

## 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<sup>1</sup>.

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<sup>2</sup> 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.
- 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.

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<sup>1</sup> Valuing People: A New Strategy for Learning Disability for the 21st Century, Department of Health, 2001  
<http://www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf>

<sup>2</sup> Health Equity Audit: People With Learning Disabilities, V Day for NHS Barking and Dagenham 2010 (Unpublished)

- 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.

### **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<sup>3</sup>. This number is predicted to increase by 761 (25%) by 2030.

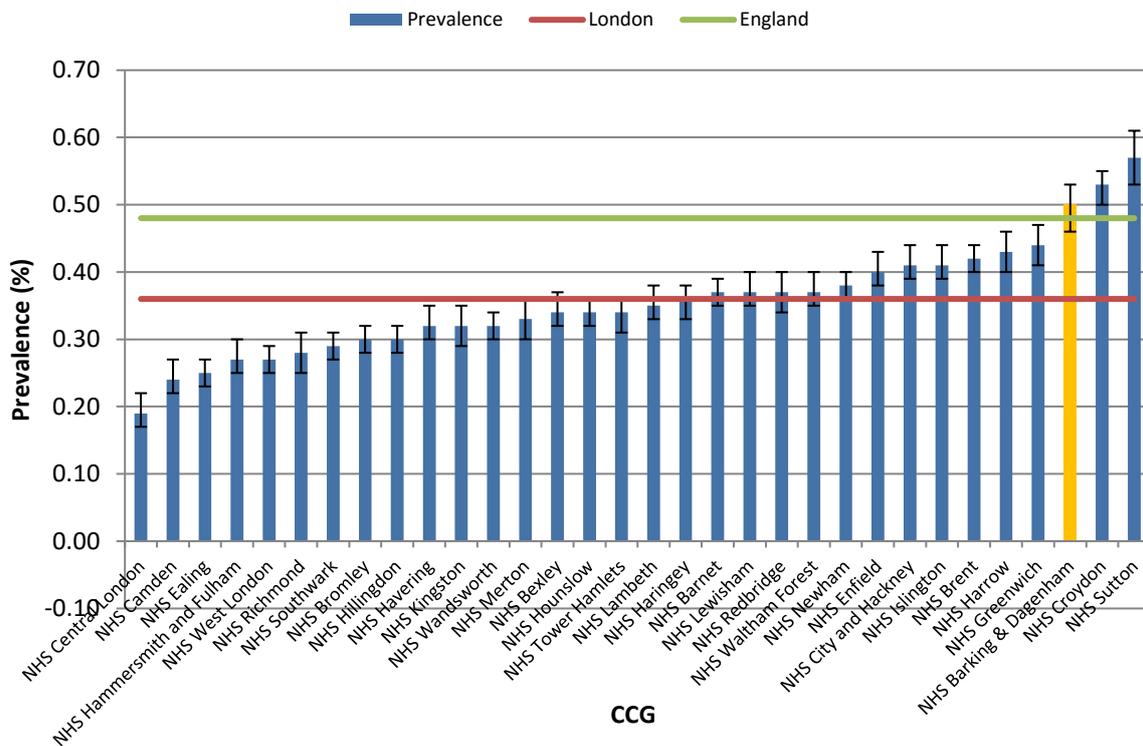
These predictions are based on prevalence base rates, adjusted to take account of ethnicity (i.e. the increased prevalence of learning disabilities in South Asian communities) and of mortality (increased survival rates of young people with severe and complex disabilities and reduced mortality among older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

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<sup>3</sup> 2014 estimates. Projecting Adult Needs and Service Information System (PANSI), 2014. [www.pansi.org.uk](http://www.pansi.org.uk) and Projecting Older People Population Information System (POPPI), 2014. [www.poppi.org.uk](http://www.poppi.org.uk)

The Health Analytics GP Information System records 832 people as being known to have a learning disability<sup>4</sup>. 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**

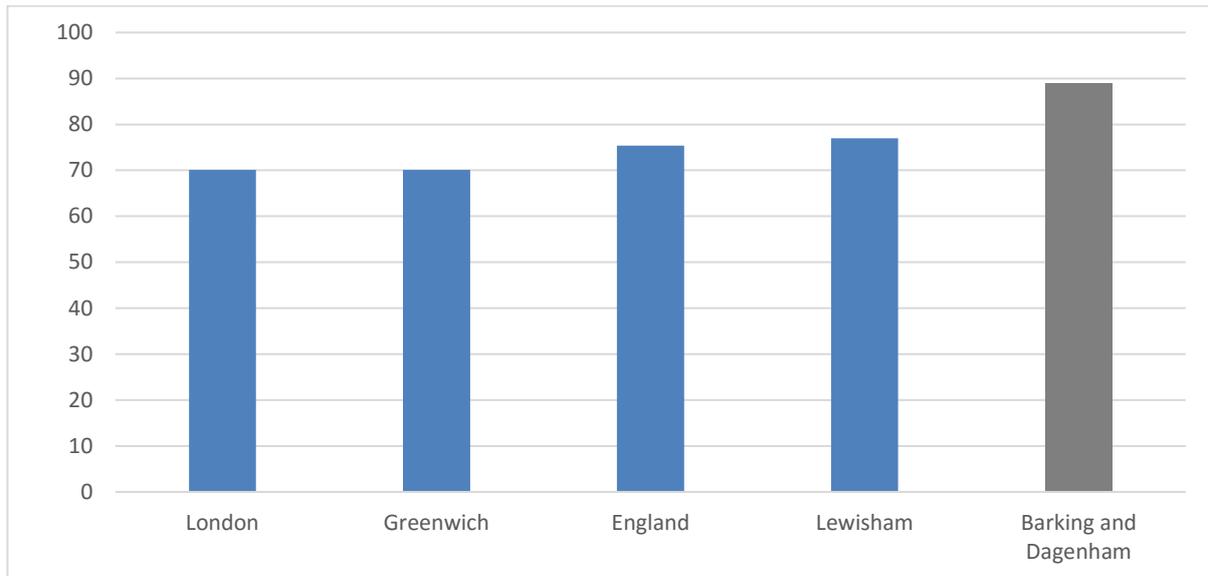


Source: QMAS, HSCIC

In 2015/16, 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 88.9% (Figure 7.2.2). This was highest number of settled accommodation across London the closest comparator is Greenwich, Lewisham and the London (70.1%) and England averages (75.4%). 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.

<sup>4</sup> Quality and Outcomes Framework (QOF), 2009/10

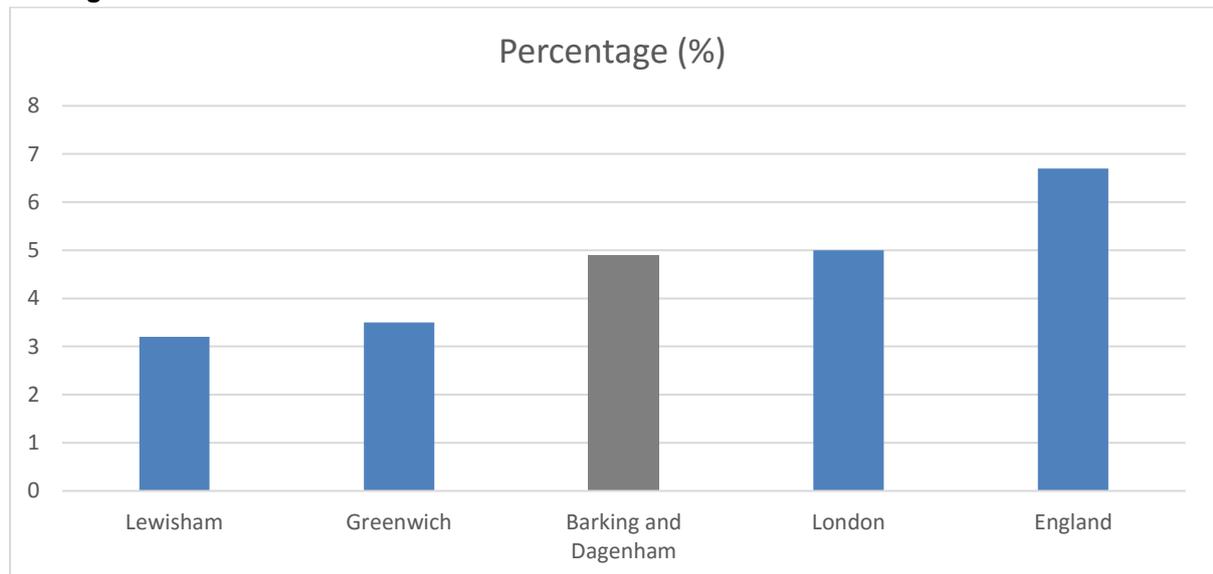
**Figure 7.2.2: Percentage of adults with a learning disability living in stable accommodation, London boroughs, 2015/16**



Source: HSCIC

The majority of adults with learning disabilities are within working age (18-64 years old)<sup>5</sup>, but only 4.9% of those known to social services are in employment<sup>6</sup> (Figure 7.2.3). This is below the national average however, this may reflect the higher unemployment levels in the total working age population in Barking and Dagenham compared with other areas.

**Figure 7.2.3: Adults with learning disabilities known to councils in paid employment, London boroughs 2013/14**



Source: Health and Social Care Information Centre

<sup>5</sup> Joint Strategic Needs Assessment, 2010

<sup>6</sup> 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 actions to address the issues continue to be developed and implemented, including:

### **Primary care**

Since the start of 2016 there has been focused energy and effort from officers in the Borough's Primary Care, Clinical Commissioning Group & Community Learning Disabilities Team to increase the take up of the Directed Enhanced Service (DES) for annual health checks for people with learning disabilities from General Practice (GP) surgeries. Commissioners and Practitioners have attended the GPs Protected Time Initiatives (PTI) forums where the importance of health checks is discussed directly with the GPs and the Practice managers.

There is a named 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.

There is a dedicated Learning Disabilities Liaison Nurse (LDLN) that works across Barking & Dagenham, Redbridge and Havering. The LDLN supports hospital staff to make reasonable adjustments for patients with learning disabilities, ensures patients have a health passport and that patients admission and discharge to hospital is carried out in a user friendly way.

### **Primary and community care**

In order to support the on-going review of Health Action Plans (HAPs), Health Facilitation officers within the CLDT have provided a series of training sessions to providers raising awareness around the process of a health checks and health action plans. This enables the providers to empower service users of their rights and expectations of having a health check.

The CLDT are working with GP practices to validate the number of people held on the GPs register. Validation of the register will assist GPs to prioritise patients that need an annual health check, and also support improved planning both specialist and generalist services for people with learning disabilities.

There is 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 professionals.

Plans include a summary of critical needs of the individual, and to be both more compact, and easier to update.

Commissioners continue to identify and address service gaps, negotiating with providers and ensuring quality assurance of services. The past year has seen an improvement in transition planning from children's to adult's services. Closer partnership working across the age barriers will ensure service users receive a seamless approach.

## **Transforming Care Partnership**

In October 2015 NHS England requested authorities to take the next step of working towards prevention into hospital where it is avoidable and working collectively across geographic borders and services segmented by age to improve outcomes for people with learning disabilities. This approach launched the **Transforming Care Partnership (TCP)**.

A three year plan sets out our vision and confirms the commitment of the Barking and Dagenham, Havering and Redbridge (BHR) Transforming Care Partnership (TCP) for improving the care and support available for children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition<sup>7</sup>. This plan addresses the needs amongst the diversity and complexity of the population for people with:

- A learning disability and/or autism who have a mental health condition such as severe anxiety, depression. Or a psychotic illness, and those with personality disorders, which may result in them displaying behaviour that challenges.
- An (often severe) learning disability and/or autism who display self-injurious or aggressive behaviour, not related to severe mental ill health, some of whom will have a specific neuro-developmental syndrome and where there may be an increased likelihood of developing behaviour that challenges.
- A learning disability and/or autism who display risky behaviours which may put themselves or others at risk and which could lead to contact with the criminal justice system.
- A learning disability and/or autism, often with lower level support need and who may not traditionally be known to health and social care services, from disadvantaged backgrounds, who display behaviour that challenges, including behaviours which may lead to contact with the criminal justice system.
- Adults with a learning disability and/or autism who have a mental health condition or display behaviour that challenges who have been in hospital settings for a very long period of time, having not been discharged when NHS campuses or long-stay hospitals were closed.

This plan, which we acknowledge is iterative, describes:

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<sup>7</sup> Hereafter people with a learning disability and/or autism

- Our TCP governance and programme arrangements for how we intend to deliver on our commitment
- The demographics of the outer north east London area covered by BHR
- The services that are currently commissioned and provided for people with a learning disability and/or autism
- Our ambition and shared vision to improve the quality of care and services over the next three years by implementing the national service model
- Our engagement plan and our high level plans describing how we intend to deliver our ambitious vision.

This plan, which builds on and further develops the good work already in place in each individual borough, has been developed through collaboration across our partnership and through engagement with people who have a lived experience of using the services, community and inpatient clinicians, social care staff, housing departments, health and social care commissioners and primary care providers.

Across BHR we have already made excellent progress in moving away from inpatient care and developing supportive community provision, however we will not stand still as we recognise there is much more to do. The work to be taken forward through this programme will be wide-ranging. Over the coming months we will continue to co-design and co-produce in partnership with people with a learning disability and/or autism, the BHR Learning Disability Partnership Boards, local third sector organisations, national organisations in the health and care system (such as Health Education England) and all members of the partnership.

The BHR TCP workstreams (and leads) are as follows:

- Empowering People and Families
- Right Care, Right Place
- Insight Programme and Quality Assurance
- Workforce Transformation
- Right Care Programme Data and Information
- Transition Special Educational Needs and Development
- Finance and Estates
- Implementation and Risks Management

We will continue develop the Transforming Care Partnership Project Team and governance processes. This will include signed-up Terms of Reference, secondment of resources to the Transforming Care Partnership, and robust governance and reporting to the Programme Board. There will be a full time Programme Manager and Project Leads from each of the organisations are already identified above. Each organisation will delegate responsibilities to other members of staff to report up through the governance process. In this way we will ensure a smooth transition from existing services to the Transforming Care Programme and full integration across the Barking and Dagenham, Havering and Redbridge area.

## **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.

Support initiatives that aim to address the 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.

To develop new models of care to achieve better outcomes for all: focussed on prevention and out of hospital care. This will be driven, in part, through the Transforming Care Partnership.