



# **Health Needs Assessment of Adults with Learning Disabilities in Hampshire**

## Version Control

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## Executive Summary

Adults with learning disabilities can be considered to be one of the most vulnerable groups in society and inequalities in care can lead to increased premature deaths. However, improving the lives of adults with learning disabilities has become 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 that they experience.

This health needs assessment reviews the health and care of adults with learning disabilities in Hampshire. The objectives are to:

- set out the prevalence of learning disability in adults in Hampshire
- define the risk factors that contribute to premature death
- understand the access to care and support for adults with learning disabilities
- provide a summary of need to enable appropriate strategies and interventions to be put in place.

Overall, 0.4% of the Hampshire population have a learning disability. There is a significant gap in the life expectancy for people with learning disabilities compared to the general population in Hampshire: 18 years in females and 14 years in males. However, there has been an increase in life expectancy in people with learning disabilities over time.

As people with learning disabilities are now living longer there has been an increase in the prevalence in dementia. Dementia can also affect people with a learning disability at a much younger age. For example, it is estimated that 1 in 50 people with Down's syndrome will develop dementia in their 30's and this rises to more than half when an individual reaches 60 years of age and over.

The three most common causes of death for people with learning disabilities in England were circulatory diseases (22.9% of deaths), respiratory diseases (17.1%) and neoplasms (cancers) (13.1%). Other causes of death that are potentially preventable include epilepsy (3.9% of deaths) and aspiration pneumonitis (3.6% of deaths). These are explored in more detail at a local level: generally, these conditions are diagnosed in people with learning disabilities at a much younger age than people without a learning disability.

It is important to ensure that people with learning disabilities can lead healthy lifestyles and are empowered to make healthy choices to minimise preventable conditions. For example, there is an increased prevalence of circulatory disease during early adulthood in people with learning disabilities. This may be due to an accumulation of lifestyle factors, such as poor diet and lack of physical activity, which are apparent throughout life. It is important to address these lifestyle factors to reduce the risk of circulatory disease.

As well as specific health conditions, there is inequality in access to the social determinants of health which enable people with a learning disability to lead healthier lives. This includes housing, employment and income. A local initiative, the Right to Work, has shown to reduce this inequality and can be built on more widely across Hampshire to share best practice.

There have been improvements in access to services for people with learning disabilities. The employment of hospital liaison nurses has been shown to improve care for some people with learning disabilities and improvements in technology have enabled people to stay independent for longer. The use of direct payments has increased overtime, which may demonstrate that people with learning disabilities who use social care are now more likely to manage their own care and spend money on the support they feel they need most, in a way which is suitable for their individual needs.

Overall, there have been improvements to the health and care of people with learning disabilities but the recommendations from this health needs assessment are provided to continue the improvements and direct focus to the areas of health and care that are needed most for people with learning disabilities.

Recommendations:

- Organisations to take a multiagency approach to reporting and learning from deaths of people with learning disabilities through the Learning Disability Mortality Review Programme (Leder).
- Continually develop the workforce supporting people with learning disabilities to recognise the early indication of ill health in adults with learning disabilities and to be able to act on this as appropriate.
- Organisations to review their workforce development programmes to enable paid and unpaid carers to help individuals to make healthier lifestyle choices including: diet, exercise, oral health, sexual health and screening uptake, with Making Every Contact Count included.
- Continue to embed Making Every Contact Count and the strength-based approach at all ages to promote independence.
- Review current commissioned behaviour change services to ensure they meet the needs of people with learning disabilities.
- Organisations to promote parity of esteem.
- Ensure adults with learning disabilities and their carers know where to access support for timely diagnosis of dementia and onward care.
- Ensure all adult social care providers sign up to the Health Charter to advocate for improved care of people with learning disabilities, which includes the provision of hospital passports for those who want it.
- Conduct the Public Health England Annual Health Check audit to analyse where support is needed to continually improve the effectiveness of the programme.
- Explore the use of social care services in the population by ethnic group to assess if services are meeting the expected level of need in BME communities.

- Ensure strategies are in place across the organisations supporting adults with learning disabilities to cater for the level of need as the population of adults with learning disabilities ages.

## 1. Introduction

Adults with learning disabilities face vulnerabilities from health inequalities and social exclusion, due historically embedded stigmatisation. Due to inequalities in care provision, adults with learning disabilities can have unidentified or untreated health conditions, which leads to increased premature mortality.

Improving the lives of adults with learning disabilities has become a national priority. Recent national reviews of the health and care of people with learning disabilities demonstrate significant inequalities. There have been improvements in the care of individuals with learning disabilities and as a result, the life expectancy has gradually increased. However, there are still significant differences between the life expectancies of adults with learning disabilities and the general population. This can be due to increased health needs, poorer access to services and fewer opportunities to benefit from the wider determinants of health.

Following national reviews, NHS England has launched a National Learning Disability Mortality Review programme to identify common themes in mortality and gaps in care provision. This health needs assessment explores the results from the national reviews in more detail at a local level to enable a better understanding of the needs in service provision for the future. It also 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*

This needs assessment investigates the health, wellbeing and causes of mortality in adults with learning disabilities in Hampshire. The report includes adults with learning disabilities (aged 18 and over) who are resident or registered with a GP within Hampshire, living in the community or in residential care (run by the local authority and other providers).

This report sets out information on the need and demand for health and social care services for people with learning disabilities to ensure they can live long, healthy and independent lives. The recommendations aim to support the strategic planning and development of services and support for people with learning disabilities in Hampshire.

The objectives of the health needs assessment are to:

- set out the prevalence of learning disability in adults in Hampshire
- understand the access to care and support for adults with learning disabilities
- investigate the risk factors that contribute to premature death
- provide a summary of need to enable appropriate strategies and interventions to be put in place.

This health needs assessment investigates learning disabilities, which does not include learning difficulties, as described in the 'Definition of Learning Disability' section. This needs assessment does not cover individuals specifically with autism, although there may be some similarities in their needs.

For information on the health needs of children with special educational needs, please see the following document <http://documents.hants.gov.uk/public-health/2017-07-17JSNA-ChildrenwithSpecialEducationalNeedsandDisabilities.pdf>

## 1.2 Definition of Learning Disability

A learning disability occurs when one or many factors affect a part of the brain. Some children are born with learning disabilities. This can be caused from genetic factors or chromosomal conditions (such as Down's syndrome), illness and complications during pregnancy or birth, or events during pregnancy such as drinking alcohol and smoking. Sometimes there is no known cause<sup>1</sup>.

There is not a universally accepted definition of a learning disability. The NHS<sup>2</sup> and the national Valuing People strategy of 2001<sup>3</sup> 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 focused on people with 'complex needs', a term used to describe a range of multiple and additional needs that people with learning disabilities may have. This can include people whose behaviour presents a challenge<sup>4</sup>.

The terms learning disability and learning difficulty are sometimes used interchangeably. In education settings, learning difficulty is a broader term which includes conditions such as dyslexia and dyscalculia. Unlike a learning disability, a learning difficulty does not affect an individual's intellect<sup>5</sup>.

People with a learning disability have an impaired intellectual functioning, resulting in an IQ of below 70<sup>6,7</sup>. It is reported across the NHS<sup>8</sup> and other organisations<sup>9,10</sup> that there are four classifications of a learning disability:

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

People with severe or profound learning disabilities will 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<sup>11,12</sup>.

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<sup>1</sup> <https://www.nhs.uk/livewell/childrenwithlearningdisability/pages/whatislearningdisability.aspx>

<sup>2</sup> [http://www.datadictionary.nhs.uk/data\\_dictionary/nhs\\_business\\_definitions/l/learning\\_disability\\_de.asp?shownav=1](http://www.datadictionary.nhs.uk/data_dictionary/nhs_business_definitions/l/learning_disability_de.asp?shownav=1)

<sup>3</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/250877/5086.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf)

<sup>4</sup> [http://webarchive.nationalarchives.gov.uk/20130105064234/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_093375.pdf](http://webarchive.nationalarchives.gov.uk/20130105064234/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf)

<sup>5</sup> <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>

<sup>6</sup> <https://www.ncbi.nlm.nih.gov/books/NBK332877/>

<sup>7</sup> <http://www.bild.org.uk/resources/faqs/>

<sup>8</sup> <https://www.nhs.uk/livewell/childrenwithlearningdisability/pages/whatislearningdisability.aspx>

<sup>9</sup> <https://nadh-uk.org/wp-content/uploads/2015/02/QCF-intro-to-LD-sample.pdf>

<sup>10</sup> <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>

<sup>11</sup> <https://www.nhs.uk/livewell/childrenwithlearningdisability/pages/whatislearningdisability.aspx>

<sup>12</sup> <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>

## 2. National Context

In 2009, the UK Government launched the three year strategy 'Valuing People Now'<sup>13</sup>. The strategy took an approach to set out the fundamental principle that people with learning disabilities have the same human rights as everybody else. The strategy set out 15 key objectives, building on the 2001 strategy 'Valuing People'. The objectives focused on creating more choice, confidence and control for people with learning disabilities in order to live as independently as possible, as equal citizens in society. The Valuing People Now strategy has since been archived, an updated strategy is yet to be released.

Although there is an absence of a recent national strategy, there are national programmes aimed at improving the health of people with learning disabilities. A strand of NHS England's Learning Disability programme is the Learning Disability Mortality Review (LeDeR)<sup>14</sup>. The programme aims to review the deaths of people with learning disabilities to understand the circumstances that lead to a death. This can then inform areas for improvement and new ways of working to prevent similar situations reoccurring. The Wessex region has been a pilot area for the LeDeR programme. Information about the findings to date can be found in the Health and Wellbeing section of this health needs assessment.

NHS England also launched a transforming care programme in 2015, aiming to improve health and care services so that more people with a learning disability can live in the community, with the right support, and close to home. This includes closing in-patient centres and creating more community services. The closure of in-patient services can help to improve quality of life, as community integration offers the opportunity to access activities, employment and social networks. For Hampshire, a programme is being led by the Southampton, Hampshire, Isle of Wight and Portsmouth (SHIP) Transforming Care Partnership (TCP)<sup>15</sup>. The main aims of the SHIP TCP are to:

- Develop learning disability liaison services in hospitals.
- Expand the intensive support team to provide a service to people aged 14-18.
- Develop a community service for people who have been in contact with the criminal justice system or are at risk of doing so.
- Increase the offer and uptake of personal budgets.
- Increase the number of annual health checks in GP practices.

The health of adults with learning disabilities has improved over the last 30 years<sup>16</sup> and this has been demonstrated through increased life expectancy<sup>17</sup>. However, it is widely acknowledged that they still have poorer health than the general population, a shorter life expectancy and an increased risk of premature death<sup>18</sup>. A review conducted by Mencap established a lack of compliance with the Equality Act, the Mental Capacity Act and of Duty

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<sup>13</sup> [http://webarchive.nationalarchives.gov.uk/20130105064234/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_093375.pdf](http://webarchive.nationalarchives.gov.uk/20130105064234/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf)

<sup>14</sup> <http://www.bristol.ac.uk/sps/leder/>

<sup>15</sup> <https://www.england.nhs.uk/learning-disabilities/tcp/south7/#southampton>

<sup>16</sup> Hardy S. et. Al. Meeting the health needs of people with learning disabilities: RCN guidance for nursing staff. Royal College of Nursing: London (May 2011)

<sup>17</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/613182/PWLDIE\\_2015\\_main\\_report\\_NB090517.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf)

<sup>18</sup> Turner S. & Robinson C. Health Inequalities and People with Learning Disabilities in the UK: 2011 Implications and actions for commissioners of Social Care. Evidence into practice report no. 1 (revised). Improving Health & Lives Learning Disability Observatory & National Development Team for Inclusion: London (Nov 2011)

of Care<sup>19</sup>. There have also been five primary reasons identified for health inequalities experienced by adults with learning disabilities<sup>20</sup>:

1. Increased risk of health problems associated with specific genetic, biological and environmental causes of learning disabilities.
2. Personal health risks and behaviours such as poor diet and lack of exercise.
3. Greater risk of exposure to social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness.
4. Communication difficulties and reduced health literacy
5. Deficiencies relating to access to healthcare provision.

All of the above can impact on quality of life and are intertwined in a complex relationship. Factors that are important to quality of life for people with learning disabilities include: being healthy, being respected, having a purpose, having relationships and having choice<sup>21</sup>. Choosing a healthy lifestyle can be difficult for many people but it can be even more challenging for an individual with a learning disability.

Many people with learning disabilities have limited choice. Those who do make choices should have an understanding of the impact their choices will have. This may be time-consuming for health professionals and carers but it is important to be respected. Some choices will involve an element of risk, and these must be supported or honoured appropriately<sup>22</sup>. Choices made on someone's behalf should be made in that persons best interest, following the Mental Capacity Act<sup>23</sup>. These should be based on the individuals' likes and dislikes, and not solely on the views or opinions of the decision maker.

### **3. Local Context**

#### *3.1 Demography*

Due to the inconsistencies in definitions of a learning disability and the challenge of integration of data systems, there is no central register of people with a learning disability across health and social care. This means that it can be difficult for service commissioners to understand the level of need in their population.

The most reliable source of data is the GP Learning Disability register within the Quality Outcome Framework (QoF). It is widely acknowledged that the QoF learning disability register still represents an underestimate of the actual numbers of people with learning disabilities<sup>24</sup>. Those on the QoF learning disability register may not be known to social care, and vice versa. There will also be a proportion of people who are not known to NHS or social care services who have a self-reported learning disability. It is likely that those who have a self-reported learning disability would have a lower level of need.

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<sup>19</sup> <https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%202074%20deaths%20and%20counting.pdf>

<sup>20</sup> Turner S. Health Inequalities and People with Learning Disabilities in the UK: 2011 Implications and actions for commissioners and providers of social care Evidence into practice report no. 4. Improving Health & Lives Learning Disability Observatory & National Development Team for Inclusion: London (Nov 2011)

<sup>21</sup> <https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/q/quality-life>

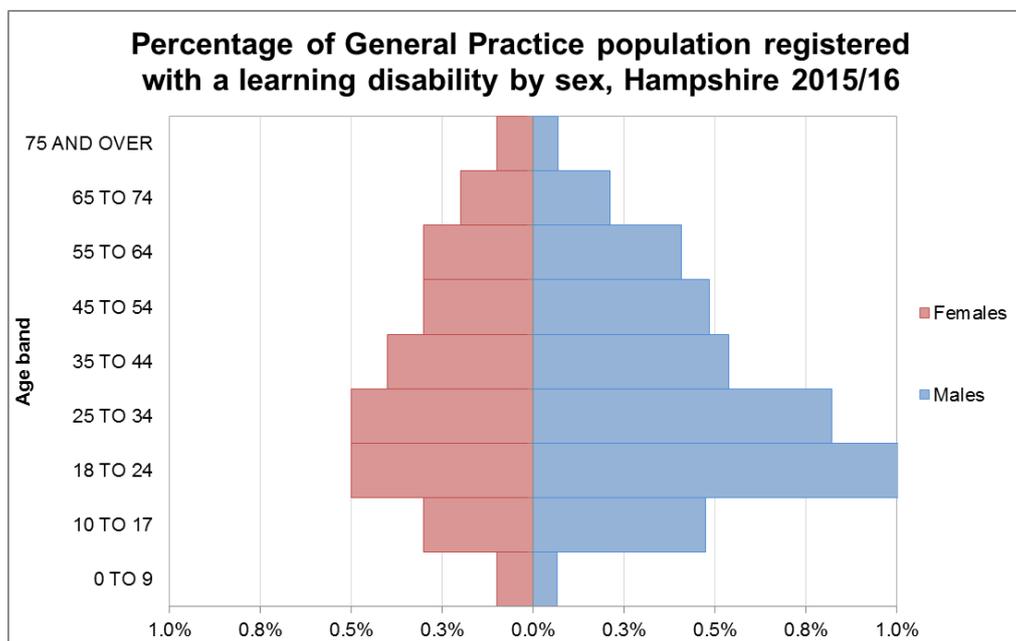
<sup>22</sup> <https://www.mentalhealth.org.uk/learning-disabilities/publications/choice-people-learning-disabilities-and-high-support-needs>

<sup>23</sup> <https://www.gov.uk/make-decisions-for-someone/making-decisions>

<sup>24</sup> [http://www.improvinghealthandlives.org.uk/uploads/doc/vid\\_11422\\_IHAL2011-06-NHSDDataGaps.pdf](http://www.improvinghealthandlives.org.uk/uploads/doc/vid_11422_IHAL2011-06-NHSDDataGaps.pdf)

Figure 1 displays a population pyramid using the GP practice learning disability register, as defined by QoF, to demonstrate the estimated prevalence of people with learning disabilities in Hampshire, by age band and sex.

Figure 1: Prevalence of learning disabilities in Hampshire by age band and sex, 2015/16<sup>25</sup>



Overall, 0.4% of the Hampshire population have a learning disability, equating to 3,922 people based on the 2015/16 registered population<sup>26</sup>. The highest percentage of the population with a learning disability is in the 18 to 24 year age group. Males in this age group have the highest prevalence of all categories. There is a very low prevalence in the youngest age group. It is expected that this is an underestimate as learning disabilities are often not identified in many children until after they start school and may not be recorded by the GP until substantially later than this. Rates begin to drop more over the age of 60, and this is likely to be due to premature deaths in people with learning disabilities.

### 3.2 Population Forecast

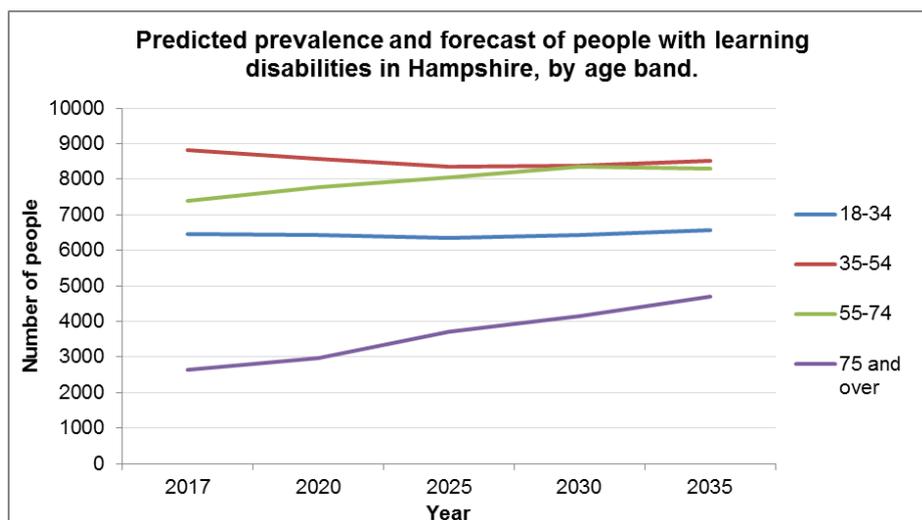
In Hampshire, the whole population is increasing and ageing. The population of people with learning disabilities is set to increase too. Population forecasts up to 2035 for people with learning disabilities have been estimated using ONS population figures and prevalence rates of learning disability reported by Emerson et al<sup>27</sup>. The rates are adjusted for ethnicity and mortality. Figure 2 presents data for the whole Hampshire population with a learning disability, and Figure 3 presents data for those in Hampshire with a severe or profound learning disability, who are more likely to require higher levels of health and social care.

<sup>25</sup> <http://digital.nhs.uk/catalogue/PUB23781>

<sup>26</sup> <http://digital.nhs.uk/catalogue/PUB23781>

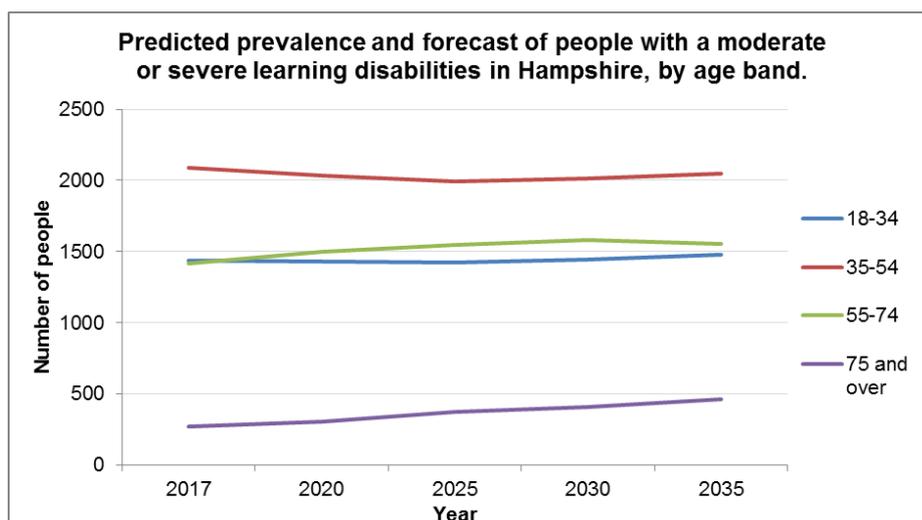
<sup>27</sup> Emerson, E and Hatton, C. Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England. Institute for Health Research, Lancaster University: Lancaster, 2004.

Figure 2: Predicted prevalence and forecast of people with a learning disability, Hampshire



Source: Projecting Older People Population Information System (POPPI)

Figure 3: Predicted prevalence and forecast of people with a severe and moderate learning disability, Hampshire



Source: Projecting Older People Population Information System (POPPI)

The predicted increase of older people (aged 75 and over) in Hampshire overall has also been reflected in adults with learning disabilities, as can be seen in figures 2 and 3. The improvement in access and supply of health and social care services can contribute to this increase. As the population of people with learning disabilities ages, there is the potential for increased demand on support services. The National Institute for Health and Care Excellence recently published guidelines on the care and support of people growing older with learning disabilities, April 2018<sup>28</sup>, which can aid organisations to identify, plan and deliver services to support individuals with learning disabilities as they age.

<sup>28</sup>[https://www.nice.org.uk/guidance/NG96?utm\\_campaign=9378944\\_SCIELine%2019%20Apr%2018&utm\\_medium=email&utm\\_source=SCIE&utm\\_sfid=003G000002gjycPIAQ&utm\\_role=&dm\\_i=4O5,5L0U8,OMKZEV,LOT4V,1](https://www.nice.org.uk/guidance/NG96?utm_campaign=9378944_SCIELine%2019%20Apr%2018&utm_medium=email&utm_source=SCIE&utm_sfid=003G000002gjycPIAQ&utm_role=&dm_i=4O5,5L0U8,OMKZEV,LOT4V,1)

### 3.3 Ethnicity

A national cross-sectional survey in 2010<sup>29</sup> of intellectual and developmental disabilities in children aged 7 to 15 years found that Black and Minority Ethnic (BME) status was generally associated with lower rates of 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 this increased 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 deprivation<sup>30</sup>.

The majority of Hampshire's population is White British, however ethnic diversity is increasing. The 2011 Census data shows there are some districts with a higher rate of ethnic groups associated with an increased risk of learning disabilities, compared to the Hampshire average. These are highlighted in yellow in table 1.

Table 1: Percentage of residents from BME Groups associated with higher prevalence of LD by Hampshire District.

Area code	Area name	Persons (%)				
		Asian/ Asian British: Indian	Asian/ Asian British: Pakistani	Asian/ Asian British: Bangladeshi	Asian/ Asian British: Other Asian	White: Gypsy or Irish Traveller
E07000084	Basingstoke and Deane	1.5	0.2	0.2	1.4	0.1
E07000085	East Hampshire	0.4	0.0	0.1	0.7	0.2
E07000086	Eastleigh	1.6	0.1	0.2	0.6	0.2
E07000087	Fareham	0.6	0.1	0.1	0.3	0.1
E07000088	Gosport	0.5	0.0	0.2	0.3	0.0
E07000089	Hart	1.0	0.2	0.1	0.9	0.3
E07000090	Havant	0.4	0.1	0.1	0.3	0.1
E07000091	New Forest	0.3	0.0	0.1	0.4	0.2
E07000092	Rushmoor	1.4	0.7	0.2	7.6	0.2
E07000093	Test Valley	0.8	0.1	0.1	0.6	0.1
E07000094	Winchester	0.6	0.1	0.2	0.8	0.2
<b>E10000014</b>	<b>Hampshire</b>	<b>0.8</b>	<b>0.1</b>	<b>0.2</b>	<b>1.1</b>	<b>0.2</b>
E12000008	South East	1.8	1.1	0.3	1.4	0.2
E92000001	England	2.6	2.1	0.8	1.5	0.1

Source: Census 2011

The prevalence of people within these BME groups is generally lower in Hampshire than the regional and national averages. The only exception is the prevalence of the Gypsy or Irish Traveller community which is greater than the national average (0.2% in Hampshire compared to 0.1% nationally). Although the prevalence is higher than the national average, overall it only represents a small number of people (2,721).

<sup>29</sup> Emerson, E., Deprivation, ethnicity and the prevalence of intellectual and developmental disabilities. Journal of Epidemiology and Community Health, 2010.

<sup>30</sup> Mir, G., Nocon, A., Ahmad, W., et al (2001) Learning Difficulties and Ethnicity. London: Department of Health.

There can be specific difficulties for people with learning disabilities from BME groups, particularly in more rural areas where small numbers could make them less visible to services and even more vulnerable to social isolation<sup>31</sup>. Access to accurate information on the number of people with learning disabilities from different BME communities is vital to ensure that sufficient and appropriate services can be planned, commissioned and provided.

**Recommendations:**

- Explore the use of social care services in the population by ethnic group to assess if services are meeting the expected level of need in BME communities.
- Ensure strategies are in place across the organisations supporting adults with learning disabilities to cater for the level of need as the population of adults with learning disabilities ages, in line with NICE guidelines.

## **4. Health and Wellbeing**

### *4.1 Life Expectancy and Mortality*

Approximately 450,000 deaths are reported each year in England. It is expected that around 3,000 of these deaths would be from people whose GP identifies them as having a learning disability. However, only approximately 1,000 death certificates were indicative of a learning disability in 2014/15<sup>32</sup>. For some it is clearly stated but for others it could be identified from a diagnosis such as Down's syndrome. Although there is an incomplete picture of deaths of individuals with learning disabilities, analysis can be undertaken on what is known.

Between 2001 and 2014, the median age of death in men and women with learning disabilities increased (from 52 to 60 years in men and 53 to 58 years in women)<sup>33</sup>. Unlike the overall population, men with learning disabilities live slightly longer than women with learning disabilities. The difference in the median age of death between those with learning disabilities and the general population has slowly decreased, yet as established in the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) report there is still a stark difference. On average, females with a learning disability have a life expectancy of 18 years younger than females without a learning disability. In males, the difference is 14 years<sup>34</sup>. Applying these figures to the Hampshire population, the estimated life expectancy for a female with a learning disability would be 66 years and 67 years for males. The overall life expectancy in Hampshire for females is 84 years and 81 years in males<sup>35</sup>.

A relatively new dataset provides further information on mortality by area. Data is collated by NHS Digital from a sample of GP surgeries to provide an overview of the health and care of people with learning disabilities. In Wessex, there was a statistically significant increase in the crude death rate for people with a learning disability between 2014/15<sup>36</sup> and 2015/16<sup>37</sup>.

<sup>31</sup> Learning Difficulties and Ethnicity: Updating a Framework for Action. Foundation for People with Learning Disabilities and Department of Health: London (2012).

<sup>32</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/613182/PWLDIE\\_2015\\_main\\_report\\_NB090517.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf)

<sup>33</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/613182/PWLDIE\\_2015\\_main\\_report\\_NB090517.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf)

<sup>34</sup> <http://www.content.digital.nhs.uk/catalogue/PUB22607/Health-care-learning-disabilities-2014-15-summary.pdf>

<sup>35</sup> <https://fingertips.phe.org.uk/search/life%20expectancy#page/0/qid/1/pat/6/par/E12000008/ati/102/are/E06000036>

<sup>36</sup> <http://digital.nhs.uk/catalogue/PUB22607>

<sup>37</sup> <https://digital.nhs.uk/catalogue/PUB23781>

Wessex was the only sub-region to show a significant increase and the rise was predominantly due to deaths in Hampshire and Southampton. Although data is based on small numbers and only represents a sample of deaths in Hampshire, the doubling of deaths (30 to 57) over this period is concerning. Data for 2016/17<sup>38</sup> has shown a non-statistically significant decrease in the crude rate of death (57 deaths in 2015/16 and 42 deaths in 2016/17).

To enable a more robust analysis, three years of data can be combined and compared to England. Data for 2014/15 to 2016/17 does not show a significant difference in the crude rate of death between Hampshire and England<sup>39</sup>. It is important to implement long-term monitoring of deaths on a multi-agency basis to analyse trends in deaths, such as contributing to the Learning Disability Mortality Review<sup>40</sup>. It is recommended this is completed on a three year rolling average to counteract the variability in small numbers.

A confidential inquiry into the premature deaths of people with learning disabilities was conducted to examine deaths between 2010 and 2014. 42% of deaths reviewed by an overview panel were assessed as being premature. The most common reasons were: delays or problems with diagnosis or treatment, problems with identifying needs and providing appropriate care in response to changing needs, and not implementing reasonable adjustments<sup>41</sup>. More locally, the Mazar's review identified that people with learning disabilities who were being cared for in residential care settings had health professionals visiting for care. However, it was highlighted that there was still a need for identifying and managing the early signs of deterioration and a prompt response by the care home or service team<sup>42</sup>.

The Learning Disabilities Observatory conducted a joint study on the mortality of 664 people with learning disabilities in England between 2010 and 2014<sup>43</sup>. The three most common causes of death for people with learning disabilities were circulatory diseases (22.9% of deaths), respiratory diseases (17.1%) and neoplasms (cancers) (13.1%). In comparison to what would be expected from the general population, there were 2.8 times the expected number of deaths from circulatory diseases and 4.9 times the number of deaths from respiratory diseases in people with learning disabilities. The number of cancer deaths was close to the expected figure, although the profile of cancer types was distinctly different with an unexpectedly high number of deaths from colorectal cancer<sup>44</sup>. The Learning Disabilities Observatory report suggested that other causes of death that are potentially preventable included epilepsy (3.9% of deaths) and aspiration pneumonitis (3.6% of deaths)<sup>45</sup>. In addition, the Learning Disability Mortality review programme identified that pneumonia (16%) and sepsis (11%) were underlying causes of death in a significant number of cases<sup>46</sup>.

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

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<sup>38</sup> <http://digital.nhs.uk/catalogue/PUB30167>

<sup>39</sup> <http://digital.nhs.uk/catalogue/PUB30167>

<sup>40</sup> <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>

<sup>41</sup> <http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>

<sup>42</sup> <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>

<sup>43</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/613182/PWLDIE\\_2015\\_main\\_report\\_NB09051\\_7.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB09051_7.pdf)

<sup>44</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/613182/PWLDIE\\_2015\\_main\\_report\\_NB09051\\_7.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB09051_7.pdf)

<sup>45</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/613182/PWLDIE\\_2015\\_main\\_report\\_NB09051\\_7.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB09051_7.pdf)

<sup>46</sup> <https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2017/#.Wz32y9GWyig>

## 4.2 Circulatory disease

Circulatory disease was the most common cause of death in individuals with learning disabilities between 2010 and 2014. Circulatory disease is an umbrella term to describe diseases affecting the heart and connecting blood vessels<sup>47</sup>. In 2015/16 data from a sample of GP practices in Hampshire on the prevalence of diseases of the circulatory system show that, although in all instances the overall prevalence of the diseases was either lower than or similar to that in the general population, the diseases are presenting in people recorded as having a learning disability at a much earlier age. This can contribute to the higher level of premature deaths in individuals with learning disabilities and that there are 2.8 times the number of expected deaths. Figures 4, 5 and 6 demonstrate the prevalence of different circulatory diseases<sup>48</sup>.

Figure 4: Percentage of Hampshire patients who have an active diagnosis of hypertension- 2015/16.

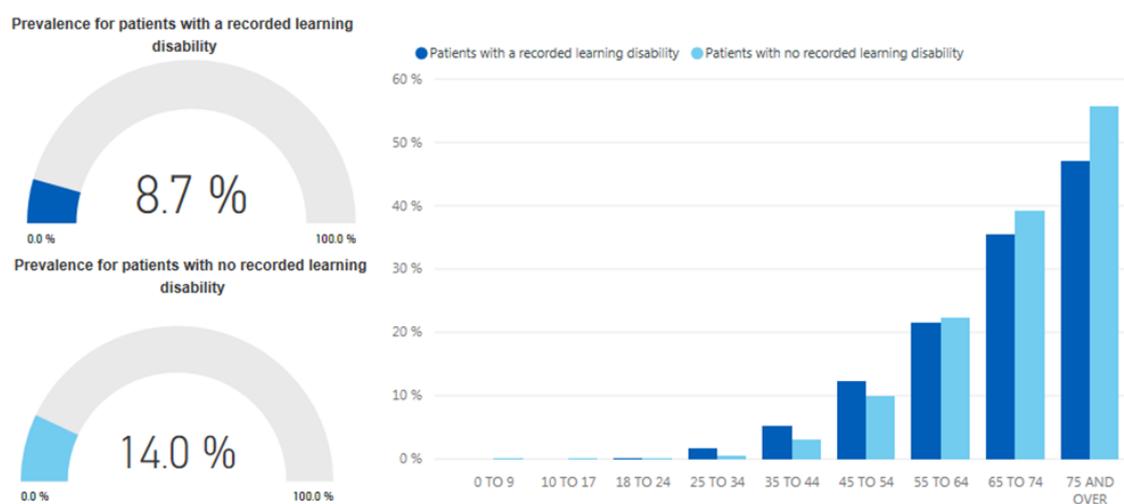
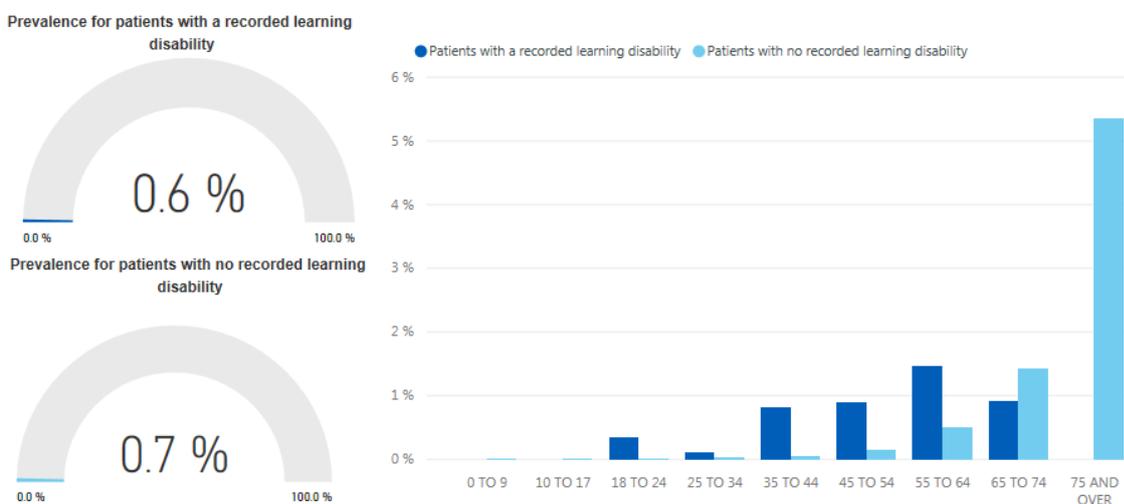


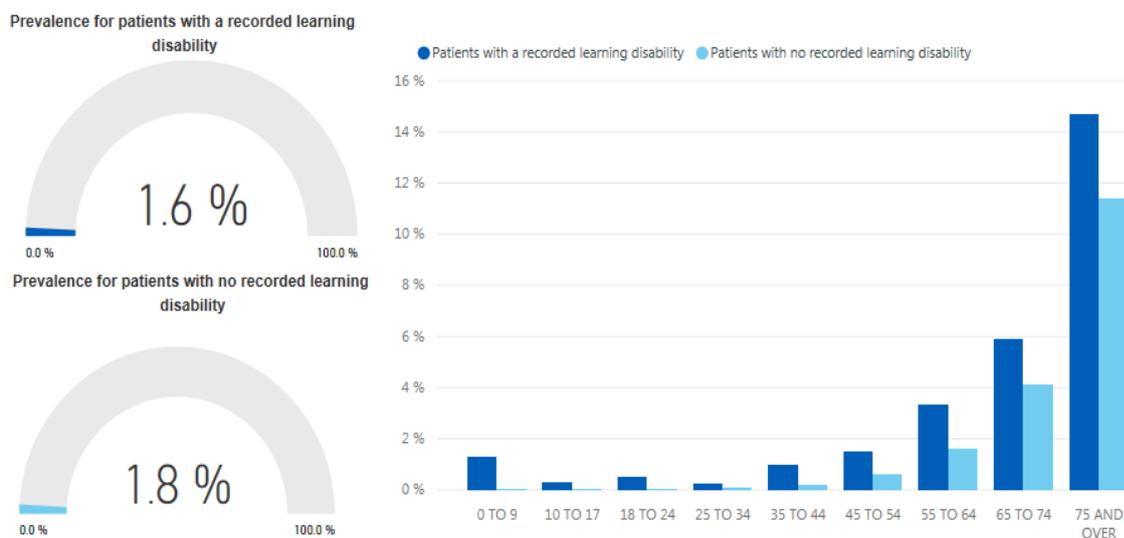
Figure 5: Percentage of Hampshire patients who have a diagnosis of heart failure- 2015/16.



<sup>47</sup> <http://medical-dictionary.thefreedictionary.com/circulatory+disease>

<sup>48</sup> <http://digital.nhs.uk/catalogue/PUB23781>

Figure 6: Percentage of Hampshire patients who have a diagnosis of stroke or transient ischaemic attack- 2015/16.



The proportion of children with learning disabilities aged 0-9 years that have had a stroke or transient ischaemic attack (TIA) is higher than the proportion of adults in all other age groups up to and including 45-54 years. A stroke in childhood can have a big impact on an individual's ability to live independently as adults, due to the co-morbidities of both a learning disability and potential physical disability.

The increased prevalence of circulatory disease during early adulthood may be due to an accumulation of lifestyle factors, such as poor diet and lack of physical activity, which are apparent throughout life. It is important to combat these lifestyle factors to reduce the risk of circulatory disease.

#### 4.3 Respiratory disease

Respiratory disease is a major cause of premature death in people with learning disabilities. A respiratory infection was identified as being the most common final event leading to a death<sup>49</sup>. There are some health conditions that people with learning disabilities have 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 airways<sup>50</sup>. Preventing avoidable risk factors, such as obesity, may then reduce the morbidity and mortality of other serious health conditions.

There are many types of respiratory infections and abnormalities that contribute to premature mortality in people with learning disabilities. It is difficult to predict 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)

<sup>49</sup> <http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>

<sup>50</sup> <http://www.bristol.ac.uk/media-library/sites/sps/leder/28.%20Nutrition%20and%20diet.pdf>

- Influenza
- Dysphagia, Aspiration Pneumonia and Pneumonia

#### 4.3.1 Chronic Obstructive Pulmonary Disease (COPD)

COPD is a term for 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 COPD<sup>51</sup>. Overall, COPD is half as prevalent in people with learning disabilities than the general population (0.8% and 1.6%, respectively)<sup>52</sup>. However, data from a sample of GP practices in Hampshire, displayed in figure 7<sup>53</sup>, show the prevalence of COPD in people with learning disabilities is more common than in the general population between the ages of 25 to 64. There is a particularly higher rate in the 25 to 34 year age group.

Figure 7: Prevalence of COPD- Hampshire 2015/16



#### 4.3.2 Influenza

Influenza is a common cause of potentially avoidable hospital admission. Following the CIPOLD report, a recommendation was made to make the influenza vaccination available to all adults with a learning disability. This was implemented in 2014/15. Uptake has increased slightly despite reports on the confusion of eligibility since the programme was spread more widely. As displayed in figure 8, uptake is highest in the older age groups<sup>54</sup>.

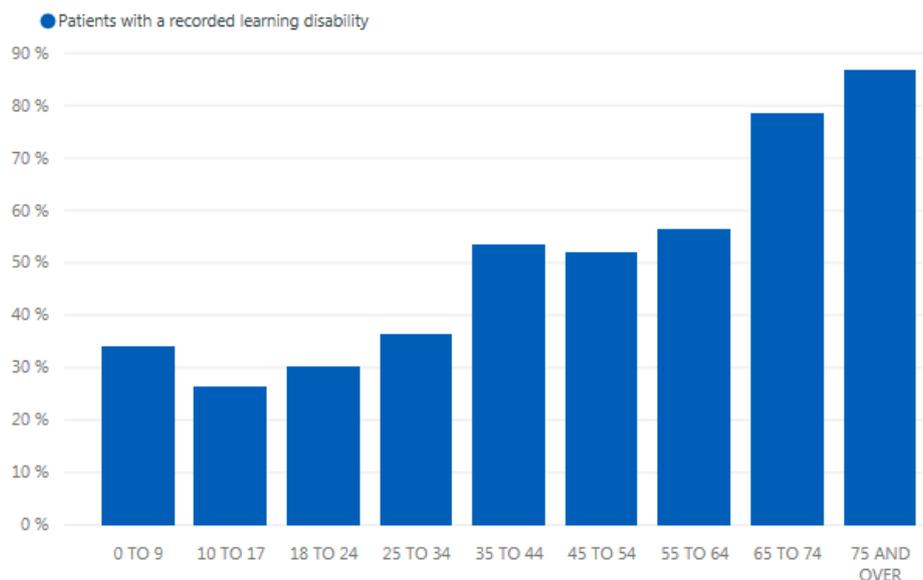
Figure 8: Uptake of the influenza vaccination, Hampshire, 2015/16

<sup>51</sup> [https://www.ndti.org.uk/uploads/files/IHAL-2013-02\\_Hospital\\_admissions\\_that\\_should\\_not\\_happen\\_ii.pdf](https://www.ndti.org.uk/uploads/files/IHAL-2013-02_Hospital_admissions_that_should_not_happen_ii.pdf)

<sup>52</sup> <http://www.content.digital.nhs.uk/catalogue/PUB23781>

<sup>53</sup> <http://digital.nhs.uk/catalogue/PUB23781>

<sup>54</sup> <http://www.content.digital.nhs.uk/catalogue/PUB23781>



As a means of making the programme more accessible to patients with learning disabilities, those that were frightened of needles could use the nasal spray vaccine. It is also important for a carer of a person with learning disabilities (whether professional or not) to get immunised against influenza as this can prevent the onward transmission of the virus.

#### 4.3.3 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 health<sup>55</sup>. Figures show that 40% of people with learning disabilities and dysphagia experience recurrent respiratory tract infections, caused by inhalation of foods or liquids<sup>56</sup>.

There are no reliable data on the prevalence of dysphagia in people with learning disabilities but it is generally accepted that rates are higher in people with learning disabilities than the general population. Estimates in people with learning disabilities have ranged from 36% (based on speech and language therapy caseloads) to over 70% (based on inpatient populations). Of those known to learning disability services 8% will have dysphagia. 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<sup>57</sup>.

The National Patient Safety Agency highlighted that dysphagia is a significant health risk and can lead to aspiration pneumonia. The CIPOLD report identified aspiration pneumonia as a significant cause of death. Aspiration pneumonia is a chest infection that can develop after accidentally inhaling something, such as a small piece of food<sup>58</sup>. It causes irritation in the lungs which may cause bacterial infection or respiratory failure<sup>59</sup>. Aspiration pneumonia can

<sup>55</sup> [https://rcni.com/sites/rcn\\_nspace/files/ldp2013.11.16.9.14.e1477.pdf](https://rcni.com/sites/rcn_nspace/files/ldp2013.11.16.9.14.e1477.pdf)

<sup>56</sup> <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities/swallowing-difficulties-dysphagia>

<sup>57</sup> <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities/swallowing-difficulties-dysphagia>

<sup>58</sup> <https://www.nhs.uk/conditions/swallowing-problems-dysphagia/complications/>

<sup>59</sup> <https://www.bristol.ac.uk/media-library/sites/sps/leder/18.%20Dysphagia%20and%20aspiration%20pneumonia.pdf>

be more common in people with learning disabilities due to increased risk of dysphagia, seizures and COPD.

The risk of choking should be identified early in people with learning disabilities to ensure that appropriate feeding practices are conducted. This can prevent future deaths. It had been recognised locally through the Mazar's review that there had been particular concerns regarding dysphagia assessments and the management of swallowing, including helping people eat and drink safely, during the practices at Southern Health NHS Foundation Trust<sup>60</sup>. Southern Health subsequently responded to the review.

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. A multi-agency steering group was formed in order to identify areas for improvement and to prevent future deaths<sup>61</sup>. There were many recommendations consisting of simple measures that commissioners and providers could already take. This included supporting uptake of annual health checks, dental health checks and the hospital passport, optimising the use of guidance from speech & language therapists and following guidance to assess and manage the risk of choking<sup>62</sup>.

The national Learning Disability Mortality Review programme identified that a significant proportion of deaths were reported to have an underlying cause of pneumonia (16%). This was most common in people aged 25-34. It is unknown 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. A recommendation of the Learning Disability Mortality Review programme was for a national focus on pneumonia in people with learning disabilities, to raise awareness about the prevention, identification and early treatment of the disease<sup>63</sup>.

#### *4.4 Cancer Screening*

The risk for an individual to develop 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. This may be difficult for some people with learning disabilities due to the ability to act on the warning signs and navigate through the health system<sup>64</sup>. This can be hindered further through organisational barriers, discussed in more detail in the sections below.

Cancer screening is available for breast, cervical and colorectal cancer. The prevalence of deaths from breast and cervical cancer in women with learning disabilities is not particularly

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<sup>60</sup> <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>

<sup>61</sup> <http://documents.hants.gov.uk/adultservices/safeguarding/Reducingtheriskofchokingforpeoplewithalearningdisability.pdf>

<sup>62</sup> <http://www3.hants.gov.uk/pact/pact-coursefinder/pact-coursedetails.htm?coursecode=PACT0968>

<sup>63</sup> <https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2017/#.Wz32y9GWyig>

<sup>64</sup> <http://www.content.digital.nhs.uk/catalogue/PUB22607/Health-care-learning-disabilities-2014-15-summary.pdf>

different to the prevalence of deaths from the same cancers in the general population. However there was a significantly higher prevalence of colorectal cancers<sup>65</sup>. In all three types of cancer, screening was lower in people with learning disabilities than the general population.

#### 4.4.1 Breast Screening

Data from a sample of GP practices in Hampshire<sup>66</sup> showed that 53.7% of adults with learning disabilities eligible for breast screening took part in the programme in 5 years leading up to 2015/16. This is compared to 71.9% of adults without learning disabilities. There has been a 3.4% increase from the 2014/15 dataset for people with learning disabilities in Hampshire. Nationally in 2015/16, 50.5% of people with learning disabilities took part and 66.5% in the general population.

Research has indicated that some women with learning disabilities may be at increased risk of breast cancer due to being less likely to have children<sup>67</sup>. The research also found there were organisational barriers for women with learning disabilities to access the breast screening service through a lack of emotional support to overcome fear, anxieties and embarrassment relating to screening. The research paper recommended that health professionals adopt a person-centered holistic approach to breast screening. This should enable women to access a service that ensures emotional needs are met whilst providing accessible information<sup>68</sup>. Public Health England have published an easy-guide on the breast screening service to help women with learning disabilities make an informed choice on accessing the service<sup>69</sup>.

#### 4.4.2 Cervical screening

Cervical cancer is the most common form of cancer in women under the age of 35, and therefore can contribute to a high number of years of life lost. Cervical screening is available every three years to eligible women aged 25 to 49 years, and every 5 years to eligible women aged 50 to 64 years.

The 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<sup>70</sup>. This can be by both health professionals and the individual's carer. Other difficulties involve understanding the process of a smear test and the ability to give appropriate consent<sup>71</sup>.

Data are not available locally, however national data shows that uptake of cervical screening is particularly lower in women with learning disabilities as displayed in figure 9.

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<sup>65</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/613182/PWLDIE\\_2015\\_main\\_report\\_NB090517.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf)

<sup>66</sup> <http://www.content.digital.nhs.uk/catalogue/PUB23781>

<sup>67</sup> <http://www.herts.ac.uk/about-us/case-studies/incidence-of-breast-cancer-among-women-with-learning-disabilities-and-the-factors-contributing-to-poor-access-to-breast-screening-reviewing-the-literature>

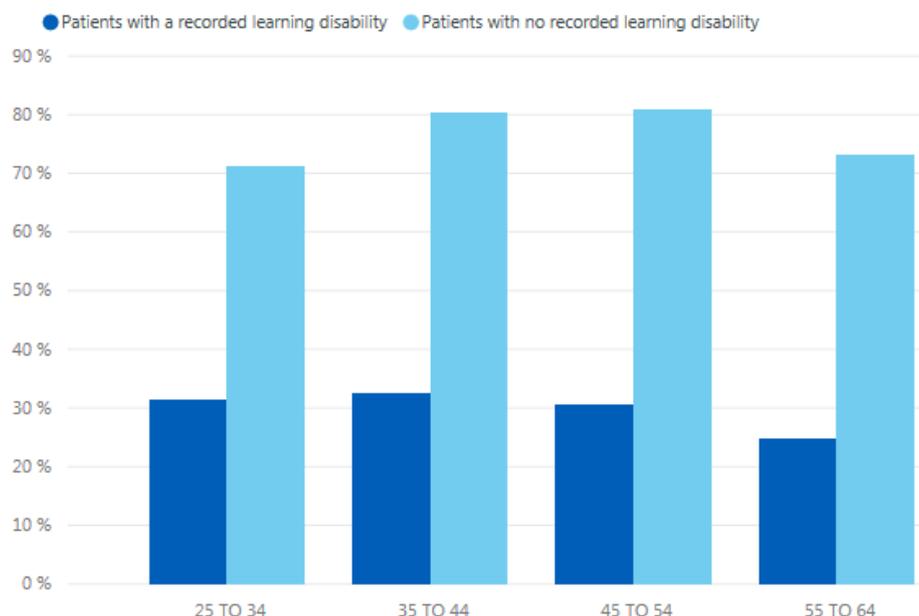
<sup>68</sup> <http://www.herts.ac.uk/about-us/case-studies/incidence-of-breast-cancer-among-women-with-learning-disabilities-and-the-factors-contributing-to-poor-access-to-breast-screening-reviewing-the-literature>

<sup>69</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/675924/Breast\\_screening\\_easy\\_guide.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/675924/Breast_screening_easy_guide.pdf)

<sup>70</sup> <http://www.bristol.ac.uk/media-library/sites/sps/leder/25.%20Cancer%20screening.pdf>

<sup>71</sup> <https://www.gov.uk/government/publications/health-matters-making-cervical-screening-more-accessible/health-matters-making-cervical-screening-more-accessible--2>

Figure 9: Percentage of eligible females aged 25 to 64 who received a cervical smear test in the 5 years prior to the end of 2015/16, England.



#### 4.4.3 Colorectal Screening

Data from a sample of GP surgeries in Hampshire showed that 84.2% of adults with learning disabilities eligible for colorectal screening took part in the programme in the 5 years leading up to 2015/16<sup>72</sup>. There is just less than 6% difference in screening uptake in people with learning disabilities compared to the general population in Hampshire. The data for 2015/16 also shows an 11.4% increase from 2014/15 dataset<sup>73</sup>. Despite the relatively similar figures for uptake of colorectal screening, there is an unexpectedly high rate of deaths in people with learning disabilities<sup>74</sup>.

A common symptom of colorectal cancer is a change in bowel habits, including increased constipation<sup>75</sup>. Constipation is a frequently reported issue in people with learning disabilities. Poor diet, inadequate hydration, lack of exercise and side effects of long-term medications contribute to a person's susceptibility to constipation. Constipation is common in people with learning disabilities as demonstrated in figure 10, which can disguise cancer. Therefore it is important to prevent constipation and to also identify when it should be investigated further.

Data from England in 2014/15 for chronic constipation is presented in Figure 10. Data was only collected for people with learning disabilities so comparison to the national prevalence is not available. The rate of constipation rose with age from the 18-24 year age group. In all age groups except 65-74 years, females had a higher prevalence than males.

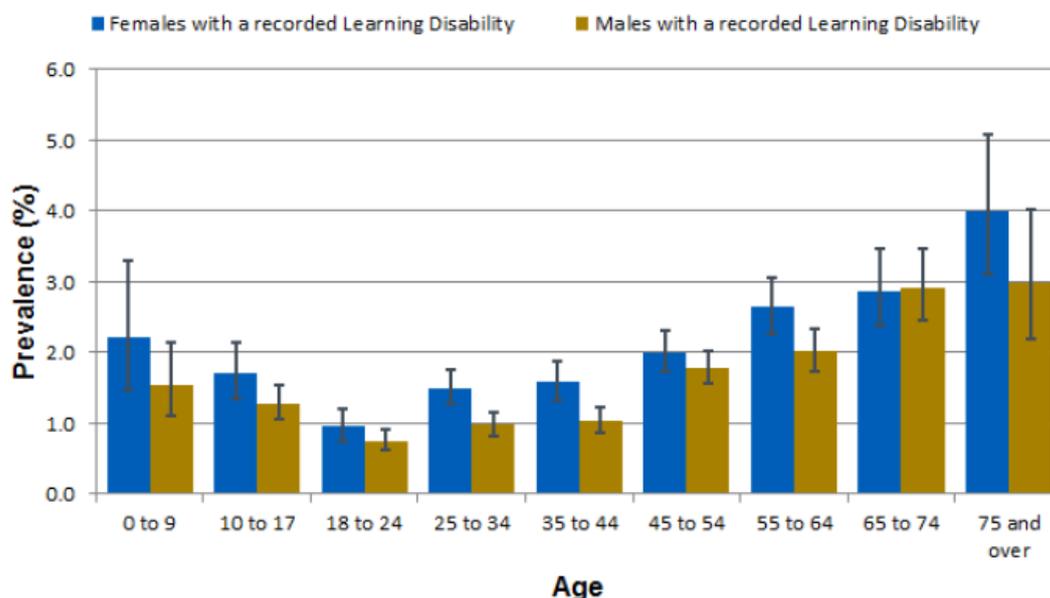
<sup>72</sup> <http://www.content.digital.nhs.uk/catalogue/PUB23781>

<sup>73</sup> <https://digital.nhs.uk/catalogue/PUB22607>

<sup>74</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/613182/PWLDIE\\_2015\\_main\\_report\\_NB090517.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf)

<sup>75</sup> <https://www.royalmarsden.nhs.uk/your-care/cancer-types/gastrointestinal/lower-gastrointestinal/colorectal-cancer>

Figure 10: Chronic constipation prevalence (%) in patients with a learning disability, by age and sex, England, 2014/15.



#### 4.5 Annual health check

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 over<sup>76</sup>. The Annual Health Check covers a range of issues relating to patients’ general physical and mental health as well as monitoring any specific previously diagnosed conditions. It provides an opportunity for GPs to provide lifestyle advice to improve health and avoid illness<sup>77</sup>.

Public Health England consider the programme to be a key reasonable adjustment to primary care services<sup>78</sup>. Reasonable adjustments are a legal duty for public organisations to ensure that services are accessible to people with disabilities as well as everybody else<sup>79</sup>. The programme intended to ensure that adults with learning disabilities have access to appropriate primary care, to ensure their health needs are met, to identify previously undiagnosed illness and minimise the need for emergency or specialist care.

The Learning Disabilities Observatory proposed that a minimum of 75% coverage should be reached to ensure that people with learning disabilities have appropriate access to primary care<sup>80</sup>. In Hampshire, 2016/17, uptake was recorded to be 58.0%<sup>81</sup>, which has now achieved the SHIP TCP’s initial target to increase uptake to 50%. Uptake was highest in the 75+ year age group at 69.2%. At CCG level in Hampshire, uptake ranged from 51.9% in North

<sup>76</sup> 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

<sup>77</sup> <https://www.nhs.uk/Livewell/Childrenwithlearningdisability/Pages/AnnualHealthChecks.aspx>

<sup>78</sup> <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities/health-checks>

<sup>79</sup> <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities/reasonable-adjustments-a-legal-duty>

<sup>80</sup> [http://www.improvinghealthandlives.org.uk/uploads/doc/vid\\_16264\\_IHAL201207%20Health%20Checks%20for%20People%20with%20Learning%20Disabilities%202008-9%20to%202011-12v2.pdf](http://www.improvinghealthandlives.org.uk/uploads/doc/vid_16264_IHAL201207%20Health%20Checks%20for%20People%20with%20Learning%20Disabilities%202008-9%20to%202011-12v2.pdf)

<sup>81</sup> <https://app.powerbi.com/view?r=eyJrIjoieTY2ZGM0ZGQzZGY0My00ZmFiLTljNTctYmNhMzA2OGJlYjczliwidCl6l9wN2YyZjMwLWVhOGMtNDE5Zi1hMTc5LTVjNGZjN2E0YmY2YiIsImMiOiN9>

Hampshire to 71.4% in South Eastern Hampshire. All GP surgeries, except one, are signed up to deliver annual health checks from the five CCGs within Hampshire<sup>82</sup>.

A report on the impact of the programme<sup>83</sup> found that uptake had led to increased identification of diseases that were associated with the Quality Outcome Framework (QoF) incentives but the identification of other diseases or health issues was varied. This may indicate that clinicians selectively undertake different elements of the checks rather than completing a comprehensive assessment. To understand how the annual health check is being delivered locally, the Public Health England 'Quality Checking Health Checks for People with Learning Disabilities' tool<sup>84</sup> can be implemented. This can lead to an action plan to ensure the programme is being delivered consistently and appropriately across all GP surgeries in Hampshire.

A more recent 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%<sup>85</sup>.

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<sup>86</sup>. Therefore, reduced hospital admission in practices delivering the annual health check may suggest improved primary care identification and treatment of some health conditions.

#### 4.6 Weight management

A learning disability can make it difficult to maintain a healthy weight. Women, people with Down's, Prader-Willi, Cohen or Bardet-Biedl Syndromes are at particular risk of obesity<sup>87</sup>. Those with excess weight are at increased risk of circulatory disease. Therefore it is important to ensure that adequate support is available to enable an individual with learning disabilities to make healthy food choices and reduce their risk of circulatory disease. The specific type of learning disability an individual has should be taken into account when implementing weight management programmes.

Underweight is an important health issue as this can lead to poor bone growth, a weakened immune system, tiredness<sup>88</sup> and reduced respiratory function<sup>89</sup>. Underweight is more

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<sup>82</sup> <http://www.southernhealth.nhs.uk/news/promoting-annual-health-checks-to-mark-learning-disability-week/>

<sup>83</sup> <http://www.networks.nhs.uk/nhs-networks/national-health-facilitation-network-learning/documents/Impact%20of%20DES%20-%20Chauhan-%20Reeve-%20Kontopantelis%20et%20al.pdf>

<sup>84</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/647512/Auditing\\_health\\_checks\\_tool\\_for\\_people\\_with\\_learning\\_disabilities.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/647512/Auditing_health_checks_tool_for_people_with_learning_disabilities.pdf)

<sup>85</sup> <https://www.ncbi.nlm.nih.gov/pubmed/27312249>

<sup>86</sup> <https://www.england.nhs.uk/wp-content/uploads/2014/03/red-acsc-em-admissions-2.pdf>

<sup>87</sup> [https://strathprints.strath.ac.uk/34862/1/vid\\_7479\\_IHaL2010\\_3HealthInequality2010.pdf](https://strathprints.strath.ac.uk/34862/1/vid_7479_IHaL2010_3HealthInequality2010.pdf)

<sup>88</sup> <http://www.nhs.uk/Livewell/Goodfood/Pages/Underweightadults.aspx>

<sup>89</sup> <http://www.bristol.ac.uk/media-library/sites/sps/leder/28.%20Nutrition%20and%20diet.pdf>

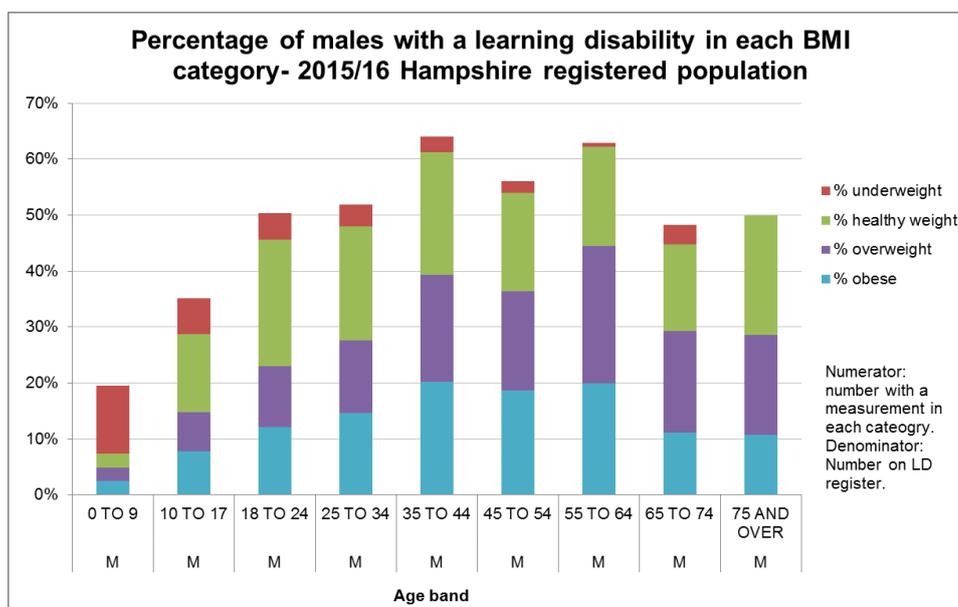
prevalent in individuals with profound learning disabilities due to poor feeding and swallowing (dysphagia)<sup>90</sup>.

Data on the body mass index (BMI) of adults with learning disabilities<sup>91</sup> in Hampshire shows BMI is under-recorded at all age groups for males and females, as can be seen in figures 11 and 12. This means percentages do not add up to 100%. Children and young people were more likely to be underweight but the level of overweight and obesity increased and peaked in the middle age groups. In females, the level of underweight increased again into the older age groups. Out of those with a measurement, 64% of adults aged 18 and over were of excess weight. This is slightly more than the general population where 62% of adults were classified as being of excess weight<sup>92</sup>. This is similar to national figures where 65.5% of the population with learning disabilities are of excess weight, compared to 61.5% of the general population.

Although there is not a large inequality in the prevalence of excess weight between the population of adults with learning disabilities and the general population, there is still a significant issue in that the majority of people with learning disabilities are of an unhealthy weight, including underweight. Within the excess weight category, adults with learning disabilities are more likely to be obese than the general population<sup>93</sup>. Therefore approaches to weight management should be accessible to people with learning disabilities.

These approaches should be multifaceted, such as improving health literacy, independence, choice and physical activity. There is very limited research on uptake of physical activity in people with learning disabilities and therefore the intelligence on the need in this area is unknown.

Figure 11: BMI category by age band in males with learning disabilities, Hampshire- 2015/16



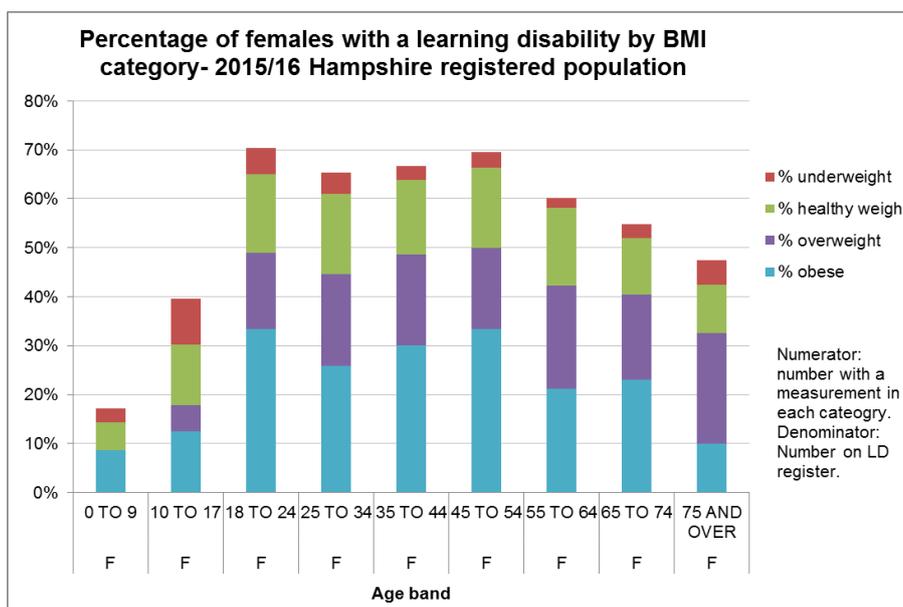
<sup>90</sup> <http://www.nhs.uk/Livewell/Disability/Pages/weight-management-learning-disabilities.aspx>

<sup>91</sup> <http://digital.nhs.uk/catalogue/PUB23781>

<sup>92</sup> <https://fingertips.phe.org.uk/search/overweigh#page/3/gid/1/pat/6/par/E12000008/ati/102/are/E10000014/iid/93088/age/168/sex/4>

<sup>93</sup> <http://digital.nhs.uk/catalogue/PUB23781>

Figure 12: BMI category by age band in females with learning disabilities, Hampshire-2015/16



It is unknown if individuals with excess weight are using Hampshire weight management services. Therefore it is not known if the services available meet needs and are accessible to adults with learning disabilities. Anecdotal evidence suggests local authority commissioned weight management services are not being regularly used by adults with learning disabilities. It is recommended that this is explored in detail.

Nationally, there's little robust research on longer-term weight loss strategies for people with learning disabilities. There are opportunities to encourage healthy eating through the annual health check, enabling families and carers to recognise excess weight and provide them with practical support to encourage healthy lifestyles<sup>94</sup>.

#### 4.7 Mental Health and Wellbeing

**“No good health without mental health.” Duncan Selbie, Chief Executive PHE**

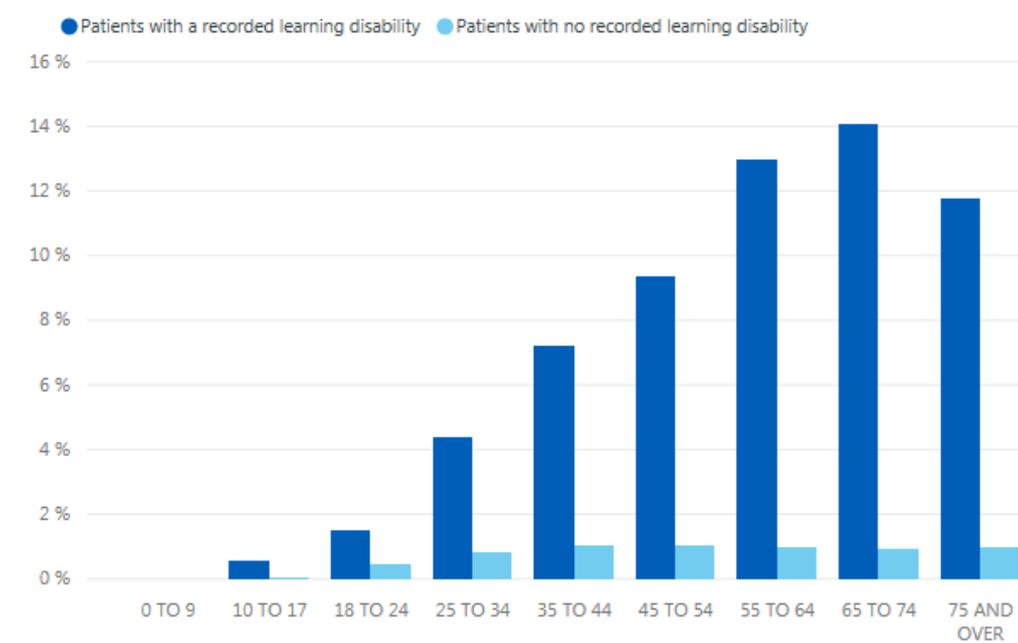
A significantly higher proportion of people with a learning disability report mental ill-health than in the general population<sup>95</sup>. Data from 2015/16 displayed in figure 13<sup>96</sup> show that approximately 6.5% of the Hampshire population with a learning disability have a severe mental health condition, compared to 0.7% of the population without learning disabilities.

<sup>94</sup> <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities/obesity-and-weight-management>

<sup>95</sup> <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health-research-and-statistics/mental-health>

<sup>96</sup> <http://digital.nhs.uk/catalogue/PUB23781>

Figure 13: Percentage of patients who have a severe mental health diagnosis, Hampshire, 2015/16



The risk factors for 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 mental health problems that can lead to increased pain and distress.
- **Higher incidence of negative life events**, such as deprivation, poor housing and abuse.
- **Lack of accessible recourses and coping strategies** to cope with life events such as leaving home. This can include support and engaging with social networks.
- **Other people's attitudes** to behavior to ensure the right care, support and diagnosis is provided, to prevent decline of health conditions<sup>97</sup>.

The NHS Mandate for 2014/15 directly states that "NHS England's objective is to put mental health on a par with physical health", known as parity of esteem<sup>98</sup>. The parity approach ensures that an individual receives a 'whole-person' attitude throughout health services, including in the local authority.

All individuals face barriers to this approach due to stigma to mental ill health. However people with learning disabilities may face additional barriers<sup>99</sup>. The lack of services available, timely diagnosis, physical barriers to accessing services and failures to make reasonable adjustments have been identified as organisational barriers for people with learning disabilities to access the care they need<sup>100</sup>.

<sup>97</sup> <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health-research-and-statistics/mental-health>

<sup>98</sup> <https://www.mentalhealth.org.uk/a-to-z/p/parity-esteem>

<sup>99</sup> <https://www.mentalhealth.org.uk/a-to-z/p/parity-esteem>

<sup>100</sup> 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

## 4.8 Dementia

Due to improved diagnosis and care of people with learning disabilities, life expectancy has dramatically increased from approximately 25 years in 1983 to over 60 years in 2015. As people with learning disabilities are now living longer, they are living to an age where they are more likely to develop dementia. Nationally, one in fourteen of the total population aged over 65 are predicted to develop dementia<sup>101</sup>. This compares to one in five people with a learning disability over the age of 65<sup>102</sup>. In Hampshire, this equates to 58 people based on 2015/16 GP learning disability registers.

Down's syndrome is a major risk factor for developing dementia. It is estimated that 1 in 50 people with Down's syndrome will develop dementia in their 30's and this rises to more than half when an individual reaches 60 years and over. Epileptic seizures are more common in people with Down's syndrome than the general population. A sign that someone with Down's syndrome has dementia is if that individual starts to develop epileptic seizures later in life. These should be fully investigated to aid early diagnosis and preparation for further care<sup>103</sup>.

Dementia largely presents in a similar manner for people with and without learning disabilities. However there are some important differences that need to be recognised. The Alzheimer's Society listed the following considerations<sup>104</sup>. People with learning disabilities:

- often show different symptoms in the early stages of dementia.
- are more likely to have other physical health conditions which are not always well managed.
- are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis.
- may experience a more rapid progression of dementia, although this can be complicated by difficulty or delay in diagnosis.
- need specific support to understand the changes they are experiencing, and to access appropriate services after diagnosis and as dementia progresses.

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.

## 4.9 Sexual health and relationships

Relationships are important to a high quality of life. They can bring happiness, fulfilment, companionship and a greater sense of choice and control to the lives of people with a

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<sup>101</sup> [https://www.alzheimers.org.uk/info/20025/policy\\_and\\_influencing/251/dementia\\_uk](https://www.alzheimers.org.uk/info/20025/policy_and_influencing/251/dementia_uk)

<sup>102</sup> [https://www.alzheimers.org.uk/download/downloads/id/1763/factsheet\\_learning\\_disabilities\\_and\\_dementia.pdf](https://www.alzheimers.org.uk/download/downloads/id/1763/factsheet_learning_disabilities_and_dementia.pdf)

<sup>103</sup> [https://www.alzheimers.org.uk/info/20007/types\\_of\\_dementia/37/learning\\_disabilities\\_and\\_dementia/4](https://www.alzheimers.org.uk/info/20007/types_of_dementia/37/learning_disabilities_and_dementia/4)

<sup>104</sup> [https://www.alzheimers.org.uk/download/downloads/id/1763/factsheet\\_learning\\_disabilities\\_and\\_dementia.pdf](https://www.alzheimers.org.uk/download/downloads/id/1763/factsheet_learning_disabilities_and_dementia.pdf)

learning disability<sup>105</sup>. Adults with learning disabilities living in Hampshire have said that they would like to have information about sexuality and relationships that is easy to understand, and to be able to openly discuss this<sup>106</sup>. 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. However, there is a specialist sexual health service in Hampshire available to people with learning disabilities.

It is also important to support carers of individuals with learning disabilities to understand the needs of the person they are caring for. This includes understanding what is appropriate for that person and supporting them to meet their emotional and health needs of a relationship. This can include understanding what a healthy relationship is, the importance of consent and of safe sex<sup>107,108</sup>. This was highlighted as a need in conversation with professionals working with people with learning disabilities.

#### 4.10 Epilepsy

Epilepsy is significantly more prevalent for people with learning disabilities than the general population. In Hampshire, 2015/16, data showed a prevalence of 19.2% of patients with a learning disability are recorded on the GP register as having an active diagnosis of epilepsy and on drug treatment. This compares to 0.6% of the population without learning disabilities<sup>109</sup>. The CIPOLD report highlighted that the most commonly reported long term condition in people with learning disabilities is epilepsy (43%)<sup>110</sup>.

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<sup>111</sup>. Diagnosis of epilepsy is difficult as there is not one single 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. It can also be more difficult for a person with a learning disability to communicate how they are feeling<sup>112</sup>.

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. The Learning Disabilities Observatory reported that epilepsy contributed to 3.9% of deaths in England<sup>113</sup>.

The CIPOLD programme reported that NICE guidelines for epilepsy and learning disabilities were not always adhered to (CG137). It was found that there was not always a trained

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<sup>105</sup> <https://www.mencap.org.uk/advice-and-support/relationships-and-sex>

<sup>106</sup> <http://documents.hants.gov.uk/adultservices/learning-disabilities/LDPlan.pdf>

<sup>107</sup> <http://documents.hants.gov.uk/adultservices/learning-disabilities/LDPlan.pdf>

<sup>108</sup> <https://www.mencap.org.uk/about-us/what-we-think/relationships-and-sex-what-we-think>

<sup>109</sup> <https://app.powerbi.com/view?r=eyJrljoiYTY2ZGM0ZGQtZGY0My00ZmFiLTJiNTctYmNhMzA2OGJlYjczliwidCI6IjgwN2YyZjMwLWVhOGMtNDE5Zi1hMTc5LTViNGZiN2E0YmY2YiIsImMiOiN9>

<sup>110</sup> <http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>

<sup>111</sup> [https://www.thh.nhs.uk/documents/\\_Patients/PatientLeaflets/proceduresConditions/Epilepsy\\_LD-MENCAP.pdf](https://www.thh.nhs.uk/documents/_Patients/PatientLeaflets/proceduresConditions/Epilepsy_LD-MENCAP.pdf)

<sup>112</sup> <https://www.epilepsy.org.uk/info/Carers/learning-disabilities/causes>

<sup>113</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/613182/PWLDIE\\_2015\\_main\\_report\\_NB090517.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf)

person on duty able to administer emergency medication when required<sup>114</sup>. This highlights both training needs and the importance of planning staff rotas appropriately.

#### 4.11 Sepsis

Sepsis is a rare condition that can have serious complication is not treated quickly. Sepsis originates from an infection in the body and can result in multiple organ failure<sup>115</sup>. The prevalence of sepsis in adults with learning disabilities in Hampshire is unknown. However, the Learning Disability Mortality Review programme identifies that sepsis was an underlying cause of death in 11% of cases reviewed. Therefore, there is a recommendation that there should be a national focus on sepsis in people with learning disabilities, to raise awareness about prevention, identification and early treatment<sup>116</sup>.

##### *Recommendations:*

- Monitor the trend in the crude rate of deaths in adults with learning disabilities on a three-year rolling analysis.
- Organisations to take a multiagency approach to reporting and learning from deaths of people with learning disabilities through the Learning Disability Mortality Review Programme (Leder).
- Review the identification pathways for colorectal cancer in adults with learning disabilities with constipation.
- Review current commissioned Public Health programmes to ensure they meet the needs of people with learning disabilities, such as tier 2 weight management.
- Work with organisational workforce development teams to review current training packages, to enable paid and unpaid carers to help individuals to make healthier lifestyle choices in diet, exercise, oral health and sexual health, with Making Every Contact Count included.
- Continually develop the workforce supporting people with learning disabilities to recognise the early indication of ill health and to act on this appropriately.
- Ensure organisations working with adults with learning disabilities take a parity of esteem approach to mental health.
- Conduct the Annual Health Check audit to analyse where support is needed to continually improve the effectiveness of the programme.
- Ensure adults with learning disabilities and their carers know where to access support for timely diagnosis of dementia and onward care.
- Continue to embed Making Every Contact Count and the strength-based approach to social care services at all ages to enable independence starting earlier and for as long as possible.

## 5. Social Determinants 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 14. This is

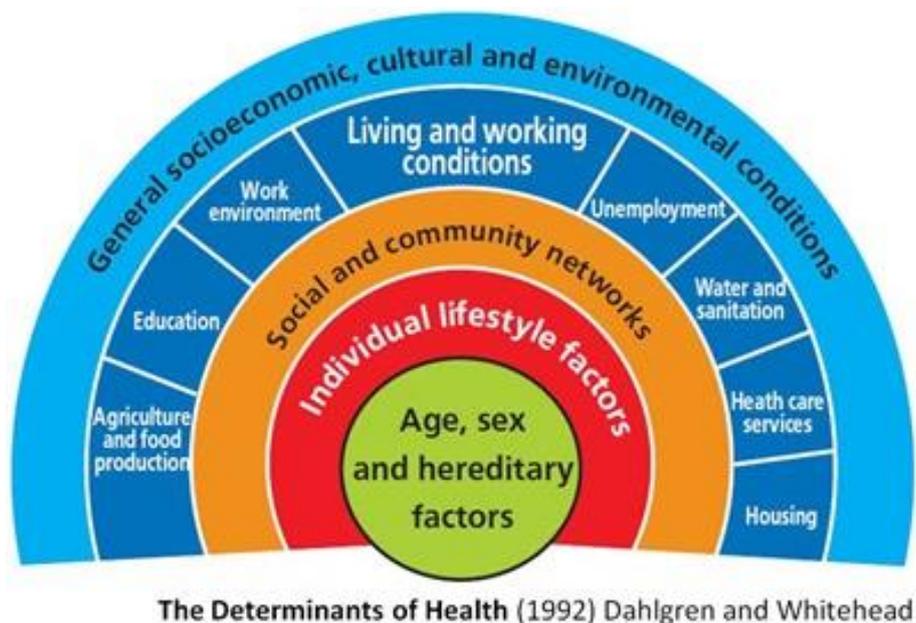
<sup>114</sup> <https://www.bristol.ac.uk/media-library/sites/sps/leder/19.%20Epilepsy.pdf>

<sup>115</sup> <https://www.nhs.uk/conditions/sepsis/#whos-at-risk>

<sup>116</sup> <https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2017/#.Wz32y9GWyig>

largely due to discriminatory socio-cultural practices that can constrain the life experiences of people with disabilities<sup>117</sup>. 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 resolving ignorance or prejudice in the workforce or culture of the organisation<sup>118</sup>.

Figure 14: The Determinants of Health



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

- Poverty
- Employment
- Housing / Accommodation

### 5.1 Poverty

Poverty can disproportionately affect people with learning disabilities. This can be due to many factors including inequity in employment (described below), poorer education, organisational barriers and additional expenses<sup>119</sup>. There is funding available from the government to support people with a learning disability, known as the Personal Independence Payment. This is in the process of being transferred from the Disability Living Allowance. Unlike the Disability Living Allowance, the Personal Independence Payment only has two levels of support for daily living; there is no longer support available for the lower level of need.

Organisational barriers can lead to a lack of a person’s autonomy to look after their own money. Access to banking is important for people with a learning disability, because many

<sup>117</sup> Emerson E. et al. Health Inequalities and People with Learning Disabilities in the UK: 2012. Improving Health & Lives Learning Disability Observatory: London (Nov 2012)

<sup>118</sup> Mencap. Death by Indifference. London: Mencap, 2007

<sup>119</sup> <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/money-and-benefits-research-and-statistics>

people need a bank account in order to get their benefits, spend their money, and manage direct payments<sup>120</sup>. It is important to challenge the stigma facing individuals with learning disabilities regarding their capacity to live independently, while maintaining a duty of care.

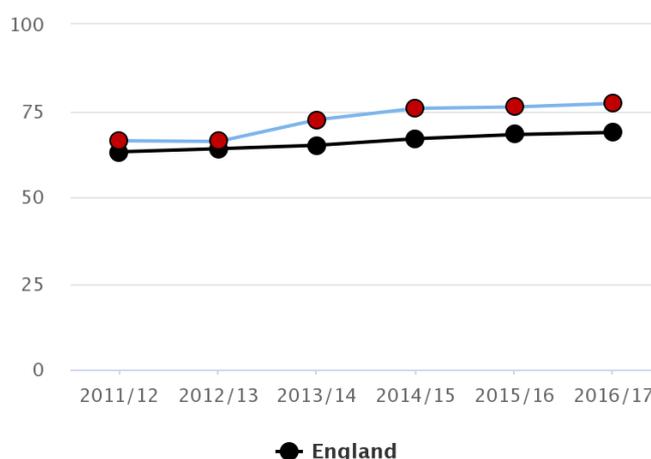
## 5.2 Employment

### ***‘Work is the key to a long, happy and healthy life’ Duncan Selbie, Chief Executive PHE***

Employment offers financial rewards, the chance to use existing skills and develop new ones, self-respect and opportunities to contribute to and be valued by the community. This has a significant impact on quality of life. The Government has committed to “ensuring that all disabled people have the opportunity to fulfil their potential and realise their aspirations”<sup>121</sup>.

In Hampshire, 2015/16, 3.6% of adults with learning disabilities receiving long term support from their local social services department were in paid employment. This is significantly lower than both the South East and England proportion (6.2% and 5.8%, respectively)<sup>122</sup>. Figure 15<sup>123</sup> displays that the gap in the employment rate between those with a learning disability and the overall employment rate in Hampshire is significantly higher than England and has increased over time.

Figure 15: Trend in the gap in employment between those with a learning disability and the overall employment rate- Hampshire (%).



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. The Right to Work supports individuals in a wide range of ‘real work’ job roles. Where possible, The Right to Work offer paid employment for people with learning disabilities, currently this is 50% of their staff team. Volunteers and staff gain improved confidence, better life chances and a greater sense of self esteem, wellbeing and fulfilment.

<sup>120</sup> <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/money-and-benefits-research-and-statistics>

<sup>121</sup> <http://researchbriefings.files.parliament.uk/documents/SN07058/SN07058.pdf>

<sup>122</sup> <https://fingertips.phe.org.uk/profile/learning-disabilities/data#page/0/gid/1938132704/pat/6/par/E12000004/ati/102/are/E06000015>

<sup>123</sup> <https://fingertips.phe.org.uk/search/employment#page/4/gid/1/pat/6/par/E12000008/ati/102/are/E10000014/iid/90283/age/183/sex/4>

It is recommended to investigate if this approach can be implemented in other day services around the County.

National evidence suggests that finding a job an individual wants to do and supporting them to learn how to do it is more effective than spending money on preparing and training people for work. A national study<sup>124</sup> highlighted 5 elements to effective delivery of employment services:

- 1) Shifting culture- increasing opportunities and making employment a central strategic outcome.
- 2) Employment as an outcome- a clear understanding of what is meant by employment –based on ‘real’ work including proven steps towards it.
- 3) Strategic direction- A comprehensive strategy, owned by key players, based on evidence linked to wider strategies that are used to guide action/delivery.
- 4) Developing the market- Having knowledgeable leadership that works with all stakeholders, but especially providers, to deliver elements 1, 2 and 3.
- 5) Performance management- Having systems in place to gather information to inform achievement and cost effectiveness.

### 5.3 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”<sup>125</sup>.*

The Valuing People Now strategy of 2009 acknowledged that accommodation options for adults with learning disabilities have improved with the shift away from hospital campus-based care<sup>126</sup>. However, there is still less choice and control over where to live than the general population<sup>127</sup>.

Figure 16 displays the accommodation status of people who are receiving long term social care support from their local authority (aged 18 to 64)<sup>128</sup>. Data is displayed for Hampshire and the top ten CIPFA neighbours and benchmarked against England. Settled accommodation is where the person can reasonably expect to stay as long as they want, where as unsettled accommodation is either unsatisfactory or, where residents do not have security of tenure, such as in residential care homes.

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<sup>124</sup> <http://www.sscr.nihr.ac.uk/PDF/Findings/RF26.pdf>

<sup>125</sup> Maxwell Y & King N. Enhancing Housing Choices for People with a Learning Disability. Housing Learning & Support Network, Department of Health: London (Nov 2011)

<sup>126</sup> Valuing People Now: The Delivery Plan: ‘Making it happen for everyone. Department of Health: London (Jan 2009)

<sup>127</sup> Wood A & Kirkpatrick K. Valuing People Now & PSA 16 Housing Delivery Plan 2010-11: Housing Delivery Plan for People with Learning Disabilities. Department of Health: London (Mar 2010)

<sup>128</sup> <https://fingertips.phe.org.uk/profile/learning-disabilities/data#page/0/qid/1938132704/pat/6/par/E12000004/ati/102/are/E06000015>

Figure 16: Accommodation status of people with learning disabilities receiving long term support from Local Authority social care, 2015/16.

		Compared with benchmark			Lower Similar Higher										Not compared	
Indicator	Period	England	Hampshire	1 - Essex	2 - West Sussex	3 - Kent	4 - Gloucestershire	5 - Warwickshire	6 - Oxfordshire	7 - Buckinghamshire	8 - Worcestershire	9 - Leicestershire	10 - Hertfordshire			
Proportion of supported working age adults with learning disability living in settled accommodation (%)	2015/16	75.2	65.9	76.9	56.7	71.8	71.6	71.2	80.1	65.9	75.0	77.6	73.1			
Proportion of supported working age adults with learning disability living in unsettled accommodation (%)	2015/16	19.8	30.6	23.1	5.3	20.1	28.4	19.5	19.6	32.4	25.0	22.4	26.7			
Proportion of supported working age adults whose accommodation status is not known to LA (%)	2015/16	5.0	3.6	0.0	38.2	8.1	0.0	9.3	0.0	2.2	0.0	0.0	0.0			
Proportion of supported working age adults whose accommodation status is severely unsatisfactory (%)	2015/16	0.14	0.00	0.00	0.00	0.14	0.00	0.00	0.00	0.00	0.00	0.00	0.34			

Although the percentage of adults with learning disabilities using long-term local authority social care services in unsettled accommodation is significantly higher than the England average, rates are relatively similar to Hampshire’s CIPFA neighbours. No residents known to social care services in Hampshire are living in severely unsettled accommodation which includes rough sleeping, use of refuge and placed in temporary accommodation by the council. The majority (86%) of those who are in unsettled accommodation are in residential social care, which may be the most appropriate accommodation type for that individual based on their needs<sup>129</sup>. Data collection is good, where status is unknown for only 3.5% of the population, however this can be improved.

**Recommendations:**

- Support organisations to participate in local initiatives, such as the Right to Work, to enable people with learning disabilities to gain employment experience.
- Develop a strategic approach to supported employment in Hampshire, with measureable outcomes.
- Improve data collection on housing for adults with learning disabilities known to Adults’ Health and Care.

**6. Access to Services**

**6.1 Adult Social Care**

It is widely accepted that only a minority of adults with learning disabilities will be in contact with local social care services. Researchers estimated that only approximately 25% of all people with learning disabilities in a local area would be known to services<sup>130</sup>. These would

<sup>129</sup> <http://digital.nhs.uk/catalogue/PUB21934>

<sup>130</sup> 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.

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. However, 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.

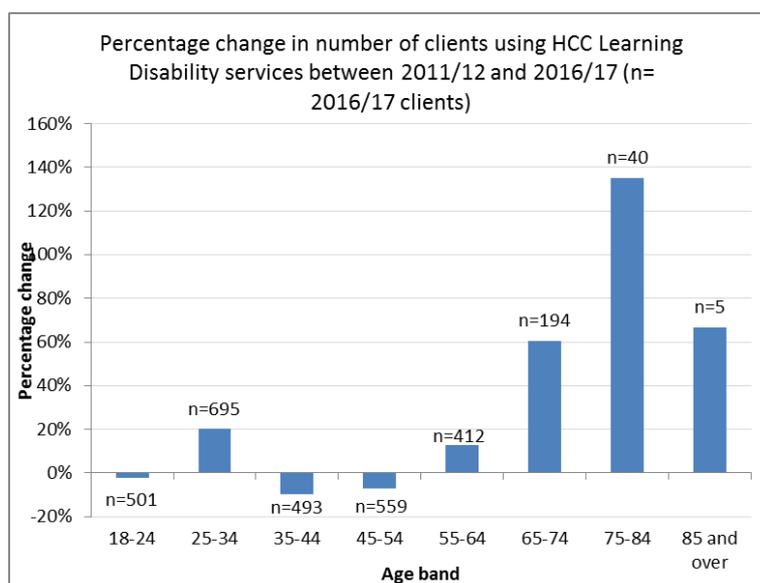
Adult social care services provide support to people who may need help with the tasks of everyday living. This can range from practical support in the home, advocacy services or residential care for people who cannot live independently. Support is available to Hampshire residents who meet the nationally set eligibility criteria<sup>131</sup>. This means people get the same access to support wherever they live and to ensure there is a fair, transparent and consistent methodology to determine who is eligible for support.

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 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.

75% of adult social care services for learning disabilities is for long term support from Hampshire County Council. Many people using social care services will be receiving more than one type of support. Overall, 2,899 people with learning disabilities use long term social care; 59% of clients are male. This is consistent with the higher prevalence of learning disabilities in males.

Figure 17 displays the change in use of social care by age band between 2011/12 and 2016/17. Although representing smaller numbers, the over 65 years age groups show a larger percentage increase in use of services. This may be reflective of the ageing population in Hampshire, and in people with learning disabilities.

Figure 17: Percentage change in use of Hampshire County Council social care services, by age band, between 2011/12 and 2016/17.

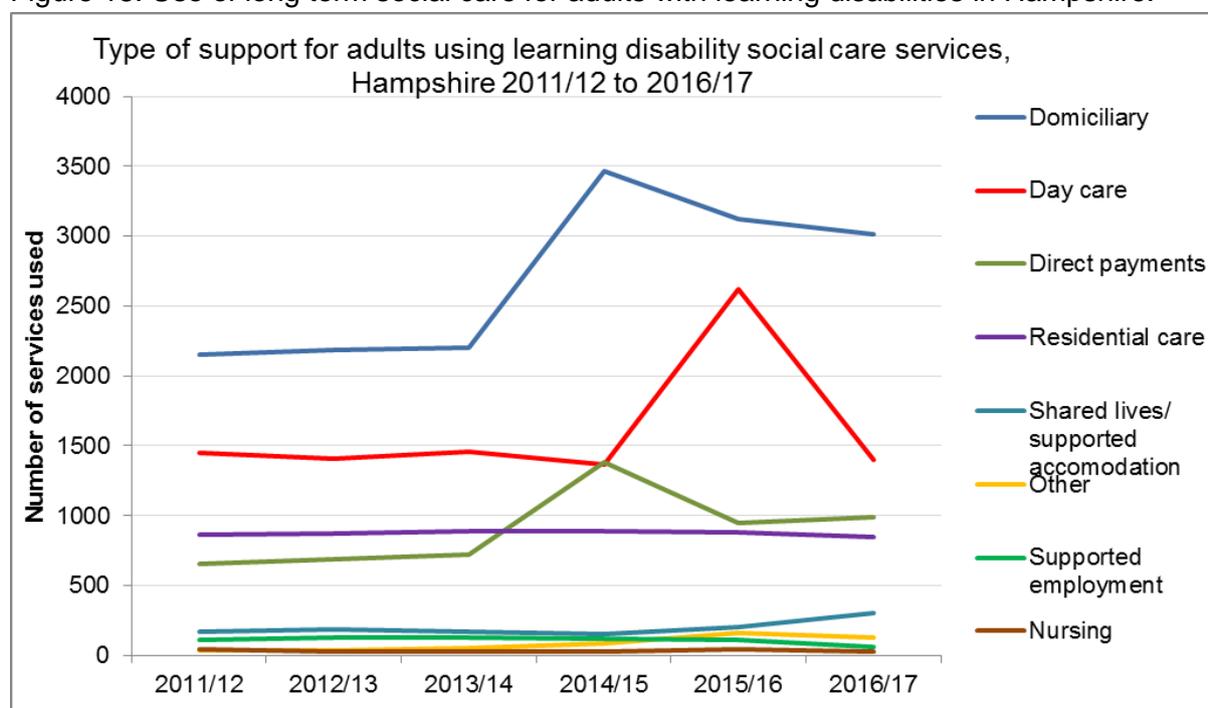


<sup>131</sup> <http://documents.hants.gov.uk/adultservices/ASpublicationsWhocangethelpfromAdultServices.pdf>

Data from the Hampshire County Council AIS database, displayed in figure 18, shows domiciliary care is the most common use of care in adults with learning disabilities, and has seen a large increase over time<sup>132</sup>. The use of direct payments has increased overtime, which may demonstrate that people using social care have more choice and independence. Those using direct payments may now be more likely to manage their own care and spend money on the support they feel they need most, in a way which is suitable for their individual needs. This may demonstrate increased levels of independence in some people with learning disabilities through self-management of their own finances.

Data suggests that supported employment has decreased over time. Figures remained around 120 supported employment services used between 2011/12 and 2015/16 but then dropped by half in 2016/17.

Figure 18: Use of long term social care for adults with learning disabilities in Hampshire.



## 6.2 Community Connector

The Community Connector programme is being piloted in Hampshire until the end of March 2018. The project aims to support Learning Disability teams and their clients in a number of ways:

- To inform and update Learning Disability teams with information on community assets and opportunities.
- Taking client referrals from the team to work in a person centred, strengths based way to understand client's goals and to work with them alongside family/carers to help them realise their goals in a sustainable and realistic way through accessing local community assets.

<sup>132</sup> Hampshire County Council Adults' Health and Care AIS data system

- Proactively engage all stakeholders and providers of learning disability services to understand what their offer is, support development of their service and help build networks and partnership working.

The common health needs that were identified through the service were:

- Mental health
- Overweight/obesity and poor food choices
- Sexual health

The needs highlighted under these topic areas were supportive of those identified in the relevant chapters in the Health and Wellbeing section.

**Case Study from RH, user of the Community Connector programme.**

RH is an adult with a mild learning disability and Down's syndrome, referred to connector programme by the Learning Disability team. RH lives in a shared supported living house and, until recently, had long term employment at local café. RH had a very busy schedule and was very friendly and sociable.

Following a breakdown of a same sex relationship, RH had been struggling to cope emotionally, becoming very anxious and depressed. RH no longer works and has become isolated from friends.

RH had art therapy sessions which are now finished, had been prescribed medications to support mental health and had some limited contact with a psychiatrist through the Learning Disability social care team. RH's functioning continued to decline including in ability to wash, dress, undertake chores and hold a conversation.

Community connector actions:

- Introduced RH to a volunteering role, with help of Mencap 1:1 support. Working within a team of others has helped boost self-esteem and sense of identity.
- Provided information about a local counsellor who specialises in LD and referred RH to MIND wellbeing centre.
- In partnership with a local library, RH will attend in-house ukulele/singing sessions.
- RH started to attend drama/communication workshops which has helped improve confidence and social connectivity.
- Attend multi-agency meeting to contribute towards care planning.

### *6.3 Mental Health Services*

Services such as ITalk which are open to self-referrals and provide talking therapies, have not always been considered appropriate for all individuals with learning disabilities. However, the services have been made friendlier for people with learning disabilities in recent years. Some ITalk bases 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 are 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. To continuously improve services for people with learning disabilities, Learning Disability teams work with Adult Mental Health services to assess case studies of people who have used the services. 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<sup>133</sup>.

#### *6.4 Health Charter*

The national Health Charter<sup>134</sup> 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 'Stopping Over-Medication of People with a Learning Disability, Autism or Both' (STOMP).
- ensuring each person supported by that organisation, and who wants one, has a health action plan and hospital passport.

The Health Charter can aid organisations to ensure that care and support provided is suitable for, and meets the needs of, people with learning disabilities. This in turn can help to reduce health inequalities.

#### *6.5 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 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. The Death by Indifference report had a recommendation that a standard hospital passport is made available to all people with a learning disability. The hospitals in Hampshire have hospital passports available on their website which can be downloaded. Anecdotal evidence suggests that they are not consistently used across all hospitals. Different hospital trusts may use different styles of the hospital passport however this should not have an impact on an individual's care as the details are usually similar.

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<sup>133</sup> [https://www.ndti.org.uk/uploads/files/Green\\_Light\\_Toolkit\\_2017.pdf](https://www.ndti.org.uk/uploads/files/Green_Light_Toolkit_2017.pdf)

<sup>134</sup> <https://www.vodg.org.uk/campaigns/learning-disability-providers-challenged-to-tackle-health-inequalities/>

## 6.6 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<sup>135</sup>.

Qualitative research nationally has shown that the hospital liaison nurses are seen as effective and valued<sup>136</sup>. 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<sup>137</sup>.

A further study suggested that Hospital Liaison Nurses contributed to NHS hospitals achieving safer practices, however, there was a risk of a lack of structural support. This includes the number of nurses employed<sup>138</sup>. Within Southern Health NHS Foundation Trust there are only five nurses employed across Southampton General Hospital and Queen Alexandra Hospital in Portsmouth<sup>139</sup>. Therefore, it is unlikely that all individuals who require support from the Liaison Nurses are able to receive it, due to the lack of availability.

Hampshire Hospitals NHS Foundation Trust does not have Hospital Liaison Nurses at present but are currently in the process of recruiting staff to fill these positions in order to meet the Death by Indifference report recommendation that learning disability liaison nurses are employed by every acute service.

## 6.7 Strategic Health Facilitators

Southern Health NHS Foundation Trust has a team of three Strategic Health Facilitators covering Hampshire (excluding the North East Hampshire and Farnham Clinical Commissioning Group area). The health facilitators work with a range of different health professionals including doctors, nurses, dentists and carers to advise on how to provide better care to people with learning disabilities.

Projects have included increasing the uptake of the Annual Health Check alongside the Mencap 'Don't Miss Out' campaign and improving the quality of data (through validation of the learning disabilities register). The health facilitators can provide training and resources to GP practices to enable their delivery of health checks. This can also include advice on

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<sup>135</sup> <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>

<sup>136</sup> <https://www.ncbi.nlm.nih.gov/books/NBK259497/>

<sup>137</sup> <http://bmjopen.bmj.com/content/6/4/e010480>

<sup>138</sup> <https://www.ncbi.nlm.nih.gov/books/NBK259497/>

<sup>139</sup> <http://www.southernhealth.nhs.uk/services/learning-disability/hospital-liaison-nurses/>

making reasonable adjustments such as improved signage, using easy read information, having longer appointment times and planning initial visits to the surgery first.

### 6.8 Telecare

A range of electronic devices are available to support individuals with learning disabilities to live independently. These can be used in a person's home, both in the community and in residential care settings. As established in a previous chapter, epilepsy is common in people with learning disabilities. Some people in care require to be checked regularly at night meaning they are awoken frequently. Devices such as the epilepsy sensor can aid a person to have undisturbed sleep. The sensor is placed underneath the mattress and monitors epileptic activity while an individual is in their bed. The lifeline is then alerted when a person has a seizure. This allows individuals to sleep at night without being regularly checked or woken by staff. This can lead to better quality sleep which can then lead to less challenging behaviour, improved mental wellbeing and a more active lifestyle.

Other devices for support are available such as the Brain in Hand app, the incontinence sensor and bogus caller alert, details of these and others can be found on the Argenti website<sup>140</sup>. There are eligibility criteria to receive telecare for free. If the criteria are not met, individuals can pay for the service.

#### **Case Study from SP's carer, Paula**

SP has been in the Shared Lives Scheme for four years since living with his mum. Paula is SP's shared lives carer and Brain in Hand supporter. When Paula first began supporting SP, around the clock care was required. SP did not travel alone and required face-to-face support when leaving the care home. SP embraces technology and his psychologist referred him to Brain in Hand. The aim was to help build his confidence and increase his independence.

One of SP's first goals was to travel independently. Paula said SP has moved on significantly since then and he is now able to travel without support. SP travels to a local shop and then to his father's house once a week.

SP has increased in confidence and ability to problem solve. SP "loves knowing that Brain in Hand is there and can use it if he needs to". His confidence with travelling independently has increased and he's now making more journeys on his own. Paula reported that just the fact that Brain in Hand is there gives SP confidence. His decision making has improved and SP now often says "it's my choice". Paula has also noted that SP has now come off medication for anxiety for the first time in 3-4 years, which although might be from other factors, could also be in part due to Brain In Hand.

#### **Recommendations:**

- Ensure all adult social care providers sign up to the Health Charter to advocate for improved care of people with learning disabilities.
- Ensure all adults with learning disabilities known to social care services have a hospital passport.

<sup>140</sup> <http://www.argenti.co.uk/products/>

## 7. Conclusion

Hampshire's population is increasing and ageing and the same pattern is seen in adults with learning disabilities. Improvements in the provision of health care and the decrease of stigmatisation towards people with learning disabilities has contributed to this. Efforts have been made to embed reasonable adjustments into services to cater for people with learning disabilities; however, there are still great injustices in the care that people with learning disabilities receive. There have been repeated reports of poor communication, a lack of adherence to the Mental Capacity Act and disregard to deaths of people with learning disabilities.

This health needs assessment has highlighted a gap in national guidance on when a death of a person with learning disabilities should be reported and reviewed. When analysing the causes of death, there was a lack of understanding of when a premature death was a preventable death. This leads to continuous loss of learning.

Adults with learning disabilities are often at higher risk of developing health conditions. Circulatory disease was reported to be the most common cause of death. It is therefore important that adults with learning disabilities are encouraged to lead a healthy lifestyle. 64% of adults with learning disabilities are reported to be of excess weight, which is a risk factor for circulatory disease. Opportunities should be taken using the 'Making Every Contact Count' approach to enable individuals with learning disabilities to make healthy choices. This includes working with the individuals' carer to tailor advice on what a healthy diet is, particularly when a person's learning disability affects their weight, such as Down's syndrome.

The annual health check is a prime opportunity to have healthy conversations and it is seen as a reasonable adjustment to GP health provision. The number of GP surgeries signed up to the programme has increased. Uptake in Hampshire has also increased from 42.4% in 2014/15 to 58.0% in 2015/16. Although there have been improvements in the number of people attending their health check, it has been reported that the quality of the health check varies. Evidence suggests that some providers deliver the aspects of the health check that are based on QoF, a scheme using incentives. It is recommended the Public Health England tool for Quality Checking Health Checks for People with Learning Disabilities is used to understand gaps in provision and to enable a more thorough health check to be undertaken.

The Chief Executive of Public Health England, Duncan Selbie, has said 'Work is the key to a long, happy and healthy life'. Although those known to Hampshire County Council adult social care are likely to have more complex needs than those who are not known to services, only 4.5% were in paid employment in 2014/15. This is significantly lower than both the South East and England proportion (7.5% and 5.9%, respectively)<sup>141</sup>. There are many schemes available to support individuals with learning disabilities to get into and stay in employment. A local initiative, The Right to Work, takes an innovative approach to day services. It is recommended that that this explored in more detail to see if it can be expanded more widely across Hampshire.

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<sup>141</sup> <https://fingertips.phe.org.uk/profile/learning-disabilities/data#page/0/qid/1938132704/pat/6/par/E12000004/ati/102/are/E06000015>

The use of direct payments has increased overtime in Hampshire, which may demonstrate that people using social care are now more likely to manage their own care and spend money on the support they feel they need most, in a way which is suitable for their individual needs. This may demonstrate increased levels of independence in some people with learning disabilities through self-management of their own finances.

There have been many improvements in the support for people with learning disabilities and this health needs assessment sets out how this can be continually improved. It is important to end the stigma that people with learning disabilities face which creates inequalities in health and care, to enable them to live healthy and independent lives.