

# JSNA 2016 Learning Disabilities (Adults)

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## Introduction

### What are learning disabilities?

Valuing People (2001) defined a learning disability (LD) as

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence (impaired intelligence, often defined as an IQ level of 70 or less), with;
- a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development.

The focus of this chapter is an adult with a LD. LD is a diagnosis, but it is not a disease, nor is it a physical or mental illness. There are no official statistics reporting the number of adults in the UK with a LD, and establishing a precise figure is not easy due to the social construct of the condition and its wide spectrum. However estimates suggest that approximately 2% of the UK adult population have a LD. In Ealing is it estimated that there are around 1,402 adults with a LD. The number of adults with a LD in Ealing is increasing and the nature of need is changing. It is anticipated that the population of those 18-64 with a LD will increase from 7% to 12% by 2030. The projections are in line with projected increases in the general adult population. The primary driver is an increase in life expectancy.

Males are more likely than females to have either a mild LD or a severe LD (1.2 males: 1 female and 1.6 males: 1 female respectively), due to some conditions associated with a LD having a sex-linked genetic cause (Emerson et al 2001). The ratio decreases with age as women typically live longer.

People with LDs have differing needs and are one of the most vulnerable groups in society, experiencing health inequalities, social exclusion and stigmatisation. In general, adults with LDs have greater and more complex health needs than those without a LD and often these needs are not identified or treated. Life expectancy of this group is shorter than the general population, though this has increased recently. In addition a number of national reports have highlighted that adults with LDs often experience barriers to accessing healthcare services and poor levels of care. Adults with LDs are more likely to die from a preventable cause than adults in the general population.

## Health of people with LDs

Compared to the rest of the population, people with LDs have<sup>1</sup>:

- **Lower life expectancy** – people with LDs have an increased risk of premature death compared to the general population. There is also a strong

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<sup>1</sup> Cooper et al (2004) People with intellectual difficulties. Their health needs differ and need to be recognised and met. *British Medical Journal* 329: 414-415

correlation between severity of LD and life expectancy (median life expectancies of 74.0, 67.6 and 58.6 for people with mild, moderate and severe LDs).<sup>2</sup> People with Down's syndrome have a shorter life expectancy than people with LDs generally, though life expectancy in this group is increasing<sup>3</sup>

- **Different causes of death** – the main cause of death amongst people with a LD is respiratory disease (accounting for approximately half of all deaths and related to pneumonia and aspiration pneumonia), followed by cardiovascular disease (related to congenital heart disease rather than ischemia)<sup>4</sup>. This compares to cancer, heart disease and cerebrovascular disease being the leading causes of death in the general population. People with a LD are more likely to die from a preventable cause than the general population.
- **Higher levels of unrecognised and unmet physical and mental health needs** – People with are less likely to receive regular health checks than the general population. A recent study in Wales undertook health screening for 181 adults with LDs. Over half the sample had health issues newly identified in the health checks, and 9% had health issues newly identified that were deemed to be serious, including breast cancer, suspected dementia, asthma, post-menstrual bleeding, diabetes, hypothyroidism, high blood pressure and haematuria<sup>5</sup>
- **Barriers to accessing health services** – people with LDs often experience barriers in accessing health services, which will impact on medical treatment and management. Barriers can include problems with communication, inadequate facilities, rigid procedures, a lack of appropriate interpersonal skills among mainstream health professionals and a lack of accessible information<sup>6</sup>. Uptake of screening amongst people with LDs is lower than the general population (in Ealing proportion of the eligible population with LD that took up screening for the different cancers was as follows cervical – 58%, breast- 50% and bowel 66%) and people with LDs are less likely to be immunized against tetanus, poliomyelitis and influenza than the general population.
- **Different lifestyle issues** – restrictions and a lack of opportunities to gain appropriate knowledge due to a lack of accessible health promotion services and materials may mean that adults with LDs have limited understanding about health risks and consequently are unable to determine own healthy lifestyle choices. In general adults with LDs<sup>7</sup>
  - have higher levels of obesity than the general population
  - are less likely to participate in the recommended levels of physical activity than the general population
  - are less likely to eat a healthy diet with an insufficient intake of fruit and vegetables than the general population

Debate exists regarding the prevalence rates of alcohol 'use' and 'misuse' and with regards to illicit drug misuse amongst those with learning disabilities. Difficulties in

<sup>2</sup> Bittles et al (2002) The influence of intellectual disability on life expectancy. *Journal of Gerontology* 57A, 7: M470-472

<sup>3</sup> Puri et al (1995) Mortality in a hospitalised mentally handicapped population: a 10-year survey. *Journal of Intellectual Disability Research* 39: 442-446

<sup>4</sup> Hollins et al (1998) Mortality in people with a learning disability: risks, causes and death certification finding in London. *Developmental Medicine and Child Neurology* 40:50-56

<sup>5</sup> Baxter et al (2006) Previously unidentified morbidity in patients with intellectual disability. *British Journal of General Practice* 56(523): 93-98

<sup>6</sup> Alborz et al (2005) Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. *Journal of Health Services Research and Policy* 10(3): 173-182

<sup>7</sup> NHS Health Scotland (2004) People with Learning Disabilities in Scotland: Health Needs Assessment Report

establishing prevalence rates arise from the definition of 'learning disabilities', the methodology employed, levels of learning disability, and whether people are known to learning disability services or not. Generally evidence suggests lower prevalence rates in those with learning disabilities however the difference in prevalence decreases when looking at those with milder learning disabilities against the general population, and evidence does suggest a degree of underestimation and under identification – of both learning disability and substance use and misuse. Most of this unidentified learning disability population are hypothesised to be those with borderline to mild learning disabilities, living independently in the community, a sub-group of people who may be at greater risk of developing a substance related disorders<sup>8</sup>.

Adults with LDs are more likely to experience epilepsy, gastro-oesophageal reflux disorder, sensory impairments, osteoporosis, schizophrenia, dementia, dysphagia, dental disease, musculoskeletal problems, accidents and nutritional problems than the general population. However, as the life expectancy of people with LDs increases, the same age-related illnesses will also be experienced. For example the incidence of cancer amongst people with a LD is rising due to an increase in longevity<sup>7</sup>.

In addition, people with LDs are more likely to be admitted to hospital as an emergency case, compared to those with no LD: - 50% of all admissions for those with LD are emergencies, compared to 31% of admissions in the general population in 2013/14. It is likely that this difference is due to problems in accessing care and lack of advance planning when people are transferred out of area.

### **Social issues for people with LD**

People with LDs do not just face challenges with healthcare. Many live in poverty and are unable to secure employment. National research suggests only 6.7% of people with a LD are in either part-time or full-time employment.

National research has shown many local authorities believe the type of housing people with LD and autism are in does not meet their needs.

National research also shows that people with LDs are at increased risk of becoming victims of violence and abuse.

The estimated proportion of people in prison who have LDs or learning difficulties that interfere with their ability to cope with the criminal justice system is around 20-30%. Many are unidentified.

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<sup>8</sup> Alcohol and illicit drug misuse in people with learning disabilities: implications for research and service development: Taggart, L., Huxley, A. and Baker, G. Advances in Mental Health and Learning Disabilities Volume 2 Issue 1 March 2008

Many people with LDs have little or no contact with friends. A research study found that 31% of adults with a LD having no contact with friends, compared to 3% of adults without a LD<sup>9</sup>.

Six out of 10 women with LDs who become a parent have their children taken in to care. Numbers of parents are small in each local authority however, they are likely to have complex and on-going support needs.

Many people with LDs are unable to travel independently and rely heavily on support to use public transport or the provision of adapted transport, often with a passenger assistant. Other issues identified for people with LD include employment and educational opportunities, hate crime, benefits changes as well as housing and support needs.

Some people with a LD display behaviour that challenges. 'Behaviour that challenges' is not a diagnosis and does not in itself imply any understanding as to the causes of the behaviour. The behaviour may be a way for someone to let people know what they want or how they feel, or to try and control what is going on around them, or be a response to physical or mental distress.

A variety of factors are likely to contribute towards the development and escalation of behaviour that challenges, these include (but are not limited to): biological and genetic factors, physical ill-health, impaired communication difficulties, mental ill-health, the impact of poverty and social disadvantage, quality of support and exposure to adversities. Some care and support environments may increase the likelihood of behaviour that challenges, including those with limited opportunities for social interaction and meaningful occupation, lack of choice and sensory input or excessive noise, as well as environments where physical health needs and pain go unrecognised or are not managed.

Behaviour that challenges can often result from the interaction between personal and environmental factors, and can include self-injury or physical aggression, severe agitation and extreme withdrawal, as well as behaviours that can result in contact with the criminal justice system – in some cases leading to someone being arrested, charged and convicted of an offence.

Some people may have a long and persistent history of behaviour that challenges, perhaps starting in childhood. In others, it may be highly episodic – arising only under specific circumstances of stress or when the individual has a physical or mental health condition. In others still, it can be traced to a specific life event, such as bereavement. This means that even if someone does not display behaviour that challenges today, they may do so in the future<sup>10</sup>.

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<sup>9</sup> Emerson E. Self-reported exposure to disablism is associated with poorer self-reported health and well-being among adults with intellectual disabilities in England: Cross sectional survey. *Public Health* 2010; 124(12):682-89.

<sup>10</sup> NHS England. Service model for commissioners of health and social care services <https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf> (accessed December 2015)

## National Policy

*Valuing People* and the more recent *Valuing People Now* set out how children and adults with learning disabilities and their families should be enabled to live full and independent lives as part of their local communities.

*Valuing People Now* set out the following national priorities:

**Personalisation** – so that people have a real choice and control over their lives and services;

What people do during the day (and evenings and weekends) – helping people to be properly included in their communities, with a particular focus on paid work;

**Better health** – ensuring that the NHS provides full and equal access to good quality healthcare;

**Access to housing** – housing that people want and need with a particular emphasis on home ownership and tenancies;

Making sure that change happens and the policy is delivered – including making partnership boards more effective.

### Key national policies and legislation:

- Health, Our Care, Our Say A new direction for community services. Department of Health 2006
- Death by Indifference and Six Lives reports, 2007
- Mental Capacity Act 2005, Code of Practice, 2007
- Services for People with Learning Disabilities and Challenging Behaviour or Mental Health
- Needs; Mansell Report revised, 2007
- Putting People First – A shared vision and commitment to the transformation of Adult Social Care, 2007
- Care Standards Act 2000, Regulation 2010
- Caring for our future: reforming care and support, 2012
- Transforming care: a national response to Winterbourne View hospital; 2012 Children and Families Act, SEND Reforms
- Health care for all
- Care Act, 2014
- Building the Right Support, 2015

Following the publication of the Mencap report “Death by Indifference” on the deaths of six people with LD in social and health care settings, there has been one independent inquiry and one major investigation carried out jointly by the Local Government Ombudsman and the Parliamentary and Health Service.

Personalisation outlined in *Putting People First (2010)* has changed the way services are commissioned and delivered. It emphasises independence, social inclusion, rights, employment, choice and control. As part of this, person-centred planning and self-directed support have become mainstream. Personal budgets are

offered to everyone eligible for publicly funded social care support other than in circumstances where people require emergency access to provision.

Since the investigation into the abuse at Winterbourne View and other similar hospitals, there has been a cross-government commitment to transform care and support for people with a learning disability and/or autism with challenging behaviour and/or mental health conditions. In October 2015 *Building the Right Support* was published which reinforces the values in *Transforming Care* and sets out the national ambition and the financial framework to support the closure of inpatient settings and shift investment into community based services, early intervention, and high quality personalised support. The national plan is aimed at improving services and support for young people or adults with a learning disability and/or autism who:

- Have a mental health condition such as severe anxiety, depression, or a psychotic illness, and those people with personality disorders, which may result in them displaying behaviour that challenges
- Display self-injurious or aggressive behaviour (not related to severe mental ill health), some of whom will have a specific neuro-developmental syndrome where there may be an increased likelihood of developing behaviour that challenges
- Display risky behaviours which may put themselves or others at risk and which could lead to contact with the criminal justice system (this could include things like fire-setting, abusive or aggressive or sexually inappropriate behaviour)
- Often have lower level support needs and who may not traditionally be known to health and social care services, from disadvantaged backgrounds (e.g. social disadvantage, substance abuse, troubled family backgrounds) who display behaviour that challenges, including behaviours which may lead to contact with the criminal justice system

The different kinds of shift in service response required to better meet these different needs are set out in more detail in a national service model

*Green Light for Mental Health (2013)* is a nationally recognised guide to auditing and improving local mental health services so they are effective in supporting people with learning disabilities.

The Autism Act 2009 indirectly introduces a number of provisions that are also relevant to clients with LD. It stresses the importance of medical diagnosis as triggers for assessment (and re-assessment if necessary) of needs. It establishes the need for developing effective methods of diagnosis for the condition in relation to the provision of services and it requires that public services should be able to identify adults with autism regardless of the severity of the conditions, and provide appropriate services for each individual.

Learning Disabilities Partnership Board and local strategy

Ealing has a local learning disabilities strategy “Working Together for Better Lives 2014-19”. The Learning Disabilities Partnership Board supports the strategy and monitors the action plan. The board also has responsibility to ensure that all partners are aware of the plan. This strategy includes people with a LD who have low or moderate social care needs and may not be eligible for specialist social care and health support. The four main priority areas which were agreed on after consulting with stakeholders include

1. people have access to affordable housing options and are supported to live in ordinary housing
2. people have access to health services which lead to improved health outcomes
3. people are supported to be part of their community, have friends and relationships, and access to work, leisure and education opportunities
4. family carers are supported to care for their relatives and have access to a range of services to enable them to have a break from their caring role

Within the strategy, commissioned services will promote independence, health and wellbeing and where possible prevent, delay or minimise a persons need for formal care and support by providing greater access to universal services and through the increased use of tele care assistive technology which can make supported living and living at home with families safer

## Level of Need in Ealing

### Number of people with LD by service in Ealing

**Table 1: Number of people with LD by service in Ealing**

Data source	Age range	Number of people with LD known to services
Local Authority	18+	<b>930 (2014/15)</b> 938 (2013/14)
Quality Outcomes Framework - GP register	18+	<b>792 (2013/14)</b> 796 (2012/13)
2015 Estimates by PANSI	18+	<b>1,402</b>

Source: Ealing Local Authority 2015, Quality Outcome Framework 2013/14, and PANSI data sets 2014

In Ealing, the figures are likely to be an underestimate. One of the reasons for this could be due to a large BME community and reluctance of some groups to seek help. Of the 930 people with Learning Disabilities known to the local authority, 217 live outside the borough of Ealing.

## Number of adults with LD who are known to services, by age, gender, ethnicity, ward, service type

There were 930 adults with LD known to the Ealing Council in 2014/15; 91% of people are within 18 – 64 age range and 60% are males. The largest group of people are in age range of 25-34 age range – 25%. 3% of adults with LD (26 people) are parents.

**Table 2: Number of adults with LD who are known to services, by age, 2014/15**

Age	Number	Percentage
18 - 64	849	91%
65+	81	9%

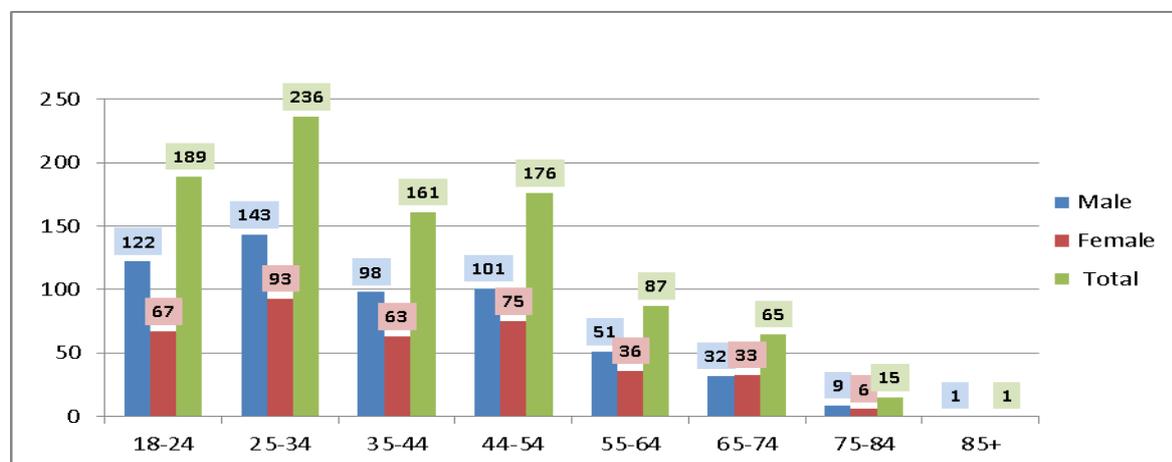
Source: Adults Performance & Management Team, 2015

**Table 3: Number of adults with LD who are known to services, by gender, 2014/15**

Sex	Number	Percentage
Male	557	60%
Female	373	40%

Source: Adults Performance & Management Team, 2015

**Figure 1: Number of adults with LD known to services, by age and gender, 2014/15**



Source: Adults Performance & Management Team, 2015

Around a half of the population of adults with LD (49%; 457 people) are of White British, Irish or Other White background. 27% (252) are Asian or Asian British, 16% (150) are Black or Black British, 3.5% (33) are Chinese or any other ethnic background, 3.9% (36) are from mixed background.

In comparison, 2015 projections for ethnic groups in Ealing as a whole, show 45% of population of White ethnic origin, 31% Asian or Asian British, 13% Black or Black British, with 9% being of Chinese or any other background<sup>11</sup>

**Table 4: Number of adults with LD known to services, by ethnicity, 2014/15**

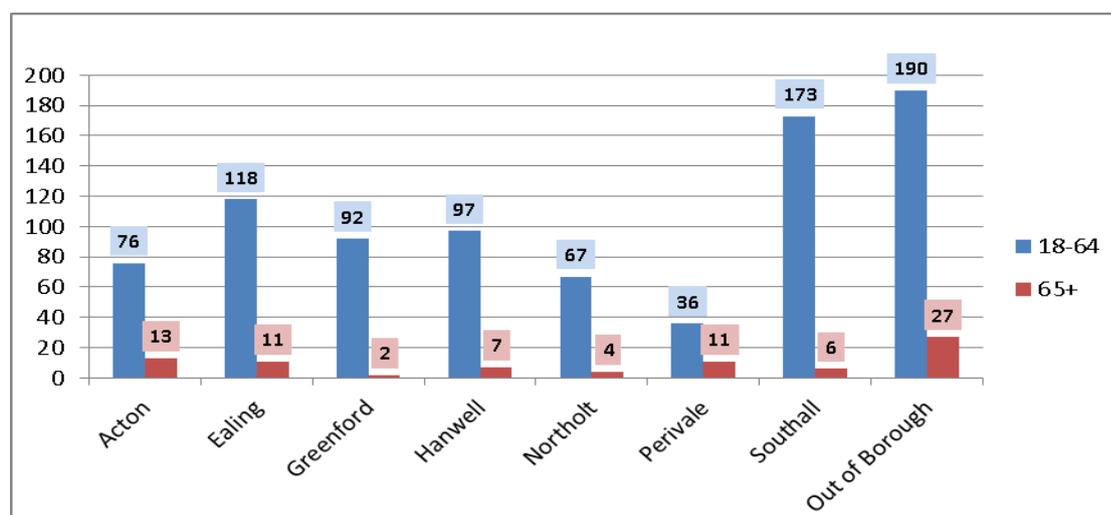
<b>Ethnicity</b>	<b>Number 18-64</b>	<b>Number 65+</b>	<b>Total</b>
<b>White</b>			
British	361	64	425
• Irish	2	6	8
• Other white background	24	0	24
<b>Mixed</b>			
• White and Black Caribbean	10	0	10
• White and Black African	2	0	2
• White and Asian	6	0	6
• Other mixed background	18	0	18
<b>Asian or Asian British</b>			
• Indian	39	2	41
• Pakistani	24	1	25
• Bangladeshi	2	0	2
• Other Asian background	177	7	184
<b>Black or Black British</b>			
• Caribbean	97	1	98
• African	18	0	18
• Other Black Background	34	0	34
<b>Chinese or other ethnicity</b>			
• Chinese	3	0	3
• Any other ethnicity	28	0	28
• Arab	2	0	2
<b>Not stated</b>	<b>2</b>	<b>0</b>	<b>2</b>
<b>Total</b>	<b>849</b>	<b>81</b>	<b>930</b>

Source: Adults Performance & Management Team, 2015

23% (217) of people with LD known to services live outside of the borough. Southall has the largest population of people with LD – 19% and Perivale has the smallest population - 5%.

<sup>11</sup> Please note: GLA Aggregated Ethnic Group (AEG) classification – White group includes Irish and White Other; Mixed White and Black ethnic group is counted as Black Other (so within Black/Black British in the table); Mixed White and Asian ethnic group is under Other Asian (so Asian/Asian British here); any other mixed ethnic heritage is counted under Other ethnic group.

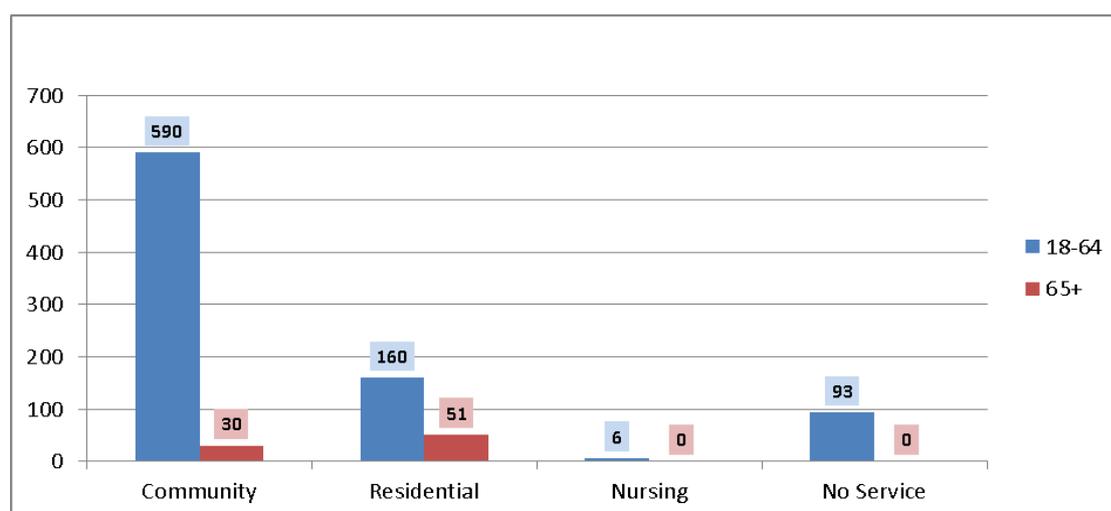
**Figure 2: Number of adults with LD known to services, by locality, 2014/15**



Source: Adults Performance & Management Team, 2015

Two thirds of the people, 66.7% (620) are receiving community services e.g. supported living, day opportunities, outreach and 22.7% (211) are in residential care. Only 6 were receiving care in nursing settings (0.6%) in 2014/15.

**Figure 3: Number of adults known to services, by service type, 2014/15**



Source: Adults Performance & Management Team, 2015

## Number of adults with LD in Assessment and Treatment

As at 1<sup>st</sup> Jan 2015

10 patients with LD in Assessment and Treatment

2 in campus provision

2 in secure hospital settings

As at 1<sup>st</sup> Jan 2016

10 patients with LD in Assessment and Treatment

2 in campus provision

2 in secure hospital settings

This total cohort represents less than 1% of the local LD and autism population. Of the total inpatient group, 13 are male, 1 is female.

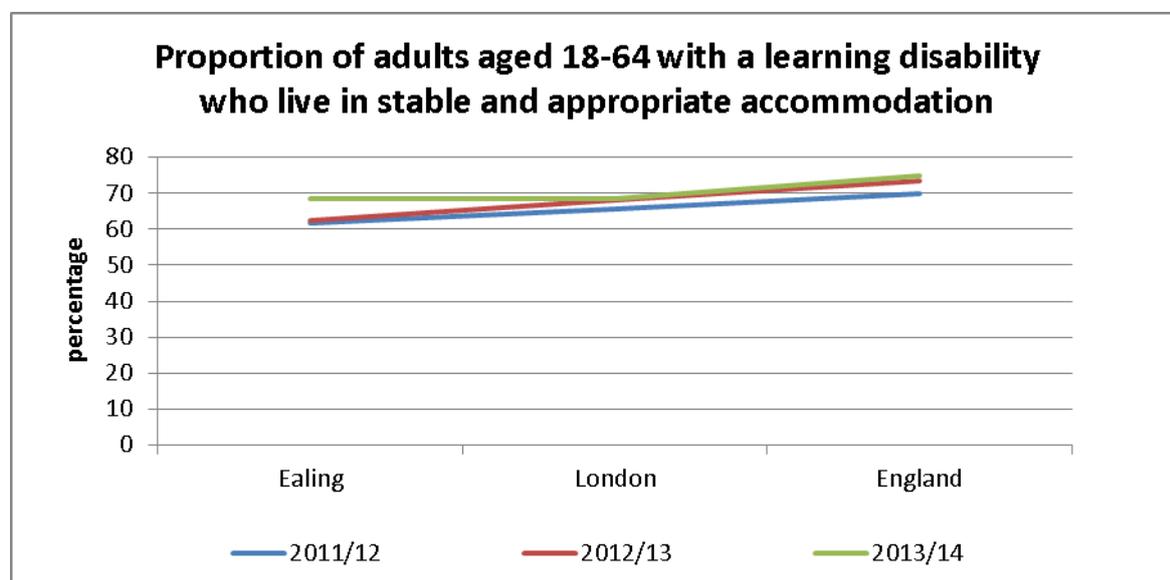
## Proportion (%) adults with LD who are known to LA in settled accommodation

**Table 11: Percentage of adults (18-64) with a LD who are known to the council, who are recorded as living in their own home or with their family**

Period	Ealing	London	England
2011/12	61.7	65.7	70.0
2012/13	62.6	68.1	73.5
2013/14	68.6	68.6	74.9

Source: HSCIC, Public Health Outcomes Framework - 2014

**Figure 9: Percentage of adults with a LD who are known to the council, who are recorded as living in their own home or with their family (supported living)**



Source: HSCIC, Public Health Outcomes Framework - 2014

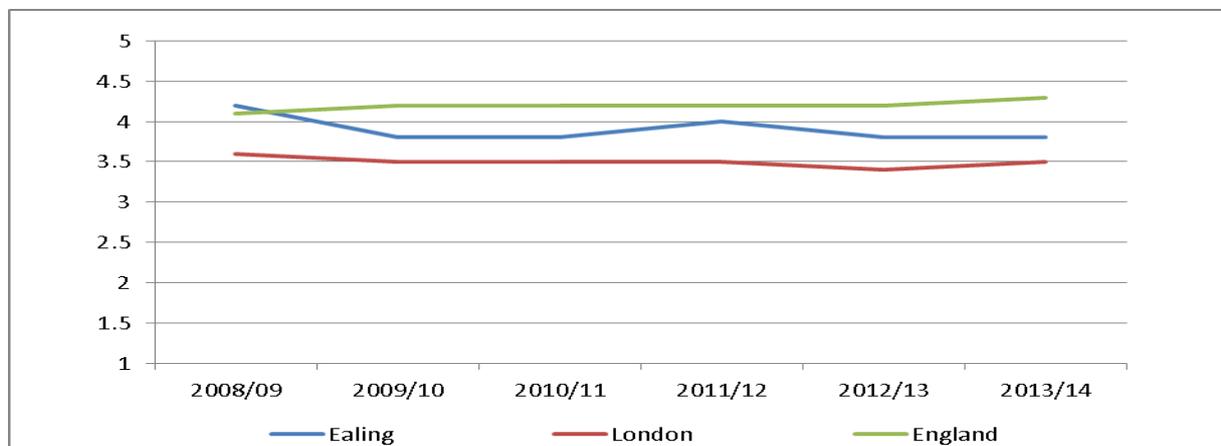
Supported living enables people with learning disabilities to live in their own homes as an alternative to shared residential care. There has been a drive nationally, supported by *Valuing People* to increase the number of people with learning disabilities living in supported living as it offers more choice, control and community inclusion in addition to achieving wider access to welfare benefits and having a tenancy.

## Adults with LD known to Local Authorities (%) across London

Quality Outcome Framework (QOF) data reflects the prevalence of conditions diagnosed by GP. As part of QOF, GPs are asked to keep register of adults (18+) who they know have LD.

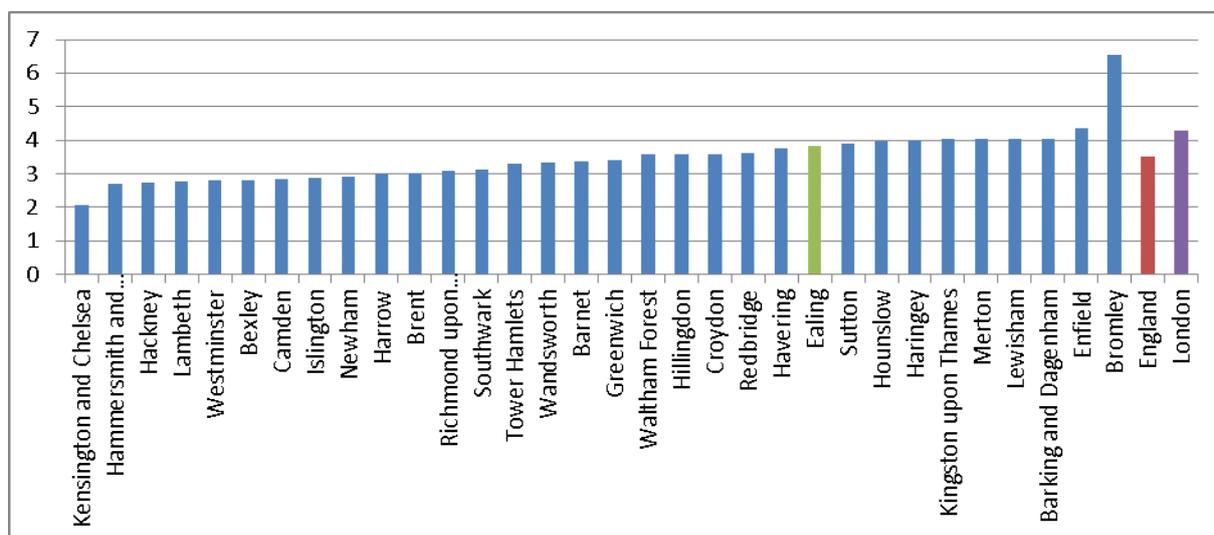
In Ealing in 2013/14, the total number of people with LD known to the LA was 930. This includes people who live out of the borough. This is similar to the number of adults as reported in the previous year. The rate for 2013/14 is indicated as 3.8 per 1000 on GP registers. This is significantly lower than England average – 4.3 per 1000 in 2013/14.

**Figure 4: Adults (18-64) with LD known to Local Authorities (rate per 1000); time trend**



Source: PHE Learning Disabilities Profiles, 2015 (HSCIC, NASCIS-1)

**Figure 5: Adults with LD known to Local Authorities (rate per 1000) across London 2013/14**



Source: PHE Learning Disabilities Profiles, 2015 (HSCIC, NASCIS-1)

## Projecting future need in Ealing

Projections of short-term and long-term future prevalence of LD give an indication of future need, but are based on national estimates therefore do not take into

account local factors<sup>5</sup>. In Ealing, the figures are likely to be an underestimate due to a large South Asian community and reluctance of some groups to seek help. In Ealing, the estimates for 2020 indicate that the number of people (aged 18 and over) who have LD is 6,791; around 1,466 people would have moderate/severe LD and therefore are likely to be in receipt of local services, 357 of those people would have severe LD. It has been estimated that around 108 people in 2020 would display challenging behaviour. Projected estimates have been calculated by applying national estimates to projected population figures

**Table 5: People 18+ projected to have a LD, by age, projected to 2030**

People predicted to have LD	2014	2015	2020	2025	2030
People aged 18-24	817	812	789	795	880
People aged 25-34	1,651	1,648	1,656	1,646	1,601
People aged 35-44	1,360	1,383	1,463	1,502	1,512
People aged 45-54	1,039	1,059	1,110	1,169	1,247
People aged 55-64	729	743	833	917	956
People aged 65-74	454	464	534	579	651
People aged 75-84	264	269	284	331	383
People aged 85 +	95	99	123	150	175
<b>Total population aged 18 and over</b>	<b>6,410</b>	<b>6,477</b>	<b>6,791</b>	<b>7,089</b>	<b>7,404</b>

Source: PANSI 2014

**Table 6: People 18+ projected to have a moderate/severe LD, by age, projected to 2030**

People predicted to have moderate/severe LD	2014	2015	2020	2025	2030
People aged 18-24	188	187	183	186	208
People aged 25-34	355	354	356	354	344
People aged 35-44	341	347	368	378	381
People aged 45-54	234	239	251	266	285
People aged 55-64	159	162	182	199	207
People aged 65-74	74	76	87	94	106
People aged 75-84	28	28	29	34	39
People aged 85 +	9	9	12	14	16
<b>Total population aged 18 and over</b>	<b>1,388</b>	<b>1,402</b>	<b>1,466</b>	<b>1,525</b>	<b>1,585</b>

Source: PANSI 2014

**Table 7: People 18-64 projected to have a severe LD, by age, projected to 2030**

People predicted to have moderate/ severe LD	2014	2015	2020	2025	2030
People aged 18-24	62	62	60	61	68
People aged 25-34	99	99	100	99	96
People aged 35-44	92	94	99	102	103
People aged 45-54	52	53	56	59	63
People aged 55-64	37	38	42	47	49
<b>Total population aged 18-64</b>	<b>343</b>	<b>345</b>	<b>357</b>	<b>368</b>	<b>379</b>

Source: PANSI 2014

<sup>5</sup> Emerson, E. and Hatton, C. (2008) *Estimating Future Need for Adult Social Care Services for People with Learning Disabilities*. Centre for Disability Research, Lancaster University.

**Table 8: People 18-64 with LD predicted to display challenging behaviour, by age, projected to 2030**

People predicted to have moderate/severe LD	2014	2015	2020	2025	2030
People aged 18-24	14	14	13	13	15
People aged 25-34	30	30	30	30	29
People aged 35-44	25	25	27	27	27
People aged 45-54	20	20	21	22	24
People aged 55-64	14	15	16	18	19
<b>Total population aged 18-64</b>	<b>103</b>	<b>104</b>	<b>108</b>	<b>111</b>	<b>114</b>

Source: PANSI 2014

## People 18-64 projected to have Down's syndrome

**Table 9: People 18-64 predicted to have Down's syndrome, by age, projected to 2030**

People predicted to have Down's Syndrome	2014	2015	2020	2025	2030
People aged 18-24	19	19	18	18	20
People aged 25-34	41	41	42	41	40
People aged 35-44	35	35	37	38	38
People aged 45-54	28	28	30	31	33
People aged 55-64	20	20	23	25	26
<b>Total population aged 18-64</b>	<b>143</b>	<b>144</b>	<b>149</b>	<b>154</b>	<b>158</b>

Source: PANSI 2014

## Autistic spectrum by age

**Table 10: People predicted to have autistic spectrum disorders, by age, projected to 2030**

People predicted to have autistic spectrum	2014	2015	2020	2025	2030
People aged 18-24	315	311	301	305	339
People aged 25-34	677	681	704	708	689
People aged 35-44	572	578	620	645	660
People aged 45-54	446	457	484	515	550
People aged 55-64	315	320	363	406	428
<b>Total population aged 18-64</b>	<b>2,325</b>	<b>2,347</b>	<b>2,471</b>	<b>2,579</b>	<b>2,665</b>

Source: PANSI 2014

Recent research by the Learning Disabilities Observatory indicates that around 20-30% of people with learning disabilities have an ASD<sup>12</sup>.

## Proportion of eligible adults with LD having a GP health check (%)

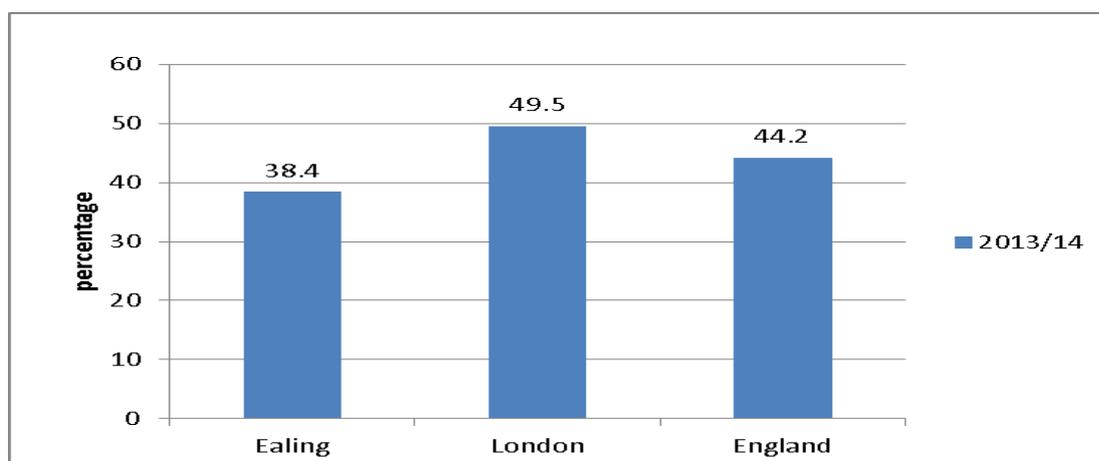
In 2013/14, 38.4% of eligible adults with LD received an annual health check (AHC) (amounts to 304 adults)<sup>13</sup>.

<sup>12</sup> Learning Disabilities Observatory. The Estimated Prevalence of Autism among Adults with Learning Disabilities in England. [http://www.improvinghealthandlives.org.uk/uploads/doc/vid\\_8731\\_IHAL2010-05Autism.pdf](http://www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf) (accessed December 2015)

<sup>13</sup> Source: Public Health Learning Disability Profiles, 2015

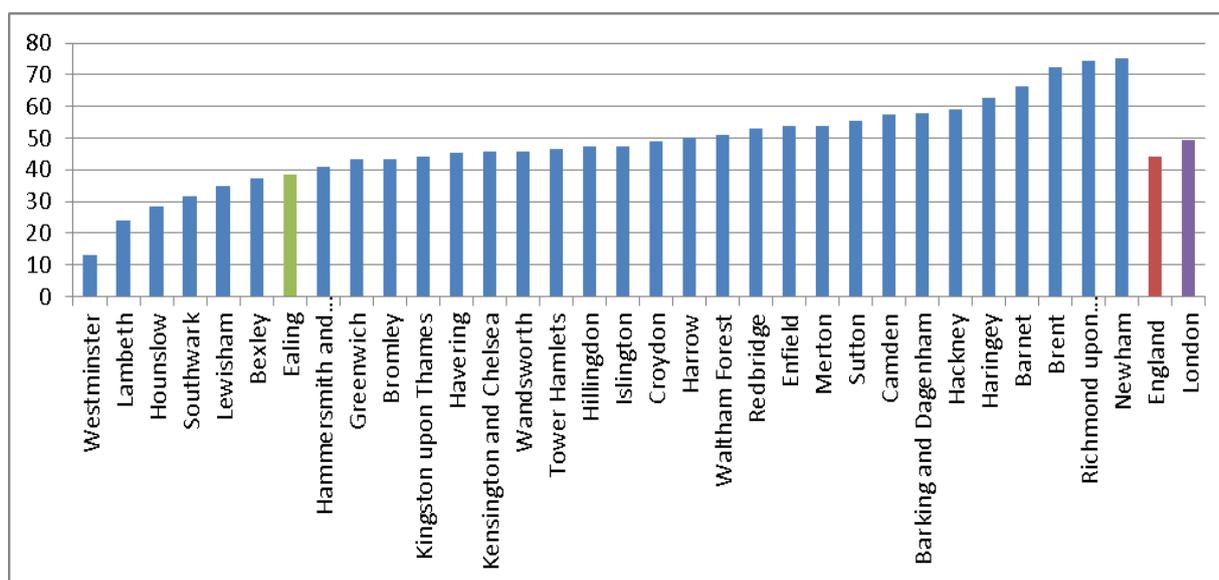
Although the local figures for 2013/14 are still significantly worse than England average (49.5%), Ealing has made a good progress to increase the numbers of health checks in a recent year and is working to deliver further improvements in this important area.

**Figure 6: Proportion of eligible adults with LD having a GP AHC (%)**



Source: Calculating Quality Reporting Service (CQRS), end of year download for 2013 to 2014 (PHE Learning Disabilities Profiles, 2015)

**Figure 7: Proportion of eligible adults with LD having a GP AHC (%) across London in 2013/14**



Source: Calculating Quality Reporting Service (CQRS), end of year download for 2013 to 2014 (PHE Learning Disabilities Profiles, 2015)

Ealing CCG in their 2015/16 Operating Plan submission to NHS England, has agreed to increase the number of health checks and health action plans for patients with Learning Disabilities, compared to the ~20% of Ealing patients on local LD registers who received these in 2014/15.

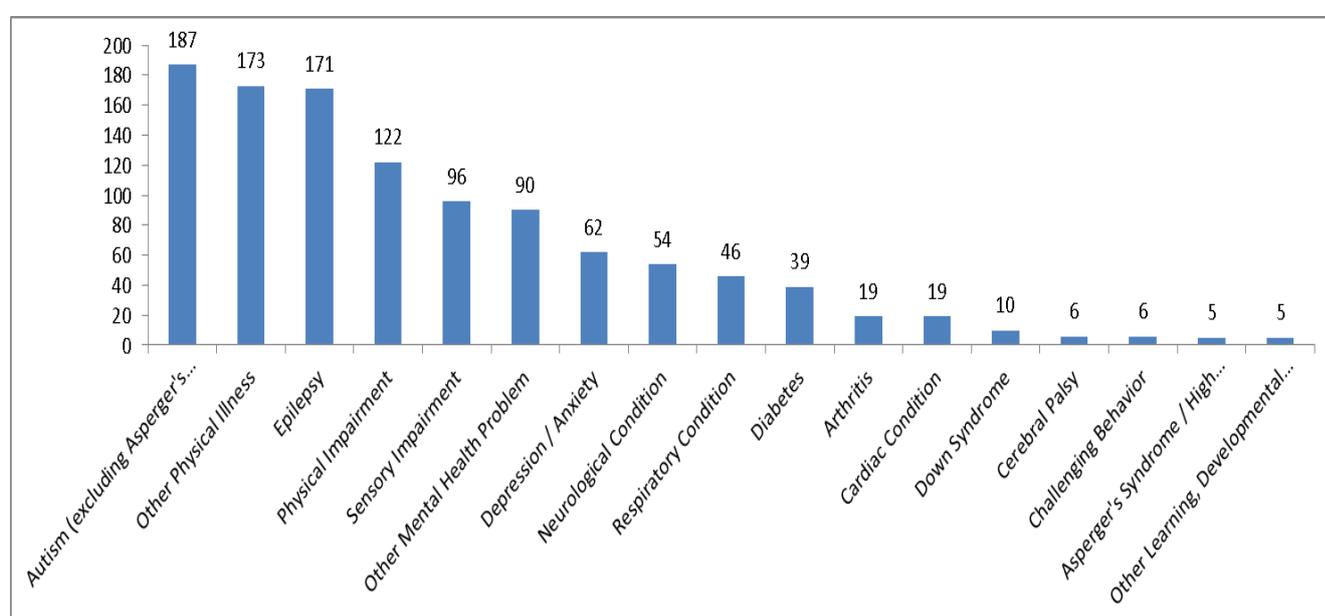
632 patients out of a possible 903 people with LDs had a health check in 2015/16. All of the 632 health checks resulted in action plans. This is a big improvement from 2014/15 where 159 patients had a health check, with only 82 of those checks resulting in action plans.

## Number of people with learning disabilities identified as having a specific condition

In 2014/15 in Ealing, the top five registered conditions for people with LD were Autism (excluding Asperger’s Syndrome/High Functioning Autism), other physical illness, epilepsy, physical impairment and sensory impairment.

There were 361 individuals with multiple conditions.

**Figure 8: Number of people with learning disabilities identified as having a specific condition in 2014/15<sup>14</sup>**



Source: Adults Performance & Management Team, 2015

<sup>14</sup> The figure shows registered health conditions for 5 or more people only

**Table 11: People with LD by condition compared to the general population**

Condition	Adults with LD		General population on QOF register 2014/15	
	Number	Prevalence	Number	Prevalence
Diabetes	39	4.9%	24,383	7.4%
Epilepsy	171	21.6%	1,752	0.5%
Depression	62	7.8%	13,538	4.2%
Other MH problem	90	11.4%	4,392 (MH)	1.1%
Respiratory condition	46	5.8%	20,813(asthma)	5.0%
			3,514 (COPD)	0.8%

Source: QOF 2014/15

## Learning Disability Statistics: Mental Health Issues<sup>15</sup>

Between 25 and 40% of people with learning disabilities also suffer from mental health problems

For children and young people, the prevalence rate of a diagnosable psychiatric disorder is 36% in children and adolescents with learning disabilities, compared with 8% of those who did not have a learning disability. These young people were also 33 times more likely to be on the autistic spectrum and were much more likely than others to have emotional and conduct disorders.

Children and young people with learning disabilities are much more likely than others to live in poverty, to have few friends and to have additional long term health problems and disabilities such as epilepsy and sensory impairments. All these factors are positively associated with mental health problems.

- People with learning disabilities demonstrate the complete spectrum of mental health problems, with higher prevalence than found in those without learning disabilities
- The prevalence of dementia is much higher amongst older adults with learning disabilities compared to the general population (21.6% vs 5.7% aged 65+)
- People with Down's syndrome are at particularly high risk of developing dementia, with an age of onset 30-40 years younger than the general population

<sup>15</sup> Foundation for people with learning disabilities. Learning Disability Statistics: Mental Health Issues <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187699/> (accessed February 2016)

- Prevalence rates for schizophrenia in people with learning disabilities are approximately three times greater than for the general population (3% vs 1%)
- Reported prevalence rates for anxiety and depression amongst people with learning disabilities vary widely, but are generally reported to be at least as prevalent as the general population, and higher amongst people with Down's syndrome
- Challenging behaviours (aggression, destruction, self-injury and others) are shown by 10%-15% of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49

## Number of children and young people with learning disabilities<sup>16</sup>

69.9% (450) of pupils in Ealing maintained special schools have Cognition and Learning Needs – 18.5% Moderate Learning Difficulties, 40.2% Severe Learning Difficulties and 10.5% Profound and Multiple Learning Difficulties. 108 pupils (16.7%) have Autism Spectrum Disorders (ASD) as their primary need.

- A fifth of children and young people living in the borough who have SEN (20%), have more than one specified need. In January 2015, the three most common dual-diagnoses account for more than a quarter (27% or 412 people) of all children and young people with more than one SEN (1537 people). These diagnoses are combinations of:
  - *moderate learning difficulties*
  - *communication and interaction needs (includes speech, language and communication needs as well as Autistic Spectrum Disorder)*
  - *social, emotional & mental health*
  - *severe learning difficulties.*

## Emergency hospital admissions as % of total

Ideally, people who need treatment in hospital should be admitted before their illness reaches a critical stage where they have to be admitted as an emergency. This is particularly relevant for people with LD and autism where planning and preparation is crucial. However, the numbers of emergency admissions nationally are substantially larger for people with LD than for general population (50.0% vs. 31.1%).

In Ealing, the number of emergency admissions to general hospitals of adults with LD in 2013/14 was 446<sup>17</sup>. This represents 47.5% of the total number of people with LD known by services in Ealing in the same year. This was lower but not significantly different than London (57%) and England (49%) in 2008/09 (no later data available on the Public Health LD Observatory 2013).

<sup>16</sup> Source: Ealing Schools Research and Statistics Team, 2015

<sup>17</sup> Source: Ealing SUS Data 2013/14; ICD 10, 2015 Diagnosis codes included: F80 – F89 (disorders of psychological development, including Autism & Asperger's Syndrome); Q90 (Down Syndrome)

## Numbers of adults with learning disabilities admitted with primary or secondary diagnosis of diabetes, asthma and epilepsy

From the total number of 446 hospital admissions of adults with LD in 2013/14, about 50% of them (225) also had a primary or secondary diagnosis of diabetes, asthma or epilepsy<sup>18</sup>.

## Employment

### Proportion (%) adults with LD who are in paid employment

Paid work provides recognition of a valued social role, useful daytime occupation, important social opportunities, and in a few cases a helpful level of financial reward. Government policy has repeatedly emphasized the importance of maximizing work opportunities for people with LD since the publication of *Valuing People* (2001).

9.3% of adults aged 18-64 with LD (80 people) were in paid employment in Ealing in 2013/14. This is a marked decrease from 2010/11 when 13% of adults were in paid employment. However this is better than London (8.8%) and significantly better than England (6.7%) average.

The National Autistic Society estimates that only 15% of adults with autism are in full-time paid employment. Gaining paid employment is a crucial part of tackling social exclusion as well as having obvious benefits to health and wellbeing.

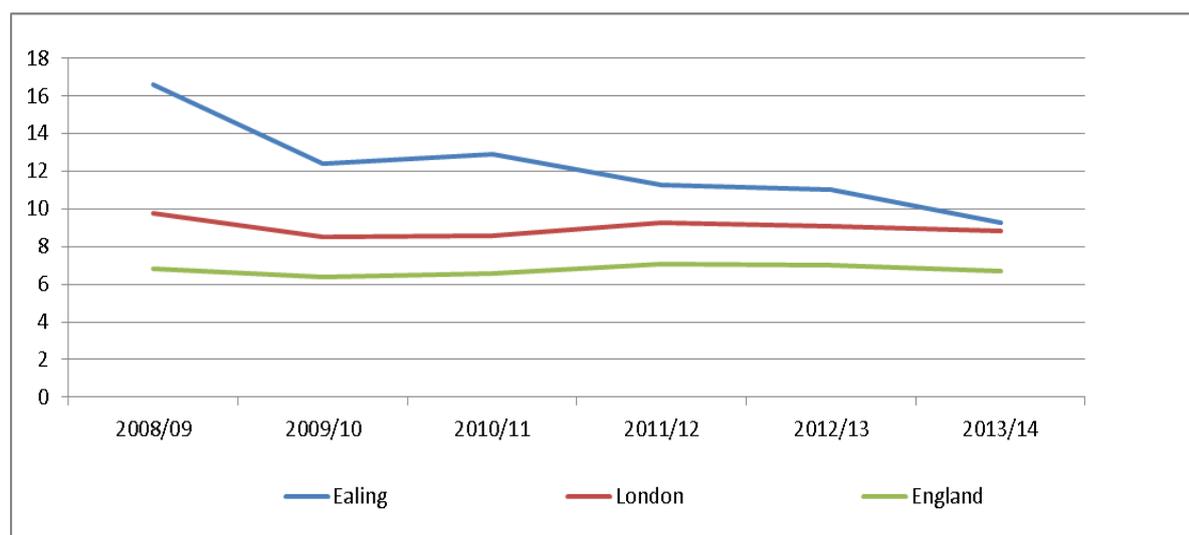
**Table 12: Proportion (%) adults with LD who are in paid employment, time trend**

Period	Ealing	London	England
2008/09	16.6	9.8	6.8
2009/10	12.4	8.5	6.4
2010/11	12.9	8.6	6.6
2011/12	11.3	9.3	7.1
2012/13	11.0	9.1	7.0
2013/14	9.3	8.8	6.7

Source: Information Centre for Health and Social Care (PHE Learning Disabilities Profiles, 2015)

<sup>18</sup> Source: Ealing SUS Data 2013/14

**Figure 10: Proportion (%) adults with LD who are in paid employment, time trend**



Source: Information Centre for Health and Social Care (PHE Learning Disabilities Profiles, 2015)

### Rate (per 1000) of referrals to adults' social care safeguarding teams of people with LD (18-64)

There were 100 referrals to adults' social care team in 2012/13 (rate of 116.3 per 1000 population). A possible reason for the increase in the rate of referrals of people with LD from GPs to adults and social care safeguarding over time could be due to more people with LDs known to GP services which is also a reflection of an increase in the number of adults with LDs due to population increases and also people living longer into adulthood.

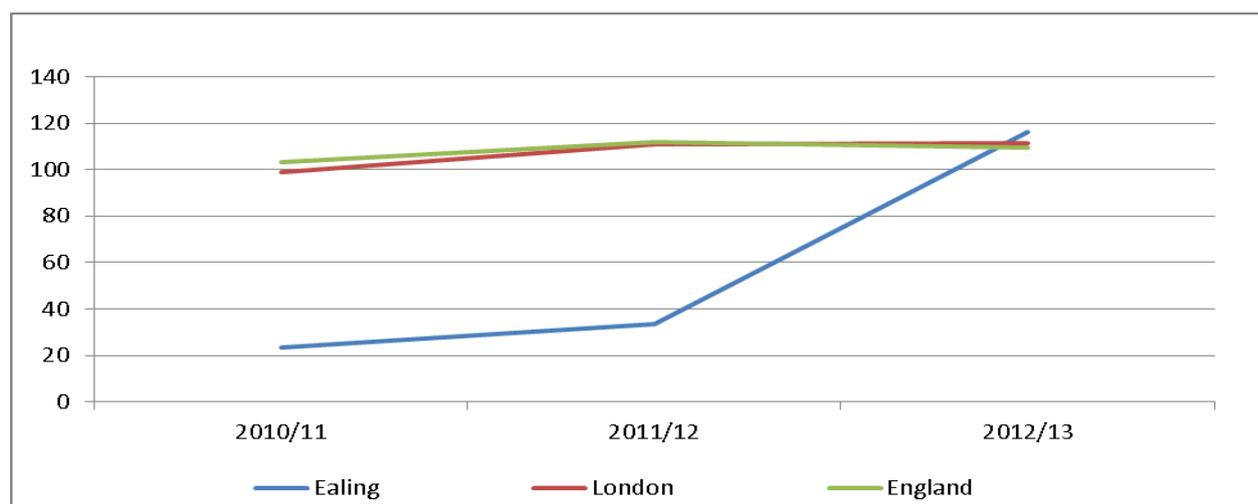
According to the latest data from Adult Performance & Management Team, in 2013/14 there were 74 referrals and in 2014/15, there were 70 vulnerable individuals who were referred.

**Table 13: Rates of referral for abuse of vulnerable persons with LD (rate per 1000)**

Period	Ealing	London	England
2010/11	23.5	98.7	103.3
2011/12	33.5	110.7	112.1
2012/13	116.3	111.5	109.3

Source: Health and Social Care Information Centre; NASCIS online analytical processor tool, from AVA table 1 completed referrals selecting age and client type to be 18-64 and LD (PHE Learning Disabilities Profiles, 2015)

**Figure 11: Rates of referral for abuse of vulnerable persons with LD (rate per 1000)**



Source: Health and Social Care Information Centre; NASCIS online analytical processor tool, from AVA table 1 completed referrals selecting age and client type to be 18-64 and LD (PHE Learning Disabilities Profiles, 2015)

## Learning Disabilities Expenditure by London Local Authorities

Net total cost (current expenditure) on people with LD by councils in London was £771 million in 2014/15<sup>19</sup>. Net total cost on all adult social care by councils in London in 2014/15 was £2.3 billion; therefore net total cost on people with LD represents 34% of all adults social care spend. This is slightly higher than other regions in England (range of spend 30% - 33%). The local spend on adults with LD is outlined below:

**Table 14: Local spend on people with learning disabilities**

Year	2010/11	2011/12
Social Care	£28.914.000	£29.210.000
Health Care	£14.899.000	£11.565.000
Total	£43.813.000	£40.775.000

Source: Ealing Social Care; LDPB Annual Report 2012

Year	2014/15
Ealing Council	£21,400,000
Ealing CCG	£5,400,000
Joint funded	£453,000
NHS England	£310,000
Total spend	£27,563,000

## Evidence of what works/Good practice

<sup>19</sup> Source: <https://www.gov.uk/government/statistics/local-authority-revenue-expenditure-and-financing-england-2014-to-2015-individual-local-authority-data>

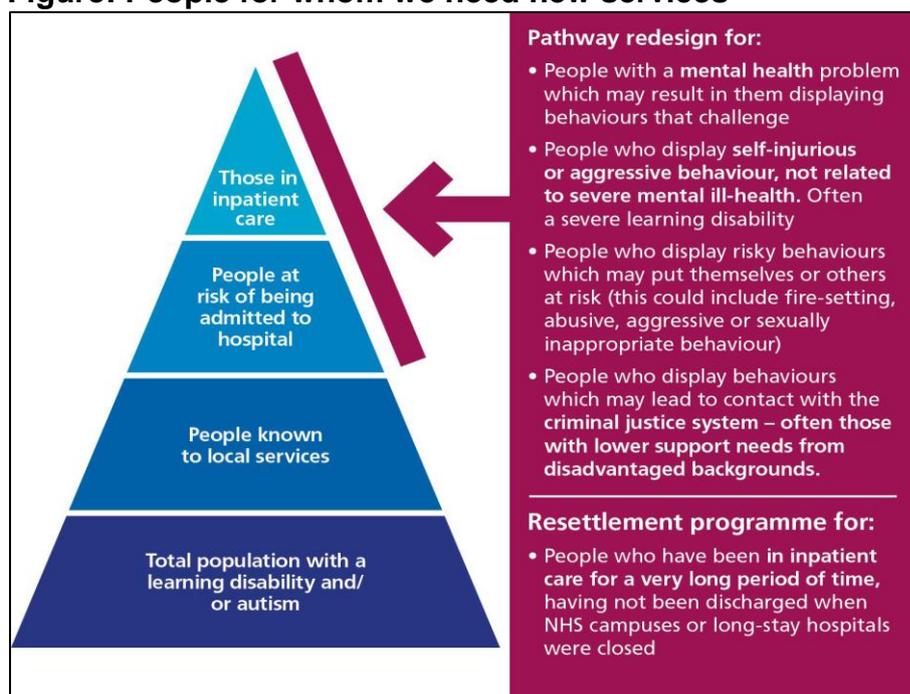
## **Building the Right Support (2015)**

A national plan to develop community services and close inpatient facilities for people with a LD and/or autism who display behaviour that challenges, including those with a mental health condition.

People with a LD and/or autism who display behaviour that challenges are a highly heterogeneous group. Some will have a mental health problem which may result in them displaying behaviour that challenges. Some, often with severe learning disabilities, will display self-injurious or aggressive behaviour unrelated to any mental health condition. Some will display behaviour which can lead to contact with the criminal justice system. Some will have been in hospital for many years, not having been discharged when NHS campuses or long-stay hospitals were closed. The new services and support we put in place to support them in the community will need to reflect that diversity.

Building the Right Support highlights the challenge facing commissioners which is as much about preventing new admissions and reducing the time people spend in inpatient care by providing alternative care and support, as it is about discharging those individuals currently in hospital. The task requires: advocacy, early intervention, prevention, ensuring the right set of services are available in the community. People for whom we need new services is summarised in figure below

**Figure: People for whom we need new services**



Building the Right Support contains the following key elements:

- National Service Model with 9 core principles
- Hospital closure programme - national expectation of 35-50% reduction of total inpatient estate once community services are in place

- A new financial framework
  - Alignment of NHS England budget with Transforming Care Partnerships
  - Pooled budgets across the NHS and Local Authorities
  - Dowries for people who have been in hospital for over 5 years
  - Personal budgets
- A Transformation Fund to support reinvestment in a range of flexible proactive community based services
  - £30 m national transformation fund to be matched by CCGs
  - £15 m capital
- Who Pays Guidance revised to remove funding barriers
- New Care and Treatment Review policy and guidance published in October 2015 to include the requirement to hold community reviews for adults and children at risk of admission

To achieve this systemic change, 49 Transforming Care Partnerships (commissioning collaborations of CCGs, NHS England's specialised commissioners and local authorities) have been established in England to work across geographical areas with people who have lived experience of these services, their families, and key stakeholders to agree robust implementation plans by April 2016 and then deliver on them over three years. Commissioners in North West London (NWL) have come together to establish a NWL Transforming Care Partnership (TCP) and one common plan.

### **National Service Model**

The national service model (2015) for commissioners of health and social care services outline what good services and support look like for people with a LD and/or autism who have mental health conditions or display behaviour that challenges, including behaviours which may result in contact with the criminal justice system. The model sets out the range of support that should be in place no later than March 2019. It is structured around nine core principles that are stated from the perspective of the reasonable expectations of someone who might use such services.

The nine principles are:

- 1) I have a good and meaningful everyday life
  - Inclusion in activities and services
  - Education training and employment
  - Relationships with people
  - Support to do things
- 2) My care and support is person-centred, planned, proactive and
- 3) I have choice and control over how my health and care needs are met
- 4) My family and paid support and care staff get the help they need to support me to stay in the community

- Support and training for families and carers
  - Short break/respite
  - Alternative short-term accommodation
  - Trained support and care staff
- 5) I have choice about where I live and who I live with
- Choice of housing and who I live with
  - Security of tenure
  - Strategic housing planning
- 6) I get good care and support from mainstream health services
- Annual health checks
  - Health action plans and hospital passports
  - Liaison workers
  - Quality checkers
  - Reasonable adjustments
- 7) I can access specialist health and social care support in the community and
- 8) If I need it I get support to stay out of trouble
- Specialist health and social care support for people
  - Intensive 24/7 function
  - Specialist forensic support
  - Inter-agency collaborative working, including with mainstream services
  - Liaison and diversion
- 9) If I am admitted for assessment and treatment in a hospital setting because my health needs can't be met in the community, it is high-quality and I don't stay there longer than I need to
- Integrated with community services
  - Admission based on a clear rationale
  - Discharge planning
  - Reviews of care and treatment (CTRs)

The human rights of people who use services are incontrovertible and must be upheld at all times; consequently there are a number of 'golden threads' that run consistently through the nine principles described and which should therefore be reflected in local commissioning strategies:

- Quality of life
- Keeping people safe
- Choice and control
- Support and interventions
- Equitable outcomes

### **NICE Guidelines for people with Learning Disabilities**

NICE guidance is available for people with learning disabilities and behaviour that challenges. The recommendations in the guidelines are structured under heading. This is just a summary drawing attention to some key points under the different headings<sup>20</sup>

<sup>20</sup> <http://www.nationalelfservice.net/publication-types/guideline/nice-challenging-behaviour-guidelines-stress-person-centred-proactive-support-but-barriers-to-achievement-still-exist/>

## **General principles of care**

- Clear focus on the person and their family and supporters, taking into account the severity of LD and developmental stage; communication difficulties, and physical or mental health problems
- Support and interventions to be delivered in the least restrictive setting aiming to prevent, reduce, or stop the development of future episodes of behaviour, focusing on improving people's support and increasing skills
- Prompt and coordinated access to specialist assessment, support, and intervention services when required for advice, supervision, and training
- Staff training for proactive strategies to reduce the risk of challenging behaviour and to deliver reactive strategies.
- Recognise impact on family members or carers and offer information on access to family advocacy and consider family support and information groups
- Provide skills training and emotional support to help family and carers take part in and support interventions.
- Strategies for early identification of initial behaviour that challenges including clear recording, awareness of physical health problems; environmental factors and changes to the person's environment
- Annual physical health checks to include review of behaviour that challenges and any link to physical health problems along with review of current health interventions, including medications and related side effects, adverse events etc.

## **Assessment**

- The process to be person centred, with a focus on outcomes of reducing behaviour that challenges and improving quality of life taking into account resilience, resources, and skills of family members and carers
- Risk assessment to include regular review of suicidal ideation, self harm and self injury; harm to others; self neglect breakdown of family or residential support; exploitation, abuse, or neglect by others; rapid escalation of the behaviour that challenges.
- Functional assessment to be varied in complexity and intensity in line with complexity and intensity of the behaviour that challenges
- If a mental health problem might underlie behaviour, consider initial screening using mental health assessment scales

## **Psychological and environmental interventions**

- Consider parent training programmes for parents or carers of children aged under 12 years with emerging, or at risk of developing, behaviour that challenges.
- Consider personalised interventions based on behavioural and cognitive behavioural principles and a functional assessment of behaviour, with clearly identified target behaviours and agreed outcomes and specified timescales to meet intervention goals.

## **Drugs**

- Consider antipsychotic drugs only in combination with psychological or other interventions and only if
- psychological or other interventions alone do not produce change within an agreed time
- treatment for coexisting mental or physical health problem has not led to a reduction in the behaviour

- the risk to the person or others is severe

Full guidelines are available here <http://www.nice.org.uk/guidance/NG11/>

## **Current Interventions & Assets**

The Community Team for People with Learning Disabilities (CTPLD) is a joint health and social service multi-disciplinary team. They work to support adults with learning disabilities to maintain their independence in the community. The team consists of social workers, senior practitioners, psychiatrists, psychologists, nurses, therapists and admin staff. CTPLD emergency social work duty team covers social care support 24/7, however the health support is limited to Mon-Fri 9-5 pm.

Care and support for people with learning disabilities and their families is currently delivered by a range of providers from the voluntary, statutory and independent sector. The Council currently commissions 14 organisations to provide a range of accommodation based and community services in Ealing as well as providing a number of services directly. The main services available include supported living, residential care, nursing care, day opportunities, respite and short breaks, outreach, homecare, transport, advocacy, and day opportunities. The local colleges deliver supported learning courses from two campuses aimed at students with LD including people with profound and multiple LD, challenging needs and autism. The sites are equipped with changing places and are able to accommodate students with mobility needs. Most courses have an employment focus and provide opportunities for work experience and internships.

In addition to directly commissioning services, the Council works in partnership with the voluntary sector and the wider community to promote access to mainstream services, facilities and activities e.g. leisure, sports, arts and culture and transport.

In Ealing there are 14 residential care services, offering accommodation for up to 83 people. There are supported living services offering accommodation for 119 people through a range of tenures – shared lives, shared ownership, private rented, and social housing. There is a London wide shortage of affordable housing stock, and it is especially difficult to identify affordable housing that is suitable for people with challenging needs who require spacious and / or self-contained accommodation.

Just over half of all adults with a LD who receive adult social care live with their parents or family members – hence supporting family carers is a key priority. People living with their families have access to a range of support, which aim to promote the health and wellbeing of both the person with LD and their family, enabling family carers to have a break from their caring role. These services include day-opportunities, outreach, support at home, and short-breaks. There are 12 resource centres in Ealing offering a base for day opportunities programmes. There are two specialist residential short breaks services in the borough; one caters for people with challenging behaviour, the other for people with profound and multiple learning disabilities. The Shared Lives scheme also provides respite to family carers.

The voluntary sector are jointly commissioned by Ealing CCG and Ealing Council to provide a range of services to the local LD population and their carers. These include:

- Travel buddy project to support the use of public transport
- Centre and community based respite
- Ealing Specialist Advice Service
- Support planning and brokerage service for people using direct payments
- Treat Me Right which provide learning disability awareness training, advice and guidance to mainstream health professionals to enable them to make reasonable adjustments to improve access to local health services for patients with LD

### **Transition**

Transition into adulthood can be a difficult time for many young people with LD. The planning process during transition is led by a transition social work team. There is a virtual multi-disciplinary team that meets weekly to discuss individual cases. Education, Health and Care planning processes cover the support that is needed up to age 25. There is significant joint working across children's and adults' services (health and social care) with input from the psychologists (adults) who provide in-reach support into schools. A transition protocol is currently being developed to support transition from child to adult psychiatric services. Mencap also provides a transition and Connexions project for young people with additional needs.

In February 2016, Treat Me Right! a co-produced project run by Certitude was successful in obtaining a grant from NHS England to engage with people who have learning disabilities – including people whose behaviour can challenge services – as well as families and carers to understand better challenges as well as successful ways to access health care. They also sought to engage with people specifically on the “Building the Right Support” service model so that their views on what in practice makes for good support can better inform the work of Transforming Care Partnerships.

Treat Me Right! held three events to engage with people across North West London and have also created easy read surveys to reach a wider cohort of people. In doing so, the views of three groups of people in west London have been obtained:

1. Families and carers of people with learning disabilities and / or autism whose behaviour can be challenging. Many have had previous / current experience of inpatient admission to hospital or assessment and treatment units.
2. People with learning disabilities and / or autism
3. Community based professionals supporting people with learning disabilities and / or autism.

Full details of the findings from these events can be found in Appendix 1. Not all the findings are Ealing specific and cover all of west London.

## **Identified Gaps**

- Ealing has a lower rate of adults with learning disabilities taking up AHC's compared to the England and London averages
- A recent audit of AHC's highlighted that fewer than 50% of AHC's generated specific health improvements
- There has been a decline in the proportion of people with learning disabilities in paid employment
- Need for an agreed way to flag that person has a LD on all the IT systems used in health and social care that follow the patient and ideally a portable care plan that can be seen by all professionals involved in the person's care
- An agreed standard of training for healthcare professionals and their non-clinical staff to recognise people with Learning Disabilities and to make reasonable adjustments and a way of monitoring the uptake of training and that it is repeated on a regular basis. For all commissioned services to have an LD champion who ensures the LD agenda is highlighted regularly
- Contractual levers for all service providers to ensure that they meet the 9 principles above where relevant to their service and that there is an agreed way of capturing and monitoring this data
- Access to easy read documentation to help with health promotion and advice

## **Recommendations for Commissioners**

**Working in partnership with people with LD, their families and providers, commissioners need to take into consideration the following recommendations when commissioning services**

- Officers from the Council and CCG to work alongside key stakeholders and the local community to raise LD awareness and to ensure that information (in line with the Accessible Information Standard) <sup>21</sup>and mainstream services are reasonably adjusted for people with LD. In particular alcohol and substance misuse, forensic and mental health services
- To increase the uptake of annual health checks that lead to health action plans amongst people with LDs to 50% of the eligible population and to work to improve screening rates (cancer) amongst people with LDs
- To develop local housing options for people with LDs who have challenging needs, including the provision of a short term accommodation for people who need crisis intervention and are at risk of placement breakdown
- To increase the offer of settled accommodation (recommended nationally) by remodelling and re-registering 5 small scale residential care homes as supported living and to evaluate the impact of settled accommodation on outcomes locally in 2 years

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<sup>21</sup> NHS England.

<https://www.england.nhs.uk/ourwork/patients/accessibleinfo/#standardImplementationofthestandardBy1September2015allorganisationshatprovideNHSorpubliclyfundedadultsocialcaremusthavebeguntoprepareforimplementationoftheAccessibleInformationStandard.Thisincludes:Assessingcurrentsystemsandprocesses> (accessed June 2016)

- Reduce the usage of assessment and treatment inpatient beds by 30% (national target)
- Ensuring people have choice and control over how their health and social care needs are met by offering personal budgets and personal health budgets (recommended nationally) with access to information, advice and support to help people understand the choices available to them. To evaluate the impact of personal budgets and personal health budgets on outcomes locally in 2 years
- Increase the numbers of people with LDs who are supported to access training, work experience, apprenticeships, and voluntary and paid employment

## **NHS ENGLAND ENGAGEMENT EVENTS: ACCESSING PRIMARY HEALTH CARE AND BUILDING THE RIGHT SUPPORT**

### **BACKGROUND**

In February 2016, Treat Me Right! a co-produced project run by Certitude was successful in obtaining a grant from NHS England to engage with people who have learning disabilities – including people whose behaviour can challenge services – as well as families and carers to understand better challenges as well as successful ways to access health care. We have also sought to engage with people specifically on the “Building the Right Support” service model so that their views on what in practice makes for good support can better inform the work of Transforming Care Partnerships.

Treat Me Right! has held three events to engage with people across North West London and has also created easy read surveys to reach a wider cohort of people. In doing so, the views of three groups of people in west London have been obtained:

4. Families and carers of people with learning disabilities and / or autism whose behaviour can be challenging. Many have had previous / current experience of inpatient admission to hospital or assessment and treatment units.
5. People with learning disabilities and / or autism
6. Community based professionals supporting people with learning disabilities and / or autism.

### **FINDINGS**

#### **The views of families and carers of people with learning disabilities and / or autism whose behaviour can be challenging - Access to primary health care**

<b>What good looks like:</b>
<ul style="list-style-type: none"><li>• Home visits from GPs can make a huge difference for people whose behaviour can be challenging – the anxiety in attending a GP surgery can increase challenging behaviour and can at times be impossible if carers do not have additional support.</li><li>• Being able to see the same GP. Without a doubt, people and their families who have built a relationship with the same Dr have a better experience and receive more consistent healthcare support. This is also critical in reducing anxiety. Dr Swords at Greenford Medical Centre was identified as excellent.</li><li>• The dentist at the Grand Union village was described on a number of occasions as excellent in supporting people as was a dentist in Acton. Taking time, not being kept waiting, going at the persons pace, explaining what is happening, ok if people don't sit in the dentists chair were all given as examples of good support.</li><li>• Blood tests are a great source of anxiety for people and their families and as a result tend to only happen when absolutely necessary – which in itself increases the likelihood of challenging behaviour. One family member said “when my son</li></ul>

has a general anaesthetic – everything gets done – blood, nails, hair teeth!!” **One family member described the success in blood tests being done for their relative at a day service – where they felt safe.** All agreed that good support with blood tests was likely to mean them happening where the person felt most comfortable not at a GP surgery or hospital.

- **One carer described the regular blood tests their relative has for clozapine testing. The routine they have established now makes this possible – having the same person take the blood, with a specific needle, on a specific day / time.** If any of these change, the person finds it difficult and challenging behaviour is more likely to occur.
- For hospital treatment – minimising the amount of appointments is great. **One mother described one hospital arranging one appointment only for the pre-op planning, consent, medical check up etc which made a big difference.**
- Knowing what reasonable adjustments can and should be in place can make all the difference – from reducing waiting times, flexibility over number of appointments – **One mother described a consultant arranging surgery on a Saturday so that it would be quieter, the person could have their own ward and there could be more flexibility in supporting the person to feel ok.** This was a huge success.
- Mainstream opticians were described as being good – particularly when they had built up a relationship over time.
- Medical professionals who have awareness of the support needs of people with learning disabilities and / or autism and make reasonable adjustments as a result without being asked.

#### **Barriers to good primary healthcare:**

- A postcode lottery remains in terms of finding good GPs – home visits largely depend on the specific GPs willingness to do them.
- Carers reported ignoring their own health until it becomes an emergency. The logistics of trying to fit in appointments with their caring role make things very difficult.
- The additional logistics and cost involved in health appointments can be significant. For people with personal budgets, it can be difficult to find additional support just for a Drs Appointment. For example central London hospital the logistics of travel and cost make the process incredibly difficult for carers. Different hospitals will be used for different conditions – eg: Charing Cross for neurology, Guys for dental work.
- Families and carers can find it just as difficult as professional experts to understand what is happening to someone who doesn’t use speech to communicate. It can be hard to pro-actively see signs of ill health. For lots of carers, the central point when their child was young was a paediatrician who could take the overview of their child’s health. Once their child starts using adult services, there is no equivalent.
- A few carers said that they had been told that due to the complexity of need, their relative was not able to have optician checks. They were not aware of the reasonable adjustments that are made for people who don’t use speech to communicate or that home visits for eye checks are available.

#### **Suggestions for improving access to healthcare:**

- Feeling ok with blood tests is more likely to happen if the person knows what is happening and its part of a routine. Pro-actively starting when young and having tests a regular occurrence is a way to build up trust.

- GP's sending reminders to carers for annual health checks.

## The views of families and carers of people with learning disabilities and / or autism whose behaviour can be challenging – Building the Right Support

### What good support looks like:

- Understanding that a family aspiration for their relative is the same irrespective of their level of need or behaviour. This means the same opportunities to live independently, to work, to have a network of important relationships including partners.
- Case – coordinators make a huge difference to families. They act as a central point of contact and advice.
- The intensive therapeutic short breaks service was described by two families as genuinely lifesaving. The ability to have a break at a time of crisis as their children were heading towards the transition of using adult services and to receive professional support to regroup and plan support for when their child returned home made a significant difference. Families didn't feel judged or criticised but supported.
- Responsive, flexible respite from people you know and trust and who like and admire your relative
- Safe support often means living with other people.
- Creating opportunities to bring families together is a helpful way of sharing support and information

### Barriers to good support:

- Case- coordinators aren't available to everyone and as one family member described
- Not having one person to ring and talk to, to get advice from. **Family members described it as "feeling like you are on your own. The anxiety about what will happen if you get ill is constant"**. Having a care-coordinator only when things are really bad is short sighted. The preventative work done by the care-coordinator in terms of pre-empting crises and ensuring family life continues on a day to day basis is vital.
- Carers described feeling they had to battle cuts in services and inconsistent support which in turn becomes a vicious cycle for worsening people's behaviour.
- Reliance on medication to reduce behaviours
- No assigned care manager leads to lack of trust and inconsistency – too difficult for the duty manager to keep on top of things.

### Suggestions for improving support:

- Pro-active support in managing life would be good – circles of support? Understanding of whole family dynamics and need. Often there are one or more people in the family home with support needs.
- Pro-active support with future planning rather than when there is a crisis would help with the constant anxiety many carers feel on a daily basis about "what if..."
- Emphasis on maintaining family values and identity
- Planning for what to do when the main carer isn't well – flexible respite and use of contingency hours.
- Pro-active support planning during puberty
- More access to respite which is local not out of borough
- Better employment support specifically for people who have autism

- One main point of contact who co-ordinates the support provided.
- Creating family networks which enabling the sharing of info and experiences.

The views of people with learning disabilities and/ or autism on accessing primary health care:

#### **What good looks like:**

- I see the same optician. I trust them
- When nurses speak Punjabi to me
- Accessible written information
- My GP takes time with me
- I get better after I see the doctor.
- I want to be treated kindly
- Knowing your doctor – seeing the same one every time.
- My doctor is good. He gives me enough time to talk.
- Speak to me nicely. Help me understand my diabetes.
- Women’s screening is explained and I know my nurse well.
- Ok about my blood test. The doctor explains about the blood test.
- Blood test is good because I will find out what’s wrong with me.
- District nurse does my blood test at home
- I like blood tests – I get pictures of mice on my plaster.
- My optician is good
- Health services come to the house
- I always get seen
- I like the comics at my doctors.
- Dietician explained things nicely
- Weekend appointment for a CT scan – got the whole ward for him

#### **Barriers to healthcare**

- Lack of training for GPs on health checks
- Receptionists can be a barrier
- I am a bit frightened of the Dr
- Having blood tests is painful – the tourniquet hurts.
- It was difficult to get a letter from my GP to support my application for a freedom pass. It took a long time.
- Waiting at the hospital for an injection.
- Not being able to get an appointment on the same day
- GP is ok, but my dentist is not.
- Seeing a different GP each time – not enough time to understand my needs
- GPs can be rushed – not take their time
- Hospitals are noisy
- 1 hour in waiting room dentist – too long
- Lack of training for GPs on health checks for people with LD/ Autism

#### **Suggestions for improvement:**

- I would have liked pictures at the dietician when they explained things to me.
- I start my own health plan and others help me finish it off.
- Speak to me directly- not to my carer
- Home visits would be better - means more accurate tests. E.g. Blood pressure as not so stressed
- More health professionals who can sign (Makaton)

**What good life looks like:**

- Being able to do things for myself – like make a cup of tea
- I live on my own – it's peaceful! I have my own keys
- Helping your friends out
- I enjoy making cakes with my flatmate and staff
- I like making my own sandwiches for lunch. My favourite is cheese and tomato.
- I like going on outings like seeing One Direction in Cardiff and Madame Tussauds.
- I enjoy having a ground floor flat – I feel very lucky
- I like the fact I don't have to eat dinner if I don't feel hungry
- I like having good holidays and parties
- I like having my own room and bathroom and my own TV. Then I can go inside the house to have food with my flatmates.
- I love my cat
- I love my fiancé
- I love where I live
- I go to the gym and use the treadmill and work at a homeless centre on Wednesdays and Thursdays. I like it but get bored sometimes.
- I am part of a number of groups
- We have personal budgets and use this to pay for the day centre.

**Barriers to good support:**

- I would like more choice in the menu our staff make.
- Not getting enough support from social services about my finances.
- Not much choice in housing in Ealing – left with no choice but to move out of borough which is causing stress to my family.
- People find it difficult to get the right care – have to jump through hoops. It is not made easy.
- I would like to have more visitors – not just on a Friday.
- I don't like the area where I live
- Safety in going for walks – getting off the main roads, getting to a safe crossing.

**Suggestions for improvement:**

- I don't know if I'd like a job. I'd like to try out different types of jobs so I can make a choice.
- I used to work. I'd like support to get a new job
- I would like to work in TK Maxx
- I would like to be able to meet friends outside of the day centre, after hours.
- I'd like more information on healthy eating and drinking

**Feedback from Professionals on Building the Right Support****What's working well**

- Having some good GP's in places ***“Some GPs are great”, “GP's make reasonable adjustments”, “Some GP's will make home visits”***
- Having CTPLD and GP's working together, as well as having CTPLD links to places like hospitals. Most people with LD in a borough are known to CTPLD so if health services liaise with CTPLD it increases the support available to the individual, based on what services already know about the person. Also, good

example of linking a LD nurse to local GP surgeries was mentioned. ***“Linking nurses to GP practices”, “Close working between CTPLD and health services”, “Establishing relationships with CTPLD”***

- Mainstream health services drawing upon specialist knowledge from CTPLD was also cited as invaluable:

#### **What’s not working well**

- People with LD can be missed by mainstream services – the knowledge is not there to support people well. One example discussed was people with LD and substance use – the gap in knowledge on how to support this. Also, people who have ASD experiencing mental health issues and the lack of specialist support available to mainstream services to accurately assess what’s going on for people.
- Sensory processing issues in people with LD and ASD often going unaddressed, but can have a big impact on their behaviour and mental health. However, there is a lack of availability of Occupational Therapists (OT) qualified to carry out sensory assessments and where they are available, their capacity is severely limited.
- CTPLD support can work well – but only if you are eligible for support. For those people who do not qualify for involved support from these teams, there is very little else available. This includes people with Autism who do not have a learning disability, but who will not be supported by other mainstream services neither due to lack of knowledge in those teams, or simply not being deemed eligible for support.
- Families and other mainstream professionals do not always know who to contact for advice. ***“A point of contact is essential”, “People don’t know what’s available”, “Can’t always get a point of contact” “People want to know where to get support from”***

#### **Suggestions for improvement:**

- Effective sharing of information between services and clarity around who to liaise with was highlighted as essential
- One point of contact for families to contact services – and case workers who are willing to look at a broader range of issues on their behalf, rather than limited to their job role or department. ***“Case co-ordination/ 1 point of contact in each area”***.
- Consider how clinical roles within CTPLD can be preserved for their particular areas of work.