



# People with Learning Disabilities

*JSNA Needs Assessment*

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**Stephan Brusch**



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# Overview

People with learning disabilities are among the most vulnerable in the community with a wide range of support and access needs. Many people with learning disabilities have additional health problems, physical disabilities and sensory impairments as well as long term health conditions.

There are three overarching outcomes within the NHS, Public Health and Social Care Outcomes framework that relate to people with learning disabilities, namely increasing employment, ensuring that people live in their own home, and reducing health inequalities.

Another national priority is to ensure that people with learning disabilities and or autism who present behaviour that is deemed to be challenging are not admitted to mental health beds for treatment. Instead local community services need to be skilled up to provide appropriate care and support as outlined in the Building the Right Support document and NICE guidances.

The [Confidential Inquiry](#) (Bristol University 2013) into the mortality of people with learning disabilities highlighted that men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population.

The predicted number of people with learning disabilities (18+) in Kingston in 2015 was 3233. According to Public Health England, this is likely to increase by 7 per cent by 2020 and by 20 per cent by 2030. This is in partly due to people with learning disabilities living longer and the rising number of people aged 65 and over. The number of people aged 65 and over with learning disabilities is expected to increase by 12 per cent by 2020 and by 44 per cent by 2030. There are also greater numbers of children and young with special educational needs who have a learning disability.

Already a high proportion of the adult social care budget is spent on people with learning disabilities, with the NHS funding potential high cost continuing healthcare packages. As the numbers and complexity of needs of people is increasing, it is essential that dedicated learning disability services are able to respond to this demand. At the same time, universal services, such as leisure, employers, housing and health services need to become better equipped in making reasonable adjustments to ensure their services are accessible.

A recent inquiry by the [Committee on the Rights of people with disabilities](#) found that the welfare reform has resulted in 'violations of the rights of people with disabilities' (CRPD 2016). People with disabilities including those with learning disabilities are 'disproportionately affected'. The Government has strongly rebutted the report but it is nonetheless likely that people will be impacted by:

- narrowing social care criteria
- changes to housing benefits,

- the criteria for parts of the Personal Independence Payment – brought in to replace Disability Living Allowance
- the closure of the Independent Living Fund
- the Spare Room Subsidy – or ‘bedroom tax’ – did not recognise that disabled people had arrangements that required additional rooms

This could jeopardise independent living and increase debt, which could detrimentally impact this vulnerable group

Responding to these challenges means that all organisations need to work better together. This should be led by strong joint commissioning between Kingston Clinical Commissioning Group and the Royal Borough of Kingston in the form of integrated service provision between health and social care and adult and children’s services. This needs to be underpinned by co-production with people with learning disabilities and their family and carers.

# Introduction

## What is learning disabilities?

The working definition for people with learning disabilities is still derived from the 'Valuing People' White Paper (DH 2001)<sup>1</sup> which defines it as:

- A significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- A reduced ability to cope independently (impaired social functioning)
- Which started before adulthood, with a lasting effect on development and being a lifelong condition.

The presence of a low intelligence quotient, for example an IQ below 70, is not, in itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. 'People with learning disabilities' is an umbrella definition which includes a wide group of people with a range of disabilities, needs and access requirements. Due to this wide range of possible needs, people can be assessed with mild, moderate, severe and profound, multiple and complex disabilities. The British Institute for Learning Disabilities (Holland 2001)<sup>2</sup> offers the following definitions:

**Mild learning disabilities** – A person who is said to have a mild learning disability is usually able to hold a conversation, and communicate most of their needs and wishes. They may need some support to understand abstract or complex ideas. People are often independent in caring for themselves and doing many everyday tasks. They usually have some basic reading and writing skills. People with a mild learning disability quite often go undiagnosed. Most people still need some support with tasks such as budgeting and completing forms.

**Moderate learning disabilities** – People with a moderate learning disability are likely to have some language skills that mean they can communicate about their day to day needs and wishes. People may need some support with caring for themselves, but many will be able to carry out day to day tasks with support.

**Severe learning disabilities** – People with a severe learning disability often use basic words and gestures to communicate their needs. Many need a high level of support with everyday activities such as cooking, budgeting, cleaning and shopping, but many can look after some if not all of their own personal care needs. Some people have additional medical needs and some need support with mobility issues.

**Profound learning disabilities** – People with profound intellectual and multiple disabilities, or profound and multiple learning disabilities (PMLD), can be some of the most disabled individuals in our communities. They have a profound intellectual disability, which means that their intelligence quotient (IQ) is estimated to be under 20 and therefore they have severely limited understanding. In addition, they may have multiple disabilities, which can include impairments of vision, hearing and movement as well as other challenges such as

epilepsy and autism.

People with learning disabilities often have a high level of co-morbidities and other conditions such as autism, difficulties with communicating, sensory impairments, severe and enduring mental illnesses, physical disabilities and higher prevalence of chronic health conditions.

A number of people with learning disabilities need support with behaviour that is deemed to be challenging (including self-injurious behaviour) to services, staff and carers.

Using labels for learning disabilities can be both helpful and unhelpful at the same time. It can be helpful to the person, their family or those people who work with them to understand their needs and what support they might need. However, the categories can be unhelpful if the person with the learning disability is defined as that label, for example 'challenging behaviour'. This can significantly impact on how people view and work with that individual.

### **The social model of disability**

The social model of disability<sup>3</sup> highlights that disability is caused by the way society is organised, rather than by a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for disabled people. When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives. As such the premise is that people with learning disabilities are residents of Kingston first and the focus has to be on citizenship and on what people can do, with support where necessary, rather than on what they cannot do.

### **What learning disability is not**

The term learning disability does not include all those who have a learning difficulty which is more broadly defined in education legislations. In UK education services, the term 'learning difficulty' includes children and young people who have 'specific learning difficulties', for example dyslexia, but who may not have a significant general impairment of intelligence. It also does not include individuals with acquired brain injuries.

### **What causes learning disabilities**

The [Foundation of People](#) (2016) with learning disabilities states that learning disabilities are caused by something affecting the development of the brain. This may occur before birth (prenatally), during birth (perinatally), or following birth (postnatally) and in early childhood.

Learning disabilities can be caused by any one of a variety of factors (Holland 2011)<sup>2</sup> or by a combination. Yet sometimes the specific cause is not known. Possible causes include the following:

- an inherited condition, meaning that certain genes passed from the parents affected the brain development, for example Fragile X, Prader-Willi Syndrome
- chromosome abnormalities such as Down's syndrome or Turner syndrome
- complications during birth resulting in a lack of oxygen to the brain
- a very premature birth
- mother's illness during pregnancy
- Foetal Alcohol Syndrome

- a debilitating illness or injury in early childhood affecting brain development
- contact with damaging material (like radiation)
- neglect, and/or a lack of mental stimulation early in life.

### **Health Inequalities of people with learning disabilities**

Lalonde's Health Field Model<sup>4</sup> outlines four areas that are important when considering people's health and wellbeing:

- Human biology and genetics
- Lifestyle
- the environment that people live in
- access to (health) organisations.

When applying this model to people with learning disabilities it becomes apparent that they are disadvantaged and vulnerable in all four of these areas, highlighting the poorer health and social outcomes, health inequalities and inequity of access to services.

The Confidential Inquiry into premature deaths (CIPOLD)<sup>5</sup> of people with learning disabilities undertaken by the [Norah Fry Research Centre](#) in 2013 found that the median age of death for men with learning disabilities was 65 years and for women 63 years old. Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population.

The inquiry also found that 42 per cent of the deaths of people with learning disabilities were premature. In the CIPOLD study, a death was considered as premature if, *'without a specific event that formed part of the "pathway" that led to death, it was probable that the person would have continued to live for at least one more year'*.

The most common reasons for deaths being assessed as premature were: delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing needs. The inquiry found that for 29 per cent of cases reviewed there was a significant difficulty or delay in diagnosis, further investigation or specialist referral. For 30 per cent there were issues with the treatment that they received.

The phenomenon of delayed diagnosis is referred to as 'diagnostic overshadowing', whereby physical ill health is being viewed as part of the person's mental health problem or learning disability and associated behaviour – and so is not being investigated or treated. These occurrences were identified by the Disability Rights Commission<sup>6</sup> in their investigation in the health inequalities experienced by people with mental health problems and learning disabilities. The specific causes of ill health, morbidity and health inequalities of people with learning disabilities were summarised by Emerson et al (2011)<sup>7</sup> in a [literature review](#):

### **Autism**

It has been estimated that between 20-33 per cent of people with learning disabilities known to local authorities also have an autistic spectrum disorder. Similarly, a study of children aged 10-14 who had a current diagnosis of an autistic spectrum disorder found that 55 per



cent also had learning disabilities. The [Autism JSNA](#) states that approximately 50 per cent of people with autism also have a learning disabilities.

## **Cancer**

Whilst the proportion of people with learning disabilities who die from cancer is lower than the general population (12-18 per cent compared to 26 per cent) people with learning disabilities have a higher rate of gastrointestinal cancer (48 -59 per cent compared to 25 per cent)<sup>7</sup>. There is a high prevalence of *Helicobacter pylori*, a class one carcinogen linked to stomach cancer, gastric ulcer and lymphoma among people with learning disabilities.

## **Challenging Behaviour**

Challenging behaviours (aggression, destruction, self-injury and others) are shown by 10-15 per cent of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49. Arron et al (2011)<sup>8</sup> highlighted that self-injurious behaviour was recorded for 27 per cent of individuals (children and adults) with learning disability, the same study reported such behaviour for between 45-93 per cent for people with certain genetic syndromes. In some instances, challenging behaviours result from pain associated with untreated medical disorders.

## **Coronary Heart Disease**

Coronary heart disease is a leading cause of death amongst people with learning disabilities (14- 20 per cent), with rates expected to increase due to increased longevity and lifestyle changes associated with community living<sup>7</sup>. Almost half of all people with Down's syndrome are affected by congenital heart defects.

## **Dementia**

The prevalence of dementia is higher amongst older adults with learning disabilities compared to the general population (22 per cent compared to 6 per cent in people aged 65+), and is associated with a range of potentially challenging behaviours and health problems. People with Down's syndrome are at particularly high risk of developing dementia, with the age of onset being 30-40 years younger than that for the general population. Amongst people with moderate to profound learning disabilities, deaths from dementia are more common in men than women, however dementia itself has been found to be more common in women<sup>7</sup>.

## **Diabetes**

Increased rates of diabetes among adults with learning disabilities have been reported in population-based studies undertaken in [the Netherlands](#) and [the USA](#).

## **Dysphagia**

Difficulties with eating, drinking and swallowing have implications for health, safety and wellbeing. It is estimated that this problem affects a little more than 8 per cent of adults known to learning disability services. Forty per cent of those with learning disabilities and dysphagia experience recurrent respiratory tract infections; other negative health consequences including asphyxia, dehydration and poor nutritional status<sup>7</sup>.

## **Endocrine Disorders**

Hypothyroidism is relatively common among people with Down's syndrome, with prevalence increasing with age. Reported prevalence rates in children with Down's syndrome range from 9- 19 per cent. There is evidence that children with profound learning disabilities are at greater risk of experiencing short stature due to untreated growth hormone deficiency.

## **Epilepsy**

The prevalence rate of epilepsy amongst people with learning disabilities has been reported as at least 20 times higher than for the general population, with seizures commonly being multiple and resistant to drug treatment. Uncontrolled epilepsy can have serious negative consequences on both quality of life and mortality. Emmerson (2011)<sup>7</sup> found evidence of the misdiagnosis of epilepsy in people with learning disabilities; this includes both false positives and false negatives and may have resulted in inappropriate treatment.

## **Gastro-Oesophageal Reflux Disease (GORD)**

GORD causes pain and may contribute to sleep disturbance, problem behaviour, anaemia and risk of oesophageal cancer. Close to half of a sample of institutionalised people with moderate and severe learning disabilities in the Netherlands were found to have GORD.

## **Genetic and biological factors**

People with moderate to profound learning disabilities are more likely than the general population to die from congenital abnormalities<sup>9</sup>.

Additionally, a number of syndromes associated with learning disabilities are also associated with some specific health risks for example:

- congenital heart disease is more prevalent among people with Down's syndrome and Williams syndrome
- early onset dementia is more common in people with Down's syndrome
- hypothalamic disorders are more prevalent among people with Prader-Willi syndrome
- mental health problems and challenging behaviours are more prevalent among people with autism spectrum disorders, Rett syndrome, Cornelia de Lange syndrome, Riley-Day syndrome, Fragile-X syndrome, Prader-Willi syndrome, Velocardiofacial syndrome, Williams syndrome, Lesch-Nyhan syndrome, Cri du Chat syndrome and Smith-Magenis syndrome
- obesity is more prevalent among people with Prader-Willi syndrome, Cohen syndrome, Down's Syndrome, and Bardet-Biedl syndrome
- Sleep problems are more prevalent among children with Williams Syndrome and Down's Syndrome.

## **Mental health**

The prevalence of psychiatric disorders is 36 per cent among children with learning disabilities, compared to 8 per cent among children without learning disabilities, with children with learning disabilities accounting for 14 per cent of all British children with a diagnosable psychiatric disorder.

The prevalence of psychiatric disorders is also significantly higher among adults whose learning disabilities are identified by GPs, when compared to general population rates.

Reported prevalence rates for anxiety and depression amongst adults with learning disabilities vary widely, but are generally at least as high as in comparison groups drawn from the general population. Anxiety and depression are particularly common amongst people with Down's syndrome.

There is some evidence to suggest that the prevalence rates for schizophrenia in people with learning disabilities may be three times greater than for the general population, with South Asian adults with learning disabilities having a higher prevalence than white adults with learning disabilities. Chaplin et al (2010)<sup>10</sup> stated that people with learning disabilities who lived with their families were found to be more likely to have anxiety disorders whilst those who lived independently of their family were more likely to have personality disorders and overall higher rates of psychopathology.

### **Oral Health**

One in three adults with learning disabilities and four out of five adults with Down's syndrome have unhealthy teeth and gums, with adults living with families having more untreated decay and poorer oral hygiene and adults living in residential services having more missing teeth<sup>7</sup>.

### **Osteoporosis**

Studies from other countries indicate that people with learning disabilities may have increased prevalence of osteoporosis and lower bone density than the general population. Contributory factors include lack of weight-bearing exercise, delayed puberty, earlier-than-average age at menopause for women, poor nutrition, being underweight and use of anti-epilepsy medication. Fractures can occur with only minor injury and can be multiple<sup>7</sup>.

## **Personal Health Risks and Behaviours**

- **Diet**

Less than 10 per cent of adults with learning disabilities in supported accommodation in the United Kingdom eat a balanced diet, with an insufficient intake of fruit and vegetables<sup>11</sup>.

- **Exercise**

Over 80 per cent of adults with learning disabilities engage in levels of physical activity below the Department of Health's minimum recommended level, a much lower level of physical activity than the general population (53-64 per cent). Also people with more severe learning disabilities and people living in more restrictive environments are at increased risk of inactivity<sup>11</sup>.

- **Obesity & Underweight**

People with learning disabilities are much more likely to be either underweight or obese than the general population. Women, people with Down's Syndrome, people of higher ability and people living in less restrictive environments are at increased risk of obesity. The high level of overweight status amongst people with learning disabilities is likely to be associated with an increased risk of diabetes<sup>7</sup>.

- **Substance Use**

Fewer adults with learning disabilities who use learning disability services smoke tobacco or drink alcohol compared to the general population within the population of people with learning disabilities. However, rates of smoking are considerably higher among adolescents with mild learning disability and among people with learning disabilities who do not use learning disability services<sup>12</sup>. People with learning disabilities with identified substance misuse were more likely to be male (61 per cent) and to misuse alcohol.

- **Safeguarding**

Research<sup>13,14,15</sup> has found that disabled children and young people with communication needs, learning disabilities, behavioural disorders and sensory impairments are more likely to experience higher levels of neglect and violence and are more likely to be abused than their non-disabled peers. However, in general, the quality and quantity of information on the abuse and protection of disabled children and adults in the UK is poor<sup>16</sup>.

- **Sexual Health**

Little is known about inequalities in the sexual health status of people with learning disabilities in the UK. A national survey undertaken by the [Family Planning Association \(FPA\)](#) found that 63% of people with learning disabilities wanted to know more about sex and relationships and yet many are prevented from accessing this information due to inappropriate attitudes and barriers that are often avoidable. Of those wanting to know more about sexual health, 38% felt it was society's attitudes that had resulted in them not knowing enough.

[Mencap](#) also reports that whilst most people with learning disabilities feel that relationships are important, only 3% actually live as a couple ([compared to 60% of the general population](#)), with many feeling they are being denied this opportunity because of societal attitudes.

There is also evidence to suggest that they may face barriers in accessing sexual health services and the informal channels through which young people learn about sex and sexuality<sup>17</sup>. A population-based study in the Netherlands reported that men with learning disabilities were eight times more likely to have sexually transmitted diseases and that high rates of unsafe sexual practices has been reported among men who have sex with men who have a learning disability<sup>18</sup>.

- **Physical Disabilities**

Among adults with learning disabilities, being non-mobile has been associated with a sevenfold increase in death and being partially mobile has been associated with a twofold increase of death when compared with individuals who were being fully mobile.<sup>7</sup>

- **Respiratory Disease**

Respiratory disease is possibly the leading cause of death for people with learning

disabilities (46- 52 per cent), with rates much higher than for the general population (15-17 per cent). People with asthma and learning disabilities were found to be two times more likely to be smokers than patients with learning disabilities who do not have asthma. More than half of women with learning disabilities and asthma are also obese<sup>5</sup>.

- **Sensory Impairments**

Of the people with learning disabilities known to services in the UK, it is estimated that 50,000 have a visual impairment and a further 15,000 are blind. Many more adults with learning disabilities not known to services may have visual impairments or blindness. Approximately 40 per cent of people with learning disabilities are reported to have a hearing impairment, while people with Down's syndrome are at particularly high risk of developing vision and hearing loss. Those living independently or with family are significantly less likely to have had a recent eye examination than those living with paid support staff (Startling et al 2006)<sup>19</sup>. Informal carers of people with learning disabilities frequently fail to identify sensory impairments, including cerebral visual impairment.

### **The 'Social Determinants' of Health**

Emerson et al (2010)<sup>20</sup> found that people with learning disabilities, especially people with less severe learning disabilities and people with learning disabilities who do not use learning disability services, are more likely to be exposed to common 'social determinants' of poorer health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination.

Exposure to bullying at school and overt discrimination in adulthood are both predictive of poorer general health among adults with learning disabilities. Given the association between minority ethnic status and poverty and the exposure of people with learning disabilities from minority ethnic communities to overt racism, it is likely that people with learning disabilities from minority ethnic communities will face greater health inequalities than people with learning disabilities from majority ethnic communities.

## **Access to and the Quality of Healthcare and Other Services**

### **Secondary Care**

The **investigation** into the healthcare of people with learning disabilities in 2007 was set up by the then Secretary of State for Health in response to the Mencap '**Death by Indifference**' **report** which outlined the cases of six individuals with learning disabilities that Mencap believed to have died unnecessarily and due to the poor healthcare that they received.

The investigation concluded that:

- high levels of health need are not currently being met and that there are risks inherent in the care system
- People with learning disabilities appear to receive less effective care than they are entitled to receive

- There is evidence of a significant level of avoidable suffering and a high likelihood that there are deaths occurring which could be avoided
- The evidence shows a significant gap between policy, the law, and the delivery of effective health services for people with learning disabilities.

### **Primary Care Services**

Compared to the general population, people with learning disabilities visit their GPs with similar frequency to the general population. However, given the evidence of greater health needs it would be expected that people with learning disabilities would be accessing primary care services more frequently than the general population. Integration and collaboration between GPs, primary health care teams and specialist services for people with learning disabilities was found to be poor<sup>7</sup>.

### **Inpatient Mental Health Services**

Many people with learning disabilities and or autism who display behaviour that is deemed to be challenging, have been and are still admitted to secondary care (level three) in patient units despite strong evidence that these are not effective in treatment formulation. [NICE Guidance](#) recommends that people are treated in the least restrictive setting. Following the exposure by the BBC of the abuse of people with learning disabilities that took place at Winterbourne View Hospital, the Government set out in a Concordat its pledge to work with others, including NHS and local government commissioners, to transform care and support for all children, young people and adults with learning disabilities and/or autism who display behaviour that challenges. The [Transforming Care](#) program followed this exposure. Subsequent inspection by the [Care Quality Commission](#) of 150 hospitals and care homes of people with learning disabilities found inadequate services that included poor person-centred care, limited appropriate activities and a lack of monitoring and learning from incidents and restraints.

A recent inquiry by the United Nations [Committee on the Rights of persons with disabilities](#) (UNCRPD) found that the welfare reform has resulted in 'violations of the rights of people with disabilities' (CRPD 2016). People with disabilities including those with learning disabilities are 'disproportionately affected'. The Government has strongly rebutted the report but it is nonetheless likely that people will be impacted by:

- narrowing social care criteria
- changes to housing benefits,
- the criteria for parts of the [Personal Independence Payment – brought in to replace Disability Living Allowance](#)
- the closure of the Independent Living Fund
- the Spare Room Subsidy – or 'bedroom tax' – did not recognise that disabled people had arrangements that required additional rooms.

The UNCRPD report observed that government changes have caused financial hardship to people with disabilities, which had resulted in debts, evictions from housing and cuts to essentials such as housing and food.

# Key drivers for changes or improvements relevant to learning disabilities

## National Outcome Frameworks

There are three indicators in the aligned Social Care (ASCOF), National Health Service (NHSOF) and Public Health Outcomes Framework (PHOF) that relate to people with learning disabilities and that Kingston reports on:

- Proportion of adults with learning disabilities in paid employment formerly National Indicator 145, ASCOF 1.D, PHOF 1.8, NHS OF2.2
- Proportion of adults with a learning disability who live in their own homes or with their families (former National Indicator 146, PHOF 1.6, ASCOF 1.G)
- Reducing premature death in people with a learning disability. Excess under 60 mortality rate in adults with a learning disability NHSOF 1.7. This outcome is part of the [Government mandate to NHS England](#).

Additionally, each GP practice establishes and maintains a register of patients with learning disabilities. The age restriction has been removed, and is no longer for just those aged 18 or over.

## Mandate from DH to NHS England

The Government requires NHS England to strive to reduce the health gap between people with mental health problems, learning disabilities and autism and the population as a whole, and support them to live full, healthy and independent lives. There is an expectation that the NHS will work to improve care and outcomes through prevention, early intervention and improved access to integrated services to ensure physical health needs are addressed.

## Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD)<sup>5</sup>

The CIPOLD review (2013) found evidence that the quality and effectiveness of health and social care given to people with learning disabilities is deficient in a number of ways, and that premature deaths could be avoided by improving the quality of the healthcare they receive.

Local areas were asked to:

- participate fully in the Self-Assessment Framework for Learning Disabilities and act on its results
- secure the provision of named care health and social care co-ordinators
- ensure reasonable adjustments are made and audited
- standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans.

National requirements were to develop clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems and the establishment of a national mortality review programme for people with learning disabilities.



### **Building the Right Support (NHS England, Association of Directors of Adult Social Services and Local Government Association, 2015)**

The three key organisations published a national action plan to develop whole system community services and close inpatient facilities for people with a learning disability and/or autism who exhibit behaviour that is deemed to be challenging. The plan aims to shift money from inpatient services to the community, and reduce the use of inpatient beds by 35-50 per cent by 2018.

### **Association of Directors of Adult Social Services (ADASS) Framework for the Future**

The ADASS framework for the future which is aligned to the Care Act 2014, it outlines the ambition for people with learning disabilities to lead safe lives and live a normal and ordinary life as equal citizens. In particular, the framework strives to deliver:

- Increased awareness and understanding of Learning Disabilities
- People with Learning Disabilities being supported to live an ordinary life
- People with a Learning Disability to have improved access to the support they need to live independently within the community
- With an underpinning value of co-production

For a full list of investigation, drivers and enablers please refer to Appendix One.

### **References for Introduction**

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# Local Picture

Whilst there is not currently a comprehensive national dataset on the number of people with learning disabilities across the lifespan, Public Health England estimated in 2013 that there were 1,068,000 people with learning disabilities in England<sup>1</sup>. This included:

- 224,930 children (identified at School Action Plus or statemented as having either a primary or secondary Special Educational Need associated with learning disabilities<sup>1</sup>).
- 900,900 adults, of whom 206,132 (23 per cent) are known to GPs as people with learning disabilities.

Adults with learning disabilities not identified as such within health and social care are likely to be adults ineligible for social care support but at potential high risk of experiencing social determinants of poor health<sup>1</sup>.

## Children with learning disabilities in Kingston

According to the [Special Education Needs and Disability \(SEND\) JSNA](#) for Kingston there are 1.2 million school aged children with identified special educational need living in England. Children with learning disabilities are likely to be identified within SEND as either having:

- Moderate learning difficulty
- Severe learning difficulty
- Profound and multiple learning difficulty
- Autism Spectrum Disorder

At 60.7%, Autistic Spectrum Disorder (ASD) is the most common primary care need and Speech Language and Communication Needs (57.1%) is the second most common primary care need followed by Moderate Learning Difficulty (51.4%).

In 2016 [Kingston had an overall school population of 28,649 pupils](#) and 2.5% have a recorded statement or an Education Health Care Plan (EHCP). As diagnosis often made within education, such as learning difficulties, it remains difficult to get an accurate picture of children with learning disabilities (as defined within adult services). Also, not every child with an EHCP and associated learning disability will be eligible for social services under the Care Act.

Other Special Educational Needs, such as sensory impairments were omitted from this table. The percentages relate to the total number of pupils with special educational need and their primary need that could lead to future involvement of adult learning disability social services. More detailed information on Children and Young People with Specialist Educational Needs and Disability (SEND) is outlined in the [dedicated JSNA chapter](#). It is likely that the higher percentage of pupils with autism is due to possible out of borough placements by other Local Authorities.

**Table 1: Special Schools: Number and percentage of pupils with special educational needs by primary type of need of moderate, severe, profound and multiple learning difficulties and autism spectrum disorder (January 2016)**

	Kingston		London		England	
	Number	%	Number	%	Number	%
Moderate Learning Difficulty	165	10.2	16,998	16.6	154,483	25.0
Severe Learning Difficulty	10	0.6	801	0.8	4,562	0.7
Profound & Multiple Learning Difficulty	3	0.2	309	0.3	1,728	0.3
Autistic Spectrum Disorder	166	10.2	8,067	7.9	38,944	6.3
Total	1,622		102,669		619,094	

Source: Department of Education. Special Educational Need in England.

Note: the percentages will not add up to 100 per cent as other special educational needs have been omitted. Children also may appear in more than one category.

### Adults with learning disabilities

The predicted number of people with learning disabilities (18+) in Kingston in 2015 was 3233. According to Public Health England, this is likely to increase by 7 per cent by 2020 and by 20 per cent by 2030. This is in part because people with learning disabilities are living longer: the number of people aged 65 and over with learning disabilities is expected to increase by 12 per cent by 2020 and by 44 per cent by 2030<sup>1</sup>.

Approximately 1.1 per cent of the national population has autism and around 50 per cent of these also have a learning disability. For further information on autism in Kingston see the Autism JSNA.

**Table 2: People predicted to have a learning disability, by age in Kingston, 2015 to 2030.**

Age group	2015	2020	2025	2030	% change 2015-2030
18-24	506	505	517	586	15.8%
25-34	682	697	697	680	-0.3%
35-44	670	717	751	763	13.9%
45-54	527	570	608	649	23.1%
55-64	370	421	469	503	35.9%
65-74	268	300	309	350	30.6%
75-84	142	161	205	227	59.9%
85 and over	67	75	88	108	61.2%
<b>Total</b>	<b>3,233</b>	<b>3,446</b>	<b>3,645</b>	<b>3,867</b>	<b>20%</b>

Source: Projecting Adult Needs and Service Information ([www.pansi.org](http://www.pansi.org))

Note: figures may not sum due to rounding.

These predictions are based on prevalence rates in a 2004 report by the Institute for Health Research. The prevalence base rates adjusted for the increased prevalence of learning disabilities in South Asian communities and for increased survival rates of young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities.

The number of people aged 18 or over likely to be in receipt of services is expected to increase by 6 per cent from 2015 to 2020 and 18.69 per cent from 2015 to 2030<sup>26</sup>.

**Table 3: People predicted to have a moderate or severe learning disability, and hence likely to be in receipt of services, by age in Kingston, 2015-2030**

Moderate or severe learning disability						Severe Learning Disability		
Age group	2015	2020	2025	2030	% change 2015-2030	2015	2030	% change 2015-2030
18-24	116	117	121	138	19.0%	38	46	21.0%
25-34	147	150	150	146	-0.7%	41	41	0.0%
35-44	168	180	189	192	14.3%	45	52	15.6%
45-54	119	129	138	148	24.4%	26	33	26.9%
55-64	81	92	102	109	34.6%	19	26	36.8%
65-74	44	48	50	57	29.5%	-		
75-84	15	17	21	23	53.3%	-		
85 and over	6	7	8	10	66.7%	-		
<b>Total</b>	<b>696</b>	<b>740</b>	<b>780</b>	<b>824</b>	<b>-</b>	<b>169</b>	<b>198</b>	<b>-</b>

Source: Projecting Adult Needs and Service Information ([www.pansi.org](http://www.pansi.org))

Note: Severe learning disability projections are only available for people aged 18-64 years

Severe learning disability numbers are a subset of moderate and severe learning disability.

Figures may not sum due to rounding.

Based on 2015 projections it is estimated that around 36 per cent of people with moderate and severe learning disabilities are living with a parent. Further projections indicate that this is likely to remain static with 35.5 per cent of people expected to be living with a parent in 2030.

Table 4 is based on a set of prevalence rates for adults with a learning disability living with a parent, established as a proportion of those known via learning disability social care registers estimates.

**Table 4: People aged 18-64 predicted to have a moderate or severe learning disability and be living with a parent, by age in Kingston, 2015-2030.**

Age group	2015	2020	2025	2030	% change 2015-2030
18-24	76	77	80	91	19.7%
25-34	75	77	77	75	0.0%
35-44	66	70	74	75	13.6%
45-54	27	30	32	34	25.9%
55-64	7	9	9	10	42.9%
<b>Total</b>	<b>252</b>	<b>262</b>	<b>272</b>	<b>285</b>	<b>-</b>

Source: Projecting Adult Needs and Service Information ([www.pansi.org](http://www.pansi.org))

Note: Figures may not sum due to rounding

The prevalence of people with a learning disability displaying challenging behaviour is set to increase by 16 per cent by 2030 but remains at proportionally 10 per cent of the total learning disability population. The prevalence rate is based on a study by Lowe et al (2007)<sup>2</sup>. In total, 4.5 people per 10,000 of the population aged 5 and over were rated as seriously challenging.

The most prevalent general form of challenging behaviour was 'other difficult/disruptive behaviour', with non-compliance being the most prevalent challenging behaviour.

**Table 5: People aged 18-64 with a learning disability, predicted to display challenging behaviour, by age in Kingston, 2015- 2030.**

Age group	2015	2020	2025	2030	% change 2015-2030
18-24	8	8	8	9	25.0%
25-34	12	12	13	13	0.0%
35-44	12	12	13	14	16.7%
45-54	10	10	11	12	20.0%
55-64	7	7	8	9	42.9%
<b>Total</b>	<b>50</b>	<b>51</b>	<b>53</b>	<b>56</b>	<b>13.7%</b>

Source: Projecting Adult Needs and Service Information ([www.pansi.org](http://www.pansi.org))

Note: Figures may not sum due to rounding

Down's Syndrome is one of the major genetic causes for having a learning disability. People with Down's Syndrome often have a number of co-morbidities such as congenital heart disease.

The **estimated local population of people with Down's Syndrome** is likely to increase by 13% within the next 15 years.

**Table 6: People aged 18-64 predicted to have Down's syndrome, by age in Kingston, 2015 to 2030**

Age Group	2015	2020	2025	2030	% change 2015-2030
18-24	12	12	12	12	0%
25-34	17	17	18	18	6%
35-44	17	17	18	19	12%
45-54	14	14	15	16	14%
55-64	10	10	12	13	30%
<b>Total</b>	<b>69</b>	<b>70</b>	<b>74</b>	<b>78</b>	<b>13%</b>

Source: Projecting Adult Needs and Service Information ([www.pansi.org](http://www.pansi.org))

Note: Figures may not sum due to rounding

### **Access of Social Care by people with learning disabilities**

The rate of people with learning disabilities receiving long term support from the Local Authority in 2014/15 was slightly higher than the London average, yet lower than the national crude rate.

**Table 7: Adults (18-64) with learning disability getting long term support from local authorities, crude rate per 1,000 general population.**

	Kingston	London	England
2014/15	3.25	2.91	3.73

Source: Health and Social Care Information Centre; NASCIS - SALT, Accessible via PHE

Note: The numerator used for calculation of this indicator is total number of adults (18 to 64) receiving long term Learning Disability support during the year to 31st March from the Local Authority.

There are a total of 416 people (58% male and 42% female) with learning disabilities open to the Social Work Team in the Royal Borough of Kingston in 2016. This is 60 per cent of the total expected learning disability population. The reason that more males access the team is likely to be due to learning disabilities being more prevalent in males than females rather than issues around accessibility<sup>1</sup>.

Based on 387 case entries, the majority of people with learning disabilities accessing the Social Work team are 'White' (82 per cent). This correlates to White British being the largest ethnic group in Kingston. The second highest recorded ethnicity is 'Asian' with 9 per cent. This is followed by four per cent from 'Any other ethnicity'; three per cent are recorded as 'Black' and two per cent did not have a recording of their ethnicity.

Based on 387 case entries, 34 per cent of individuals with learning disabilities accessing the social work team are between 18- 30 years. With 16 per cent each, there is an equal distribution of people who are aged between 31-40 and 41-50 and 10 per cent of individuals are over 65 years old.

**Table 8: Learning Disability ethnicity recording in the Social Work Team in Kingston, 2016.**

Recorded Ethnicity	Count of Ethnicity
White	316
Black	12
Asian	37
Other	14
Not recorded yet	7

Source: Local review of case note entries relating to equality status

### Primary Care

All the GP practices in Kingston have established and maintained a register of patients with learning disabilities. GP registers hold a list of all people with a learning disability of any type, age and at any level of severity, including those with mild learning disability, who may not be in receipt of services. In 2014/15 and 2015-16, there were 535 people of all ages living in Kingston with a learning disability known to their GP; this equates to 0.28% of the population. This is lower than both the London and England figures of 0.34% and 0.44% respectively. GP surgeries record the number of patients with learning disabilities registered at their practice as part of the Quality Outcomes Framework (QOF).

### How Kingston compares to other parts of England

Kingston supports more people with learning disability into employment compared to London and England. There has also been a two percent increase in 2015/16 compared with the previous year:

**Table 9: Percentage of people with learning disabilities in paid employment<sup>3</sup>**

	Kingston	London	National
People with learning disabilities in paid employment (2014/15)	11.1%	7.7%	5.9 %
People with learning disabilities in paid employment (2015/16)	13.1%	7.5%	5.8 %

Source: NHS Digital (2016) Measures from the Adult Social Care Outcome Framework England 2015-16  
Nationally, there are significant differences in the employment status between men and women, with 17.3 per cent of males with learning disabilities being in paid employment compared to 7.3 % of women<sup>3</sup>.

In 2014/15 there was a higher percentage of people with learning disabilities in Kingston who lived in their own home or with their family when compared to London and England. In 2015/16 this dropped slightly and whilst Kingston is doing slightly better than the London-wide average, it is now below the national one.

**Table 10: Percentage of people with learning disabilities in settled accommodation 2014/15 and 2015/16<sup>3</sup>**

	Kingston	London	National
People with learning disabilities who live in their own home or with their family (2014/15)	73.9%	69%	72.9%
People with learning disabilities who live in their own home or with their family (2015/16)	73.5%	70.1%	75.4 %

Source: NHS Digital (2016) Measures from the Adult Social Care Outcome Framework England 2015-16.

Arranging where people with learning disabilities live is likely to pose difficulties. As part of their role in assisting them to live as independently as possible, local authority social service departments commonly help them find and keep accommodation. Types of accommodation can be divided broadly into 'settled' accommodation, where the person can reasonably expect to stay as long as they want and 'unsettled' accommodation which is either unsatisfactory or, where, like in residential care homes, residents do not have security of tenure. Local authorities are asked each year about the sort of accommodation the working age adults with learning disability for whom they provide long term support are living in.

Categories of 'settled accommodation' include:

- Settled mainstream housing with family/friends (including flat-sharing)
- Supported accommodation/Supported lodgings/Supported group home (accommodation supported by staff or resident caretaker)
- Shared lives scheme
- Approved premises for offenders released from prison or under probation supervision (eg Probation Hostel)
- Sheltered Housing/Extra care sheltered housing/Other sheltered housing
- Mobile accommodation for Gypsy/Roma and Traveller community.

Table 11 shows the percentage of adults (aged 18 to 64) with learning disability, receiving long term support from their local authority who are living in any one of these types of accommodation.

**Table 11: Accommodation status of people with learning disability in Kingston, 2014/15.**

	Kingston (%)	London (%)	England (%)
Living in settled accommodation	73.6	69.0	72.9
Living in unsettled accommodation	26.4	31.8	26.7
Accommodation status not known to LA	0.0	5.6	5.6
Accommodation status is severely unsatisfactory	0.0	0.18	0.14

Source: Health and Social Care Information Centre; NASCIS - SALT, Accessible via PHE.



A small number of types of accommodation could be seen as serious emergency situations for people with learning disability. These situations are undesirable for anybody, but for people particularly likely to be vulnerable to abuse or exploitation, or in need of particular support they are especially serious. They include:

- Refuge
- Placed in temporary accommodation by the council (including Homelessness resettlement) - eg Bed and Breakfast.

This indicator above shows the proportion of working age adults with learning disability known to local authorities reported as being in any of these types of accommodation. Numbers for this indicator are fortunately low and in most cases where the figure is not zero the exact number is not known (because rounding is introduced into the statistics as reported for confidentiality reasons); in any case it is likely that numbers reported are out of date by the time that tables are published.

### **Annual Health Checks for people with learning disabilities (Direct Enhanced Service contract for GPs)**

217 people with learning disabilities in Kingston received a health check in 2013/14. The percentage of people with learning disabilities who had had a health check in 2013/14 is similar to the national average. However, the percentage of people with learning disabilities who had a health check in 2013/14 was 5.2 per cent lower than the rest of London (Public Health England fingertips profiles). The number of annual health checks in 2014/15 and 2015/16 were not published. However information from NHS England, as the lead commissioner indicate that 60 health checks were commissioned in 2015/16 equating to 14% of the total population.

### **Safeguarding**

Kingston has a higher referral rate for adult safeguarding when compared to London or national level. This should not be seen as people with learning disabilities being at higher risk in Kingston, but could mean that there are a higher number of services for people with learning disabilities and staff have a greater awareness of safeguarding risks of children and adults with learning disabilities and of referral pathways.

**Table 12: Referrals of people with learning disabilities for adult safeguarding per 1,000 people (general population) (crude rate) on the GP Learning Disability register, Kingston, 2014/15**

	Kingston	London	England
2014/15	93.5	77.0	62.2

Source: Health and Social Care Information Centre publications, Accessible via PHE

### **Sexual Health**

No data is routinely collected by sexual and reproductive health services regarding whether patients have learning disabilities and therefore it is difficult to gather information regarding the prevalence of sexually transmitted infections (STIs), contraceptive use and any other sexual health need amongst people living with learning disabilities.

At a local level, Kingston has been able to collect some information regarding sexual health



need through its specialist sexual health clinic (the **Connect clinic**) for people living with learning disabilities. Since the numbers attending the clinic are very small, little statistical significance can be attributed to it, but it does provide a starting point for further investigation.

Between **April 2014 and March 2016**, there were 62 attendances at the service with an age range of 16 to 40 years.

Seven STIs were diagnosed during this time, with chlamydia being the most common. Six different methods of contraception were prescribed including three forms of long acting reversible contraception (LARC).

52 percent of clients attending the clinic disclosed information that raised safeguarding concerns, including a high prevalence of sexual assault. These were followed up as appropriate by clinicians working within the clinic using relevant local safeguarding procedures.

## **References**

1. Hatton C, Emerson E, Glover G, Robertson J, Baines S & Christie A (in press). People with learning disabilities in England 2013. London: Public Health England.
2. Lowe et al (2007). Challenging behaviours: Prevalence and Topographies. *Journal of Intellectual Disability Research*, Vol. 51.
3. NHS Digital (2016) Measures from the Adult Social Care Outcome Framework.

# What Works

There is a plethora of evidence and best practice guidance that are relevant to people with learning disabilities and which are addressed at various stakeholders:

## **NICE Guidance relating to people with learning disabilities:**

- **Mental Health problems in people with learning disabilities: prevention, assessment and management.**  
This guidance outlines how the mental health of people with learning disabilities should be addressed in all settings (education, social care, forensic and health setting) and the leadership required to achieve this. It outlines reasonable adjustments that need to be made to pathways and how involvement of people with learning disabilities and their carers is essential.
- **Challenging Behaviour and learning disabilities: prevention and interventions for people whose behaviour challenges**  
It recommends a holistic psycho-social-environmental approach with interventions delivered in the least restrictive setting.

## **NICE guidance that make references to people with learning disabilities because of high prevalence:**

- **Autism spectrum disorder in adults: diagnosis and management**  
This guidance outlines the identification and assessment of people with autism, relevant intervention and service models. It includes specific consideration for people with learning disabilities who also have an autism spectrum condition.
- **Transition from children's to adult's services for young people using health or social care services**  
This guidance aims to support young people and their carers to have a better experience of transition by improving the way this is planned and carried out. It addresses the social care and health pathway.

## **Evidence Based Guidance**

- **Building the right Support:** A national plan to develop community services and close inpatient facilities for people with learning disabilities and / or autism who display behaviour that challenges, including those with a mental health condition:
- The guidance suggests a whole system approach across health and social care to ensure that people with learning disabilities receive services from all sectors that promote good quality of life, keeps them safe and support their choice and control.
- **Improving the Health and Wellbeing of People with Learning Disabilities:**

An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs).

- This guidance assists Clinical Commissioning Groups to ensure that they commission high quality, cost effective general and specialist health services for people with learning disabilities. It also recommends jointly commissioning with Local Authorities to improve outcomes.
- **Learning Disability Competency Framework and Learning Needs Analysis Tool** (Skills for Health, Skills for Care and Health Education England).
- Supports universal and dedicated learning disability services to have in place the right competencies and skills.
- **The Health Equality Framework and Commissioning Guide**  
The Health Equality Framework (HEF) is an outcomes tool based on the determinants of health inequalities designed to help commissioners, providers, people with learning disabilities and their families understand the impact and effectiveness of services.
- **The Learning Disability Self-Assessment Framework**  
The framework is grouped around three outcomes: staying healthy, keeping safe and living well and requests Local Authorities and CCGs to work with families and people with learning disabilities to demonstrate progress.
- **Green Light Toolkit**  
A guide to auditing and improving mental health services so that they are effective in supporting people with autism and people with learning disabilities.

# Current Services

There are three statutory organisations providing services for people with learning disabilities in Kingston as well as a great number of voluntary sector providers:

## 1. Achieving for Children (AFC) is a Community Interest Company for Children

- **Integrated Children and Disability Team (Moor Lane):**

Children and young people with learning disabilities can access the integrated social care and multidisciplinary health team. The service provides assessment and planning for social care, clinical services provided by a Community Paediatrician, Speech and Language Therapist, Occupational Therapy, Physiotherapy, Psychology and Nursing.

The service also provides short break services for children and young people and portage - a home teaching service for pre-school children whose learning and development is significantly delayed.

- **Special Educational Needs and Disability Service -**

The service provides support and guidance on special educational needs including support with the development of Education, Health and Care Plans.

Services provided by social care, health, education and the independent sector that are available to children, young people and their families is outlined on the [Local Offer](#) administered by AfC.

## 2. Royal Borough of Kingston (RBK)

- **Social Work Team, Transition and Brokerage Service (Sessions House) for people with Learning Disabilities**

This is a team of Social Worker, Placement Monitoring Officers, Brokers and a Transition Social Worker. The team offer support on assessment and care planning for individuals over the age of 18 who have a learning disability and or autism. The service provides support around staying safe, independent and well.

The transition team will usually start to work with individuals who have been identified by AfC as potentially meeting adult social Care Act criteria and will commence work before the age of 18.

- Public Health (RBK) commissions the [Connect Clinic](#) at Kingston Hospital (see Local Picture for data on attendees). In conjunction with the first two years of the launch of Connect Clinic, a training programme developed and delivered sex and relationships education (SRE) programmes for young people with learning disabilities in both mainstream and specialist schools across Kingston. To ensure the sustainability of the scheme, approximately 15 staff from within these organisations and other stakeholders have been trained to be able to design and deliver such programmes

themselves. Information resources on sexual health for people with learning disabilities (PLD) have been developed locally including lesson plans, schemes of work for schools to use and leaflets regarding [Relationships, the Internet, and You](#) for 11-16 year olds and for adults. These were designed with people with learning disabilities to ensure they are helpful to this population group.

### **3. Your Healthcare is a Community Interest Company for the local NHS community services**

#### **Neurodevelopmental Service**

This is a multidisciplinary specialist healthcare team comprising of Psychiatry, Psychology, Occupational Therapy, Physiotherapy, Speech and Language Therapy and Community Learning Disability Nursing.

The service provides specialist assessments including diagnostic, specific treatment and specialist healthcare interventions for adults affected with the following conditions:

- Services for Adults with Learning Disabilities
- Attention Deficit and Hyperactivity Disorder (ADHD) Clinic
- Autistic Spectrum Conditions (Kingston and Richmond).

Kingston's CCG commissions the Neurodevelopmental Service as well as commissioning Continuing Healthcare (CHC) and Personal Health Budgets (PHB). Assessments for adults with learning disabilities is supported by Your Healthcare. There are currently 10 individuals with learning disabilities receiving a PHB. There are a further 12 children or young people who are in receipt of CHC and two individuals receiving a PHB, who will be eligible for adult CHC when turning 18. The provider assessing children is Focused Healthcare.

#### **Voluntary Sector Organisations**

The Royal Borough of Kingston commissions from a range of voluntary organisations. Currently 36 per cent of the adult social care budget is spent on learning disability service (£20.1 million).

There are 77 voluntary organisation providing dedicated services for people with learning disabilities. A full list of organisations is provided in appendix three. Destination Kingston, the strategic plan for the Royal Borough of Kingston and a Market Positioning Statement is currently in development to outline the type of service provision that Kingston Local Authority wishes to stimulate. This includes:

- An All Age Learning Disability Service, which streamlines the transition between children and adult services
- Further accessible respite options for individuals who exhibit behaviour that is deemed challenging

- Supportive Living Arrangements which can provide services for people with more complex needs
- Dementia Services
- Increase of housing options for people with learning disabilities.

## Health Provision

NHS England and Kingston CCG commission all GPs in Kingston to provide annual health checks for people with learning disabilities (14+).

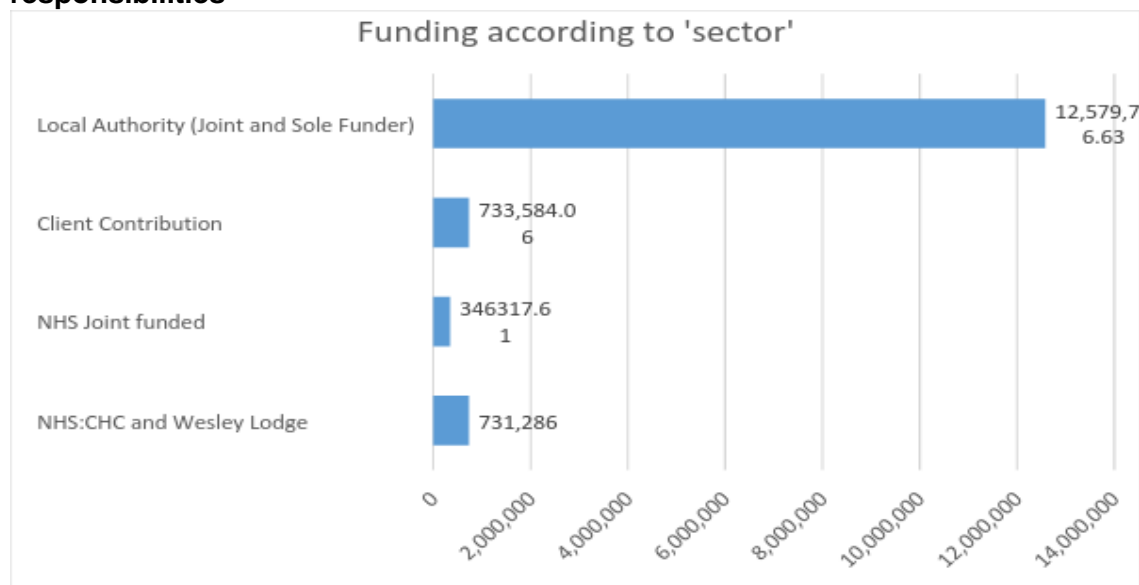
Public Health Kingston commissions a dedicated sexual health clinic for people with learning disabilities called Connect which is provided by Kingston's Hospital **Wolverton Centre for Sexual Health**.

Your Healthcare provides an **Acute Liaison Service for people with learning disabilities in Kingston Hospital**. The team support patients with learning disabilities and clinical team within the hospital to make reasonable adjustments to their care.

## Finances of Individual Care Packages

In 2015, £14,390,904 was spent on individual care for people with learning disabilities across the NHS and Local Authority. 87 per cent of care is funded through Local Authority with client contribution, joint funding and Continuing Healthcare making up the remaining 13 per cent of funding.

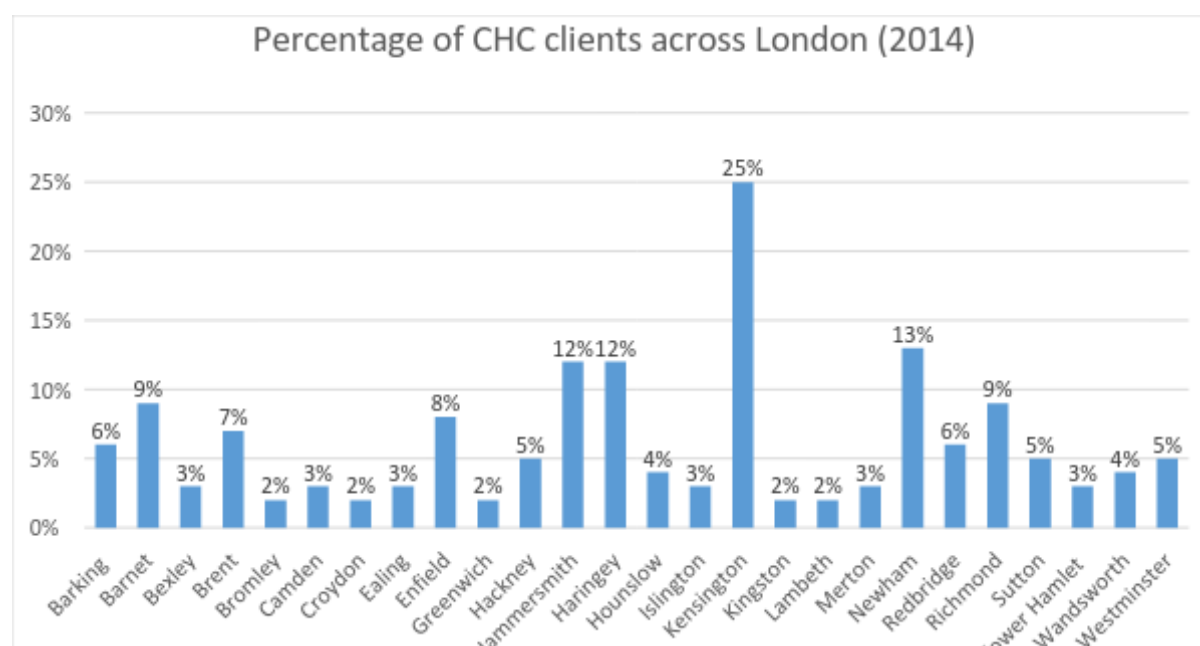
**Figure 1: Breakdown of individual care packages according to funding responsibilities**



Source: IAS search of care packages. December 2016.

Approximately two per cent of people with learning disabilities in Kingston are funded through Continuing Healthcare. This is slightly below the London's average of six per cent being funded through the NHS (Public Health 2014/15).

**Figure 2: Percentage of continuing health care compared to people with learning disabilities known to Local Authorities**



Source: Public Health England (2015) Learning Disability Self-Assessment Framework. [Online] Available at <https://www.improvinghealthandlives.org.uk/projects/jhscsaf2014results>

The current service provision for adults with learning disability includes: day care, supported living, respite, residential care, nursing care, work activities, employment support, social activities, sport, and leisure activities. A high proportion of adults with a learning disability in Kingston live with their parents or family members - hence supporting family carers remains a key priority.

**Table 1: Proportion of Learning Disability budget according to service type**

Type of Service	Proportion of the Learning Disability Budget
Supported living	16%
Day care	22%
Respite	8%
Residential care	32%
Nursing Care	2%
Independent Specialist provision	4%
Direct Payment	12%
Other Services	4%

Source: Market Positioning Statement for Kingston 2016-17  
[https://www.kingston.gov.uk/downloads/download/614/market\\_position\\_statement\\_2016-17](https://www.kingston.gov.uk/downloads/download/614/market_position_statement_2016-17)

### Strategic Partnership and user voice

**Kingston Parliament** is the local self and peer advocacy service that ensures that the voice of people with learning disabilities is heard by strategic partners.

**Learning Disability Partnership Board** is the local partnership that meets to discuss and

make decisions about the issues affecting people with learning disabilities in Kingston.

**Kingston Mencap** supports people with learning disabilities and their family and carers.

The learning disability commissioning team holds bi monthly quality monitoring and commissioning group meetings. This forum oversees all quality monitoring activities, identifies service needs and gaps and suggests service developments. The group is chaired by the Royal Borough of Kingston and includes representatives from the CCG, Your Healthcare, Housing, Care Quality Commission, family members and people with a learning disability.

The learning disability commissioning team procures a quality checker service, which includes people with learning disabilities and a family / carer who are recruited and trained to quality monitor service providers.

### **Kingston's Joint Health and Social Care Learning Disability Self-Assessment Framework**

This is an annual exercise whereby the local economy undertakes a red/amber/green scoring of how well services are doing with regards to people with learning disabilities. The Framework requests local areas to provide numbers, such as women with learning disability accessing breast screening services, governance and assurance documents and feedback from carers and people with learning disabilities.

The framework has three sections, namely staying healthy, keeping safe and living well with a total of 26 indicators. The results from 2014 can be found on the [Public Health England website](#).

Kingston scored itself predominately as amber across most indicators.

<b>Outcome</b>	<b>Indicator</b>	<b>Kingston Response and Scoring</b>
Keeping Healthy	Offender Health and Criminal Justice System	There is no systematic collection of data about the numbers of people with LD in the criminal justice system. There is no systematic learning disability awareness training for staff within the criminal justice system. The local offender health team does not yet have informed representation of the views and needs of people with learning disability.
Keeping Healthy	GP register: The Learning Disability Quality and Outcome Framework register in Primary Care	LD registers reflect prevalence data but are not stratified in every required data set (e.g. age / complexity).
Keeping Healthy	Long Term Health Conditions: Finding and Managing Long Term Health Conditions:	We compare treatment and outcomes for some of the conditions between people with learning disabilities and the general population



	obesity, diabetes, cardiovascular disease and epilepsy	in the area.
Keeping Healthy	Health Action Plans: Health Action Plans are generated at the time of Annual Health Checks in Primary Care	50% - 69% of Annual Health Checks generate specific health improvement targets (Health Action Plan).
Keeping Healthy	Primary and Secondary Care Communication: Primary Care communication of learning disability status to other health providers	There is evidence of a local area team/clinical commissioning group wide system for ensuring LD status and suggested reasonable adjustments if required, are included in referrals. There is evidence that both an individual's capacity and consent are inherent to the system employed.
Keeping Healthy	Acute Liaison Function: Learning Disability liaison function in acute hospital	Designated learning disability liaison function or equivalent process in place and details of the provider sites covered has been submitted. Providers are not yet using known activity data to effectively employ LD liaison function against demand.
Keeping Healthy	Reasonable Adjustments in primary care: Dentistry, optometry, community pharmacy and podiatry	Some of these services are able to provide evidence of reasonable adjustments and plans for service improvements.
Keeping Safe	Individual health and social care package reviews: Commissioner know that all funded individual health and social care packages across all life stages are reviewed regularly	Evidence of at least 90% of all care packages including personal budgets reviewed within the 12 months covered by this self-assessment.
Keeping Safe	Learning Disability service contract compliance: Contract compliance assurance for services primary commissioned for people with learning disabilities	Evidence of at least 90% of health and social care commissioned services for people with learning disability: 1) have had full scheduled annual contract reviews; 2) demonstrate a diverse range of indicators and outcomes supporting quality assurance. Evidence that the number regularly reviewed is reported at executive board level in both health & social care.
Keeping	Compassion, dignity and	Family carers and people with a learning

Safe	respect: Family and carers and people with learning disabilities agree that providers treat people with compassion and respect	disability agree that some providers do.
Keeping Safe	Commissioning strategic impact assessments: Commissioning strategies for support, care and housing are the subject of impact assessment.	Up to date commissioning strategies and Impact Assessments are in place.
Keeping Safe	Complaints lead to change. Commissioners can demonstrate that all providers change practice as a result of feedback.	50-89% of commissioned services can demonstrate improvements, based on the use of feedback from people who use services (for example complaints, surveys, quality checking). There is evidence of effective use of a whistleblowing policy where appropriate
Living Well	Effective joint working across health and social care	There are some examples of functioning formal partnership agreements and arrangements between health and social care organisations. There is clear evidence of at least one of the following: <ul style="list-style-type: none"> <li>· single point of health and social care leadership,</li> <li>· joint commissioning strategy and/ or pooled budgets</li> <li>· integrated health and social care teams.</li> </ul>
Living Well	Sports and Leisure	Local but not widespread examples of people with learning disability having access to reasonably adjusted sports and leisure activities and venues for example use of local parks, leisure centres, swimming pools and walking groups.
Living Well	Transition to adulthood: preparing for adulthood in education, health and social care.	There is some evidence of clear preparing for adulthood services or functions that have joint education, health & social care scrutiny and ownership across children and adult services
Keeping Safe	Adult Safeguarding: Assurance of safeguarding for people with learning disabilities	Evidence of robust, transparent and sustainable governance arrangements in place. In all statutory organisations including Local Safeguarding Adults Board(s), Health & Well-Being Boards and Clinical Commissioning Executive Boards.
Keeping Safe	Involvement of self-advocates and carers in training and	In Learning Disability specific services there is evidence of all of services involving people

	recruitment	with learning disabilities and families in recruitment and training. Commissioners of universal services can provide evidence of contracting for Learning Disability awareness training
Living Well	Local Amenities and transport	Extensive and equitably distributed examples of people with learning disability having access to reasonably adjusted local transport services, changing places and safe places
Living Well	Arts and Culture	Extensive and equitably distributed examples of people with learning disabilities having access to reasonably adjusted facilities and services that enable them to use amenities such as cinema, music venues, theatre, festivals and that the accessibility of such events
Living Well	Employment: Supporting people with learning disability into and in employment.	Clear published local strategy for supporting people with learning disabilities into paid employment. Relevant data is available and collected and shows the strategy is achieving its aims.
Living Well	Involvement in service planning and decision making: People with learning disability and family carers are involved in service planning and decision making.	Clear evidence of co-production in universal services and learning disability services. The commissioners use this to inform commissioning practice.

# Community Voice

In 2016 the Royal Borough of Kingston commissioned the Really Useful Change Company to undertake 16 in depth interviews with carers and people with learning disabilities. The aim of the interviews was to gain an understanding of what people thought worked and did not work regarding the services for people with learning disabilities. Participants felt that the roll out of personal budgets was working well as this gave more choice and control to the person and their family. There were also positive examples of services working in a person centred way and in partnership. In particular, individuals valued the brokerage services as it was able to provide creative solutions for people with complex needs.

There were a number of common themes of what was not working well across the local health and social care economy. These included:

- Capacity issues within the social work team with service not being responsive enough
- Carers and parents felt that they were not listened to
- Lack of named worker
- Lack of annual reviews and support plans
- Transition was identified as a problem with gaps between children and adult services.

Throughout August 2016, 51 individuals from across local organisations, carers and people with learning disabilities attended three workshops. The workshops focused on aspirations of people with learning disabilities and current and future support needs. Emphasis was also given as to how key organisation could work better together in the future. The focus was on three pathways (Education to Employment, Independence and Health). The main outcomes people wanted were:

1. Having person-centred care and support and care
2. Having staff that help to navigate the health and social care system
3. Having a job, being in education or having meaningful things to do in the day
4. Support to paid staff and family carer
5. Choice of housing and where the person lives
6. Access to mainstream and universal services (across leisure, housing, health etc.).  
People with a learning disability also want more opportunity to connect with the wider community and individuals who do not have a learning disability.
7. Good specialist health and social care support that are working together
8. Good Health
9. Communication (among people, staff, organisation, signposting).

Another important theme that has been raised regularly through a number of engagement channels people with a learning disability wanting more support to make and maintain friendships and relationships. People often only have people in their life who are paid staff. Supporting personal relationships, sexuality and sexual health is important. [A needs assessment commissioned by Public Health Kingston](#) in 2013 identified that there needed to be a system-wide response to support young people with disabilities around their sexual

needs.

Specific feedback on an all age learning disability service stated that there should:

- Be a focus on prevention rather than crisis management
- be one main point of contact in a one-stop-shop
- be a system whereby people do not have to repeat information
- be information that could be shared across organisations and could be accessed by all professionals using the same IT system
- be a skilled workforce
- be one point of access into the all age service
- holistic and joint assessment
- a creative sharing of resources.

But:

- The Service would need to be closely aligned with mental health services so that there is better access for people with learning disabilities and or autism.
- Other parts of the system would need to do 'their bit' and change (Housing, Leisure etc.) for the service to work well.
- there is concern about the impact this service may have on young people.

For the full feedback please refer to the Engagement Report.

## References

Public Health England (2015) Learning Disability Self-Assessment Framework. [Online] Available at <https://www.improvinghealthandlives.org.uk/projects/jhscsaf2014results>

# Recommendations

## **Kingston Local Authority**

1. To embed the NICE guidance relating to learning disabilities and best practice guidance across service provision that are in scope of those guidelines.
2. To develop and facilitate the local market to meet current and future demand.
3. To increase choice and availability of housing options for people with learning disabilities.
4. To work with partners to further increase the rate of employment in people with learning disabilities.
5. To ensure that the learning disabilities social work team has capacity to undertake statutory assessments, reviews and care plans.
6. To strengthen the local transition arrangements from children's to adult support services through the All Age Learning Disability Service.
7. To ensure that reasonable adjustments for people with learning disabilities are made across all Local Authorities commissioned services.

## **Public Health**

8. In collaboration with Kingston CCG, to undertake a health equity audit of the GP QOF register for learning disabilities to ascertain the local prevalence rate of health conditions and co morbidities in people with learning disabilities.
9. Ensure that Public Health commissioned services have in place reasonable adjustments for people with learning disabilities and that these are monitored.
10. Raise awareness of bone health initiatives across the Learning Disability population.

## **Kingston CCG**

11. Increase uptake of annual health checks to 75% by 2020, through seeking a GP champion, develop a primary care friendly health check template, underpinned by training and improved information flow between Achieving for Children, Your Healthcare and primary care.
12. Monitor the quality of annual health checks and work with partners to ensure that there is alignment with health action plan and education, health and care plans for young people.
13. Reduce premature mortality by improving access to health services, education and

training of staff and by making reasonable adjustments for people with learning disabilities and or autism.

14. Work with NHS England to ensure that there are reasonable adjustments made to the cancer and non-cancer screening services and that GPs promote cancer screening when people with learning disabilities access their service.
15. Deliver on Transforming Care Partnership plans with partners enhancing community provision for people with learning disabilities and ensuring that there is a Transforming Care at risk registers for people with learning disabilities and that people in secure settings are appropriately identified.
16. To embed the NICE guidance and Green Light toolkit for mental health services to ensure that there is seamless access to mental health provision for people with learning disabilities and autism.
17. To support the all age service through considering commissioning case management and / or health navigation from Neurodevelopmental Service and ensuring that there is health input from specialist learning disability healthcare provision into transition, including the assessment of Continuing Healthcare for people with learning disabilities.

### **Strategic Partnerships**

18. To ensure that the Joint Commissioning Unit has sufficient capacity and competencies to lead on learning disabilities on the Transforming Care Agenda, addressing health inequalities and social care in order to meet demand.
19. Consider further integration joint learning disability commissioning into the Integrated Commissioning Unit
20. To support the implementation of a Learning Disability All Age Service that provides a single point of access, is aligned to Kingston Coordinated Care and its principles and ensures integrated information sharing arrangements.
21. To ensure full participation in the Self-Assessment Framework for Learning Disabilities and act on its results.
22. To ensure that the local criminal justice system works for people with learning disabilities
23. To ensure that there is a local integrated outcome and performance framework to ensure that progress is being monitored.
24. To strengthen local integration (commissioning and provision) between health and social care and adult and children services and ensure it focuses on prevention, has

a single point of access and is underpinned by strong information sharing and skilled workforce.

25. To embed learning disabilities competencies across the local health and social care economy.

26. To ensure Learning Disabilities is reflected in the Sustainable Transformation Plans.



# Glossary

## **Cornelia de Lange syndrome**

Cornelia de Lange syndrome is a developmental disorder that affects many parts of the body. The features of this disorder vary widely among affected individuals and range from relatively mild to severe.

Cornelia de Lange syndrome is characterized by slow growth before and after birth leading to short stature; intellectual disability that is usually moderate to severe; and abnormalities of bones in the arms, hands, and fingers. Most people with Cornelia de Lange syndrome also have distinctive facial features, including arched eyebrows that often meet in the middle (synophrys), long eyelashes, low-set ears, small and widely spaced teeth, and a small and upturned nose. Many affected individuals also have behaviour problems similar to autism, a developmental condition that affects communication and social interaction.

## **Cri du Chat syndrome**

Cri-du-chat syndrome (CDCS) is a relatively rare chromosome disorder affecting approximately 1 in 37,000-50,000 live births. At birth, the main clinical diagnostic feature of the syndrome is a high pitched, monochromatic 'cat-like' cry that is always present in the new-born but may disappear with age. Other features include a round, full face ("moon face"), widely spread eyes (hypertelorism), an extra fold of skin at the inner corners of the eyes (epicanthal folds), a flattened and widened nasal bridge and ears that are positioned low on the head.

Most children with CDCS will have feeding problems from birth including failure to thrive, poor sucking and slow weight gain. They may also be some medical complications but these will not affect every child. Several surveys have discovered an excess of behavioural problems in CDCS children. These include hyperactivity, aggressive and oppositional behaviour as well as sleep problems (see above/below). Why this should be is a complex question; however, the degree of learning disability, communication difficulties and aspects of temperament such as high levels of irritability are important factors.

## **Down's Syndrome**

Down's syndrome, also known as Trisomy 21, is a genetic condition that typically causes some level of learning disability and characteristic physical features. Many babies born with Down's syndrome are diagnosed with the condition after birth and are likely to have:

- reduced muscle tone leading to floppiness
- eyes that slant upwards and outwards
- a small mouth with a protruding tongue
- a flat back of the head
- below-average weight and length at birth.

People with Down's syndrome also vary in personality and ability. Everyone born with Down's syndrome will have a degree of learning disability, but the level of disability will be different for each individual.

### **Fragile-X syndrome**

Fragile X Syndrome is the most common known inherited cause of learning disabilities, affecting around 1 in 4000 males and 1 in 8000 females. It can cause a wide range of difficulties with learning, as well as social, language, attentional, emotional, and behavioural problems.

There are a wide range of characteristics associated with Fragile X, but an individual person may only experience some of these. Learning disabilities occur in almost all boys with Fragile X, to differing degrees. Some boys have severe learning disabilities, although this is rare. Girls usually have milder learning disabilities than boys, but this is not always the case. Some girls with Fragile X Syndrome may be clinically unaffected

As well as learning disabilities, common behavioural features include short attention span, distractibility, impulsiveness, restlessness, over activity and sensory problems. Girls with or without learning disabilities may show concentration problems and social, emotional and communication difficulties related to extreme shyness and anxiety in social situations.

### **Prader Willi Syndrome (PWS)**

PWS is a rare genetic condition that causes a wide range of problems.

These may include:

- a constant desire to eat food, which seems driven by a permanent feeling of hunger and can easily lead to dangerous weight gain
- restricted growth, leading to short stature
- reduced muscle tone (hypotonia)
- learning difficulties
- lack of sexual development
- behavioural problems

### **Rett syndrome**

Rett syndrome is a rare neurological disorder affecting mainly females and very few males. It is present from conception and usually remains undetected until major regression occurs at around one year of age, when children may lose acquired skills and become withdrawn. Genetic but largely not inherited, Rett syndrome is usually caused by a fault on a gene called MECP2 which is found on the X chromosome. People with Rett syndrome have profound and multiple physical and communication disabilities and are totally reliant on others for support throughout their lives.

### **Riley-Day syndrome**

In individuals with Riley Day syndrome, a progressive neurogenetic disorder, the autonomic and sensory nervous systems malfunction. Symptoms vary, and may include insensitivity to pain, unstable blood pressure and body temperature, absence of overflow tears, frequent pneumonia, and poor growth. Riley Day Syndrome is often associated with a shortened lifespan. Individuals with Riley Day Syndrome suffer from episodes of cyclical vomiting accompanied by extremely high blood pressure and increased heart rate, sweating and fever. These “autonomic crises” are one of the most devastating symptoms of this disease, often requiring hospitalization.

### **Smith- Magenis syndrome**

Smith-Magenis syndrome is a genetic disability due to a microdeletion or abnormality of

chromosome 17. The major features of Smith-Magenis Syndrome (SMS) include mild to moderate intellectual disability, delayed speech and language skills, distinctive facial features, sleep disturbances, and behavioural problems.

### **Williams syndrome**

Williams syndrome, also called Williams-Beuren syndrome, is a rare genetic disorder that causes multiple developmental problems. This can include heart and blood vessel issues (including narrowed blood vessels), musculoskeletal problems, and learning disabilities. According to the [Williams Syndrome Association](#), the disorder occurs in approximately 1 in 10,000 people. Although a genetic link is present, a person can be born with the syndrome without having a family history of it.

## Other Needs Assessments

[Carers JSNA](#)

[Children and Young People Needs Assessment \(Kingston 2016\)](#)

[Children and Young People's Needs Assessment \(Kingston\) – Executive Summary](#)

[Special Education Needs and Disability JSNA](#)

[Autism JSNA](#)

[Kingston Sexual Health Needs Assessment of Young People with learning Disabilities](#)

## Useful Links

[Achieving For Children Local Offer Website](#)

[Kingston Learning Disability Website](#)

[Kingston Mencap](#)

[Kingston Carer's Network](#)

[Public Health England Learning Disability Observatory](#)

[NHS England Learning Disabilities Program](#)

[Learning Disability Services Monthly Statistics - England Commissioner Census \(Assuring Transformation\) - September 2015, Experimental Statistics](#)

[A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability](#)

[Easy health](#)

[AfC Protection and Early Help Services Booklet](#)

[JSNA Summary Information of People with SEND, Autism, and Learning Disabilities May 2017](#)

## Help and Information

[Contact a Family for families with disabled children](#)

[Cornelia De Lange Syndrome \(CLDLS Foundation UK and Ireland\)](#)

[Down's Syndrome Association](#)

[Prader Willi Syndrome Association UK](#)

[Rett UK Support Group for Rett Syndrome](#)

[Smith- Magenis Syndrome Foundation UK](#)

[Supporting Cris du Chat Syndrome and their families](#)

[The Fragile X Society](#)

[Williams Syndrome Association](#)

[Connect sexual health clinic for people with learning disabilities](#)

[Relationships, the Internet, and You](#)

[Don't Miss Out: Mencap's guide to obtaining support](#)

[Mencap's guide to join learning disability register to gain extra support when making & attending appointment with GP, support to understand information, & possible Annual Health Check](#)

# Appendices

## Appendix One: Drivers and Enablers

### Policy/ Legislation/ Guidance/ Inquiries and Reports

<b>Title of Evidence</b>	<b>Who by and date of Publication</b>	<b>Core focus of document</b>	<b>Organisations that need to take note</b>
Building the right support	LGA, ADASS and NHS England	A national plan to develop community services and close inpatients facilities for people with learning disabilities and/or autism who display behaviour that challenges including people with mental health conditions	Transforming Care Partnerships, CCG, Local Authority, local health and social care economy
Service Model for Commissioners of health and social care services		Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition	
A Life Like Any Other? Human Rights of Adults with Learning Disabilities	Joint Committee on Human Rights 2007	Evidence to the Committee suggests that adults with learning difficulties are more liable to social exclusion, poverty, isolation and unfair access to justice, and that efforts to improve their lives have had little impact on some.	All Sectors
Valuing every voice, respecting every right: Making the case for the Mental Capacity Act	HM Government response to House of Lords Debate 2014	Outlines that too many people who may lack capacity may be missing out on the legal rights that the MCA gives them. The House of Lords report included comment on lack of knowledge in the police	All Sectors

Mental Capacity Act 2005: Deprivation of liberty safeguards - Code of Practice to supplement the main Mental Capacity Act 2005 Code of Practice	Ministry of Justice 2008	Provides a framework for approving the deprivation of liberty for people who lack the capacity to consent to treatment or care in either a hospital or care home	Hospital, Residential Care Homes and also Supported Living
Care Act	HM Government 2014	Reformation of the law relating to care and support for adults and the law relating to support for carers, to make provision about safeguarding adults from abuse or neglect, to make provision about care standards	Local Authority and other sectors
Children and Families Act 2014	HM Government 2014	<ul style="list-style-type: none"> <li>• Special Education Needs and disability:</li> <li>• single 0–25 assessment process and combined Education, Health and Care Plan (EHCP) Joint commissioning across children/adults to improve transition</li> </ul>	Local Authorities, Education and Health
Autism Act and Strategy	HM Government and DH 2009	First Syndrome specific legislation outlines key changes to local service provision from diagnosis to post diagnostic support	Local Authorities, CCG, other sectors
No Secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse	Department of Health 2012	Guidance to local agencies to investigate and take action when a vulnerable adult is believed to be suffering abuse	All sectors, Making safeguarding everybody's business
The Bradley Report: Lord Bradley's review of people with mental health problems or learning	Department of Health 2009	Examination of offenders with mental health problems or learning disabilities and whether in appropriate cases, they could be diverted from prison to	Health in the Justice, Police and Prisons

disabilities in the criminal justice system		other services and the barriers to such diversion.	
The Bradley Report five years on	Bradley Commission 2014	Review of progress and updated recommendations, including a study of prevalence and making liaison & diversion an 'all stage' model	Health and Justice, CCGs
Six Lives: the provision of public services to people with learning disabilities	Health and Local Government Ombudsman March 2009	The report responds to complaints brought by the charity Mencap on behalf of the families of six people with learning disabilities who died whilst in NHS or local authority care between 2003 and 2005	NDTI, CQC, Monitor, NHS providers, CCG and NHS England, HEE , Local Authorities
Healthcare for All Independent Inquiry into healthcare for people with learning disabilities	Sir Jonathan Michael 2008	Highlighted stark health inequalities and inequity in accessing health care	NDTI, Monitor, CQC, NHS England, CCG, NHS provider, Professional Regulator, HEE
Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)	Bristol University and IHAL Lives Learning Disability Public Health Observatory March 2013	A study to investigate the sequence of events leading to all known deaths of people with learning disabilities over a 2 year period in 5 Primary Care Trust (PCT) areas of South West England	NHS England, CCG, NHS Providers, HEE, CQC, NDTI, Monitor
Death by indifference 74 deaths and counting. A progress report 5 years on	Mencap February 2012	This report looks into 74 hospital deaths that have been reported since the death by indifference report 5 years ago. It identifies some of the traits which are repeatedly seen in the cases and the recommendations from the 'Healthcare for All'	NHS England, CCG, NHS Providers, HEE, CQC, NDTI, Monitor
Valuing people now: a new three-year strategy for people	Department of Health January 2009	Sets out a three year strategy for social inclusion of people with learning disabilities	All sectors and organisations

with learning disabilities			
Draft ADASS National Framework for Learning Disabilities	ADASS TBC	To support people with learning disabilities to get and stay safe, get and stay healthy and live a normal life.	All sectors and organisations
DH Winterbourne View Review Concordat: Programme of Action	Department of Health December 2012	Outlines a programme of change to transform health and care services to improve the quality of the care for people with learning disabilities to ensure better care outcomes for them	Restraint/Seclusion Mental Health needs Challenging behaviour Physical Health - Access to acute Offender Health
Transforming care: A national response to Winterbourne View Hospital	Department of Health December 2012	A report sets out timetabled actions for health and local authority commissioners working together to transform care and support for people with learning disabilities or autism who also have mental health conditions or behaviours viewed as challenging	Restraint/Seclusion Mental Health needs Challenging behaviour Physical Health - Access to acute Offender Health
Hidden in plain sight Inquiry into disability-related harassment	The Equality and Human Rights Commission August 2011	An inquiry into disability-related harassment as unwanted, exploitative or abusive conduct against disabled people	All sectors and organisations
No One Knows: Main project report plus Police responses to suspects with learning disabilities and learning difficulties	Prison Reform Trust May 2008	Evidences that people with learning difficulties are being let down by the criminal justice system. Police safeguards for dealing with suspects with learning disabilities were inconsistent and increase the likelihood of miscarriages of justice	Health in the Justice, Police and Criminal Justice System
Positive and Proactive Care: reducing the need	Department of Health 2014	Helping health and care services manage difficult patient behaviour	Health and Social Care



for restrictive interventions			
Understanding the patient safety issues for people with learning disabilities	National Patient Safety Agency June 2004	Report outlining the work that the NPSA has done to find out what the patient safety priorities are for people with learning disabilities.	NHS Organisations
Positive Practice, Positive Outcomes	Department of Health 2011	Handbook for professionals in the criminal justice system working with offenders with learning disabilities	Health and Justice
Mental health and learning disabilities in the criminal courts	Prison Reform Trust 2013	Information for magistrates, district judges and court staff; valuable reading for liaison and diversion practitioners	Health and Justice
Personal Health Budgets – including people with learning disabilities	Think Local Act Personal	Guide and practical examples for commissioners	CCGs

## Evidence

<b>Title of Evidence</b>	<b>Who by and date of Publication</b>	<b>Core focus of document</b>	<b>Organisations that need to take note</b>
Quarterly Data collection on in patient care for people with LD	NHS England 2014	To oversee the WV deliverable to reduce hospital care for people with Learning Disabilities	CCG, NHS England
Market Positioning Statement For Learning Disabilities Requirements and Provision in London	NHS England 2013	Document collating market intelligence of Learning Disabilities service requirements and provision for adults in London	CCG,NHS England, Local Authorities and service providers

People with Learning Disabilities in England 2011: Services & Supports	iHAL - Improving Health and Lives Learning Disability Public Health Observatory April 2012	Reviews the range of supports and service types available across the UK to people with a learning disability and provides figures and statistical evidence	CCG,NHS England, Local Authorities and service providers
Abuse of Vulnerable Adults in England 2010-11: Experimental Statistics Final Report	The NHS Information Centre, Social Care Team March 2012	Provides the key findings from the Abuse of Vulnerable Adults data collection for the period 1 April 2010 to 31 March 2011	CCG,NHS England, Local Authorities and service providers
Reasonable adjustments for people with learning disabilities in England: A national survey of NHS Trusts	iHAL - Improving Health and Lives Learning Disability Public Health Observatory March 2011	Outlines that, despite legal duties, NHS services are not making the 'reasonable adjustments' required to reduce health inequalities	NHS England, CCG,NDTI, CQC, Monitor and NHS providers
Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs)	iHAL - Improving Health and Lives Learning Disability Public Health Observatory October 2012	A guide to support Clinical Commissioning Groups (CCGs), to commission health services in ways that achieve better health outcomes for people with learning disabilities	CCG, NHS England
Improving services for offenders with learning disabilities or learning difficulties: a literature review	3SC, BILD, Dyslexia Action, NAS, Institute for Criminal Policy Research 2013	Review of literature covering the whole criminal justice pathway,	Health and Justice, CCGs, social care
Joint Inspection of the Treatment of Offenders with Learning Disabilities within the Criminal Justice System - Phase 1 From Arrest to Sentence	Criminal Justice Joint Inspection	Inspection report offering up-to-date evidence on the experience of offenders with learning disabilities	Health and Justice

## Quality Assurance Mechanisms

<b>Title of Evidence</b>	<b>Who by and date of Publication</b>	<b>Core focus of document</b>	<b>Organisations that need to take note</b>
The Health Equality Framework and Commissioning Guide	National Development for Improvement	The Health Equality Framework (HEF) is an outcomes tool based on the determinants of health inequalities designed to help commissioners, providers, people with learning disabilities and their families understand the impact and effectiveness of services.	CCG, Local Authorities, Community Learning Disability Team, dedicate LD providers
National Commissioning for Quality Learning Disability Health Self-Assessment Framework (LD HSAF) 2012/13	iHAL - Improving Health and Lives Learning Disability Public Health Observatory April 2012	A commissioner led nationally agreed framework for benchmarking localities against pre-determined criteria.	CCG, Local Authorities, NDTI, CQC, Providers, NHS England
Autism Self-Assessment Framework	iHAL - Improving Health and Lives Learning Disability Public Health Observatory April 2012	The Autism Self-Assessment Exercise 2013 aimed to assist local authorities and their partners in assessing progress in implementing the 2010 Adult Autism Strategy	CCG, Local Authorities, NDTI, CQC, Providers, NHS England
Greenlight toolkit	National Development Team for Inclusion 2013	The Greenlight toolkit self-assessment exercise aims to assist mental health providers to assess how reasonable adjusted they are with regards to patients with learning disabilities	Mental Health Providers, CCGs, Local Authorities, Community LD Teams
Safeguarding Audit	NHS England (London) and London Safeguarding Board Chairs Network 2014	Audit of Safeguarding and Mental Capacity Act governance, processes and outcomes.	CCG, NHS Providers, NHS England and other sectors, Safeguarding Boards

The National Learning Disability SAFE Audit Tool	NHS England 2013	To provide an audit tool for NHS providers to undertake a case audit linked to key levers for learning disabilities	NHS providers, CCG and NHS England
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## Appendix Two

Voluntary Sector organisations in Kingston providing dedicated support to people with learning disabilities

Provider
Balance
Enhanceable Living
London Care Partnership
United Response
Seeability
HF Trust Limited
Cambian
The Grace Eyre Foundation
Care Management Group
Home Farm Trust
Heathcotes Care Limited
Priors Court Foundation, Priors Court School
Christies Care Ltd, Christies Care Supported Living
Consensus
St. Ann's Lodge
Independence Homes
Welmede Housing Association
Spectrum (D&C Autistic Community Trust), St Erme Campus
Fircroft
LB Richmond
The Regard Partnership Limited,
SHC Rapkyns Group Limited
Stanmore Care Homes Ltd, Stanmore Care Homes - Supported Living
Clearwater Care Group Ltd, Kacee Lodge
Community Care Solutions Ltd, Kimbolton
Titleworth Neuro Limited,
Choice Care Group, Elliott House
David Lewis Centre
Mencap
Progress Housing, Bramshaw House
Optima Care Limited, Seahaven
Cornfields, Liaise Loddon, Cornfields
Regard
Leonard Cheshire Disability
The Grange Centre for People with Disabilities,
Dimensions, Dimensions 59 Lion Road
Autism East Midlands, Whitegates
Living Ambitions Limited

Action on Hearing Loss (formerly Viridian Housing), Harding House
The Meath Trustee Company Limited,
Downing - Chertsey Road, The Chestnuts
Counticare Ltd, Grosvenor Court
DOSH, DOSH - Individual Service Fund
Prime Time Recruitment, Prime Time Recruitment - Home Care
Reflective Care
MISS
Stallcombe House Farm Trust
Camphill Devon Community, Hapstead Village
FRANCIS TAYLOR, FRANCIS TAYLOR Care Home
Cherrytrees Residential Home
20 Station Road
The National Autistic Society,
Whytecliffe Limited, Glentworth House
Medihands Lodge
Anette and Poul Langhave
Family Investment Homes Ltd, Broadstreet House
Mrs Patten, The Crescent RCH Care Home
Sheila Cassidy - APS
Alpenbest, Alpenbest NEW CONTRACT
Bupa, Lynton Hall Nursing Centre
Whatever your needs
Eleanor Nursing and Social Care Ltd, Eleanor Homecare - NEW CONTRACT
Voyage Care
Divine Motions Acacare Ltd, Divine Motions Acacare
Michelle Porter
Tan-bridge Cars
Mogul Cars
Yvonne Jurd
Kingston Eco-op
Allied Care (Ashprime Properties Ltd), Allied Care Supported Living
Pond Farm, Pond Farm - Day Care
Apasenth
Marston Avenue Respite
Supreme Care Services, Supreme Homecare - NEW CONTRACT
Orione House provided by The Sons of Divine Providence, Molesey Horticultural Centre - Day Care
RBK Kingston upon Thames, RBK Kingston upon Thames - Carers Support Direct Payments
Caremark, Caremark - Home Care
B V Nordsjernen, B V Nordsjernen - Day Care