

## 7. ADULTS

### 7.11 Learning Disability

This chapter looks at health and wellbeing issues affecting adults. Some issues are specific to particular health conditions and disablements. Information in this chapter can help identify priorities to help reduce inequalities experienced by these groups across different geographic areas and different socio-economic groups.

#### *7.11.1 The impact of learning disability*

Adult users of social care form the largest group of service users and are a significant pressure on health & social care budgets. Advancements in healthcare treatments have enabled people to live longer and therefore are at increasing risk of developing multiple long term health conditions that will require specialist treatment. This increase in demand will not be matched by more money and therefore the spending gap between service needs and available funding will widen year on year.

There is estimated to be up to 1.14 million people in England with a learning disability. Although the terms learning disability and learning difficulty are deemed by many as interchangeable they are quite different and so need to be defined separately.

Although there is no formally agreed definition, a learning difficulty is often used in educational settings. It refers to individuals who have specific problems with learning as a result of either medical, emotional or language problems<sup>i</sup>. A learning difficulty does not affect general intelligence (IQ) and includes conditions like dyslexia, ADHD and dyspraxia.

In contrast, a person with a learning disability would have difficulty understanding new or complex information, learning new skills and coping to be independent. A learning disability occurs when a person's brain development is affected either before they are born, during their birth or in early childhood (Department of Health, Valuing People 2001)<sup>ii</sup>.

People with a learning disability can and do lead happy and fulfilled lives. They may have loving relationships; children, friends, employment, a variety of interests and hobbies, and campaign and advocate on behalf of themselves and their peers.

However, for the majority of people with a learning disability, the chances and opportunities to lead an ordinary, fulfilled life are much less than for other people. People with a learning disability are often treated as “different” and as a consequence are subjected to discrimination, inequalities, are disadvantaged and have fewer life opportunities and poorer health than the rest of the population.

The health and wellbeing of people with a learning disability tends to be poorer than that of the general population, with higher rates of preventable illnesses, long term conditions and mortality.

By better understanding the reasons why people with a learning disability are dying prematurely we can better target health promotion and preventative activities.

People with a learning disability continue to experience social deprivation; poor access to and outcomes from health services, live in social isolation and are at risk of being victims of hate crime and abuse. Ensuring that health services are equally accessible to all people with a learning disability, including by using accessible advice and information for those that may have difficulties in understanding healthcare messages, will improve their health outcomes.

### *7.11.2 Information on Learning Disability*

There is no definitive record of the number of people with a learning disability in England. However, data gathered from a number of sources by Public Health England, at the Learning Disabilities Observatory estimates that in England in 2012 there were 1.14 million people with a learning disability. Of this total an estimated 908,000 adults had learning disabilities of which 21% are known to learning disability services.<sup>1</sup>

In the Buckinghamshire there are an estimated 5870 adults with learning disabilities, aged 18-64yrs, of those:

- 4,590 have moderate learning disabilities (MLD)
- 1,120 adults are estimated to have severe learning disabilities (SLD)
- 160 people have profound and multiple learning disabilities (PMLD)

Of these totals approximately 1280 people aged 18-64 with profound, multiple and severe learning disabilities will be in receipt of health and/or social care services.

In line with the general population figures for Buckinghamshire, of the people with learning disabilities aged 18-64:

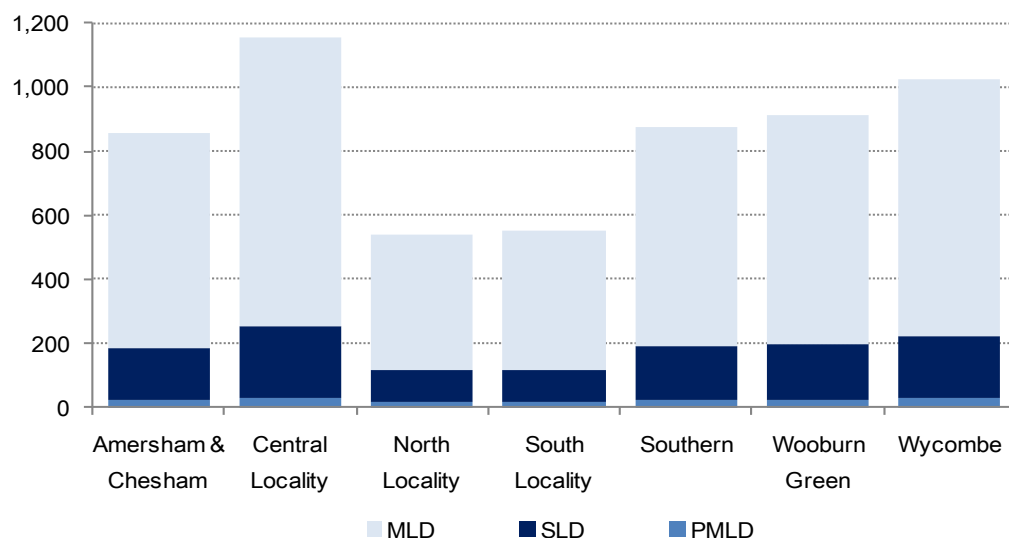
- 37% live in Aylesbury Vale
- 33% live in Wycombe
- 17% in Chiltern
- 13% in South Bucks

The chart below shows the estimated number of people with Learning Disabilities by severity for each of the Buckinghamshire CCG localities.

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<sup>1</sup> [People with Learning Disabilities in England 2012: Improving Health and Lives](#)

**Figure 1 The estimated number of people with learning disabilities by severity for each of the Buckinghamshire CCG localities**



A detailed understanding of the population of older adults with a learning disability is covered in chapter 8.

### 7.11.3 Trends

Whilst overall the number of people with learning disabilities aged 18-64yrs in Buckinghamshire is projected to make small increase, however there will be greater increases in the number of people with profound and multiple learning disabilities (Table 1).

**Table 1 Percentage of change in number of people with learning disabilities**

	2013	2023	2033	% change 2013 - 2033		
				Buckinghamshire	South East	England
Profound and multiple LD	160	180	220	38%	43%	49%
Severe LD	1,120	1,130	1,150	2.7%	4.3%	8.9%
Moderate LD	4,590	4,590	4,600	0.2%	2.7%	7.5%
SLD/ MLD with serious challenging behaviour	100	100	100	0%	0%	4.9%
<b>Total</b>	<b>5,870</b>	<b>5,900</b>	<b>5,970</b>	<b>1.7%</b>	<b>4.0%</b>	<b>8.6%</b>

Source: Planning4care estimates 2013<sup>iii</sup>

Table 2 shows the estimated number of people with Learning Disabilities by severity by CCG, in 2013.

**Table 2 Estimated number of people with learning disabilities by severity by CCG in 2013**

	PMLD	SLD	MLD	Total
Aylesbury Vale CCG	61	427	1,754	2,243
Chiltern CCG	100	700	2,868	3,668
Buckinghamshire	160	1,120	4,590	5,870

#### 7.11.4 Inequalities

It is estimated that people with a learning disability are two and half times more likely to have health problems than other people (Disability Rights Commission 2006)<sup>iv</sup>. People with a learning disability are fifty eight times more likely to die under the age of fifty and four times as many people with a learning disability die of preventable causes compared to people in the general population (Hollins et al 1998<sup>v</sup>, Michael, 2008).

There are a number of key issues for people with learning disabilities, including:

##### 7.11.4.1 Physical health conditions

People with learning disabilities have high levels of physical ill health. When combined with other factors such as poor access to services; this has resulted in significant levels of inequalities in general health. People with learning disabilities have an increased risk of early death compared to the general population<sup>2</sup>, although the life expectancy of this population is increasing over time and, for people with mild learning disabilities, approaching that of the general population.<sup>3</sup>

In addition, people with learning disabilities are likely to find it more difficult than others to describe their symptoms. As a result it is more difficult for healthcare workers to identify health needs among people with learning disabilities, thus leaving some problems left unrecognised. It has also been found that people have reduced access to universal preventative screening and health promotion programmes, such as breast or cervical screening.

The types of health needs that are greater within the learning disability population include:

- Cancer; in particular gastro-intestinal cancers
- Coronary heart disease; the second highest death rate in people with a learning disability
- Dental issues; more likely to have gum disease, tooth decay

<sup>2</sup> Source: Hollins et al., 1998; McGuigan et al., 1995

<sup>3</sup> Source: Carter & Jancar, 1983; Puri et al., 1995)

- Diabetes
- Epilepsy; 33% of people with learning disability have epilepsy compared to 1% of the general population
- Gastro-intestinal problems; constipation, Gastro oesophageal reflux disease (GORD)
- Obesity; more noticeable in those with mild learning disabilities
- Respiratory disease; this is the main cause of death in people with learning disabilities
- Sensory impairments; sight and hearing problems are common
- Swallowing and feeding problems

#### 7.11.4.2 Higher mental health needs<sup>4</sup>

The prevalence of psychiatric disorders among children with learning disabilities is 36%, compared to 8% among children without learning disabilities.

#### 7.11.4.3 Co-existing autism spectrum disorders<sup>5</sup>

The prevalence of autism has been reported to be as high as 20-30% in people with learning disabilities known to services. <sup>vi</sup> Conversely two thirds of autistic people do not have a learning disability and therefore Autism Syndrome Condition is considered in section 7.10.

#### 7.11.4.4 Challenging behaviours

Challenging behaviours are shown by 10%-15% of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49. Emerson (2001)<sup>6</sup> suggests that approximately 10 -15% of people with a learning disability present with behaviours that challenge services. These behaviours may include self-injurious behaviour, aggression toward others and destruction of property.

#### 7.11.4.5 Social inclusion and opportunities<sup>7</sup>

People with learning disabilities, especially those with less severe disabilities who do not use learning disability services, are more likely to be exposed to common “social determinants” of health such as poverty, poor housing conditions, unemployment and social disconnectedness.

Less than 1 in 5 people with a learning disability work (compared with 1 in 2 disabled people generally). Of those people with a learning disability that do work, most only work part time and are low paid.

Just 1 in 3 people with a learning disability take part in some form of education or training.

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<sup>4</sup> Emerson, E.Baines, S. Allerton, L. and Welch, V. (2011) A detailed analysis of the health inequalities suffered by PWLD is available at: Health Inequalities & People with Learning Disabilities in the UK.

<sup>5</sup> [Guidance for commissioners of mental health services for people with learning disabilities \(May 2013\) Joint Commissioning Panel for Mental Health](#)

<sup>6</sup> Emerson, E (2001, 2<sup>nd</sup> Edition) Challenging Behaviour, Analysis and intervention in people with learning disabilities.

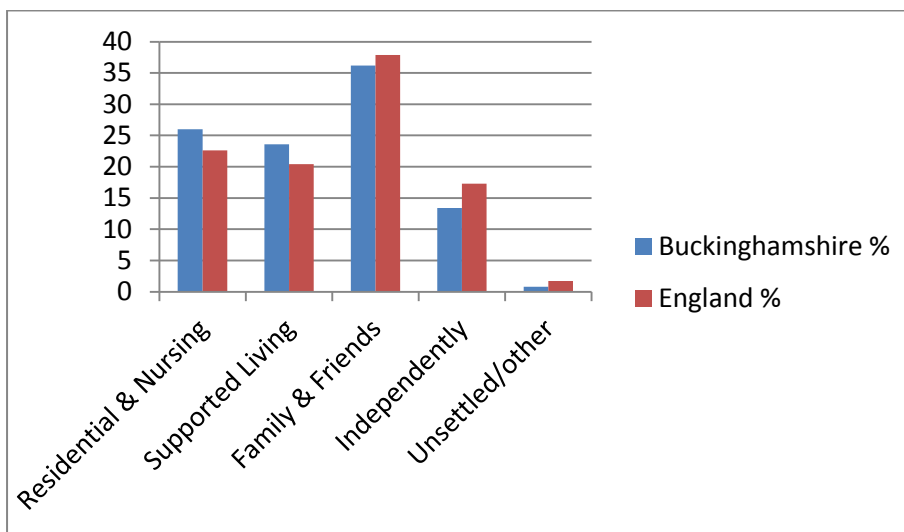
<sup>7</sup> [Mencap facts about learning disabilities](#)

- Many adults with learning disabilities still live with their parents, without the opportunity to gain independence, learn key skills and make choices about how they live their lives.<sup>vii</sup>
- 58,000 people with a learning disability are supported by day care services.
- Less than a third of people with a learning disability have some choice about with whom they live with, and less than half have some choice over where they live.
- 7 out of 10 families caring for someone with profound and multiple learning disabilities have reached or come close to 'breaking point' because of a lack of short break services.
- 29,000 adults with a learning disability live with parents aged 70 or over, many of whom are too old or frail to continue in their caring role. In only 1 in 4 of these cases have local authorities planned alternative housing.

#### 7.11.5 Comparisons

In Buckinghamshire it is estimated that 36% of the total population of adults with a learning disability are living permanently with family or friends and 13% live independently in owner-occupied or rented accommodation. This represents a higher proportion of people living in supported accommodation, and a lower proportion living independently, than the national average. The following chart show how this relates to the national average.

**Figure 2 Proportions and number estimates of people with learning disabilities in different forms of accommodation as a percentage**



Source: National Adult Social Care Intelligence Service (NASCIS), 2011/12

Of those supported in the community, a lower than average proportion receive direct payments, or a carer service. A higher than average proportion receives home care, short term residential care (other than respite) and professional service.

It has been calculated that an average of 44.2% of people with a learning disability have received an annual health check nationally. In Buckinghamshire 36.2% of those eligible adults with a learning disability received a health check. Buckinghamshire is performing below the national average but better than the regional average.

The table below shows how the number of annual health checks as a proportion of the learning disability population compares with similar local authorities.

**Table 3 The number of annual health checks as a proportion of the learning disability population compared with similar local authorities**

Indicator	Period	England	South East	Oxfordshire	Milton Keynes	Surrey	Kent	Windsor & Maidenhead	Buckinghamshire
Proportion (%) of eligible adults with a learning disability having a GP health check	2013/14	44.2	29.2	47.4	54.1	17.5	41.4	33.3	36.2

#### 7.11.6 Demand

In line with national trends, there are anticipated significant increases in the numbers of adults with profound and multiple learning disabilities. Also reflected in national projections is the numbers of adults with complex behaviours that challenge and/or autism and mental health conditions are also increasing.

There is a higher prevalence of learning disability among Afro-Caribbean and other ethnic minority groups, particularly in South Asian communities where prevalence of learning disabilities are up to three times higher than in other communities; 12% - 18%. It is, however, important to note that whilst ethnic minority groups are disproportionately affected, the majority of people with a learning disability in Buckinghamshire are of white British origin.

The prevalence of autism among adults with a learning disability is estimated to be approximately 33% and so we can expect that about 1900 of the population of adults with a learning disability may have autism.

### *7.11.7 Horizon scanning*

The Transforming Care Agenda aims to ensure permanent changes to the delivery of learning disability services. The national plan “Building the Right Support”, follows on from the Winterbourne View Review and will deliver new and better care options in the community and significantly reducing the need for lengthy stays in specialist hospitals, for those individuals with a learning disability who have behaviours that challenge and/or mental health conditions. The national plan aims to half the number of specialist learning disability inpatient beds in 3 years. Services will need to be developed to ensure interventions at the earliest opportunity to minimise the need for specialist inpatient provisions.

Alongside this are a number of programmes, launched by NHS England, to further investigate and address physical health inequalities. In Buckinghamshire further work is planned to support GPs in coordinating health care for people with a learning disability, improving the numbers of health checks completed, access to health screening and promoting the use of health passports across the population.

In addition to the specialist learning disability health services in Buckinghamshire, there are a number of providers offering specialist community support to individuals. However, to meet these growing areas of need it is recognised that current capacity and skills across the provider market will require further development.

### *7.11.8 Public views*

#### **Engagement with carers and people with a learning disability<sup>viii</sup> identified areas for improvement**

“Health Passports need to be used more consistently as a central source of information about the person. There also needs to be easily accessible information for professionals and carers about healthcare for people with learning disabilities”.

Adrian Timon  
Learning Disability/Autism Commissioner  
*October 2016*



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- <sup>i</sup> Eric Emerson, Pauline Heslop, A working definition of Learning Disabilities. IHL, 2010
- <sup>ii</sup> Department of Health (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: Department of Health.
- <sup>iii</sup> Baseline figures are derived from Emerson and Hatton (2004b) age-gender prevalence rates of 'administrative' and 'true' rates of Learning Disability. This prevalence is locally adjusted using Odds Ratios for deprivation and ethnicity (Emerson, unpublished). Projected estimates are based on 2008 ONS sub-national
- <sup>iv</sup> Disability Rights Commission (2006) *Equal treatment: closing the gap. Health formal investigation report*. London: Disability Rights Commission.
- <sup>v</sup> Hollins, S., Attard, M.T., von Fraunhofer, N. & Sedgwick, P. (1998). Mortality in people with learning disability: risks, causes, and death certification findings in London. *Developmental Medicine & Child Neurology*,
- <sup>vivi</sup> Emerson, E. and Baines, S. (2010) *The estimated prevalence of autism among adults with learning disabilities in England*. Stockton-on-Tees
- <sup>vii</sup> [www.mencap.org.uk](http://www.mencap.org.uk)
- <sup>viii</sup> Talkback, Adult Social Care, Buckinghamshire CCGs Consultation: Working with you to get better services for people with learning disabilities in Buckinghamshire' (2015)