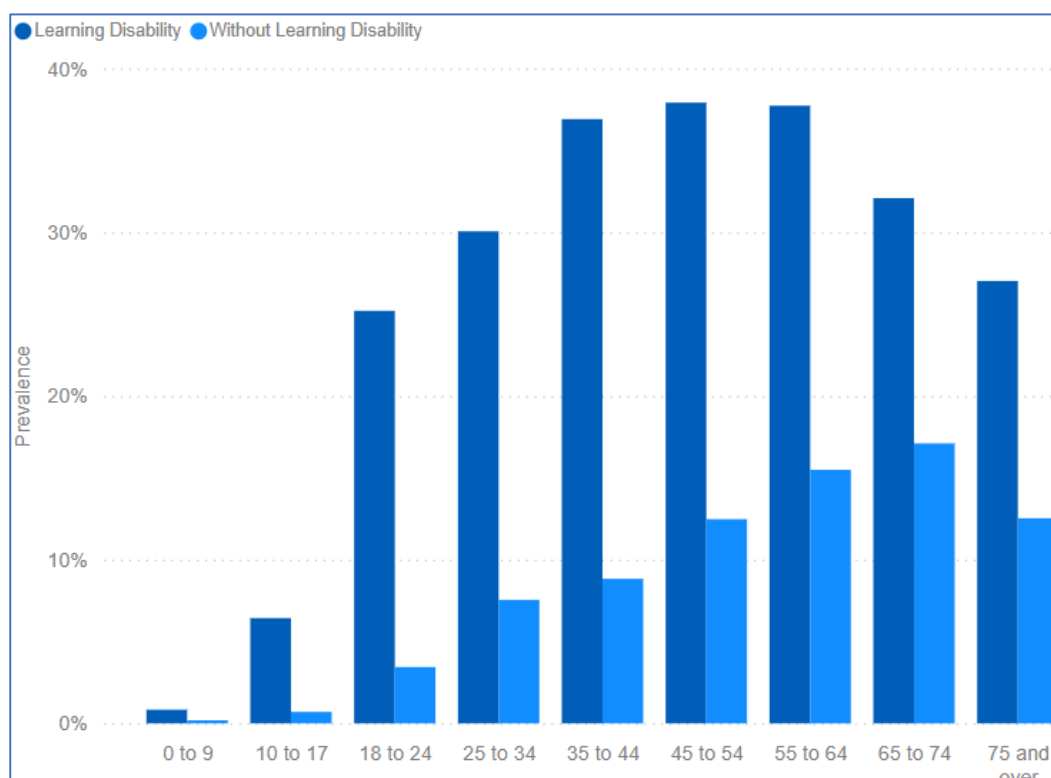
Figure 32: Percentage of patients in HLOW ICB whose most recent BMI assessment classification (or Down’s syndrome BMI centile classification) is obese (BMI ≥30.0) in the 15 months up to 31 March 2023, by age band



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

In Frimley ICB (see Figure 33), recorded obesity levels follow a similar high and sustained pattern, peaking in the 45 to 54 age band at 37.9% and dropping to 27.0% in ages 75 and over, but without the spike in 65 to 74 year olds.

Figure 33: Percentage of patients in Frimley ICB whose most recent BMI assessment classification (or Down’s syndrome BMI centile classification) is obese BMI ≥300) in the 15 months up to 31 March 2023, by age band



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Trend data in Table 13 illustrate the rise in recorded obesity in both ICBs and England over the past five years.

Table 13: Trend in the prevalence of obesity in people with learning disabilities in the two ICBs and England

	2018/19	2019/20	2020/21	2021/22	2022/23
HIOW ICB	23.1%	24.1%	23.8%	24.5%	26.2%
Frimley ICB	21.3%	22.5%	22.5%	25.1%	26.7%
England	22.7%	24.1%	22.6%	25.2%	27.0%

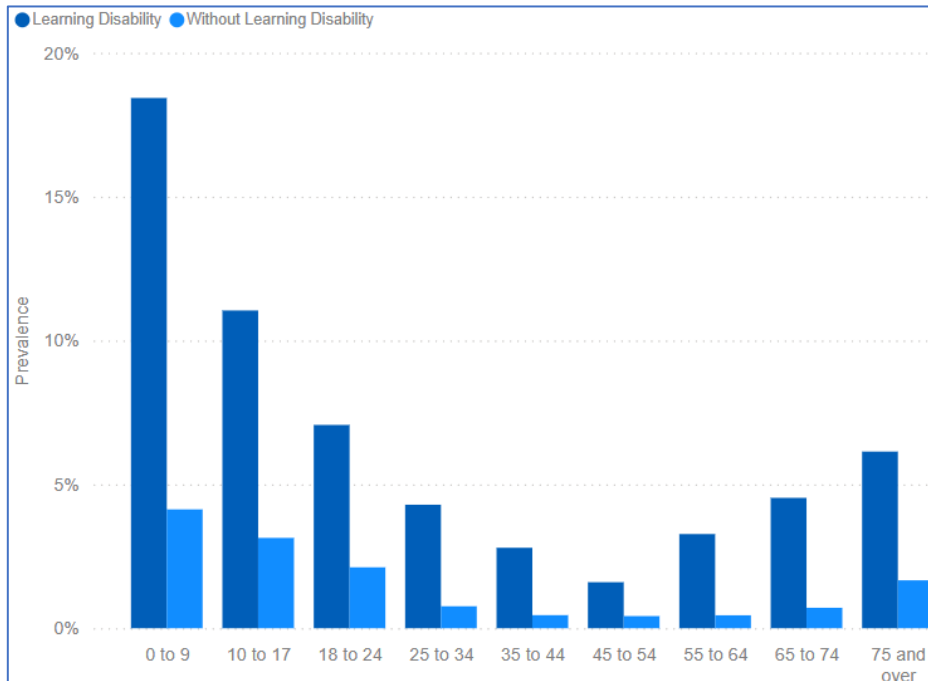
Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

3.5.3 Underweight

People with learning disabilities are also more likely than others to be underweight, as shown in the *Health and Care of People with Learning Disabilities 2022/23* data for both ICBs. Figures 34 and 35 show that an underweight BMI is more prevalent in people aged less than nine years, followed by a steady decline to 45 to 54 after which it starts to rise again. An estimated 5.7% of people with learning disabilities were underweight compared to 1.5% without learning disabilities in the HIOW ICB. For

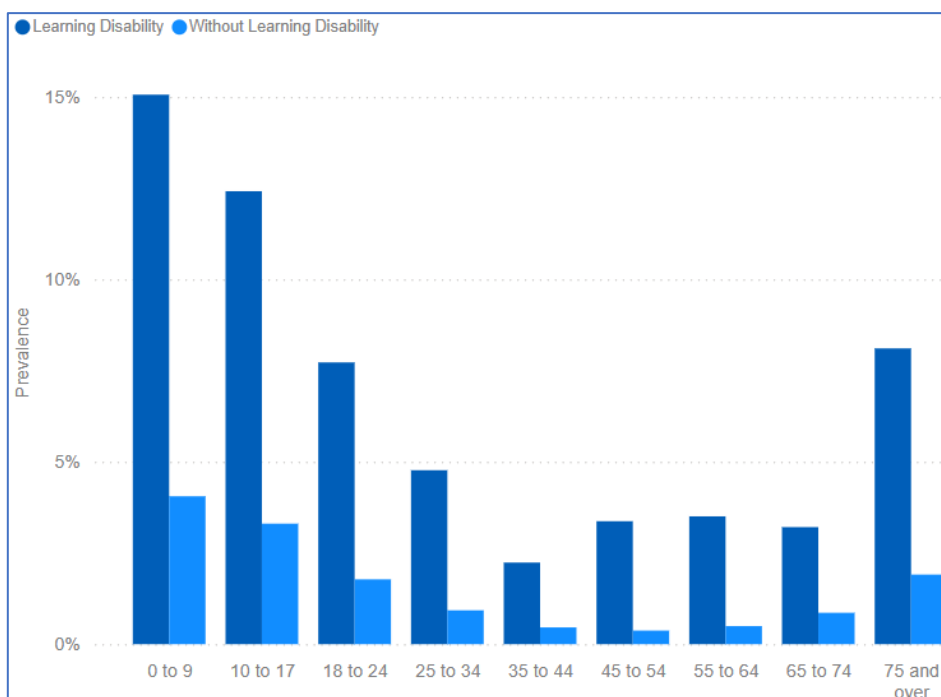
Frimley ICB, 6.3% of people with learning disabilities were underweight compared to 1.5% without learning disabilities.

Figure 34: Percentage of patients in HLOW ICB whose most recent BMI assessment classification (or Down’s syndrome BMI centile classification) is underweight BMI ≤184) in the 15 months up to 31 March 2023, by age band



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Figure 35: Percentage of patients in Frimley ICB whose most recent BMI assessment classification (or Down’s syndrome BMI centile classification) is underweight BMI ≤184) in the 15 months up to 31 March 2023, by age band



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

The rates of underweight BMI have been increasing over time in people with a learning disability and may be due to better recording of BMI (see Table 14).

Table 14: Trend in the prevalence of underweight in people with learning disabilities in the two ICBs and England

	2018/19	2019/20	2020/21	2021/22	2022/23
HLOW ICB	4.0%	4.0%	4.6%	5.1%	5.7%
Frimley ICB	3.3%	3.8%	4.3%	5.5%	6.3%
England	4.2%	4.4%	4.2%	4.8%	5.6%

Source: NHS Digital. *Health and Care of People with Learning Disabilities, 2022/23*

Approaches to weight management in adults with learning disabilities should be multi-faceted, such as improving health literacy, independence, choice and physical activity. Public Health England outlines the following methods to reduce obesity and support weight management in people with learning disabilities:

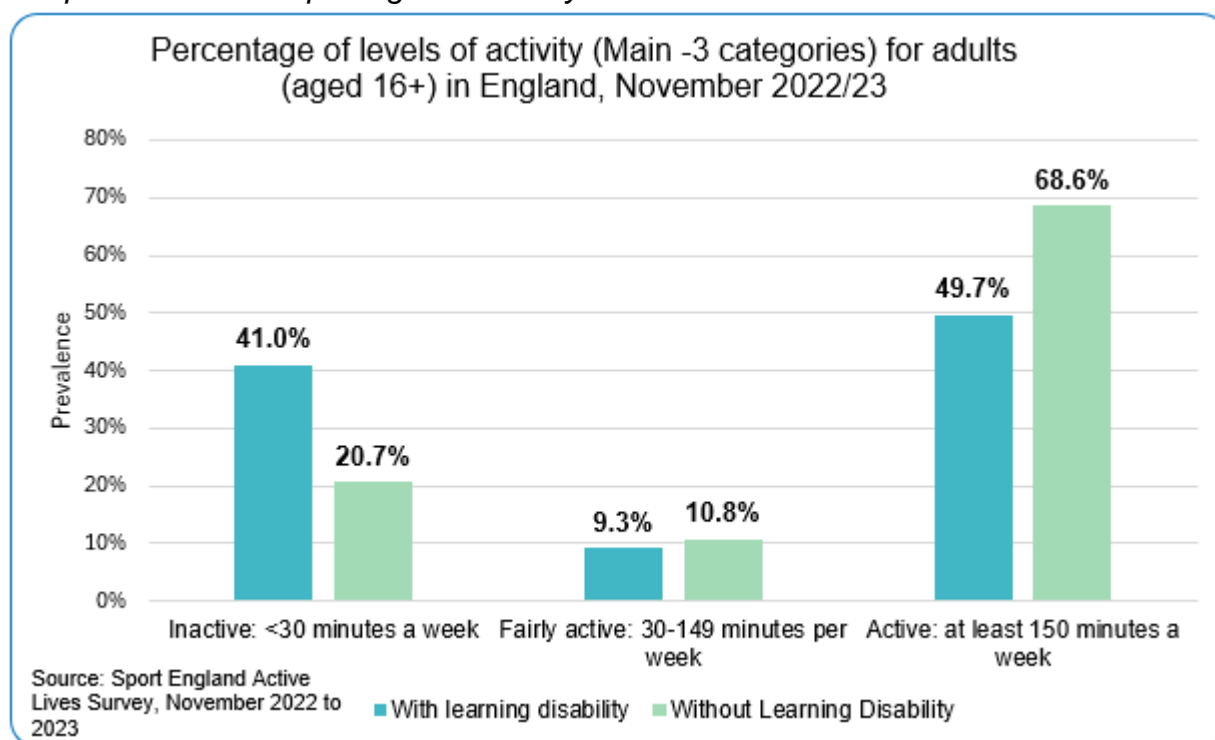
- Ensure there is adequate assessment of healthy weight for people who may have atypical body shapes or may be using a wheelchair.
- Raising awareness of excess weight with people with learning disabilities and their family carers.
- Ensure there are actions for clinicians, the individual and their supporters in the health action plan that follows an annual health check.
- Enable families and social care staff to provide motivational and practical support.
- Ensure mainstream weight management interventions are accessible.
- Address environmental, social and personal factors such as transport and finances.
- Work within an individuals' capacity and choice around diet and physical activity³⁴.

3.6 Physical Activity

Whilst physical activity has been shown to improve wellbeing and physical health, including long-term conditions, people with learning disabilities have lower levels of physical activity than those without a learning disability. The [Sport England Active Lives Survey](#) (see Figure 36) demonstrates that people with learning disabilities have much lower levels of physical activity compared with people who report no disability. Covering the period from mid-November 2022 to mid-November 2023, the Active Lives Adult (aged 16+) survey shows a higher proportion of adults with learning disabilities being classed as inactive, with a 20.3 percentage point difference between those with learning disabilities, and those without. Equally, we see more adults without a learning disability are active, with over two-thirds achieving the recommended levels of activity. However, this is not the case for adults with a learning disability, who fall behind by 18.9 percentage points.

³⁴ [Obesity and weight management for people with learning disabilities: guidance - GOV.UK \(www.gov.uk\)](https://www.gov.uk/guidance/obesity-and-weight-management-for-people-with-learning-disabilities)

Figure 36: Levels of activity reported among people with a learning disability compared to those reporting no disability



The [UK Chief Medical Officers' Physical Activity Guidelines](#) of being active every day is pertinent to adults with learning disabilities: 'For good physical and mental health, adults should aim to be physically active every day. Any activity is better than none, and more is better still.'

Research into the evidence base for interventions to increase physical activity in adults with learning disabilities is under-developed and can often result in inconsistent findings. Suggested strategies for increasing physical activity in people with learning disabilities in the 2018 PHE (now OHID) report [Health Inequalities: Physical Activity](#), include reward systems, a 'buddy' system, and recording progress on wall charts. The [Activity Alliance's Impairment Report and Annual Disability and Activity Survey 2022/23](#), which complements Sport England's Active Lives Adult Survey, reported that the motivation of people with learning disabilities for being active were to improve/maintain their mental health (59%), meet new friends (18%) or to learn a new skill/improve their existing skills (19%). Some of the main barriers to people with learning disabilities to be active are, their impairment or health condition (65%), feeling less confident (49%), previous bad experiences (33%) or negative attitudes from others (27%). Whilst respecting an individual's choice, the 2016 PHE report [Making reasonable adjustments to obesity and weight management services for people with learning disabilities](#) suggests targeting better training and education to people with learning disabilities, clinicians, family carers and paid social care staff. This is supported by the 2022/23 [Activity Alliance's Annual Disability and Activity Survey](#) findings that show family, support workers, friends and community leaders are seen as important sources for providing advice on being active.

Monforte J *et. al*³⁵. in their research highlighted that disabled people identified social workers as a professional force that can increase their chances to become, and stay, physically active. However, at the time of the research there was no formal training and education for social workers to learn about how to offer appropriate PA guidance and become confident and consistent messengers. The ['Moving Social Work'](#) programme aims to change the widespread lack of training and education in this workforce. Whilst social workers are one important target workforce, it is important to ensure all those involved in the care or support of adults with learning disabilities are reinforcing the same positive messages relating to being active.

3.7 Mental Health, wellbeing and neurological conditions

A significantly higher proportion of people with a learning disability report mental ill-health than in the general population.

3.7.1 Depression

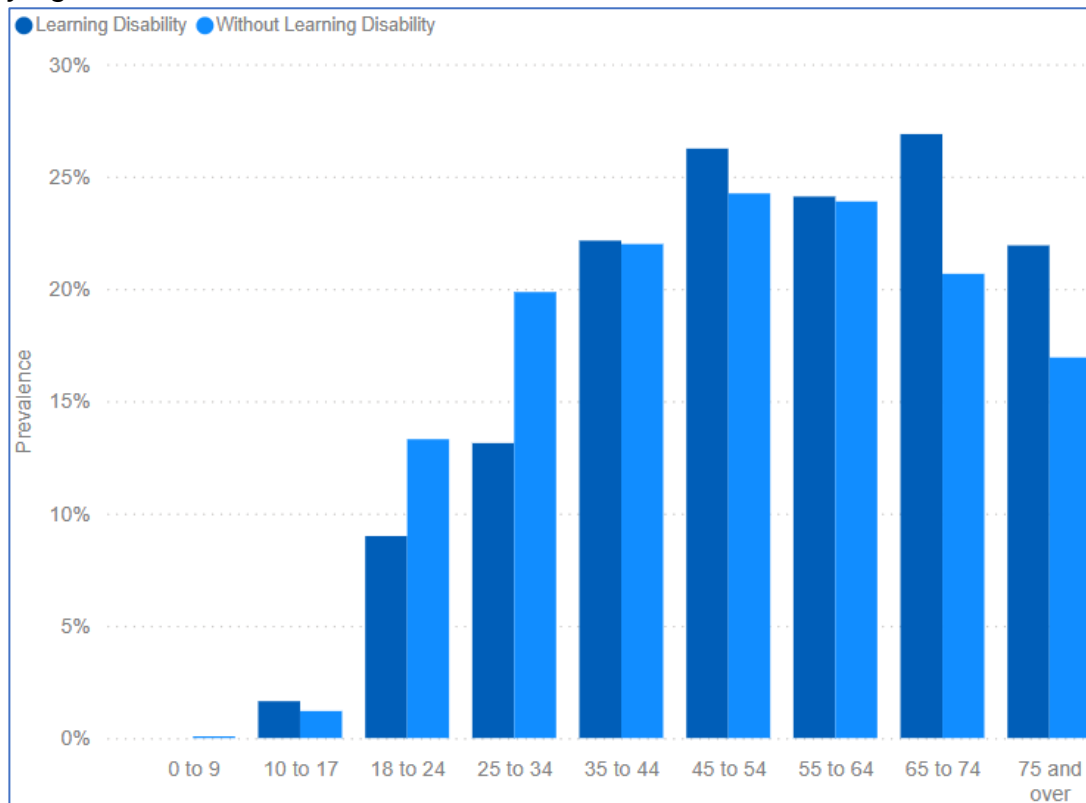
In people with learning disabilities, particularly those with limited ability to communicate, depression can be expressed in behavioural ways understood by carers or care staff as 'challenging', making contextualising particularly important for diagnosis.

Health and Care of People with Learning Disabilities 2022/23 data show that in HIOW ICB, 15.5% of adults with learning disabilities had an active diagnosis of depression, slightly lower or similar to the rate in the population who did not have learning disabilities (16.3%). This varies by age as shown in Figure 37. The percentage of patients with a diagnosis of depression is highest in the 65 to 74 age group (26.9%). Adults with learning disabilities aged 18-34 have a lower diagnosis rate than the same age band who did not have learning disabilities (9.0% vs. 13.3%).

In Frimley ICB, however, the prevalence of depression was higher among people with a learning disability (15.7%), than those without (12.7%). The largest difference in diagnosis between the population with and without learning disabilities is in the 35 to 44 age band, a variance of 10.1 percentage points as shown in Figure 38. In this age band in the population with learning disabilities 25.5% have an active diagnosis of depression, as opposed to 15.4% in those without learning disabilities.

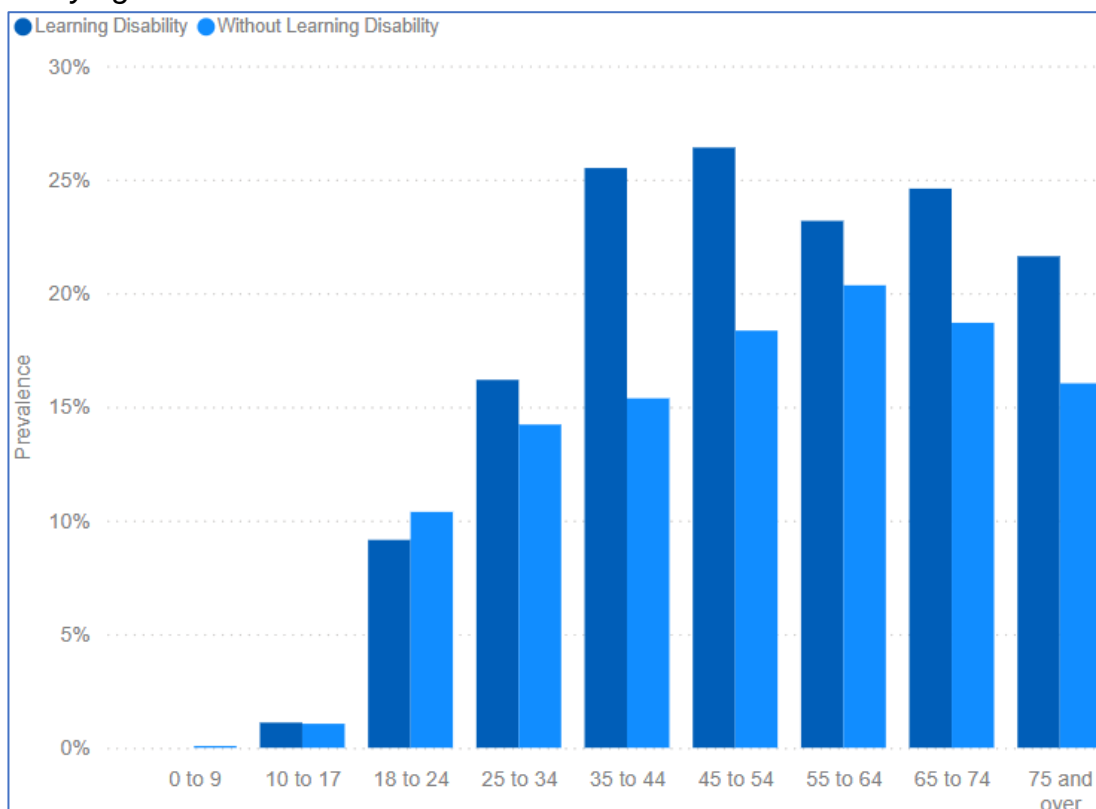
³⁵ Monforte, J., Smith, M., & Smith, B.(2022). Designing a programme to train social workers on how to promote physical activity for disabled people: A Delphi study in the UK. *Health & Social Care in the Community*,30, e2805–e2817. <https://doi.org/10.1111/hsc.13724>

Figure 37: Percentage of patients with an active diagnosis of depression in HIOW ICB by age band in 2022/23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Figure 38: Percentage of patients with an active diagnosis of depression in Frimley ICB by age band in 2022-23



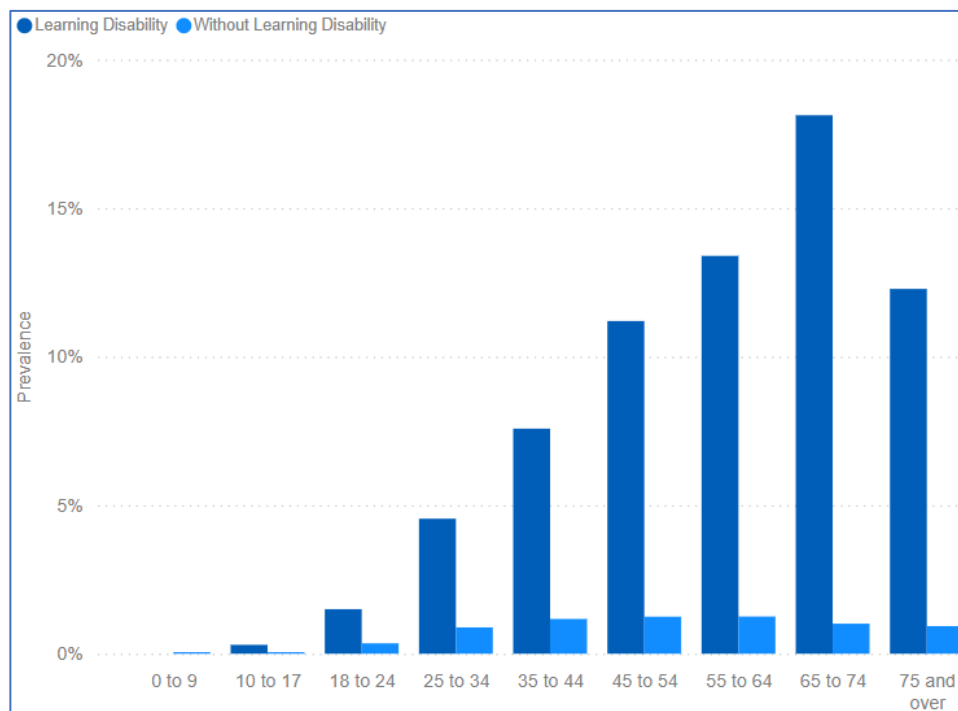
Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

3.7.2 Severe Mental Illness

People with learning disabilities are known to suffer more commonly with severe mental illnesses (SMI) than people without learning disabilities, but the extent is difficult to assess since diagnosis of these conditions is more challenging, particularly in those with more severe learning disabilities and difficulties with verbal communication. In people without learning disabilities, psychotic disorders are relatively uncommon in childhood, appearing usually in adolescence or young adulthood. [The National Institute for Health and Care Excellence \(NICE\) guideline on mental health problems in people with learning disabilities, NG54](#), makes recommendations to address their poorer mental health.

Data from *Health and Care of People with Learning Disabilities 2022/23* based on GP learning disabilities registrations show that approximately 6.5% of the HIOW ICB population with a learning disability have a SMI recorded, compared to 0.8% of the population without learning disabilities. This varies by age, steadily rising from 18 to 24, peaking in 65 to 74 with the highest SMI prevalence of 18.1%, then falling in the 75 and overs, as shown in Figure 39.

Figure 39: Percentage of patients with a diagnosis of severe mental illness in HIOW ICB, 2022/23



Source: NHS Digital. *Health and Care of People with Learning Disabilities, 2022/23*

In Frimley ICB, GP SMI registrations show that 8.1% of patients with a learning disability had a severe mental illness recorded, compared to 0.7% of the population without a learning disability. Unlike HIOW ICB, the prevalence of SMI in patients with a learning disability increases with age, peaking at 21.6% in patients aged 75 and over, as presented in Figure 40.

Figure 40: Percentage of patients with a diagnosis of severe mental illness in Frimley ICB, 2022/23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

According to [Mencap](#) the risk factors for poor mental health can affect anyone, but people with learning disabilities are more likely to have increased exposure. This can include:

- Biology and genetics, which may increase vulnerability to poor mental health
- Higher incidence of negative life events, such as deprivation and abuse
- Access to fewer resources (such as social support) and coping skills, which can ‘increase the stress and burden felt by people with a learning disability when they are exposed to negative life events’
- The impact of stigma and discrimination

Achieving parity of esteem between mental and physical health has been emphasised with ‘parity of esteem’ gaining prominence in the Government’s [No health without mental health](#) and enshrined as law within the *Health and Social Care Act 2012* along with publication of successive NHS Mandates setting objectives for parity. The parity approach ensures that an individual receives a ‘whole-person’ attitude throughout health services, including in the local authority.

A 2014 British Medical Association (BMA) report³⁶, stated that ‘While people with mental health problems do not have parity with physical health, the case is even worse for those with intellectual disabilities’. It identified the lack of services available, need for staff awareness, timely diagnosis, physical barriers to accessing services and failures to make reasonable adjustments, as organisational barriers for people with

³⁶ British Medical Association Board of Science. 2014 Recognising the importance of physical health in mental health and intellectual disability. Achieving parity of outcomes. British Medical Association: London

learning disabilities to access the care they need. The BMA report has now been superseded by [*Beyond parity of esteem – Achieving parity of resource, access and outcome for mental health in England*](#), in 2020.

Services such as NHS Talking Therapies which are open to self-referrals and provide a range of support, have not always been considered appropriate for all individuals with learning disabilities. However, some NHS Talking Therapies services have Learning Disabilities Champions who can advocate for reasonable adjustments to the service. This includes holding face to face appointments for those who need it. Although the services have made some adjustments, they may be more appropriate for people with less severe learning disabilities and may not meet the needs of those with more complex needs.

For individuals with more complex learning disabilities, a referral can be made by the individual's GP to the Learning Disability team or the Adult Mental Health team, depending on the primary need. Learning Disability teams work with Adult Mental Health services assessing case studies of people who have used the services to continuously improve services for people with learning disabilities. The teams review what can be learnt and how referrals can be smoothly transitioned. The Learning Disability team can provide Adult Mental Health services with advice and support on making reasonable adjustments to their services to best meet the needs of adults with learning disabilities. Furthermore, the [*Green Light toolkit*](#) can enable Adult Mental Health services to ensure that their provision is open to people with learning disabilities.

Data on mental wellbeing is even more limited than that on mental ill-health. Mental wellbeing is the foundation for a positive outlook on life. Hampshire County Council's [*Five Ways to Wellbeing*](#) pages acknowledge that although mental wellbeing does not mean that we are happy all the time, it does mean that we are more resilient and able to cope with life's ups and downs. Evidence shows that there are five key elements which contribute to mental wellbeing: connect, be active, keep learning, give and take notice. Some elements of the five ways to wellbeing are explored in more detail in this needs assessment, such as physical activity and employment which demonstrate inequalities in access and uptake between adults with learning disabilities and the general population.

It is important to ensure there are a range of activities that benefit mental wellbeing that are accessible to adults with learning disabilities, either through inclusivity and/or groups explicitly targeting adults with learning disabilities. This can help break down social isolation or loneliness, challenging stigmas and support independence.

3.7.3 Dementia

People with learning disabilities are at an increased risk of dementia, face an earlier onset, experience delays in diagnosis, encounter quicker progression, have pre-existing health conditions, and may present differently, compared to the general population. With an increasing life expectancy dementia prevalence is likely to increase, especially in those who have Down's syndrome. According to the

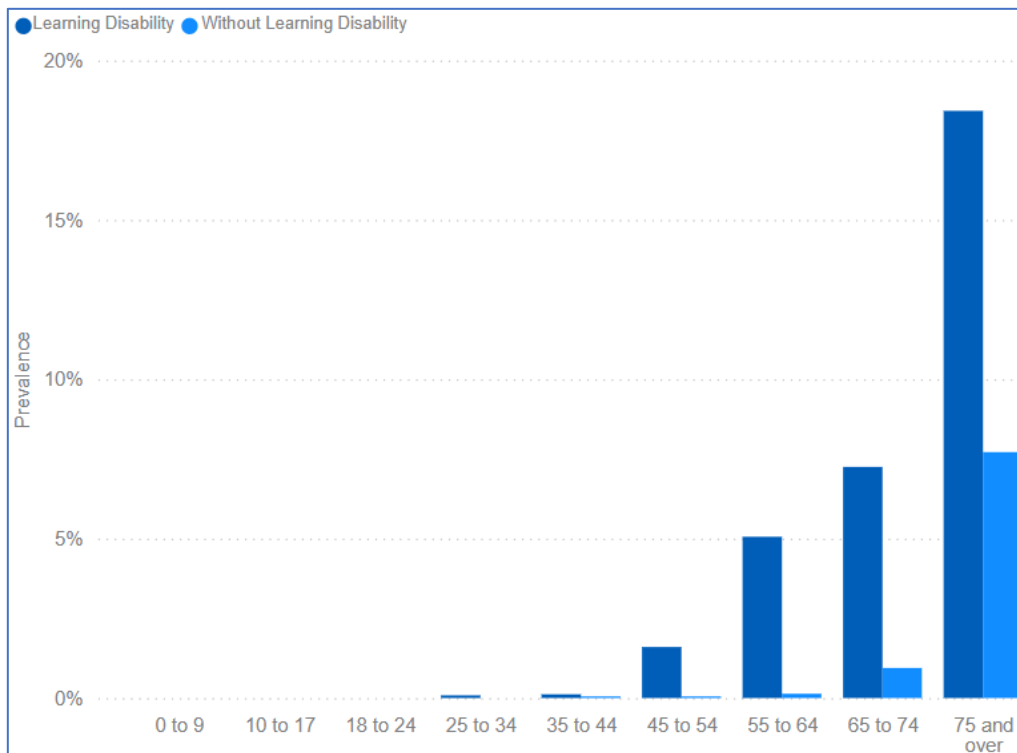
[Alzheimer's Society](#) it is estimated that 1 in 50 people with Down's syndrome will develop dementia in their 30s, with approximately 2 in 3 people over the age of 60 developing dementia. Development of epileptic seizures in someone with Down's syndrome later in life is often a sign of dementia and should be fully investigated to aid early diagnosis and preparation for further care. In addition to these considerations, the Alzheimer's Society note that individuals may not be able to understand the diagnosis and need specific support to understand the changes they are experiencing, and to access appropriate services after diagnosis and as dementia progresses.

Diagnosing dementia in people with learning disabilities can be difficult because it depends on assessment of the level of deterioration of mental functioning from an initially low base. Early diagnosis and treatment with medication for dementia is increasingly important to improve their health. When individuals develop dementia, it is important to enable those who are using services to continue to receive the support they need for their learning disability throughout their dementia journey. When care changes suddenly, health tends to deteriorate, and this change can be confusing for people with both learning disabilities and dementia. If an individual with a learning disability living in a residential care setting develops dementia, needs are assessed on an individual basis as to whether they stay residing in a learning disability setting or transfer to either nursing care or older people's care. In either case, there needs to be consistency in the support available to meet the requirements for both elements of their health care needs.

In HIOW ICB, *Health and Care of People with Learning Disabilities 2022/23* data show that 1.6% of patients with a learning disability received a diagnosis of dementia, compared to 0.8% of patients without a learning disability. The prevalence is slightly higher in the Frimley ICB with 2.0% of patients with a learning disability diagnosed with dementia against 0.7% of patients without a learning disability.

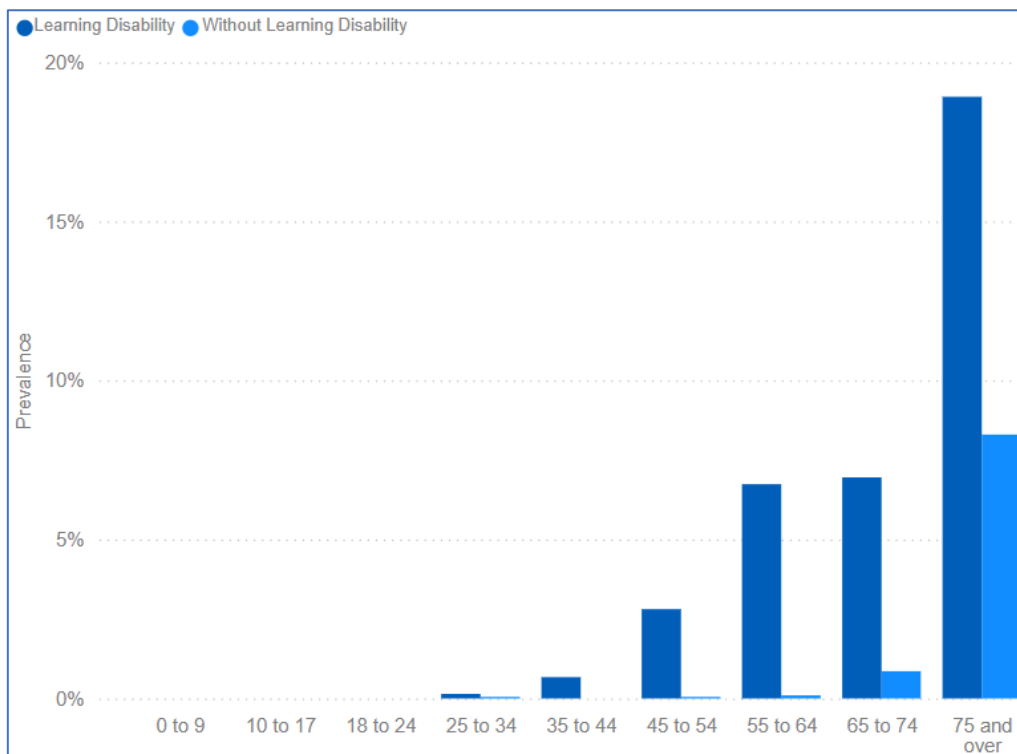
Prevalence increases with age, more sharply in older ages, as seen in Figures 41 and 42 in both ICBs. The earlier presentation is also clearly seen in the figures. At all ages diagnosis is higher in the population with learning disabilities.

Figure 41: Percentage of patients with a diagnosis of dementia in HIOW ICB, 2022/23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Figure 42: Percentage of patients with a diagnosis of dementia in Frimley ICB, 2022/23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

3.7.4 Epilepsy

It is acknowledged that epilepsy is more prevalent in people with learning disabilities, which is usually as an additional complication of the condition causing the learning disability. The [Epilepsy Society](#) states that:

- About 1 in 3 people (32%) who have a mild to moderate learning disability also have epilepsy.
- The more severe the learning disability, the more likely that the person will also have epilepsy.
- Around 1 in 5 people (20%) with epilepsy also have a learning disability.

It further clarifies that having a learning disability does not cause someone to have epilepsy and vice versa. Both a learning disability and epilepsy are symptoms of underlying brain damage or dysfunction. Diagnosis of epilepsy is difficult as there is not a singular test to confirm a diagnosis. It can be particularly difficult to diagnose an individual with a learning disability with epilepsy due to behaviours such as repeated movements and staring that can be mistaken as a seizure. Treatment is challenging due to the nature of their seizures and underlying cause. Finally, that it can be more difficult for a person with a learning disability to communicate how they are feeling.

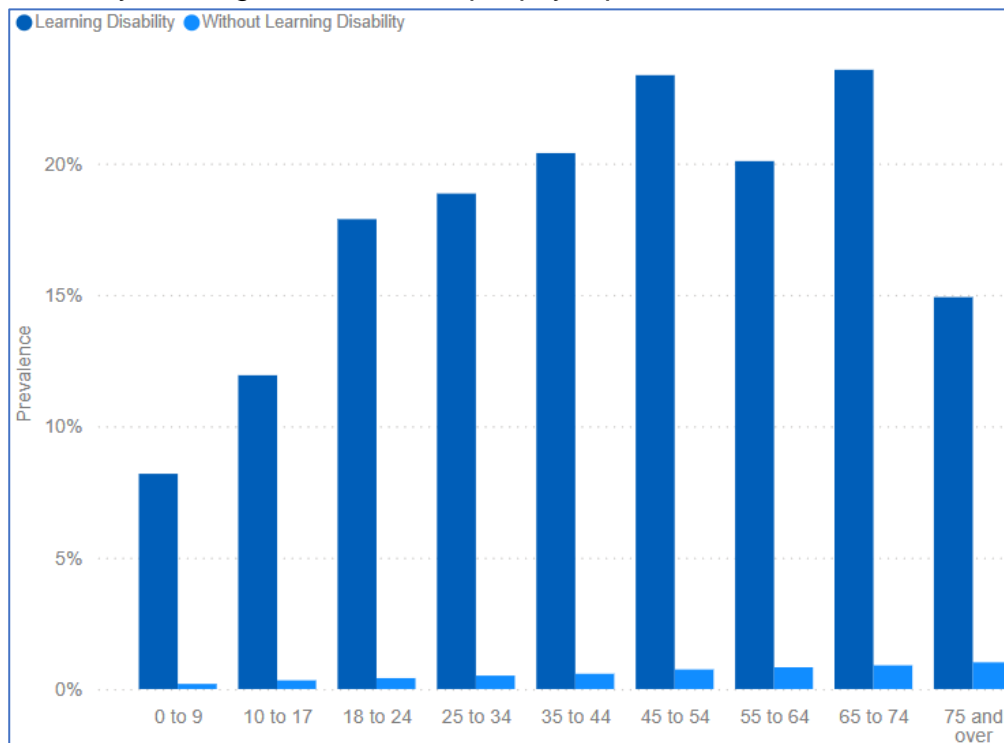
People with learning disabilities and epilepsy are at increased risk of mortality. Epilepsy has been highlighted as one of the most common preventable causes of death for people with learning disabilities. In the 2015 [PHE Learning Disabilities Observatory](#) report, epilepsy was reported to have contributed to 3.9% of deaths in England. The [LeDeR 2022](#) review found that epilepsy was the long term health condition most strongly associated with dying at a younger age.

The [2013 CIPOLD](#) reported that NICE guidelines for epilepsy and learning disabilities were not always adhered to (CG20 replaced by CG137 in 2012, and by NG217 in 2022). It was found that there was not always a trained person on duty able to administer emergency medication when required. This highlights both training needs and the importance of planning staff rotas appropriately. Of note [NICE's Epilepsies in children, young people and adults NG 217](#) includes specific sections on learning disability and a specific summary of the recommendations on extra support for people with learning disabilities - [Epilepsy and learning disabilities](#).

Health and Care of People with Learning Disabilities 2022/23 data show that 18.4% of people with learning disabilities were recorded as having epilepsy in HIOW ICB, compared to 0.6% for people without learning disabilities. In Frimley ICB, 17.3% of patients with a learning disability had an epilepsy diagnosis, compared to 0.5% in the population without learning disabilities.

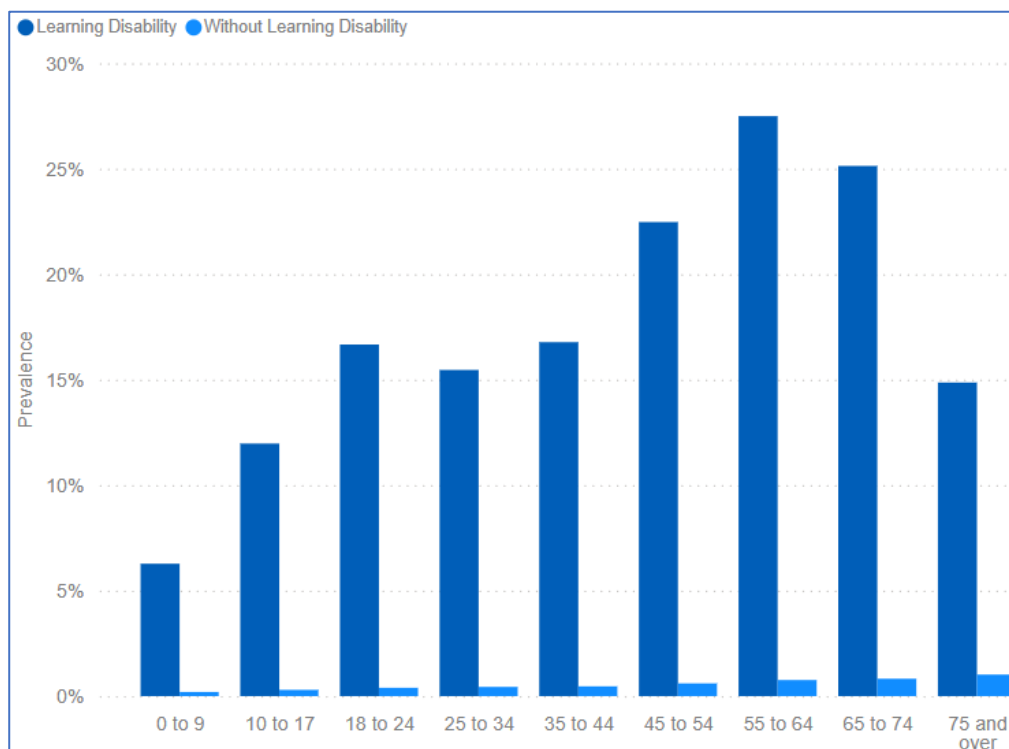
In people with learning disabilities the epilepsy rate rose with age until age 54 years and then fell for HIOW ICB; falling after age 64 years for Frimley ICB (see Figures 43 and 44). By contrast for people without learning disabilities the epilepsy rate rose with age almost in a straight line until the oldest age group.

Figure 43: Percentage of patients in HLOW ICB, with an active diagnosis of epilepsy and are currently on drug treatment for epilepsy, up to 31 March 2022/23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Figure 44: Percentage of patients in Frimley ICB, with an active diagnosis of epilepsy and are currently on drug treatment for epilepsy, up to 31 March 2022/23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Standardised prevalence ratios for mental health and neurological conditions are presented in Table 14 and shows that epilepsy and SMI are much more prevalent than expected in people with learning disabilities. The HIOW ICB SPRs are similar to the England figures, apart from the SPR for dementia and epilepsy which are higher than those for England. Frimley ICB has much higher SPRs for epilepsy, SMI and dementia than England. The SPR for depression appears to be similar across the ICBs and England.

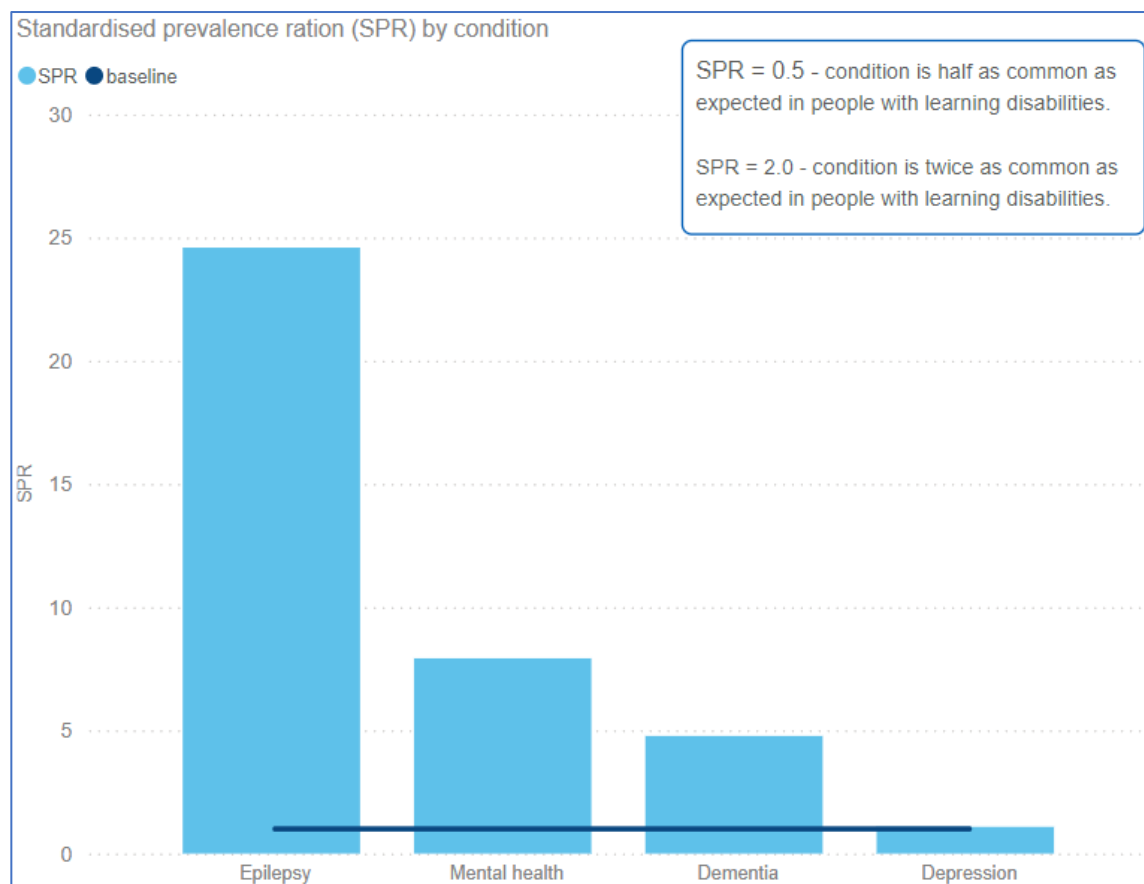
Table 15: Standardised prevalence ratios for mental health and neurological conditions in the ICBs and England, 2022/23

Mental health & neurological conditions	HIOW ICB	Frimley ICB	England
Depression	1.0	1.3	1.1
SMI	8.1	11.7	7.9
Dementia	7.0	7.9	4.8
Epilepsy	27.1	30.5	24.6

Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

The England SPRs, graphically presented in Figure 45 show just how highly prevalent epilepsy, serious mental illness and dementia are in people with learning disabilities.

Figure 45: Standardised prevalence ratios for mental health and neurological conditions in England, 2022/23



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

3.8 Sexual health and relationships

In the [2016 Hampshire Learning Disability Plan for Adults](#), adults with learning disabilities said they would like to have information about sexuality and relationships that is easy to understand, and to be able to openly discuss this. Solent NHS Trust commissioned some research that showed that most of the participants got their information from a family member or support worker. All individuals with learning disabilities need to have support from health professionals about safe sex and staying healthy in a way they can understand. This includes the ability to use generic healthcare services for contraception and sexual health screening. Recognising that relationships can bring happiness, fulfilment, companionship and a greater sense of choice to the lives of people with a learning disability [Mencap](#) has produced several resources on the topic. *Let's Talk About It - Solent NHS Sexual Health services* provide a range of resources to support professionals for example '[Learning Disability and Additional Support](#)' and [webinars](#). For people with a learning disability, the service has introduced a new model consisting of a clinical front door tailoring the appointment to the person's need with extra time.

It is also important to support carers of individuals with learning disabilities to understand the needs of the person they are caring for and there are [Mencap Sexuality and relationships](#) resources that explain what a healthy relationship is and the importance of consent and of safe sex. It also includes understanding what is appropriate for that person and supporting them to meet their emotional and health needs in a relationship. This was highlighted as a need in conversations with professionals working with people with learning disabilities.

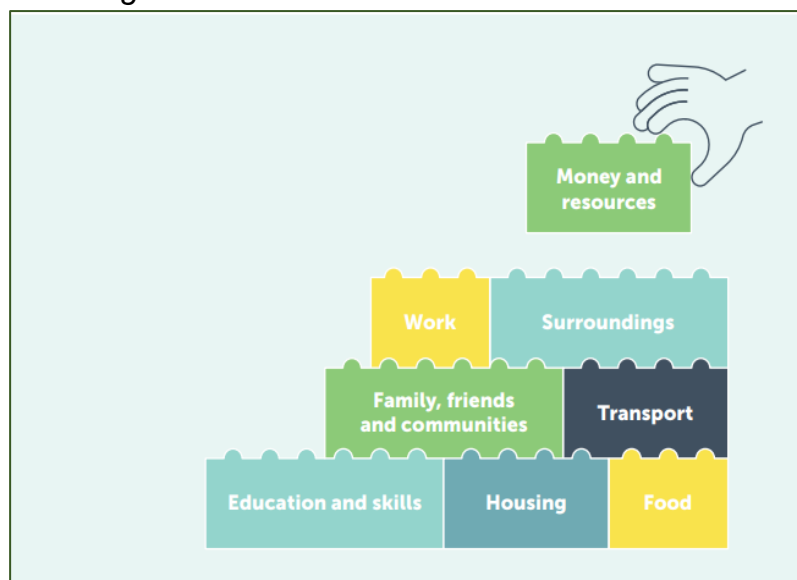
4. Building blocks of health

As well as increased exposure to the risk factors for poor health, adults with learning disabilities are also less likely to have access to the factors associated with better health such as education, employment and healthcare services, as displayed in Figure 46. This may be connected to discriminatory socio-cultural practices that can constrain the life experiences of people with disabilities³⁷. Mencap have used the term "institutional discrimination" to describe the difficulties that adults with learning disabilities face when organisations fail to adapt services to accommodate people's specific needs. This includes not resolving ignorance or prejudice in the workforce or culture of the organisation³⁸.

³⁷ Emerson E. et al. Health Inequalities and People with Learning Disabilities in the UK: 2012. Improving Health & Lives Learning Disability Observatory: London (Nov 2012)

³⁸ Mencap. Death by Indifference. London: Mencap, 2007

Figure 46: The Building Blocks of Health



Source: [How to talk about the building blocks of health. The Health Foundation; 2022](#)

This section explores what is known about the following determinants of health and the impact of this on adults with learning disabilities including:

- Poverty
- Employment
- Housing/ Accommodation

4.1 Poverty

Poverty can disproportionately affect people with learning disabilities and they are more likely to experience deprivation. A factsheet published by the British Association of Social Workers (BASW) [Anti-Poverty Spotlight: People with Learning Disabilities](#) covers factors such as inequity in employment (described below), poorer education, barriers to accessing essential support services, including banking and additional expenses. It is important to challenge the entrenched stigma individuals with learning disabilities face regarding their capacity to live independently, while maintaining a duty of care. The Department for Work and Pensions (DWP) provide a range of benefits and financial support, including the [Personal Independence Payment \(PIP\) for people with a learning disability](#), replacing the former Disability Living Allowance (DLA). Personal Independence Payments support people with learning disabilities, with their daily living activities and ability to get around.

4.2 Employment

Being in good work is better for health than being out of work. Employment can offer financial rewards, social interaction, the chance to use existing skills and develop new ones and a sense of purpose. This has a significant impact on quality of life. A 2023 Commons Library Research Briefing [Learning disabilities: health policies](#) committed to 'ensuring that all disabled people have the opportunity to fulfil their potential and realise their aspirations'.

In 2022/23, [Adult Social Care Outcomes Framework \(ASCOF\)](#) data suggest that 6.0% of people with a learning disability receiving long-term social care support were in paid employment in Hampshire, a rise on 4.9% in 2021/22, slightly better than England (4.8%) but lower than the South East (6.6%). [Learning Disability Profile](#) figures from OHID show Hampshire's gap in the employment rate between those with a learning disability and the overall employment rate is wide and tracking significantly above England figures. However, Hampshire disability employment gap figures for 2022/23 at 72.7 percentage points, though still wide, are a reduction on 2021/22 (75.6 percentage points) and not significantly different than the England gap of 70.9 percentage points. This figure is [caveated by OHID](#) and should be interpreted with some caution because the definition of individuals with a learning disability is restricted to those 'known to the council'. It is confined to adults with a primary support reason of learning disability support who have received long term support during the year in the settings of residential, nursing and community (excluding prison). 'It is not known what proportion of the population with a learning disability this captures and how this varies between areas, therefore it is not possible to know the impact of this on area level variation and so differences between areas should be interpreted with caution.'

On the Isle of Wight access to employment is higher, with greater proportions of people with a learning disability in paid employment (8.0%) and a narrower disability employment gap of 57.8 percentage points, tracking below and significantly better than England.

A local initiative in Havant, '[The Right to Work](#)', takes an innovative approach to day services for adults with learning disabilities to enable them to be equally valued in their community and wider society. Right to Work supports individuals in a wide range of job roles. Where possible, it offers paid employment for people with learning disabilities. Volunteers and staff gain improved confidence, better life opportunities and a greater sense of self-esteem, wellbeing and fulfilment.

A new initiative [Work Wise](#) will be piloted in the Frimley Integrated Care System footprint, by Surrey County Council, covering the Rushmoor and Hart areas of Hampshire. The Work Wise employment support will be integrated within primary care pathways, ensuring employment is seen as a key enabler of long-term recovery, wellbeing and independence. The programme will provide access to work and in-work support to ensure participants are able to enter and maintain employment. Work Wise includes a range of enabler activities to increase the employment opportunities available.

National evidence suggests that finding a job an individual wants to do and supporting them to learn how to carry out the role is more effective than spending money on preparing and training people for work. A national study³⁹ conducted between October 2011 and November 2013 by researchers at the National Development Team for Inclusion (NDTi) concluded that supported employment in learning disability services are the most effective ways of supporting people to achieve paid work outcomes and that sites working to evidence-based models of employment support typically delivered

³⁹ [SSCR Findings 26 Employment support for disabled people \(nihr.ac.uk\)](#)

the most cost-effective outcomes. Following this in 2021 the NDTi published a [Guide to Recruiting Individuals with Learning Disabilities into the Workplace](#) outlining effective practice.

4.3 Housing and accommodation

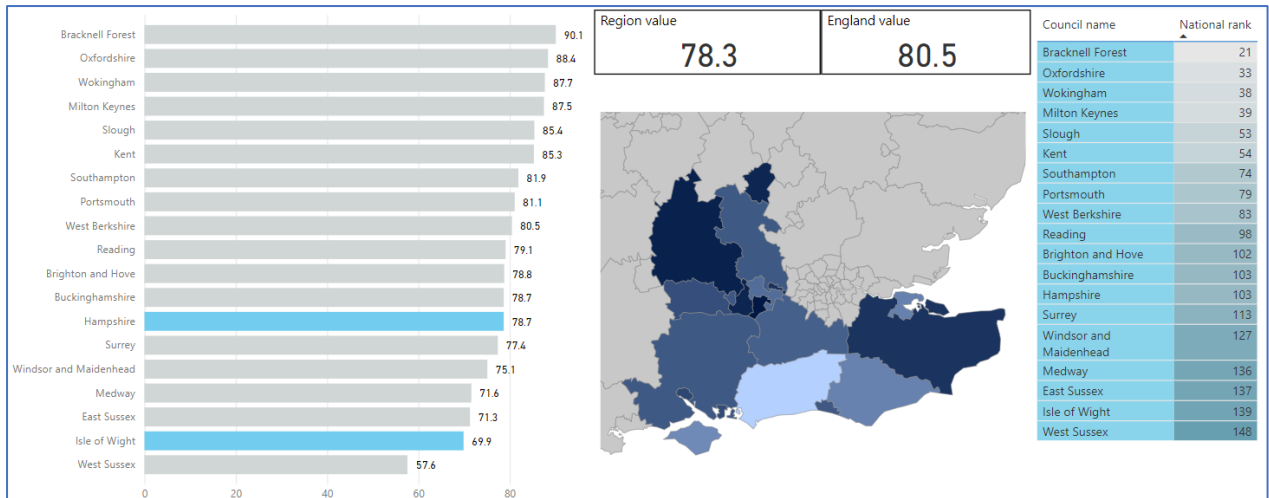
“Good quality housing, with the right care and support, can enable almost anybody to live independently. It makes it possible to choose where and with whom to live. It should enable people with a learning disability to link in with their local community; to access services and opportunities such as leisure, employment, transport and education. This enables building wider networks of support both formal and informal”⁴⁰

The 2009 [Valuing People Now](#) strategy acknowledged that accommodation options for adults with learning disabilities have improved with the shift away from hospital campus-based care. Supported living models are preferable to traditional residential care options for young people and working age adults with a learning disability as they provide the opportunity for more choice and control over how their accommodation, care and support needs are met, resulting in greater independence and autonomy over how individuals live their lives in their communities. A range of resources to transform the local housing offer for people with a learning disability are cited in the Local Government Association (LGA)’s [Housing for people with a learning disability or autistic people](#) briefing, including the [Building the right home](#) document.

Data on accommodation status relate to clients with learning disabilities known to the local authority - they are adults of working age with a primary support reason of learning disability support who have received long-term support during the year. Living on their own or with their family describes arrangements where the individual has security of tenure in their usual accommodation, for instance, because they own the residence or are part of a household whose head holds such security. Based on [ASCOF data](#), 78.7% of Hampshire service users with a learning disability (2,279 people) were living in their own home or with family in 2022/23, similar to South East (78.3%) but below England (80.5%) figures. However, at 69.9% the Isle of Wight had lower proportions of service users with a learning disability (339 people) living in their own home or with family. The Hampshire and IoW proportions and how they compare and rank across South East councils, with Hampshire ranking 103rd and IoW 139th, are presented in Figure 47.

⁴⁰ Maxwell Y & King N. Enhancing Housing Choices for People with a Learning Disability. Housing Learning & Support Network, Department of Health: London (Nov 2011)

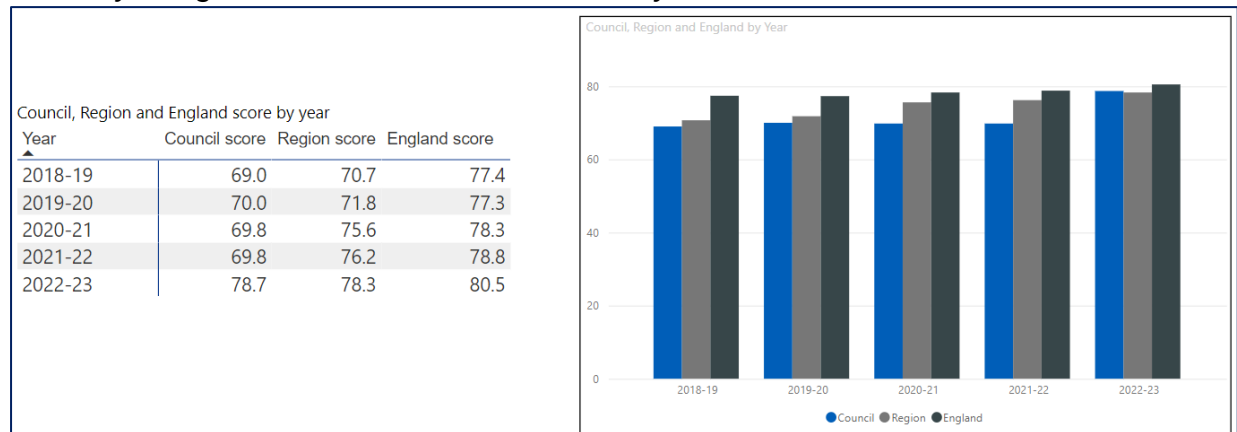
Figure 47: Percentage of Hampshire and IoW service users with a learning disability living in their own home or with family



Source: NHS England Measures from the Adult Social Care Outcomes Framework (ASCOF), 2022-23

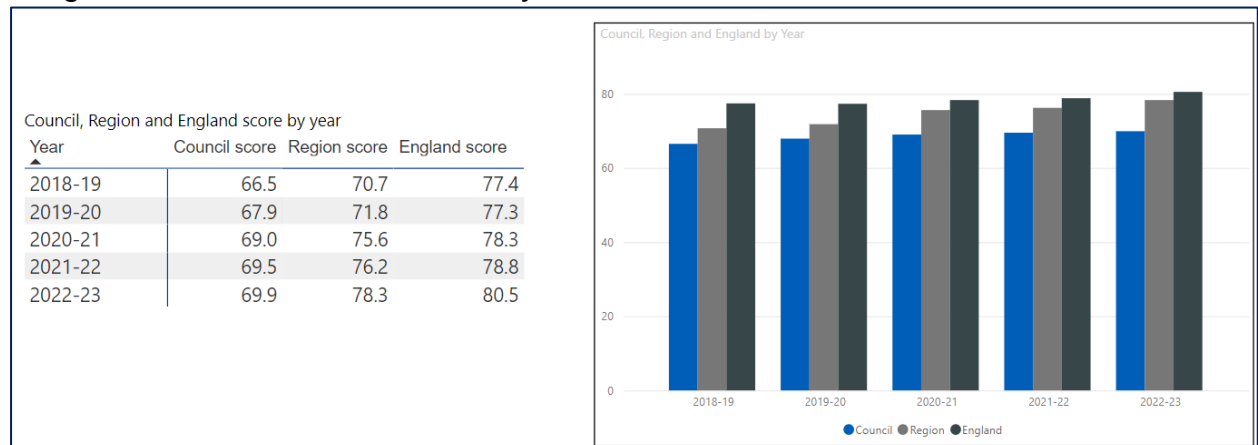
Trends in this indicator are presented in Figure 48 for Hampshire and Figure 49 for IoW.

Figure 48: Trend in the percentage of Hampshire service users with a learning disability living in their own home or with family



Source: NHS England Measures from the Adult Social Care Outcomes Framework (ASCOF), 2022-23

Figure 49: Trend in the percentage of IOW service users with a learning disability living in their own home or with family



Source: NHS England Measures from the Adult Social Care Outcomes Framework (ASCOF), 2022-23

This helps to highlight the importance of a home being more than a roof over your head. The quality of a home and wider community is a core determinant of health and wellbeing and should be considered further when supporting adults with learning disabilities.

5. Access to Services

5.1 Health

5.1.1 GP Learning Disability Friendly Practices or PCNs

Learning Disability Friendly GP practices or Primary Care Networks (PCNs) are GP surgeries/PCNs that are trained to support people with learning disabilities in different ways. Accreditation of this status is by achieving criteria such as ensuring a Learning Disability Champion, the surgery is person centred, reasonable adjustments are offered as appropriate, good quality Learning Disability Annual Health Checks are offered, and service users have a Health Check Action Plan in place after their Annual Health Check. An estimated 47 GP practices are accredited as GP learning disability friendly practices across the HIOW ICS with plans to roll out this initiative further.

5.1.2 The GP Learning Disability Register

The GP learning disability register consists of a record of patients known to have a learning disability maintained by GP practices. The register enables practices to deliver dedicated care and support to people with a learning disability. Once on the learning disability register people with a learning disability receive reasonable adjustments, including longer appointments especially for cancer screening and vaccinations that improves uptake, easy read information, support with making decisions, as well as invitations for an annual health check, flu and COVID-19 vaccinations and screening programmes. Information about people with a learning disability is sourced from learning disability teams, social care services and self-referrals of eligible people, then specifically coded onto the register. However, the register is incomplete with three quarters of people with a learning disability not registered and missing out on their entitlement to vital checks and support. Maintenance of a learning disability register is incentivised in the national Quality Outcome Framework (QOF). Access on to the register and increased registration must be prioritised across the system, possibly through awareness raising campaigns, especially among underrepresented communities. In June 2024, a record of 8,602 patients aged 14 and over with learning disabilities were identified and maintained on GP learning disabilities registers in HIOW ICB and 3,327 in Frimley ICB.

5.1.3 The Annual Health Check

The Annual Health Check covers a range of issues relating to general physical and mental health as well as monitoring any specific previously diagnosed conditions in people with a learning disability. It provides an opportunity for GPs to provide lifestyle

advice to improve health and prevent illness⁴¹. Since 2009, general practices have been invited to participate in an optional programme to provide Annual Health Checks for people with learning disabilities aged 14 and over⁴². At the time of the needs assessment all surgeries within the HIOW ICB footprint are signed up to deliver the programme. The learning disabilities health check scheme is a [GP directly enhanced service \(DES\)](#) and is dependent on an up-to-date learning disability register that forms the basis for the health check invite. They are considered to be a key reasonable adjustment to primary care services⁴³. The programme intends to ensure that adults with learning disabilities have access to appropriate primary care and their health needs are met, identify previously undiagnosed illness and minimise the need for emergency or specialist care.

The [NHS Long Term Plan](#) set an ambition that by 2023/24, at least 75% of people aged 14 or over with a learning disability will have had an annual health check. The latest data presented below show that the two ICBs have already achieved this target. Following COVID-19's impact on services for people with a learning disability the *Government's 2022–23 Mandate to NHS England* focuses on improving the delivery of learning disability annual health checks.

Health and Care of People with Learning Disabilities 2022/23 data show that, 79.4% of people aged 14 and over on the learning disability register had an annual health check in HIOW ICB, a statistically significant increase from 68.8% in 2021/22. In Frimley ICB, this was much higher at 84.7% and also a significant increase on 2021/22 figures. Frimley ICB figures are above the England average whilst HIOW figures are either below or on par with them (see Table 16).

Table 16: Trend in the percentage of patients with a learning disability aged 14 and over who have received an annual health check in the two ICBs and England

	2018/19	2019/20	2020/21	2021/22	2022/23
HIOW ICB	64.0%	57.8%	76.2%	68.8%	79.4%
Frimley ICB	63.1%	55.2%	75.0%	78.7%	84.7%
England	59.3%	57.8%	75.2%	71.8%	79.8%

Source: NHS Digital. *Health and Care of People with Learning Disabilities, 2022/23*

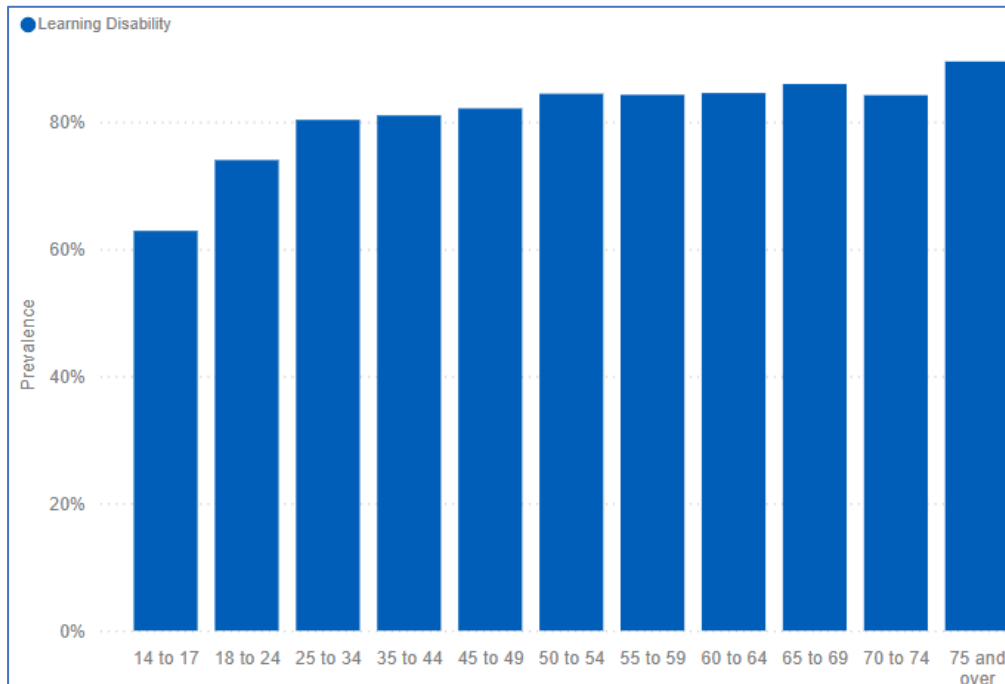
There is some variation in the percentage uptake, with the lowest uptake of 62.8% in those aged 14-17, higher and more consistent uptake in the middle age bands, followed by the highest uptake of 89.5% in the 75 and over age band as shown in Figure 50.

⁴¹ [Learning disabilities - Annual health checks - NHS \(www.nhs.uk\)](#)

⁴² Impact of the English Directly Enhanced Services (DES) for Learning Disability, Chauhan, D. Reeve, R. Evangelos, K. Hinder, S. Nelson, P. Doran, D, University of Manchester, March 2012

⁴³ [Reasonable adjustments for people with a learning disability - GOV.UK \(www.gov.uk\)](#)

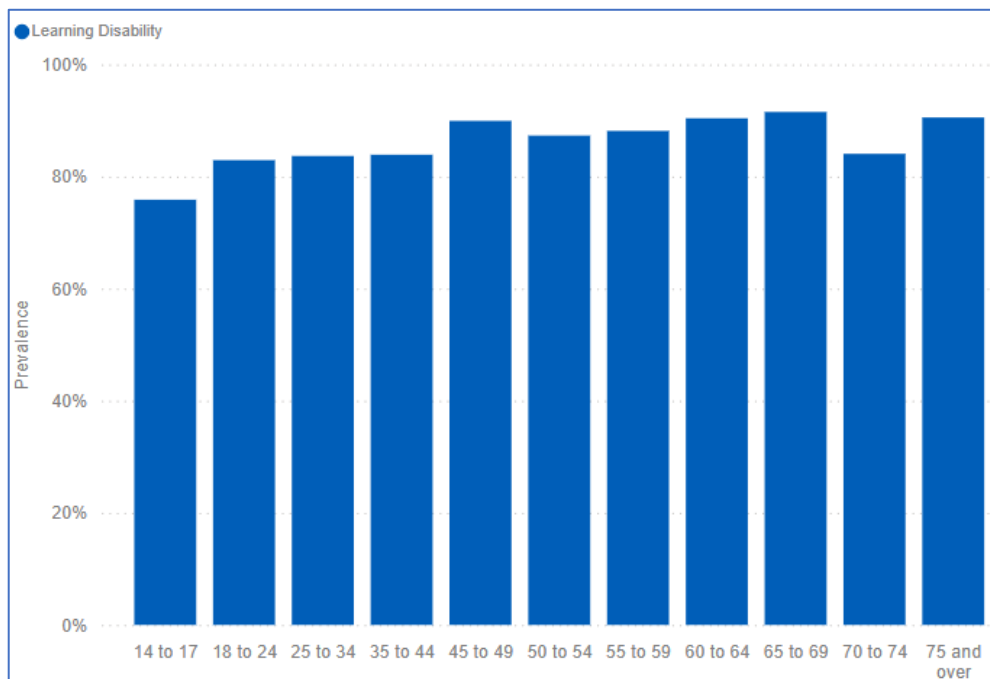
Figure 50: Percentage of patients who had a learning disability health check under the learning disabilities Enhanced Service in the last 12 months in HIOW ICB up to 31 March 2023



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

In Frimley ICB (Figure 51) there is a higher and more consistent take up of the annual check across age bands, apart from the slight drop of 84.1% the 70-74 age band. The 14-17 age band has the lowest uptake of 75.9%, and the over 75s the highest (90.5%).

Figure 51: Percentage of patients who had a learning disability health check under the learning disabilities Enhanced Service in the last 12 months in Frimley ICB up to 31 March 2023



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

A report on the impact of the programme⁴⁴ found that uptake had led to increased identification of diseases associated with QOF incentives, but the identification of other diseases or health issues was varied. As part of the Learning Disability Friendly award, practices are encouraged to participate in quality auditing for Annual Health Checks. Practices can also use the 'Quality Checking Health Checks for People with Learning Disabilities' tool⁴⁵ to self-assess. This can lead to an action plan to ensure the programme is being delivered consistently and appropriately across all GP surgeries.

A 2017 analysis compared emergency hospital admissions for adults with learning disabilities from GP practices delivering annual health checks to those that do not offer the programme. There was no difference in emergency admission rates overall but there was a significant reduction in emergency admissions for ambulatory care sensitive conditions (ACSCs), by 26%⁴⁶. ACSCs are conditions which can be managed within community care and through effective case management. This includes conditions such as asthma, diabetes, epilepsy, hypertensive disease and dementia. An emergency admission for an ACSC is 'often a sign of the poor overall quality of primary and community care'⁴⁷. Therefore, reduced hospital admissions in practices delivering the annual health check may suggest improved primary care identification and treatment of some health conditions.

5.1.4 Annual Health Check Health Action Plan

Development of 'Health Action Plans' to meet healthcare needs identified at the Annual Health Check are integral to facilitating effective delivery of healthcare services for people with a learning disability. The plan should encompass actions to improve physical and mental health (including blood tests, medicine reviews, cardiovascular checks, dental, vision and hearing assessments), preventative actions such as vaccinations, breast screening, support around diet and exercise, and follow up with specialist services if needed). The plan should include the person responsible for addressing the needs and a timeframe for their achievement. Health action plans, being an integral part of health checks, are part of the primary care contract direct enhanced services (DES).

Whilst annual health action plans are an opportunity to improve treatment of people with a learning disability, a record of a health action plan (HAP) was found for 8.8% of people with learning disabilities of the 79.4% who had a health check in HLOW ICB. Though recording was slightly better in Frimley ICB HAP uptake was still low at 11.5% of the 84.7% individuals who had an annual health check. This suggests variation in the completion and recording of action plans, and discrepancy between the number of health checks reported and action plans completed. Trends in the proportion of the population who had a HAP are presented in Table 17.

⁴⁴ [Impact of the English Directly Enhanced Service \(DES\) for Learning Disability \(networks.nhs.uk\)](https://networks.nhs.uk/impact-of-the-english-directly-enhanced-service-des-for-learning-disability)

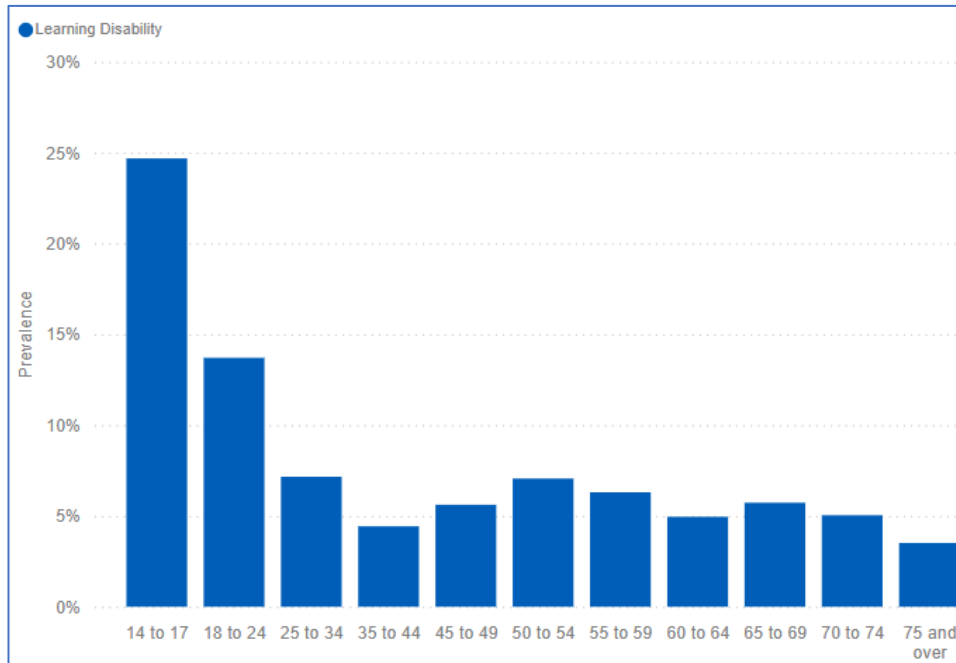
⁴⁵ [Quality checking health checks for people with learning disabilities \(publishing.service.gov.uk\)](https://publishing.service.gov.uk/quality-checking-health-checks-for-people-with-learning-disabilities)

⁴⁶ [Do health checks for adults with intellectual disability reduce emergency hospital admissions? Evaluation of a natural experiment - PubMed \(nih.gov\)](https://pubmed.ncbi.nlm.nih.gov/28111111/)

⁴⁷ [red-acsc-em-admissions-2.pdf \(england.nhs.uk\)](https://www.england.nhs.uk/red-acsc-em-admissions-2.pdf)

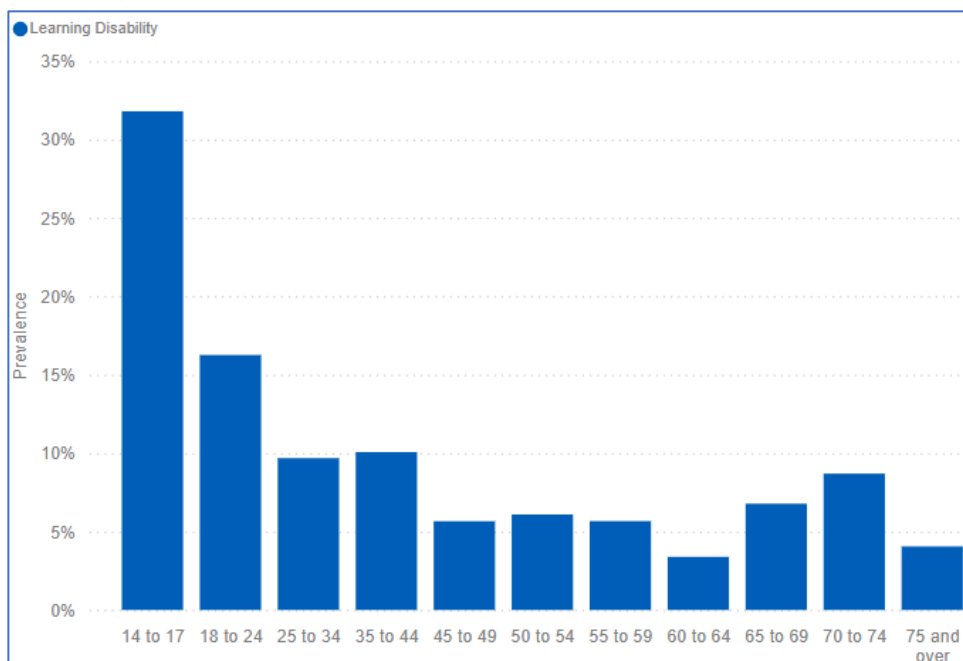
Figures 52 and 53 present HAP completion by age band for both the ICBs and show that the percentage of patients with learning disabilities who received an annual health check and have been provided with a HAP is highest among those aged 14 to 17.

Figure 52: Percentage of HIOW ICB patients with learning disabilities who received an annual health check and have been provided with a health action plan up to 31 March 2023, by age band



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Figure 53: Percentage of Frimley ICB patients with learning disabilities who received an annual health check and have been provided with a health action plan up to 31 March 2023, by age band



Source: NHS Digital. Health and Care of People with Learning Disabilities, 2022/23

Table 17: Trend in the percentage of patients with a learning disability aged 14 and over who have an action plan after an annual health check in the two ICBs and England

	2018/19	2019/20	2020/21	2021/22	2022/23
HIOW ICB	10.0%	6.3%	12.3%	9.7%	8.8%
Frimley ICB	11.1%	8.4%	12.5%	15.8%	11.5%
England	8.1%	7.2%	11.5%	11.7%	10.1%

Source: NHS Digital. *Health and Care of People with Learning Disabilities, 2022/23*

5.1.5 Health Charter

The 2017 [Health Charter for Social Care Providers](#) and associated [guidance](#) aims to support adult social care providers to improve the wellbeing of people with learning disabilities by reducing inequalities in health and social care. By signing up to the Health Charter, organisations commit to a number of pledges including:

- listening to, respecting and involving family/carers to achieve the best possible outcomes for the individual.
- providing accessible information.
- tackling over-medication by following the actions set out in an easy read version '[Stopping Over-Medication of People with a Learning Disability, Autism or Both](#)' ([STOMP](#) and [professional resources](#)).
- ensuring each person supported by that organisation, and who wants one, has a health action plan and hospital passport.

5.1.6 Hospital Passports

Hospital passports are booklets designed primarily for people with learning disabilities to take with them to hospital. The booklets contain a plethora of information about the individual such as medical information, best ways to communicate and their likes and dislikes. A person with a learning disability can complete the booklet before they go to hospital to enable staff to deliver personalised care, tailored to the individual's needs. Following Mencap's 2007 [Death by Indifference](#) report, the Sir Jonathan Michael review [Healthcare for All: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities](#) in 2008 identified the need to improve the hospital experience for people with a learning disability and recommended the use of hospital passports. Subsequently two progress reports, the 2010 [Six lives: the provision of public services to people with learning disabilities](#) and 2013 [Six Lives - Progress Report on Healthcare for People with Learning Disabilities](#), charted progress against the review. More recently, [NHS England's 2024 Health and care passports: implementation guidance and templates](#) supports integrated care systems (ICS) to review existing arrangements for health and care passports (or hospital passports) to address recommendations by the Health Services Safety Investigations Body (HSSIB), and to improve health outcomes for people with a learning disability and autistic people. Hospitals in Hampshire have hospital passports available on their website which can be downloaded. Though different hospital trusts use different styles of the hospital passport this should not have an impact on an individual's care as the details are usually very similar and the [HIOW LeDeR Annual Report 2021/22](#) documented best practice around the use of hospital passports in the HIOW system.

5.1.7 Hospital Liaison Nurses

Hospital Liaison nurses can add value to the Hospital Passport. Hospital Liaison Nurses are qualified learning disability nurses who work with hospital staff. They help people with learning disabilities who are using hospital care to get their needs identified quickly and to get the right support. The [Mazar's report](#) highlighted that these services are an important aspect of ensuring reasonable adjustments are made to make acute care a safe place for people who cannot communicate and whose behaviour can become challenging when either in pain or in a strange environment.

Qualitative research nationally has shown that hospital liaison nurses are effective and valued⁴⁸. Another national study focusing on quantitative outcomes identified that an epilepsy risk assessment was more likely to be conducted in hospitals where a learning disability liaison nurse was employed (p=0.043). There was also a non-significant trend towards greater use of a health passport, or similar (p=0.055). The study was considered underpowered which can contribute to significance not always being achieved in the latter analysis. However, there are many opportunities for Hospital Liaison Nurses to have an impact, including their role as an advocate, facilitating reasonable adjustments, mediating between services and professionals, and enhancing communication.⁴⁹ For Hampshire Hospitals, a [Hospital Liaison Team for people with learning disabilities](#) consisting of a Hospital Liaison nurse and learning disability specialist practitioner are available at Andover War Memorial Hospital, Basingstoke and North Hampshire Hospital and the Royal Hampshire County Hospital, Winchester. In Southampton, there are two nurses along with support workers that facilitate the [Hospital Liaison Team](#) at Southampton General Hospital to support hospital appointment and the transition into adult services. On the Isle of Wight there is a [Learning Disability Liaison Team](#) which consists of a Hospital Liaison Nurse and a Liaison Assistant Practitioner both who support adults with a learning disability accessing St Marys Hospital and acute mental health services. In Portsmouth hospitals the [Learning Disability Hospital Liaison Team](#) consists of two Registered Nurses for people with a Learning Disability (RNLD). Frimley Health's [Learning Disability Liaison Service](#) currently has two learning disability nurses. In Frimley Park Hospital two learning disability nurses work in the [Liaison Team](#). Learning disability mortality reviews in the [HIOW LeDeR Annual Report 2021/22](#) identified the positive impact the hospital learning disabilities liaison teams make on supporting in-patient stays for people with a learning disability in the acute hospital setting. The teams also support staff in the acute setting to consider and make reasonable adjustments and where available, use of hospital passports.

In September 2023, NHS England launched the [Reasonable Adjustment Digital Flag](#) for use by health and care professionals to indicate reasonable adjustment requirements for a person with learning disability and promote tailored and personalised care. Organisations need to ensure the tool is more widely implemented across the system.

⁴⁸ <https://www.ncbi.nlm.nih.gov/books/NBK259497/>

⁴⁹ <http://bmjopen.bmj.com/content/6/4/e010480>

5.1.8 Learning Disability Training in health and care

Training on Learning Disability and Autism was mandated in the [Health and Care Act 2022](#) to make sure everyone working in health and care has training to help them understand the needs of people with a learning disability and autistic people with recommendation of the '[Oliver McGowan Mandatory Training](#)' training programme. As of August 2024, 81% of eligible staff in the had completed the training.

5.1.9 Learning Disability Access Keyworker

The Learning Disability and Autism Programme is a national programme that has been developed in response to the NHS Long Term commitment that by 2023/24, children and young people who are autistic, have a learning disability, or both, with complex needs have a designated keyworker. Funding is provided centrally to Integrated Care Boards to deliver this service. Children and young people are referred via the Dynamic Support Register (DSR). The service aims to provide sensitive and appropriate support to all eligible children and young people.

5.2 Adult Social Care

It is suggested that only a minority of adults with learning disabilities will be in contact with local social care services. Researchers estimated that approximately 25% of all people with learning disabilities in a local area would be known to services⁵⁰. However, this is higher on the Isle of Wight, where adults social care support approximately 50% of those identified in GP practice figures.

Adults with learning disabilities supported by social care would primarily be those with profound or severe learning disabilities or those with complex health and social care needs. Those with mild or moderate learning disabilities are often supported by families, friends and social networks, although may be supported by the local authority for aspects like employment, housing or day opportunities. The needs of all people with a learning disability must be considered during the planning and commissioning of mainstream and specialist health and social care services.

Adult social care services provide support to people who may need help with tasks of everyday living. This can range from practical support in the home (including supported living), advocacy services or residential care for people who cannot live independently, with further resources highlighted in the [Connect to Support Learning Disabilities](#) section. [Who can get help from Adults' Health and Care](#) is an easy read publication on support that is available to Hampshire residents who meet the nationally set eligibility criteria. This means people get the same access to support wherever they live, ensuring there is a fair, transparent and consistent methodology to determine who is eligible for support.

⁵⁰ Emerson,E and Hatton,C. Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England. Institute for Health Research, Lancaster University: Lancaster, 2004.

As of October 2023, there were 324 clients aged 65 or over with a current provision of support from Hampshire County Council’s learning disabilities services. There may be an additional number of people with learning disabilities receiving support from Hampshire County Council but where their primary need may be a physical disability or more specialised support for older adults, and not included in this figure. An additional number receive occasional respite support but otherwise live without social care services are also not included in the number receiving support. About 50.7% of those aged 18-64 receiving long term support in the year had a primary support reason of learning disability

Support can be either short term or long term. Short term care is provided as a means of rehabilitation, such as when a person needs extra help for a short period of time after leaving hospital. Long term care can include support for an individual to live independently in their own home or can include residential care where a persons’ needs cannot be met through other means. The data in Figure 29 sets out the types of long-term support people receive from Hampshire County Council.

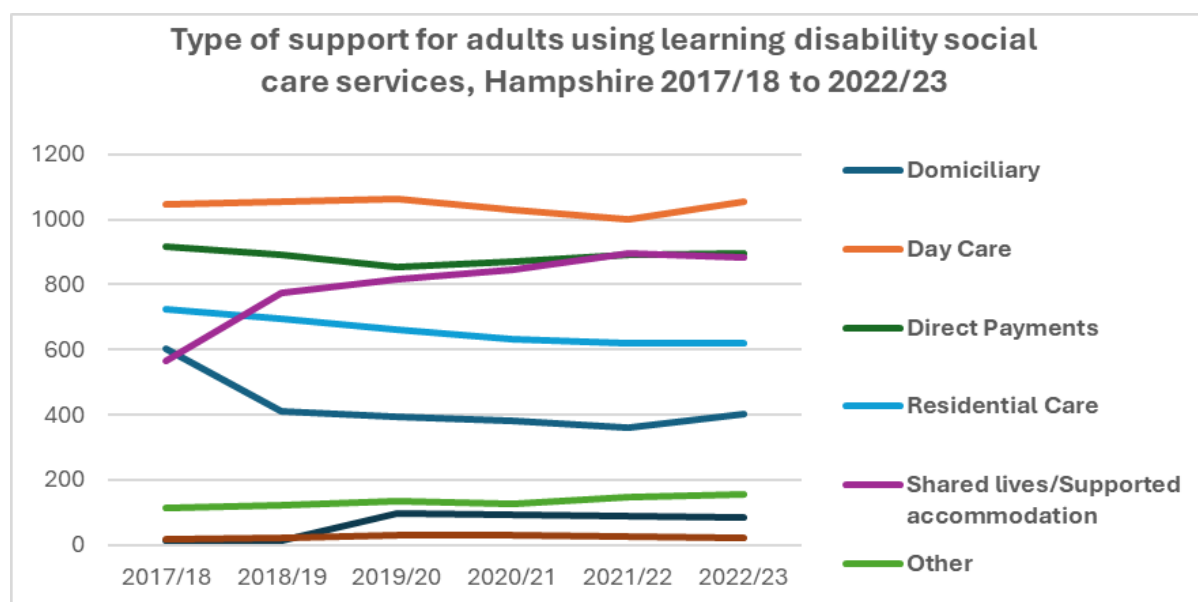


Figure 29: Use of long-term social care for adults with learning disabilities in Hampshire between 2017/18 and 2022/23

Note: part of the respective decrease / increase in supported accommodation and domiciliary care service between 2017/18 and 2018/19 relates to commissioning activities and a change in recording for each individual the commissioned shared support for instance.

To support adults with a learning disability who are accessing social care, teams identify services, clubs or activities in the individual’s community that can help them to live longer, happier and healthier lives, and prevent the need for increased care and support.