

Why is this issue important?

A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.¹

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people.¹

People with certain specific conditions can have a learning disability too. For example, people with Down's syndrome and some people with autism have a learning disability.¹

It is estimated that nationally for every 1,000 people, 20 will have a learning disability.² This is likely to increase as people with learning disabilities are living longer. People with learning disabilities often experience poorer health and poorer healthcare than the general population.³

Key outcomes

- **Adults with a learning disability who live in stable and appropriate accommodation (Public Health Outcomes Framework)**
- **Gap in the employment rate between those with a learning disability and the overall employment rate (Public Health Outcomes Framework)**
- **Adults with learning disabilities in stable accommodation (Adult Social Care Outcomes Framework)**
- **Adults with learning disabilities in employment (Adult Social Care Outcomes Framework)**
- **Social care related quality of life (Adult Social Care Outcomes Framework)**
- **Service users with control over their daily life (Adult Social Care Outcomes Framework)**

- **Client satisfaction with care and support (Adult Social Care Outcomes Framework)**
- **People who use services and feel safe (Adult Social Care Outcomes Framework)**

Impact in Brighton & Hove

Based on national prevalence rates, there were an estimated 4,746 adults aged 18-64 years with a learning disability living in Brighton & Hove in 2015, with around 6% with a severe learning disability.⁴

In 2014/15⁵:

- 825 people with learning disabilities were receiving long term support from Brighton & Hove City Council.
- Of these, 725 were aged 18-64 (88%).
- Of these 725, 575 (80%) were living in settled accommodation (where a person can reasonably be expected to stay as long as they want) and 150 (20%) were living in non-settled accommodation (where residents do not have security of tenure).

Some people with learning disabilities are placed in residential care outside of the city due to a lack of specialist accommodation and insufficient supported accommodation options. When local vacancies arise however, they are being moved back where possible.

Adults with learning disabilities have a higher prevalence of gastrointestinal cancer, early onset dementia, overweight, obesity and osteoporosis, as well as difficulty with eating, drinking and swallowing. One in three has unhealthy teeth and gums. Due to increasing life expectancy, people with learning disabilities are now more likely to develop long-term conditions such as diabetes.⁶

In 2014/15, of the 725 people with a learning disability aged 18-64 years, 90 (12%) were in paid employment.⁵ The gap in the employment rate between those with a learning disability and the

¹ Mencap. <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability> [Accessed 02/09/2016]

² Public Health England. Improving Health and Lives. Available at: <http://www.improvinghealthandlives.org.uk/numbers/laestimates> [Accessed 02/09/2016]

³ Mencap. Health - what we think. 2016. Available at: <https://www.mencap.org.uk/about-us/what-we-think/health-what-we-think> [Accessed 30/06/2016]

⁴ Institute of Public Care. Projecting Adults Needs and Service Information (PANSI). Available at: www.pansi.org.uk (Registration required) [Accessed 30/06/2016]

⁵ Health and Social Care Information Centre. Community Care Statistics, Social Services Activity, England - 2014-15.

⁶ Emerson E, Baines S (2010). Health Inequalities and People with Learning Disabilities. Improving Health and Lives: Learning Disabilities Observatory. PPT presentation, available at: http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf [Accessed 02/09/2016].

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overall employment rate was 62 percentage points in Brighton and Hove.⁷

The Adult Social Care Survey asks those receiving adult social care services how satisfied or dissatisfied they are with indicators of quality of life, such as personal cleanliness and safety. These answers are then combined to give an overall score of social care related quality of life. In 2014/15 Brighton & Hove scored 19.5 points out of a possible 24 for this measure, which is slightly higher than the national average of 19.1.⁸

The survey also asks users of social care if they feel they have control over their daily life. Locally 79% feel they have as much control as they want or an adequate level of control over their daily life. Again this is slightly higher than the national average of 77%.⁸

When asked about satisfaction levels of care and support services, 66% of users of local services were either extremely or very satisfied with their care and support. The national average was 65%.⁸

Also, 69% of those who are using care and support services in Brighton and Hove, said that they feel as safe as they want, which is the same as the national figure.⁸

Where we are doing well

A local Learning Disability Strategy has been developed. 'A Good, Healthy and Happy Life' is our plan for adults with a learning disability for 2015 – 2019.

An action plan has been developed to address the four main areas identified in the strategy as being important to people with a learning disability:

1. Being my own person
2. Feeling a part of things
3. My choices, me decisions
4. Healthy and happy

As at March 2015, there were 993 people aged 14 or over recorded on a GP practice's learning

disability registers. In total, there were 1,255 registered patients identified as having a learning disability. Every adult or young person aged 14 or above on the learning disability register is entitled to an annual health check. In 2014/15, 475 people (48%) received an annual health check, compared with 251 in 2008/09 (33%).^{9,10}

All those who are on the learning disability register are also entitled to a health action plan. In 2014/15, 185 people (19%) received a health action plan. Although this percentage is low, 87% of health action plans that were completed also contained a health improvement plan.

Although the proportion of those on the learning disability register who have had a health check has increased over recent years, there is still a large gap between the estimated number of people with a learning disability in the city (4,746 aged 18-64) and registered patients who have been identified as having a learning disability (1,255 all ages).

Under the Transforming Care Agenda the number of people with a learning disability in a specialist hospital placement has been reduced from 14 people in 2015, to 8 in 2016.

Brighton & Hove City Council has also developed an Enhanced Crisis Response provision within our Community Learning Disability Team to continue to support discharge from specialist hospital placements and also to prevent future admissions.

The 2014 Joint Health and Adult Social Care Learning Disability Self Assessment Framework collected responses from 30 out of 47 GP practices in the city.

The Annual Best of Health event is organised jointly with Public Health and the Community Learning Disability Team. The event demonstrates ways to improve health and to take part in healthy activities. In 2014, 94% of people who attended rated the event as very good and 83% learnt new ways to be healthy.

Locally 12% of those with a learning disability are in paid employment, compared to 6% nationally.⁵ The

⁷ Public Health Outcomes Framework tool. Available at: <http://www.phoutcomes.info/> [Accessed 02/09/2016]

⁸ Adult Social Care Outcomes Framework. Available at: <http://ascof.hscic.gov.uk/Outcome> [Accessed 02/09/2016]

Only a sample of users of social care has been surveyed for the measures mentioned, and the sample is not comprised exclusively of those with learning disabilities.

⁹ Health and Social Care Information Centre, GP Contract Services 2014-15, Learning Disability Health Check Scheme: <http://www.hscic.gov.uk/pubs/gprac1415> [Accessed 20/07/2016].

¹⁰ Improving Health and Lives, Learning Disability Health Checks 2008-9 to 2011-12. Available at: <http://www.improvinghealthandlives.org.uk/numbers/healthcheck2014> [Accessed 02/09/2016]

gap in the employment rate between those who have a learning disability and the overall employment rate is 62% locally and 67% nationally.⁷

In 2015/16 support with money was commissioned for 75 individuals with learning disabilities in the city; 72% had been identified as vulnerable to financial abuse, and in many cases support with money was part of a protection plan.¹¹

Speak Out Advocacy supports adults with learning disabilities to have a voice and be heard by Social Care and Health Services. Speak Out is commissioned by the CCG to provide intelligence from Brighton & Hove residents with learning disabilities on their experiences of health services and how these can be improved. In 2015 they held six focus groups and nine 1:1 interviews to gather information on Brighton & Sussex Universities Hospitals Trust support for patients with learning disabilities. Four carers/support workers for individuals with complex needs were also asked for feedback. In total 48 people were consulted.

They found that there is clearly good practice within the hospital setting in supporting people with learning disabilities. However peoples' experiences are often quite mixed. Areas to improve across hospital services included:

- Understanding the diversity of experience of people with learning disabilities
- Ensuring people are treated with respect, dignity and given privacy
- Not making assumptions about someone because they have a learning disability
- Lack of accessible information - written and verbal
- Many people talked about not understanding explanations by Doctors. Some people complained about being bypassed and not being involved in discussions
- Finding out and recording the communication needs of individuals with learning disabilities
- Changing dates and cancelling appointments and treatments is very difficult for some people with learning disabilities
- Co-ordinating with and Involving support workers/carers

- Anxiety in waiting and isolation
- Using individuals' Hospital Passports and Other tools to help Health Staff
- Using Learning Disability Liaison Nurses
- Supporting patients with complex learning and physical disabilities.

Local inequalities

Of the 725 people with a learning disability aged 18-64 years living in Brighton & Hove who were known to the City Council, 435 were male (60%) and 290 were female (40%).⁵

Nationally, learning disabilities are three times more prevalent in South Asians than in other ethnic groups.¹²

Both nationally and in the city, learning disabilities are more prevalent at ages 18-34 years.⁴

Some GP practices have lower prevalence rates for the number of people with learning disability on registers, which may be a health inequality linked to deprivation. However this may also be due to differences in the way GP practices identify and record patients with learning disabilities.

Engagement with people with learning disabilities who use day services, and their carers, highlighted very little knowledge about direct payments and personal budgets.

The current number of people with a learning disability receiving a direct payment is 149.

Predicted future need

It is estimated that there will be a 3.6% increase in the number of adults with learning disability in the next five years and a 6.8% increase in the next ten years (Table 1).⁴

There will be an estimated additional 74 people with moderate or severe learning disabilities in the next ten years.⁴

The age group with the highest predicted increase of those with learning disabilities is 55-64 years old.⁴

It is estimated that by 2020 there will be an increase of between 89 to 244 people with a learning disability eligible for local social care.¹³

¹¹ Money Advice Plus. Call for evidence. JSNA 2016.

¹² Emerson et al (1997). Is there an increased prevalence of severe learning disabilities among British Asians?, *Ethnicity and Health* 2: 317-321

Table 1: Estimated number of people aged 18 and over with learning disability, Brighton & Hove, 2015 to 2030

	2015	2020	2025	2030
Learning disability	5,532	5,732	5,912	6,149
Moderate or severe learning disability	1,190	1,230	1,264	1,311

Source: Institute for Public Care. PANSI⁴

What we don't know

There is no evidence available on sexual orientation, religious belief, ethnicity or those who identify as transgender.

Key evidence and policy

Following the Winterbourne View Scandal, the national Transforming Care Agenda, led by NHS England has developed a new national plan for supporting people with learning disabilities:

'Building the Right Support: A national plan to develop community services and close inpatient facilities for people with a learning disability and / or autism who display behaviour that challenges, including those with a mental health need.' NHS England 2015.

<https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

There is little data available on cost-effectiveness of services for people with learning disability, but a UK study has shown that 74% of social care costs are spent on accommodation.¹⁴ A US study suggests semi-supported living is more cost-effective than residential care.¹⁵

¹³ Emerson E, Hatton C (2010). Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England, Centre for Disability Research.

¹⁴ Strydom A, Romeo R, Perez-Achiaga N, Livingston G, Kind M, Knapp M, Hassiotis A (2010). Service use and cost of mental disorders in older adults with intellectual disability. *British Journal of Psychiatry*, 196: 133-138.

¹⁵ Felce D, Perry J, Romeo R, Robertson J, Meek A, Emerson E, Knapp M (2008). Outcomes and costs of community living, semi-independent living and fully staffed group homes (2008). *American Journal of Mental Retardation*, 87-101.

Psychological therapies, annual health checks and supported employment policies are all cost-effective.¹⁶

Recommended future local priorities

1. The learning disability commissioning plan will be revised and implemented to meet the needs for current and future accommodation and support options.
2. The Adult Learning Disability JSNA recommendations should continue to be implemented to meet unmet needs relating to information, housing, social care and employment; and focus on those in transition with the most complex needs. Overseen by the Learning Disability Partnership Board.
3. The community learning disability team, specialist mental health nurse and hospital learning disability liaison team should continue to support and promote the health of people with learning disabilities.
4. Further work needs to be carried out to ensure that people with learning disabilities and their carers have information about and access to personal budgets and direct payments.

Key links to other sections

- Carers
- Employment and unemployment
- Housing
- Good nutrition and food poverty
- Children and young people with disabilities and complex health needs
- Healthy weight (Adults and older people)
- Adults with autistic spectrum conditions
- Adults with physical disabilities
- Adults with sensory impairments
- Dementia
- Primary care
- End of life care

¹⁶ NHS Brighton & Hove and Brighton & Hove City Council. JSNA for Adults with Learning Disability. March 2011. Available at <http://www.bhconnected.org.uk/content/needs-assessments>

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Further information

Brighton & Hove JSNA for Adults with Learning Disability. March 2011.

<http://www.bhconnected.org.uk/content/needs-assessments>

Improving Health and Lives – Learning Disabilities Public Health Observatory.

<http://www.improvinghealthandlives.org.uk/>

Mencap <http://www.mencap.org.uk/>

Disability in Brighton & Hove data report and Equalities profile, 2015.

<http://www.bhconnected.org.uk/content/reports>

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