

Leicestershire Joint Strategic Needs Assessment 2015

Chapter 8: **Learning disabilities**



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CHAPTER 8 - LEARNING DISABILITIES

The most widely adopted definition of learning disability is:

- a significantly reduced ability to understand new or complex information or to learn new skills;
- a reduced ability to cope independently; and
- an impairment that started before adulthood, with a lasting affect on development.

People with learning disabilities are more likely to have co-morbid conditions such as autism, mental health conditions, physical and sensory impairments. At the most complex end of the scale of learning disabilities are people who are described as having a "profound and multiple learning disability" (PMLD) or a profound and multiple intellectual disability (PMID). Some people exhibit behaviours which challenge services. Challenging behaviour is described as;

"behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to limit or delay access to and use of ordinary community facilities"

People with learning disabilities are more likely to experience health inequalities and have a lower life expectancy than the rest of the population as a result. Following an increasing wealth of evidence into health inequalities a Confidential Inquiry into the premature deaths of people with learning disabilities took place from 2010 to 2013.

The inquiry found that on average men with learning disabilities died 13 years earlier than men in the general population, women with learning disabilities, died on average, 20 years earlier than women in the general population. This was attributed to delays in identifying health conditions and accessing treatment.

More recently, following an expose into the abuse of people with learning disabilities at the mental health hospital "Winterbourne View" by the BBC programme Panorama, there has been a drive to reduce admissions of people with learning disabilities (and/or autism) into mental health inpatients and alternative hospital settings. NHS England, working with ADASS and the Local Government Association (LGA) have published a national implementation plan called "Building the Right Support" alongside a service model for Commissioners to support the development of better care options in the community.¹

There is a greater emphasis on the development of care and support in community based settings, this has been emphasised through the Department of Health Green paper "No Voice unheard, no right ignored" (March 2015).² The paper describes four things it wants to achieve by enacting legislation and strengthening existing guidance on:

- people in charge, supported by family and friends;
- inclusion and independence in the community;
- the right care in the place; and
- very clear accountability and responsibility through the system.

1. Evidence of Need

Children

- Data has been collected about children with a learning disability known to GP's. However, the returns (total of 240) are assumed to be vastly under reported. There is no evidence to explain the under identification, it is however, assumed that families maintain contact with their community paediatrician rather than go to their GP with concerns regarding the general health of their child.³
- 3.3% of school pupils have a learning disability. 2700 children have a statement of educational need (SEN). This number will include children who do not have a learning disability as described earlier in the chapter.

Adults

- Estimates of learning disability prevalence indicate there are 9,723 people with a learning disability across Leicestershire. This represents 0.40% of the total population of Leicestershire which is significantly lower than the England average (0.47%).
- Information collected from GP practices in 2014 shows that 2705 (over 18) people with learning disabilities are known to GP surgeries.⁴
- 1500 people with learning disabilities are known to adult social care. This represents 3.3 per 1000 population which is significantly lower than the national rate of 4.3 per 1000 populationⁱ

- Of those known to GP's 30% (656) had a complex and profound learning disability and 18% (346) also had autistic spectrum disorder.
- 68.2% of all eligible adults with a learning disability in Leicestershire had a GP health check in 2011/12. This is significantly higher than the England average of 52.5%. Whilst the number of people in having health checks is higher than the England average, people with learning disabilities and family carers have expressed concern over the consistency of Health Checks in Leicestershire.
- 68% of people with a learning disability known to GP's had a record of their body mass index. Of those 35% had a body mass index of 30 or higher and are consequently categorised as having excess weight. 1.2% were deemed to be underweight.
- A cohort study in the UK has concluded that people with learning disabilities are significantly less likely to receive cancer screening tests than those without learning disabilities.⁵ This pattern is reflected in the latest data for Leicestershire.
 - In Leicestershire, 64.3% of the eligible female population (aged 25-64 years) had a cervical smear test in the last three years (1st April 2011 to 31st March 2014 inclusive). In the same time period, 132 females with LD were screened for cervical cancer, only a fifth (19.7%) of the eligible female population with LD.³
 - In Leicestershire, 58.5% of the eligible female population (aged 50-69 years) were reported as having received breast cancer screening in the last three years (1st April 2011 to 31st March 2014 inclusive). In the same time period, 120 females with LD were screened for breast cancer, 41.0% of the eligible female population with LD.³
 - In Leicestershire, 79.0% of the eligible population (60-69 years) were reported as having received bowel cancer screening in the last two years (1st April 2012 to 31st March 2014). In the same time period, 154 people with LD were screened for bowel cancer, 64.7% of the eligible population with LD.³
- The median age of death of people with learning disabilities in Leicestershire is 57 which is comparable to the population of people with learning disabilities in England but is significantly worse than the average age of death (75.5) for the general population in the most deprived areas of Leicestershire

- There is a higher prevalence of learning disability in South Asian and African Caribbean populations but an under presentation in the uptake of learning disability services.⁶
- There is very little research on the numbers of people with learning disabilities from the Lesbian, Gay and Bi sexual (LGB) community. The Leicestershire Equality strategy (2013-2016) acknowledges that there are approximately 6-10 % of any population are LGB. Based on this approximation there are between 583 and 972 adults with learning disability who identify as LGB.⁷

Table 1: Estimated Number of Adults with Learning Disabilities, England 2010

Age Group	Men with Learning Disabilities in Population	Men Known to LD Services	Women with Learning Disabilities in Population	Women Known to LD Services	Adults with Learning Disabilities in Population	Adults Known to LD Services
18-19	22,773	5,799	13,892	3,308	36,665	9,107
20-29	110,360	23,265	73,289	17,377	183,649	40,642
30-39	97,876	21,553	67,960	16,686	165,836	38,238
40-49	105,945	25,346	73,649	19,238	179,593	44,585
50-59	76,747	15,292	55,113	12,995	131,860	28,286
60-69	61,059	10,731	44,215	8,698	105,275	19,429
70-79	34,315	4,287	26,898	3,583	61,214	7,870
80+	16,851	1,631	18,801	1,681	35,652	3,312
Total	525,927	107,904	373,817	83,565	899,744	191,469

Source: Taken from People with Learning Disabilities in England 2010⁸

- The prevalence of dementia amongst older adults with learning disabilities is 22% (the prevalence is 6% for the general population of those aged 65+). Onset for people with Downs syndrome is estimated to be 30-40 years earlier than for the general population.⁹

2. Service Review

Too many people with learning disability or autism are admitted to inpatient settings and stay there for long periods of time, in some cases years, very far from home¹⁰. These people could be supported in their community, closer to family or friends. This is not just costly for the individuals and their families but they can also be a poor use of taxpayer money as many of these inpatient placements are very expensive. The 2014 learning disability census data showed an average cost per person commissioned by the NHS of over £177,000 a year. In comparison, fully staffed

average living costs in the community for those with higher needs are £140,000 a year – over 20 per cent less.¹¹

In 2011/12, the gross current expenditure for residential personal social services per 1,000 people known to local authorities with learning disabilities in Leicestershire was £27.70. This is significantly higher than the national expenditure of £21.50 per 1,000 people.¹²

In 2014 in Leicestershire, £87 was spent per head on adults aged under 65 with learning disabilities. This is lower than the England average (median) of £94.¹³

3. Gap Analysis

There is a lack of data on the gender, sexual orientation and ethnicity of people with learning disabilities in Leicestershire.

Across Leicestershire there is a high incidence of dementia in people with learning disabilities particularly those with Downs Syndrome.

There is a need to better understand the contributors to the early morbidity of people with learning disabilities.

4. Recommendations

It is recommended that:

- Minimum standard outcome frameworks are developed to differentiate between providers who offer support in specialised areas such as supporting people with behaviour that challenges.
- There is further development of services which will support people into employment and work related activity
- There is an increase the uptake of health screening services.

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