

## Learning Disabilities

### What does this mean?

Learning Disabilities is the preferred term used by the UK government, replacing the term “mental handicap.” The term was introduced during the 1990s, and describes the population defined in the Health and Social Care White Paper, ‘Valuing People’<sup>1</sup> as having:

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



This definition is broadly consistent with the World Health Organisation’s ‘International Classification of Disease’ (ICD-10), which uses the term “mental retardation.” The term “intellectual disability” is also used increasingly in international circles, to describe the same population.

In Bristol the preferred term of use is “learning difficulties.” This is used at the request of local people, helping to ensure that that they are not “labelled as disabled”, a term associated with stigmatisation. This view relates to the social model of disability. The social model adopts the view that society disables people with impairments, due to its inability to meet all needs to all people.

Use of the term “learning difficulty” can cause some misunderstanding as the same term is used in education to describe people who have specific learning difficulties, such as dyslexia. Specific learning difficulties are not associated with an impairment of intelligence.

### Why is this important?

People with learning disabilities are amongst the most vulnerable and socially excluded in our society. They experience multiple health inequalities, including reduced access to employment, poor access to good housing and increased rates of bullying and harassment. They have higher levels of ill-health and much higher rates of premature death than the general population.



\*Photo from Photo Symbols 3

When using health and social care services people with learning disabilities experience inequalities and discrimination due to lack of knowledge and understanding, negative attitudes, poor access to services and lack of appropriate service provision relevant to their needs.

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## What do we know about people with learning disabilities in England?

Valuing People suggests that people with learning disabilities constitute 2% of the general population. Emerson and Hatton<sup>2</sup> estimate that 828,000 adults with learning disabilities currently live in England, 85% of which have mild learning disabilities. Just under 0.5%, (177,000 people) access specialist learning disability services.

Changing demographics, social expectations and medical advances are resulting in different patterns of needs for future service planners. Recent studies suggest the numbers of people with learning difficulties are increasing, with one estimate<sup>2</sup> that this will increase by 14% between 2011-2021. Changing patterns of need include: an increasing number of parents with learning disabilities, older adults with learning disabilities and young people with severe and complex needs.

### Learning Disability Facts

- Males experience learning disability more frequently than females.
- Down's Syndrome is the most recognised cause of learning disability, with 1 in 800 born with the condition.
- Approximately 1 in 200 people have an Autistic Spectrum Disorder, with an estimated 50% associated with learning disabilities.
- One study<sup>3</sup> suggests that people with learning disabilities have higher rates of early death and are 58 times more likely to die before the age of 50 years, than the general population.
- People with learning disabilities have a different picture of health needs than the general population. and are more likely to experience a wide range of conditions including epilepsy, mental illness and dementia.
- They have higher rates of vision and hearing loss and are less likely to have received regular physical health, dental, vision or hearing checks.
- Women are much less likely to access breast or cervical screening.
- They have reduced access to health promotion initiatives including healthy diet and exercise, smoking cessation and sexual health.
- An estimated 60% of adults with learning disabilities live, or get their main support from a family carer, 40% of which are over 60 years old. The majority of people with severe and profound multiple learning disabilities live with a parent.
- Over 4 in 5 of people with learning disabilities of working age are unemployed.
- During 2006/07 total government spending on learning disability services was about £5.57 billion



## What is the picture in Bristol?

We do not know the exact number of people with learning difficulties living in Bristol. The best source of information is through GP learning difficulty practice registers. These have been compiled by sharing specialist learning disability health and social care registers with GPs.

At present approximately 1,800 adults with learning disabilities are identified on practice registers, being approximately 0.4% of the Bristol patient population. An evaluation of the needs of 1,078 adults with learning difficulties on GP practice registers in Bristol was carried out in 2008. These findings discovered:

- More than 3 out of 4 women with Down's syndrome were overweight or obese.
- 1 in 5 patients were diagnosed with epilepsy, compared with less than 1 in 100 in the general population.
- Twice as many 16-24 year olds were found to have asthma, compared with the same age group in the general population.
- The prevalence of type 2 diabetes was substantially higher and those affected much younger than in the general population.
- One in three of the patients aged 35-44 years were recorded as having mental ill-health.
- 60% of patients were overweight or obese and 7% had a BMI of 40 or more.
- People with asthma, mental ill-health or behaviour problems had very high rates of smoking.

## What is happening in Bristol to support people with learning disabilities?

- All GP practices in Bristol have a learning disability practice register. Since 2009, 50 out of 56 practices have engaged with a voluntary Directly Enhanced Scheme (DES) where they offer an annual health check to patient with learning disabilities. In the first 14 months, just over 700 people had a health check. Public Health will be producing a report in 2011, further analysing the health needs of this population.



\*Photo courtesy of Mencap

- NHS Bristol employ a team of health trainers with learning difficulties, who work with other people with learning difficulties to help them access health care. They also employ a staff member with learning difficulties who helps make information accessible
- Both University Hospitals Bristol and the North Bristol Trust Acute Trusts have learning disability liaison nurses working in their hospitals. NHS Bristol employs a public health specialist for people with learning difficulties.
- Bristol Learning Difficulty Service has 3 multi disciplinary community teams and an intensive response team, that work across the city.
- Bristol Link has an active learning difficulties working group.
- People First, a self advocacy organisation, organise regular information days on a variety of topics. Other activities include Black and Asian members group meetings, a parents support group and a dating agency Stars in the Sky.
- Bristol Learning Difficulties Partnership board has representation from all stakeholder groups and is the main strategic forum for commissioning, planning and developing services for people with learning difficulties. The board oversees the implementation of Valuing People in Bristol.

## What do people with learning difficulties in Bristol tell us that they want?

In 2010, Bristol Link Learning Difficulties working group told NHS Bristol that they had 8 key issues that they wanted to be met locally. These included:

- People should communicate with them in a way that they understand.
- They need to give permission themselves before anything happens to them.
- Healthcare professionals should make sure that they understand all of the information about their health and health treatment.
- Information about their learning difficulty should be recorded and shared between different health staff.
- Individual needs are different should be considered when organising healthcare
- People should be told about and helped to access services they don't know about.
- Time needs to be taken to understand what stops some people attending health appointments
- Services should be easy to get to and use.



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## How to make your information more accessible

The Disability Discrimination Act introduced a duty to make reasonable adjustments to ensure people with learning difficulties receive equal access to health care. Reasonable adjustments include the need to make health and social care information accessible. The following lists some of the methods you should consider to make information accessible:

- Use easy words and short sentences.
- Don't put lots of words on a page. Use pictures and photos.
- Do not use jargon.
- Use large type. 20 point font is recommended.
- Use clear writing like this. This is simple font. Use a font like arial or comic sans.
- *Do not use italics or fonts like this. This is Times New Roman.*
- DO NOT WRITE EVERYTHING IN CAPITAL LETTERS.
- Use capital letters and small letters like this.
- Not everyone understands symbols. Pictures and photos are better.
- Find out if people use British Sign Language. It may be their first language.
- Make a tape of the words in easy English.
- Think about making a cd or video to get your message across.

**Most importantly, ask people with learning disabilities what they think. Don't think that everyone with an impairment needs the same thing. Everyone's access needs are different.**

## References

1. ***Valuing People; a New Strategy for Learning Disability for the 21<sup>st</sup> Century***, Department of Health (2001).
2. ***People with Learning Disabilities in England***, Centre for Disability Research: Lancaster University, Emerson E, Hatton C. (2007).
3. ***Mortality in people with learning disability: risks, causes and death certification findings in London***. Dev Med Child Neurology 40(1) 50-6, Hollins S, Attard MT, von Fraunhofer N, McGuigan S, Sedgewick P (1998)

## Further Reading

- ***Death by Indifference***, Mencap (2007), London: Mencap.
- ***Healthcare for All: Independent inquiry into access to healthcare for people with learning disabilities***, Michael J (2008).. London. Aldrick Press.

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