7.2 Adults with learning disability and the health issues they face

People with learning disabilities have a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which starts before adulthood, and has a lasting effect on their development\(^1\).

There are multiple causes of learning disability, most occurring before a baby is born or at birth. Whatever the cause, the outcome is that to a greater or lesser extent a person with learning disability finds it harder to learn, understand and communicate than someone without a learning disability. There is a spectrum of learning disability from very mild to very severe. Although learning disability itself is not an illness or a disease, people with a learning disability are at greater risk of having physical and mental health conditions that need treatment and care.

Because of the nature of learning disability, people often experience more difficulty than those without a learning disability in accessing services, including health and social care, education, benefits and housing support.

Health concerns for people with learning disabilities

People with a learning disability are at greater risk from some diseases and this risk increases with age. For example, there is a strong association between Down’s syndrome and cardiac problems. A Health Equity Audit\(^2\) carried out for Barking and Dagenham in 2010 identified some common health issues for people with learning disability at a national level, as comprehensive local data was not available:

- Around one person in three with learning disabilities is obese, compared with one in five of the general population.
- The incidence of respiratory disease is three times higher in people with learning disabilities than in the general population, and the most common cause of death.
- Coronary heart disease is the second most common cause of death in people with learning disabilities.
- Some 40% of people with learning disabilities have a hearing impairment and many have common visual impairments.
- The rate of dementia is four times higher and the rate of schizophrenia three times higher than in the general population. People with Down's syndrome are particularly at risk from developing dementia.
- People with learning disabilities tend to have substantially less bone density and experience higher levels of osteoporosis.

\(^1\) Valuing People: A New Strategy for Learning Disability for the 21st Century, Department of Health, 2001
\(^2\) Health Equity Audit: People With Learning Disabilities, V Day for NHS Barking and Dagenham 2010 (Unpublished)
Epilepsy is over 20 times more common in people with learning disabilities than in the general population. Sudden unexplained death in epilepsy is five times more common in people with learning disabilities than in others with epilepsy.

Both adults and children with learning disabilities are at an increased risk of early death; those under the age of 50 are 55 times more likely to die prematurely, and for those over 50, the risk is 58 times more likely.

Patterns of illness have a significant impact on use of secondary care. Some 26% of people with learning disabilities are admitted to hospital each year, compared with 14% of the general population.

The investigation into the deaths of six people with learning disabilities carried out by the Health Service Ombudsman in 2008/09 was the latest in a number of reports highlighting systematic failings in services. It concluded that there were “Significant and distressing failures in service across both health and social care, leading to situations in which people with learning disabilities experienced prolonged suffering and inappropriate care”. It further stated that “the findings of our investigations pose serious questions about how well equipped the NHS and councils are to plan for and provide services tailored to the needs of people with learning disabilities”. The subsequent inquiry into access to healthcare for people with learning disabilities drew attention to the challenges for people with learning disabilities in accessing healthcare services and made clear statements about how these should be addressed. In response to the Ombudsman Report a local six lives action plan was delivered and agreed across the partnership.

How many adults living in Barking and Dagenham live with learning disabilities?

According to estimates by Projecting Adult Needs and Service Information, based on the Institute of Health research prevalence figures and ONS population projections, an estimated 3,013 adults (age 18 and over) in Barking and Dagenham in 2015 are living with a learning disability. This number is predicted to increase by 761 (25%) by 2030.

These predictions are based on prevalence base rates, adjusted to take account of ethnicity (i.e. the increased prevalence of learning disabilities in South Asian communities) and of mortality (increased survival rates of young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities). Therefore, figures are based on an estimate of prevalence across the national population.

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5 Getting it Right Six Lives Audit of Health and Social Care in Barking & Dagenham/Action Plan 2010

The Health Analytics GP Information System records 832 people as being known to have a learning disability\(^7\). Of the current total 832 service users, 127 are aged under 18 with 705 aged over 18 of this figure 424 adults are receiving a service. This number is far below expected prevalence, which suggests that large numbers of people with Learning Disabilities remain undiagnosed (Figure 7.2.1).

**Figure 7.2.1: Patients with learning disabilities on disease register, prevalence, London CCGs, 2013/14**

In 2013/14, the percentage of adults with learning disabilities known to the Council who were living in settled accommodation in the community at the time of their assessment or latest review was 85.3% (Figure 7.2.2). This was highest number of settled accommodation across London the closest comparator is Greenwich, Lewisham and the London (68.6%) and England averages (74.9%). Living in settled accommodation means that they were living somewhere where their right to live there was secure, i.e. not in hostel or other temporary accommodation.

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\(^7\) Quality and Outcomes Framework (QOF), 2009/10
The majority of adults with learning disabilities are within working age (18-64 years old)\(^8\), but only 6.7% of those known to social services are in employment\(^9\) (Figure 7.2.3). This is similar to the national average but much lower than the London average; however, this may reflect the higher unemployment levels in the total working age population in Barking and Dagenham compared with the rest of London.

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\(^8\) Joint Strategic Needs Assessment, 2010

\(^9\) Adults who are: 1 – working full-time as an employee or self-employed (16 or more hours per week); 2 – working as an employee or self-employed (5 to 15 hours per week); 3 – working as an employee or self-employed (1 to 4 hours per week)
Over the next twenty years the number of people with learning disabilities is expected to increase steadily, largely due to the overall population increase. By 2030, around 120 more people with moderate or severe learning disabilities will live in the borough; many of these will need personal care packages, and the majority are likely to need ‘reasonable adjustments’ to be made by services, or to have enhanced advocacy services and support to ensure that they are able to understand and access the services they need. As more people with learning disabilities are identified, the demand for the London Borough of Barking and Dagenham’s adult social care services, including Community Learning Disabilities Team is likely to increase.

Many of the recommendations set out in the Health Equity Audit are still relevant and continue to need to be implemented including:

**Primary care**
Increase the take up of the Directed Enhanced Service (DES) for annual health checks for people with learning disabilities.

For a GP with a special interest in learning disabilities to continue to provide leadership and support to primary care, and to advise the CCG on the needs of people with learning disabilities.

**Primary and community care**
On-going review of Health Action Plans (HAPs), with agreement on the contribution of primary care, so that annual health checks and HAPs are completed efficiently and without duplication.

Develop a system for population analysis of the health needs identified from the annual health check, and use as a basis for planning both specialist and generalist services for people with learning disabilities.

**Community services**
Review the governance, organisation, and roles of the various members of the Community Learning Disabilities Team, building both strong leadership and advocacy across health and social care for people with learning disabilities and ensuring expert care at all times.

Review the access to information and the information needs of health and care professionals, so that all staff use a single system based on person centred plans. Develop efficiency and performance measures as a basis for determining caseload and numbers of posts in the Community Learning Disabilities Team, including a review the role and responsibilities of Health Facilitators.

On-going review of Health Action Plans, with particular regard to the format to develop Plans that are more user-friendly for both individual and professional. Plans should include a summary of critical needs of the individual, and be both more compact, and easier to update.
Identify and address service gaps, negotiating with commissioners as necessary how services should be developed. Transition from children’s to adult’s services has been identified as any area needing particular attention.

**Current major programmes of service change**

The Council is currently working to personalise a suite of supported living schemes which were put out for tender and awarded to new contractor sin February 2015. The timescale for this is to November 2015. At the same time, all users receiving services under a block contract arrangement with the Osborne Partnership are being reviewed with a view to moving their eligible care to a personal budget with which they can make choices about the services they receive. This is alongside the closure of the Maples day service, which is similarly necessitating the review of all service users’ care. It is expected that these will conclude around September/October 2015.

These three schemes present an opportunity to ensure that health needs of service users are being properly considered as part of the support planning for their future, personalised care. A review should be timetabled for January 2016 to consider how effectively health improvement has been considered as part of this substantial programme of support planning.

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**Recommendations for Commissioners**

Commissioners continue to address not only specialist services but more particularly the general health needs and ‘reasonable adjustments’ that must be made by all mainstream services, including health improvement and promotion, acute, community and mental health. There should be a particular focus in care pathways for those conditions which have a higher prevalence in people with learning disabilities. Specifications should be written and included within all contracts.

**Learning Disabilities Partnership Board**

The Board and its subgroups should continue to be reviewed against key actions outlined in the Winterbourne View Final Report and Concordat and the Health and Social Care self assessment template and action taken to address shortcomings.

**Preventative care**

Additionally, knowing that there are greater health inequalities and decreased life expectancy for this population, some of which is attributable to lifestyle choices such as diet and smoking, accessible preventative services should be commissioned aimed at bringing about changes in lifestyle.