

JSNA 2022 Learning Disabilities (Adults)

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Contents

Introduction	2
Health of people with LDs	4
National Policy	10
Level of Need in Ealing	14
Projecting future need in Ealing	20
Proportion of patients who had a learning disabilities health check (aged 14+), under the learning disabilities enhanced service in the 12 months up to 31 March 2021 (%)	23
Number of people with learning disabilities identified as having a specific condition	25
Learning Disability Statistics: Mental Health Issues	27
Number of children and young people with learning disabilities	28
Emergency hospital admissions as % of total	29
Employment	30
Rate (per 1000) of referrals to adults' social care safeguarding teams of people with LD (all ages)	32
Learning Disabilities Expenditure by London Local Authorities	33
Evidence of what works/Good practice	35
Current Interventions and Assets	37
Identified Gaps	39
Recommendations for Commissioners	40

Introduction

What are learning disabilities?

In the latest published LD definition summary (2022), The National Institute of Health and Care Excellence (NICE)¹ states that a learning disability is generally defined by 3 core criteria:

- lower intellectual ability (usually an IQ of less than 70);
- significant impairment of social or adaptive functioning;
- onset in childhood.

The World Health Organisation (WHO)² classifies severity of an intellectual disability as:

- **Mild** — approximate IQ range of 50 to 69 (in adults, mental age from 9 to under 12 years); Likely to result in some learning difficulties in school; Many adults will be able to work and maintain good social relationships and contribute to society;
- **Moderate** — approximate IQ range of 35 to 49 (in adults, mental age from 6 to under 9 years); Likely to result in marked developmental delays in childhood but most can learn to develop some degree of independence in self-care and acquire adequate communication and academic skills; Adults will need varying degrees of support to live and work in the community;
- **Severe** — approximate IQ range of 20 to 34 (in adults, mental age from 3 to under 6 years); Likely to result in continuous need of support;
- **Profound** — IQ under 20 (in adults, mental age below 3 years); Results in severe limitation in self-care, continence, communication and mobility.

It is important to note that conditions such as Autism and Asperger's Syndrome are a spectrum. This means that some people who have one of these conditions may or may not have a learning disability. That will depend on where on the spectrum they sit³.

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 LD⁴.

In Ealing, there are currently 1,473 people aged 14 and over on their GP's Learning Disabilities Register⁵.

¹ [Definition | Background information | Learning disabilities | CKS | NICE](#)

² The ICD-10 Classification of Mental and Behavioural Disorders: Clinical descriptions and diagnostic guidelines (who.int)

³ [What is Autism and Asperger's Syndrome? | Mencap](#)

⁴ [People with intellectual disabilities | The BMJ](#)

⁵ Learning Disabilities Report, Ealing Council, March 2022

There are an estimated 6,000 adults with learning disabilities in Ealing (Projecting Adult Needs and Service Information System).^{6 7} Most have mild learning disabilities and can live independently with little or no formal support; they are likely to be significant users of other public services such as social housing and advice and information services, and to be at high risk of involvement in the criminal justice system as victims or perpetrators. About 1,300 have moderate or severe learning disabilities and are likely to need formal support arranged by the council or NHS either over their whole life or for significant lengths of time.

In the period to 2030 it is expected that^{8 9}:

- There will be a small increase in the total number of adults with learning disabilities
- There could be a slight decrease in the number that need specialist support
- There could be a slight decrease in the number of people with Down's Syndrome
- There will be fewer people with learning disabilities aged 18-64, but this will be offset by the increase in those aged 65 and over.

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.

⁶ Projecting Adult Needs and Service Information System (PANSI) (pansi.org.uk)

⁷ Projecting Older People Population Information System (POPPI) (poppi.org.uk)

⁸ Learning Disabilities Report, Ealing Council, March 2022

⁹ [How the population changed in Ealing, Census 2021 - ONS](#)

Health of people with LDs

In March 2022 there were 1,473 GP patients aged 14 and over on the Learning Disability Register.¹⁰ Over recent years more people with learning disabilities in Ealing have had an annual health check and health action plan:

Year	Number on GP registers	Number of completed health checks	Percent of completed health checks	Number of completed health action plans	Percent of completed health action plans
2018-19	1123	807	72%	776	69%
2019-20	1240	885	71%	866	70%
2020-21	1425	1184	83%	1170	82%
2021-22	1473	1225	83%	1186	82%

The current national target is for 75% of people with learning disabilities to have a health check and health action plan. Nationally in 2020-21 the proportion of people with learning disabilities who had a health check was 75.2% and this has increased from 56.3% in 2016-17.¹¹

Inequalities faced by people with learning disabilities

Around 60% of children and young people with learning disabilities live in poverty. Children and young people with LD, when compared to their non-disabled peers, are more likely to live in rented housing, overcrowded housing or poor housing. They are also more likely to be socially excluded and 8 out of 10 are bullied, having fewer friends and less social support. They are less likely to have consistent parenting and family stability; as well as to receive timely and appropriate healthcare (Dr Marilena Korkodilos, PHE, 2017)¹².

In adulthood, people with LD continue to be disproportionately more affected by the inequalities. PHE's report "Disparities in the risk and outcomes of COVID-19"¹³ (2020), is a descriptive review of a range of data highlighting that the impact of COVID has replicated existing health inequalities, and, in some cases increased them. As the pandemic has highlighted, some groups of population, including people with LD, were more adversely impacted by the virus and the lockdown (Local Government UK Report: '*Perfect Storm: Health Inequalities and Impact of COVID-19*')¹⁴.

A recent report from the Race Equality Foundation examined how the health inequalities are exacerbated for people with a learning disability from Black, Asian

¹⁰ Learning Disabilities Report, Ealing Council, March 2022

¹¹ [Health and Care of People with Learning Disabilities Experimental Statistics 2020 to 2021 - NHS Digital](#)

¹² [Disabilities in children and young people in London \(slideshare.net\)](#)

¹³ [Disparities in the risk and outcomes of COVID-19 \(publishing.service.gov.uk\)](#)

¹⁴ [A perfect storm - health inequalities and the impact of COVID-19 | Local Government Association](#)

and minority ethnic groups, with the impact of the COVID pandemic demonstrating just how serious the situation is. Throughout the pandemic, people from BAME communities have died disproportionately, as have people with a learning disability, with the Race Equality Foundation's report pointing out that people with a learning disability are six times more likely to die from COVID - and 40% of the deaths were of people from Black and Pakistani communities (Mencap: *'Double Discrimination: The Healthcare Inequalities facing People with a Learning Disability from Black, Asian and Minority Ethnic Communities'*(2021)¹⁵.

Compared to the rest of the population, people with LDs have¹⁶:

- **Lower life expectancy** – people with LDs have an increased risk of premature death compared to the general population. The median age of death for people with a learning disability in 2021 was 62¹⁷. The median age of death for the general population in 2018-2020 was 82.7 (this is the latest available data). There is also a strong correlation between severity of LD and life expectancy (median life expectancies of 62, 63 and 57 years for people with mild, moderate and severe LDs, whilst those with profound and multiple learning disabilities, have a median life expectancy of only 40 years).¹⁸ People with Down's syndrome have a shorter life expectancy than people with LDs generally (median of 58 years¹⁹), though life expectancy in this group is increasing.²⁰
- **Different causes of death** – prior to the pandemic, in 2018 and 2019, the main cause of death amongst people with a LD was 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) and the third most frequently reported underlying cause were congenital and chromosomal disorders²¹. 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. Studies have consistently demonstrated that health checks are effective in identifying unmet needs in people with learning disabilities, for example: health checks resulted in the identification of previously undetected health conditions in 51% to 94% of patients. These conditions included serious and life-threatening conditions such as cancer, heart disease and dementia (PHE, 2016²²).

¹⁵ [Double Discrimination: The Healthcare Inequalities facing People with a Learning Disability from Black, Asian and Minority Ethnic Communities | Mencap](#)

¹⁶ 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

¹⁷ [Latest LeDeR Take home facts \(A4 Document\) \(contensis.com\)](#)

¹⁸ University of Bristol Norah Fry Centre for Disability Studies, 2019

¹⁹ [Demography – DSMIG, 2020](#)

²⁰ Puri et al (1995) Mortality in a hospitalised mentally handicapped population: a 10-year survey. *Journal of Intellectual Disability Research* 39: 442-446

²¹ [LeDeR-bristol-annual-report-2020.pdf](#)

²² [Annual health checks and people with learning disabilities - GOV.UK \(www.gov.uk\)](#)

- **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 staff knowledge/skills, joint working with learning disability services, service delivery model, uptake, appointment making, carer/support role, relationship with staff, time, accessible information and communication²³. Uptake of screening amongst people with LDs is lower than the general population (nationally, proportion of the eligible population with LD that took up screening in the five years prior to 31st March 2019²⁴ for the different cancers was as follows: cervical 34%, breast 49% and colorectal 83%) 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 LDs²⁵
 - 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 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 disorders²⁶.

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,

²³ Anna Cantrell et al (2020), Access to primary and community health-care services for people 16 years and over with intellectual disabilities: a mapping and targeted systematic review - PubMed (nih.gov)

²⁴ [Cancer Screening - NHS Digital](#)

²⁵ Source: PHE, 2017 - [Supporting people with learning disabilities to have a healthy diet and be active \(publishing.service.gov.uk\)](#)

²⁶ 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

the incidence of cancer amongst people with a LD is rising due to an increase in longevity⁷.

In addition, people with LDs are more likely to be admitted to hospital as an emergency case, compared to those with no LD. A study by Fay J. Hosking et al in 2017²⁷, compared emergency admissions in England for two common ambulatory care-sensitive conditions (ACSCs) - lower respiratory tract infections and urinary tract infections, between adults with and without intellectual disabilities. The two conditions accounted for 33.7% of emergency admissions among the former compared with 17.3% among the latter. Identifying strategies for better detecting and managing ACSCs, including lower respiratory and urinary tract infections, in primary care could reduce hospitalizations.

The impact of COVID-19 on people with learning disabilities

COVID-19 has had a significant impact on people with learning disabilities including increased risk of early death, long-term ill health, disruption to services, loss of confidence and skills needed to maintain independent living, anxiety and social isolation. Ealing's Annual Public Health Report 2022²⁸ detailed the impact of the pandemic on our community and Ealing Power Group also published a report about the impact on residents with learning disabilities²⁹.

According to the Learning Disabilities Mortality Review (LeDeR) 2021³⁰ report, in 2020, COVID-19 replaced cancer as the first leading cause of death in people with a learning disability, accounting for 22% of all deaths (compared to 12.2%³¹ in the general population). The proportion of deaths due to COVID-19 decreased to 20% in 2021 (v 11.6% in general population), although it remained the leading cause of death of those reviewed by LeDeR.

During 2021 the rate of excess deaths was more than two times higher for people with a learning disability compared to the general population (21.5% v 10.4%).

The LeDeR report from 2020 showed an increase in deaths due to COVID-19 during the first wave of the pandemic³². Since then, several reports confirmed that people with a learning disability have an increased risk for poor outcomes if they developed COVID-19, which is particularly high for those with Down syndrome³³. There have also been evidence of inequalities in access to treatment such as respiratory support and admission to intensive care units for people with a learning disability who have been admitted to hospital with COVID-19³⁴.

²⁷ Preventable Emergency Hospital Admissions Among Adults With Intellectual Disability in England - PubMed (nih.gov)

²⁸ [Annual public health reports | Ealing Council](#)

²⁹ Living Through Lockdown, Ealing Power Group, July 2021

³⁰ [leder-main-report-hyperlinked.pdf \(kcl.ac.uk\)](#)

³¹ NOMIS - Nomis - Official Census and Labour Market Statistics (nomisweb.co.uk)

³² [NHS England » University of Bristol LeDeR annual report 2020](#)

³³ [https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(21\)00049-3/fulltext](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00049-3/fulltext)

³⁴ <https://bmjopen.bmj.com/content/11/10/e052482.abstract>

The Council for Disabled Children found that the pandemic had been a very demanding experience for many disabled children and their families³⁵.

The learning from the pandemic regarding people with learning disabilities is:

1. **Preparation:** Being better prepared to respond to surges in new variants of the COVID-19 virus that may be more harmful to health and equally to the risks of other similar pandemics
2. **Communication:** To keep in touch with people during times of uncertainty and be clear about what is going to happen and by when. Check understanding and allow the person to ask questions and check with the person their preferred form of communication. Use communication to build trust, confidence and to empower.
3. **Support:** To help people understand their rights, to continue to learn (including for children and subjects outside the core curriculum), to use technology to have access to technology equipment and ensure that technology is inclusive for people with learning disabilities. To provide outdoor activities, and to ensure people have enough food.
4. **Mental health and wellbeing:** Create a culture where it is encouraged to ask for support with mental health and ensure staff are trained to support mental health difficulties. Enable people to connect and spend time with their friends and family, promote physical activity and provide training on the use of any new medical equipment.

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 5.6% 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 needs³⁶.

National research also shows that people with LDs are at increased risk of becoming victims of violence and abuse³⁷.

A significant amount of people within the criminal justice system have learning disabilities or some form of specific learning difficulty³⁸. Evidence from the Prison Reform Trust shows that up to 7% of adult prisoners have an IQ under 70, another 25% have an IQ under 80, and this proportion is higher in children and young people. 60% of prisoners have problems with communication - either understanding or expressing themselves or both.

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

³⁵ Lessons Learnt from Lockdown: The highs and lows of the pandemic's impact on disabled children and young people: [Council for Disabled Children](#)

³⁶ [Learning Disability today 2022](#)

³⁷ [Mental Health Foundation](#)

³⁸ [Criminal justice system | Foundation for People with Learning Disabilities](#) (accessed Sep 2022)

adults without a LD³⁹. People with profound and multiple learning disabilities (PMLD) have smaller social networks, which consist mainly of family members (Kamstra et al., 2015)⁴⁰.

In 2013, Wilson et al (2013) estimated that between 40 and 60 per cent of parents with a learning disability have their children removed from their care due to being assessed as unable to provide an adequate standard of parenting⁴¹. 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 future⁴².

³⁹ 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.

⁴⁰ [Learning Disability - Friendships and Socialising Stats Mencap](#)

⁴¹ [Pregnancy and learning disability | Womens health | Royal College of Nursing \(rcn.org.uk\)](#)

⁴² 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*⁴³ and the more recent *Valuing People Now*⁴⁴ 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

The Valuing People programme from 2001 was transformational but stalled since 2010 by the impact of austerity. More recently other national initiatives have had positive impacts on the lives of many people with learning disabilities, including the National Strategy for Autistic Children, Young People and Adults 2021 to 2026, the NHS 10 Year Plan, STOMP (Stop Overmedicating People with Learning Disabilities campaign) and STAMP (Supporting Treatment and Appropriate Medication in Paediatrics campaign), and Building the Right Support (Transforming Care). The National Disability Strategy published in 2021 set out the following practical steps to improve disabled people's everyday lives, including:

- Rights and perceptions: removing barriers to participating fully in public and civic life and wider society
- Housing: creating more accessible, adapted and safer homes
- Transport: improving the accessibility and experience of everyday journeys
- Jobs: making the world of work more inclusive and accessible
- Education: ensuring children and young people fulfil their potential
- Shopping: creating more consumer choice and convenience
- Leisure: widening access to arts, culture, sport, and the great outdoors
- Public services: making access as smooth and easy as possible

⁴³ Valuing People: A New Strategy for Learning Disability for the 21st Century (Cm 5086) Department of Health (2001)

⁴⁴ Valuing people Now: Summary Report March 2009 to September 2010, Department of Health (2010)

Key national policies and legislation:

- Care Act 2014
- Children and Families Act 2014
- Health and Social Care Act 2012
- Equality Act 2010
- Mental Capacity Act 2005
- Human Rights Act 1998
- Mental Health Act 2005
- National Health Service Long Term Plan 2019
- Learning Disabilities Health Check Scheme
- Learning Disabilities Mortality Review Programme
- Health & Social Care Act 2022
- Down Syndrome Act 2022

The Health & Social Care Act 2022 introduced Integrated Care Systems working across health and social care, and (delayed until 2025) new arrangements for the funding of social care for adults who currently pay for it themselves.

The Down Syndrome Act was given Royal Assent in May 2022. It created a new duty on the Secretary of State for Health and Social Care to issue guidance to relevant authorities (health, education, and local authorities in respect of social care and housing) on how to meet the specific needs of people with Down's syndrome; and for relevant authorities to have due regard to the guidance in providing services. The Government began consultation on the guidance in July 2022, but it has not said when the guidance will be issued or what it will contain. Therefore, further actions under the umbrella of the council's LD strategy may need to be developed later.

The other relevant legal change in the pipeline is an amendment to the Mental Health Act introducing the Liberty Protection Standards to replace the Deprivation of Liberty Standards process. This has been delayed from the planned start date of April 2022 and the Government has not yet announced a new date.

In December 2021, the government published a white paper: *People at the Heart of Care*, that outlined a wide ranging 10-year vision that puts personalised care and support at the heart of adult social care, ensuring that people:

- Have the choice, control and support they need to live independent lives
- Can access outstanding quality and tailored care and support
- Find adult social care fair and accessible

This white paper established the main pillars of investment and transformation of the adult social care system over including:

- Housing and home adaptations
- Technology and digitisation
- Workforce training and wellbeing support
- Support for unpaid carers, and improved information and advice
- Innovation and improvement

Legislation to support this, is now included in the Health and Care Act 2022.

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. In July 2022 a new Building the Right Support Action Plan was published.

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 new integrated all-age commissioning strategy for people with learning disabilities and autism 2022-2027 and this is currently under development. The strategy is being co-produced with Ealing's Power Group - an expert by experience reference group. 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 strategy sets out the shared commissioning priorities of the North West London Borough Based Partnership and Ealing Council for services for people with learning disabilities in Ealing. The seven priority areas include:

1. Leading a meaningful life in the community - this priority has 5 parts to it:
 - 1.1 Social connection - friends and family
 - 1.2 Day opportunities and activities
 - 1.3 Employment
 - 1.4 Accommodation - where people live
 - 1.5 Service delivery
2. **Feeling and keeping safe** - people with learning disabilities need to feel and be safe at home and in the community
3. **Travel** - people with learning disabilities should have choice and control relating to transport
4. **Lifelong learning** - people with learning disabilities need to be able to access opportunities for lifelong learning
5. **Improving health and lives** – the aim is to reduce health inequalities and the gap in life expectancy between people with learning disabilities and the general population

6. **Transitions** - we aim for all young people with learning disabilities to be prepared for adulthood
7. **Good networks, information and communication** - people with learning disabilities need to be able to easily find out about services and opportunities available to them. Information and communications must be in formats that are accessible to people with learning disabilities.

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+	730 (2021/22) 710 (2020/21)
Quality Outcomes Framework - GP register	14+	1,473 (2021/22) 1,425 (2020/21)
2022 Estimates by PANSI	18+	1,184

Source: Ealing Local Authority 2022, Draft Learning Disabilities Strategy 2022 and PANSI data sets 2020

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 730 people with Learning Disabilities known to the local authority, 198 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 730 adults with LD known to the Ealing Council in 2021/22; 89% 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 – 24%.

Table 2: Number of adults with LD who are known to services, by age, 2021/22

Age	Number	Percentage
18 - 64	650	89%
65+	80	11%

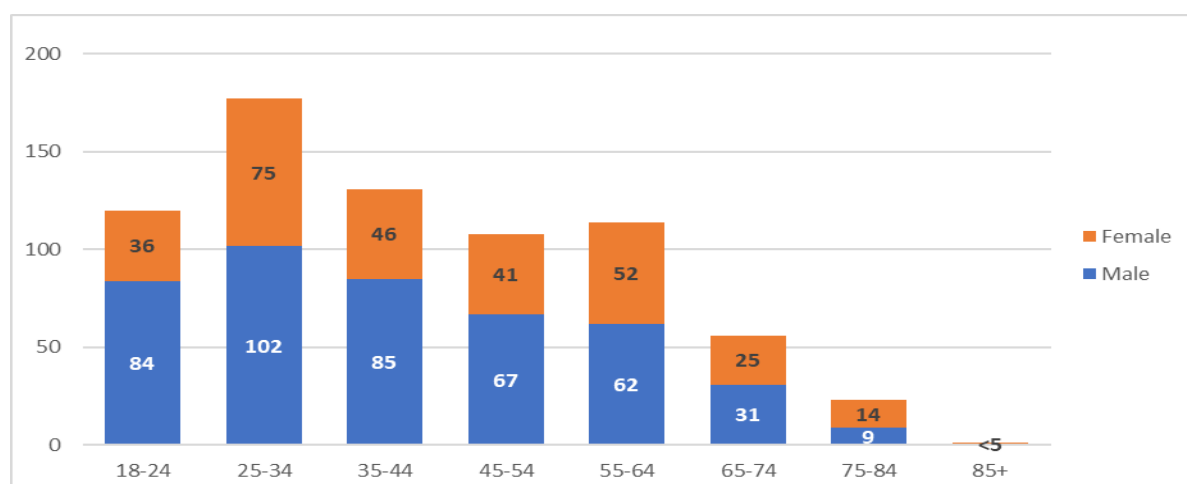
Source: Adults Performance & Management Team, 2022

Table 3: Number of adults with LD who are known to services, by gender, 2021/22

Sex	Number	Percentage
Male	440	60%
Female	290	40%

Source: Adults Performance & Management Team, 2022

Figure 1: Number of adults with LD known to services, by age and gender, 2021/22



Source: Adults Performance & Management Team, 2022

Around two in five of the population of adults with LD (43%; 311 people) are of White British, Irish or Other White background. 25% (186) are Asian or Asian British, 21% (152) are Black or Black British, 7% (50) are Chinese or any other ethnic background, and 4% (28) are from mixed background.

In comparison, 2020 projections for ethnic groups in Ealing as a whole, show 46% of population of White ethnic origin, 30% Asian or Asian British, 11% Black or Black British, with 8% being of Chinese or any other background and 5% of Mixed heritage⁴⁵.

Table 4: Number of adults with LD known to services, by ethnicity, 2021/22

Ethnicity	Number	Number	Total
	18-64	65+	
White			
• British	201	58	259
• Irish	20	6	26
• Other White background	23	3	26
Mixed			
• White and Black Caribbean	7	0	7
• White and Black African	1	0	1
• White and Asian	6	0	6

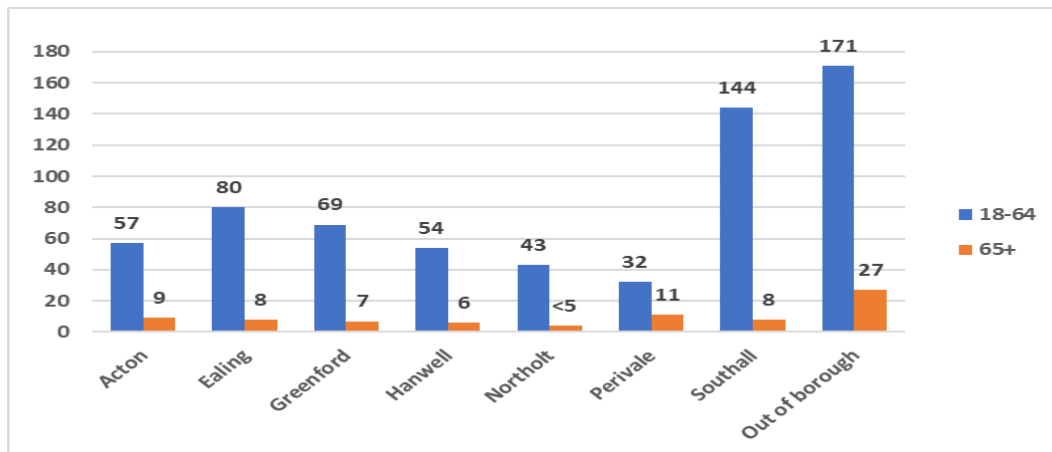
⁴⁵ GLA 2016-based Central Trend Ethnic Group Population Projections for 2020.

Ethnicity	Number 18-64	Number 65+	Total
• Other Mixed background	14	0	14
Asian or Asian British			
• Indian	30	3	33
• Pakistani	24	1	25
• Bangladeshi	1	0	1
• Other Asian background	122	5	127
Black or Black British			
• Caribbean	77	4	81
• African	57	0	57
• Other Black background	14	0	14
Chinese or other ethnicity			
• Chinese	2	0	2
• Arab	31	0	31
• Any other ethnicity	17	0	17
Not stated	3	0	3
Total	650	80	730

Source: Adults Performance & Management Team, 2022

27.1% (198) of people with LD known to services live outside of the borough. Southall has the largest population of people with LD – 20.8% and Perivale has the smallest population – 5.9%.

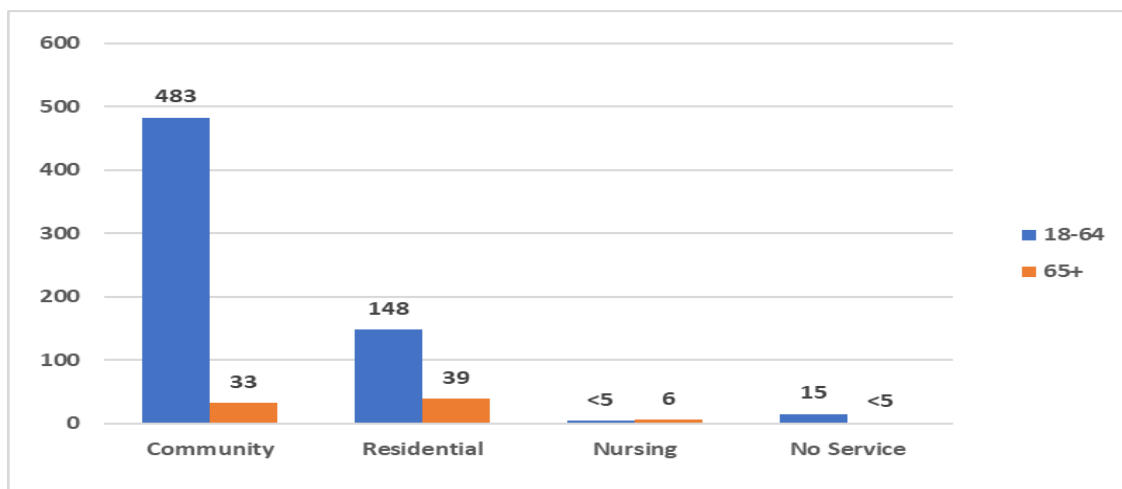
Figure 2: Number of adults with LD known to services, by locality, 2021/22



Source: Adults Performance & Management Team, 2022

More than two thirds of the people, 70.7% (516) were receiving community services e.g. supported living, day opportunities, outreach and 25.6% (187) were in residential care. Only 10 were receiving care in nursing settings (1.4%) in 2021/22.

Figure 3: Number of adults known to services, by service type, 2021/22



Source: Adults Performance & Management Team, 2022

Number of adults with LD in Assessment and Treatment

As at 8 Aug 2022:

2 patients (1 male, 1 female) with LD (one of these patients are autistic only) in assessment and treatment.

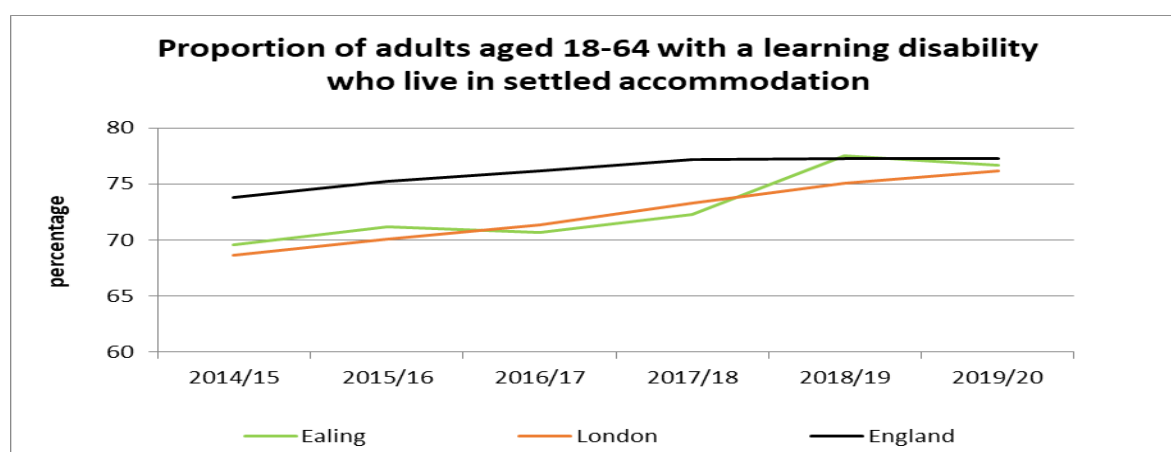
Proportion (%) of adults with LD who are known to LA in settled accommodation

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
2014/15	69.6	68.6	73.8
2015/16	71.2	70.1	75.2
2016/17	70.7	71.3	76.2
2017/18	72.3	73.3	77.2
2018/19	77.5	75.1	77.3
2019/20	76.7	76.2	77.3

Source: OHID, Learning Disabilities Profiles, 2021

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: OHID, Learning Disabilities Profiles, 2021

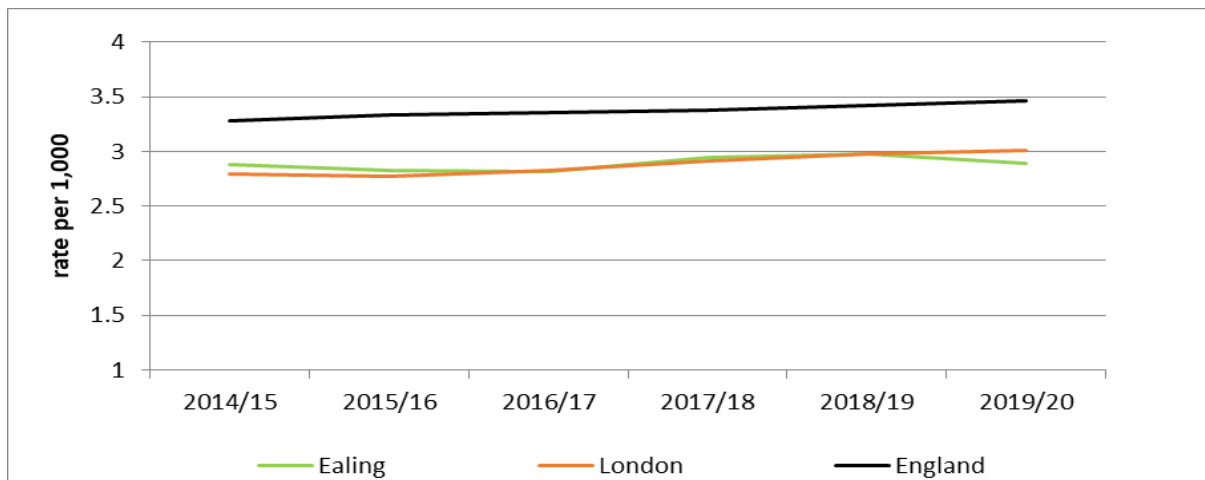
Supported living enables people with learning disabilities to live in their own homes as an alternative to shared residential care. There has been a drive nationally, supported by *Valuing People* to increase the number of people with learning disabilities living in supported living as it offers more 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

According to the 2019/20 Quality Outcome Framework (QOF)⁴⁶ data, prevalence of learning disabilities in Ealing was 0.4% of the GP registered population. This figure was the same for London (0.4%) and lower than for England (0.5%).

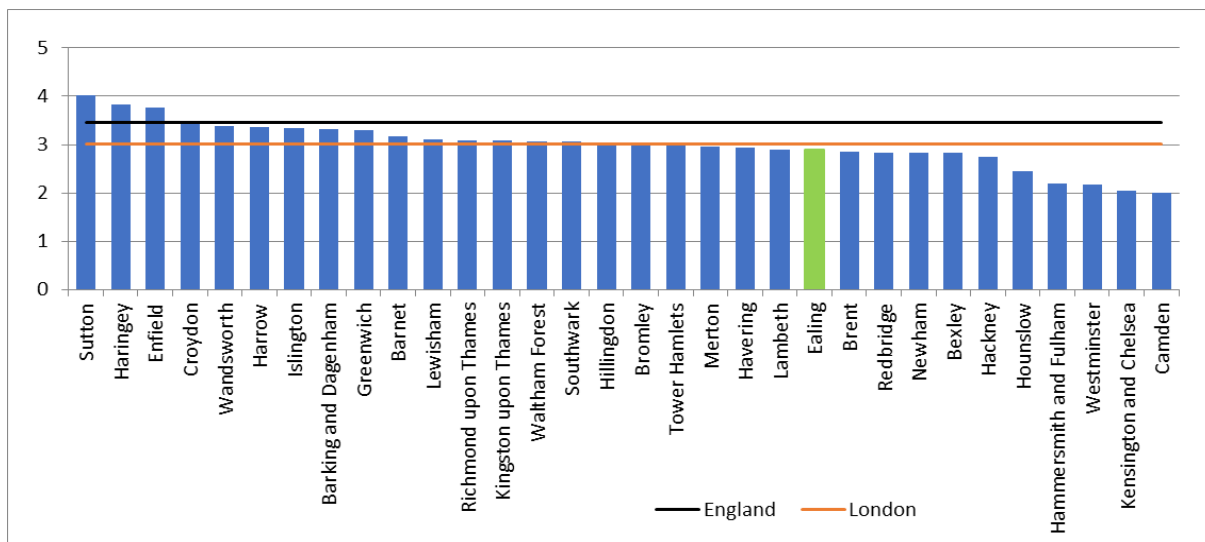
In Ealing in 2019/20, the total number of people with LD supported by the LA was 750. This includes people who live out of the borough. This is slightly lower than the number of adults as reported in the previous year (775). The rate for 2019/20 is indicated as 2.9 per 1000 population. This is significantly lower than England average (3.5/1,000), but statistically similar to London rate of 3.0 per 1,000.

Figure 4: Adults (18+) with LD receiving long-term support from Local Authorities (rate per 1000) - time trend



Source: OHID, Learning Disabilities Profiles, 2021

Figure 5: Adults (18+) with LD receiving long-term support from Local Authorities (rate per 1000) - across London 2019/20



Source: OHID, Learning Disabilities Profiles, 2021

⁴⁶ Source: QOF, NHS Digital (OHID, Learning Disabilities Profiles, 2021)

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 and therefore do not take into account local factors⁵. 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 2030 indicate that the number of people (aged 18 and over) projected to have LD is 6,240; around 1,315 people would have moderate/severe LD and therefore would likely to be in receipt of local services, 305 of those people would have severe LD. It has been estimated that around 92 people in 2030 would display challenging behaviour. Projected estimates have been calculated by applying national estimates to projected population figures. There is a significant increase in ageing population for people with LD - this will also give rise to additional needs associated with frailty.

Table 5: People 18+ projected to have a LD, by age, projected to 2040

People predicted to have LD	2022	2025	2030	2035	2040
People aged 18-24	688	697	768	778	718
People aged 25-34	1,215	1,170	1,128	1,173	1,257
People aged 35-44	1,273	1,198	1,088	1,029	997
People aged 45-54	1,115	1,113	1,098	1,047	981
People aged 55-64	871	914	940	943	942
People aged 65-74	570	600	669	731	754
People aged 75-84	305	333	387	430	488
People aged 85 +	132	146	161	197	231
Total population aged 18 +	6,168	6,173	6,240	6,329	6,369

Source: PANSI 2020

Table 6: People 18+ projected to have a moderate/severe LD, by age, projected to 2040

People predicted to have moderate or severe LD	2022	2025	2030	2035	2040
People aged 18-24	161	164	182	185	172
People aged 25-34	261	251	242	252	270
People aged 35-44	320	302	274	260	252

⁵ 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.

People predicted to have moderate or severe LD	2022	2025	2030	2035	2040
People aged 45-54	252	253	250	238	224
People aged 55-64	190	199	203	204	203
People aged 65-74	93	98	109	119	122
People aged 75-84	32	34	40	44	50
People aged 85 +	12	14	15	18	21
Total population aged 18+	1,320	1,314	1,315	1,319	1,313

Source: PANSI 2020

Table 7: People 18-64 projected to have a severe LD, by age, projected to 2040

People predicted to have moderate/severe LD	2022	2025	2030	2035	2040
People aged 18-24	53	54	60	61	57
People aged 25-34	73	70	68	71	76
People aged 35-44	86	81	74	70	68
People aged 45-54	56	56	55	53	50
People aged 55-64	44	47	48	48	48
Total population aged 18-64	313	309	305	302	298

Source: PANSI 2020

Table 8: People 18-64 with LD predicted to display challenging behaviour, by age, projected to 2040

People predicted to display challenging behaviour	2022	2025	2030	2035	2040
People aged 18-24	11	12	13	13	12
People aged 25-34	22	21	20	21	23
People aged 35-44	23	22	20	19	18
People aged 45-54	21	21	21	20	18
People aged 55-64	17	18	19	19	19
Total population aged 18-64	95	94	92	91	90

Source: PANSI 2020

People 18-64 projected to have Down's syndrome

Table 9: People 18-64 predicted to have Down's syndrome, by age, projected to 2040

People predicted to have Down's Syndrome	2022	2025	2030	2035	2040
People aged 18-24	16	16	18	18	17
People aged 25-34	31	29	28	29	32
People aged 35-44	32	30	27	26	25
People aged 45-54	30	30	29	27	26
People aged 55-64	24	25	26	26	26
Total population aged 18-64	132	131	128	127	125

Source: PANSI 2020

Autistic spectrum by age

Table 10: People predicted to have autistic spectrum disorders, by age, projected to 2040

People predicted to have autistic spectrum	2022	2025	2030	2035	2040
People aged 18-24	264	268	296	298	274
People aged 25-34	509	494	476	492	530
People aged 35-44	527	495	458	437	422
People aged 45-54	474	474	469	446	421
People aged 55-64	376	397	409	411	414
Total population aged 18-64	2,149	2,128	2,108	2,084	2,061

Source: PANSI 2020

According to the latest data from 2020/21, 28.6% of people with learning disability in England have been diagnosed with ASD⁴⁷.

⁴⁷ Source: [Health and Care of People with Learning Disabilities Experimental Statistics 2020 to 2021 - NHS Digital](#) (accessed Sep 2022)

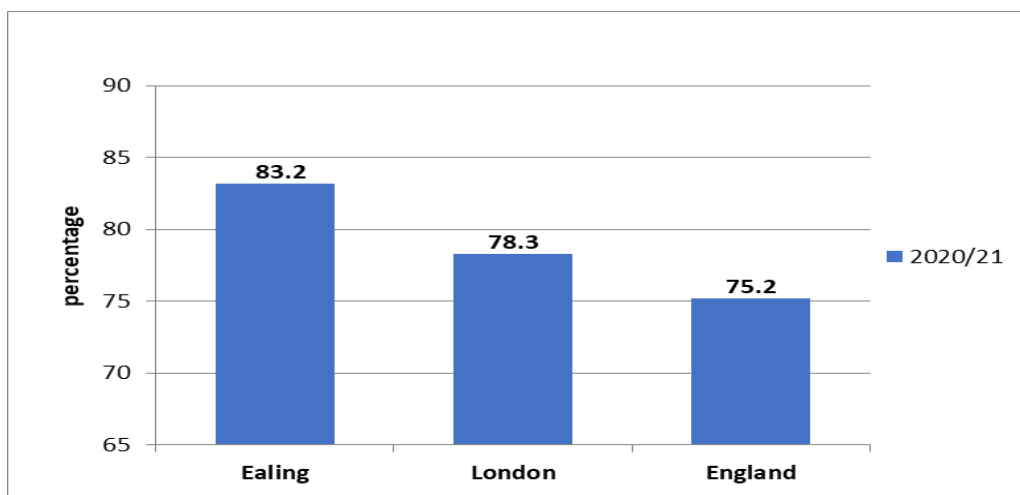
Proportion of patients who had a learning disabilities health check (aged 14+), under the learning disabilities enhanced service in the 12 months up to 31 March 2021 (%)

In 2020/21, 83.2% of patients aged 14+ with LD received an annual health check (AHC) (amounts to 1,225 patients)⁴⁸.

The local figures for 2020/21 are higher than both London and England average (78.3% and 75.2% respectively).

Ealing is also the best performing borough in Northwest London (Figure 7), based on achieving 83.2% of annual health checks and 81.9% of associated action plans. Although Brent achieved 83.4% of AHCs, it lagged behind Ealing in associated action plans, with 79.5%.

Figure 6: Proportion of patients aged 14+ with LD having a GP AHC (%)

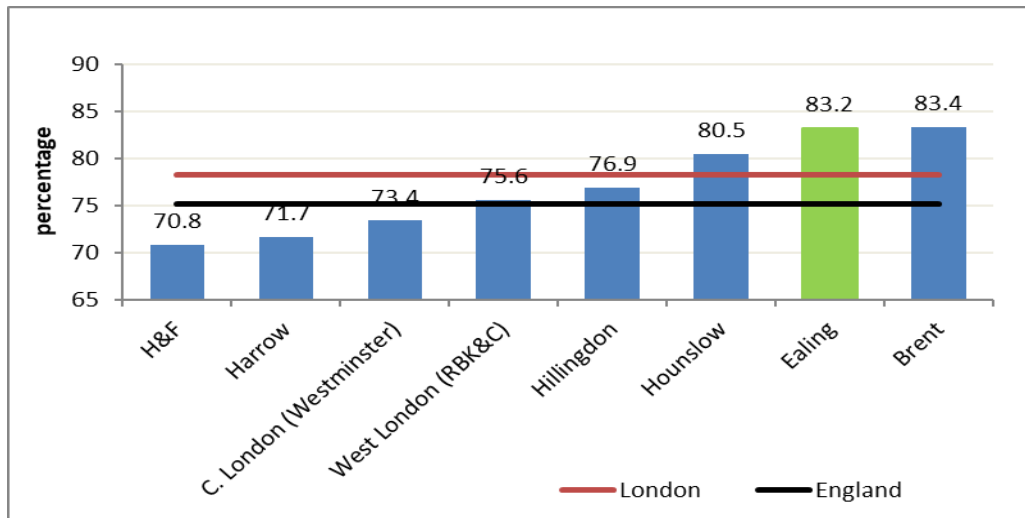


Source: NHS Digital, Health and Care of People with Learning Disabilities - Interactive Tool⁴⁹ (Experimental Statistics), 2022; NWL CCG, 2022

⁴⁸ Source: NWL CCG, 2022

⁴⁹ Source: <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2020-to-2021>

Figure 7: Proportion of patients aged 14+ with LD having a GP AHC (%) across Northwest London in 2020/21



Source: NHS Digital, Health and Care of People with Learning Disabilities - Interactive Tool (Experimental Statistics), 2022; NWL CCG, 2022

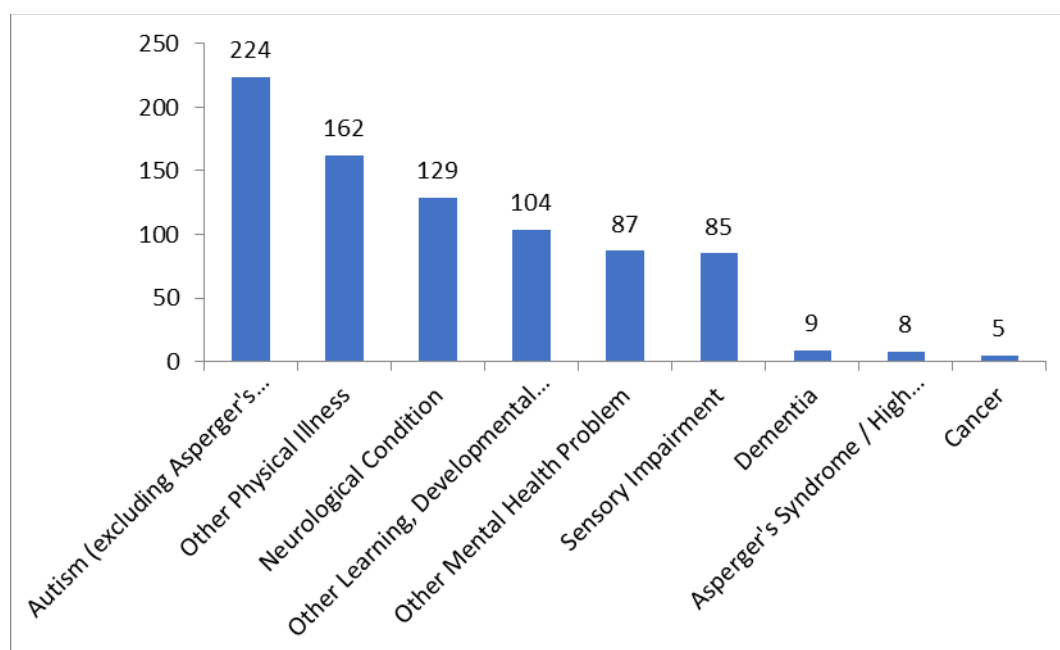
1,225 patients out of a possible 1,473 people with LDs had a health check in 2020/21. 1,207 health checks resulted in action plans. This is a big improvement from 2014/15 where 159 patients had a health check, with only 82 of those checks resulting in action plans.

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

In 2021/22 in Ealing, the top five registered conditions for people with LD were Autism (excluding Asperger's Syndrome/High Functioning Autism), other physical illness, neurological condition, other learning, developmental or intellectual disability and other mental health problem.

There were 224 individuals with multiple conditions.

Figure 8: Number of people with learning disabilities identified as having a specific condition in 2021/22⁵⁰



Source: Adults Performance & Management Team, 2022

Table 11: People in NW London with LD by condition compared to the general population - 2020/21, all ages

	NWL population with LD	NWL general population
Condition	Prevalence	Prevalence
Diabetes	6.9%	5.6%
Epilepsy	16.2%	0.4%
Depression	11.2%	7.9%
Mental Health	9.9%	1.0%
Asthma	8.2%	4.5%

⁵⁰ The figure shows registered health conditions for 5 or more people only

	NWL population with LD	NWL general population
Condition	Prevalence	Prevalence
COPD	0.9%	0.9%

Source: NHS Digital, Health and care of people with learning disabilities - experimental statistics, 2022

Learning Disability Statistics: Mental Health Issues⁵¹

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;
- 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.

⁵¹ Foundation for people with learning disabilities. Learning Disability Statistics: Mental Health Issues <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187699/> (accessed Aug 2022)

Number of children and young people with learning disabilities⁵²

67.8% (631) of pupils in Ealing maintained special schools have Cognition and Learning Needs – 19.4% Moderate Learning Difficulties, 38.2% Severe Learning Difficulties and 9.5% Profound and Multiple Learning Difficulties. 239 pupils (25.7%) have Autism Spectrum Disorders (ASD) as their primary need.

Thirty percent of children and young people living in the borough who have an Education, Health and Care Plan (SEN), have more than one specified need.

In January 2022, the three most common dual-diagnoses account for more than a quarter (55% or 505 people) of all children and young people with more than one SEN (922 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 and mental health
- severe learning difficulties.

⁵² Source: Ealing Schools Research and Statistics Team, 2022

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 population⁵³.

In Ealing, the number of emergency admissions to general hospitals of adults with LD in 2021/22 was 248⁵⁴. The actual number of admitted patients was 134, which represents 18.4% of the total number (730) of people with LD known by services in Ealing in the same year and 10.8% of all adults with LD on the GP register (1243⁵⁵). The rate of emergency admissions (199.5 per 1,000 population diagnosed with LD) is statistically higher than NW London rate (160.1/1,000).

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

From the total number of 248 hospital admissions of adults with LD in 2021/22, 32% of them (79) also had a primary or secondary diagnosis of diabetes, asthma or epilepsy⁵⁶.

⁵³ [Rates of emergency admissions to hospital higher for people with learning disabilities \(nationalelfservice.net\)](https://www.nationalelfservice.net)

⁵⁴ Source: NWL CCG, WSIC Data 2021/22; ICD 10, 2022 Diagnosis codes included: F80 – F89 (disorders of psychological development, including Autism & Asperger's Syndrome); Q90 (Down Syndrome)

⁵⁵ There were 1,243 patients with LD aged 18+ on Ealing's GP register, as of 5th Aug 2022

⁵⁶ Source: WSIC Data 2021/22

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).

4.3% of adults aged 18-64 with LD (30 people) were in paid employment in Ealing in 2018/19 (latest available data). This is a marked decrease from 2014/15 when 9.6% of adults were in paid employment. This is lower than London (8.0%) and England (5.9%) average in the same year.

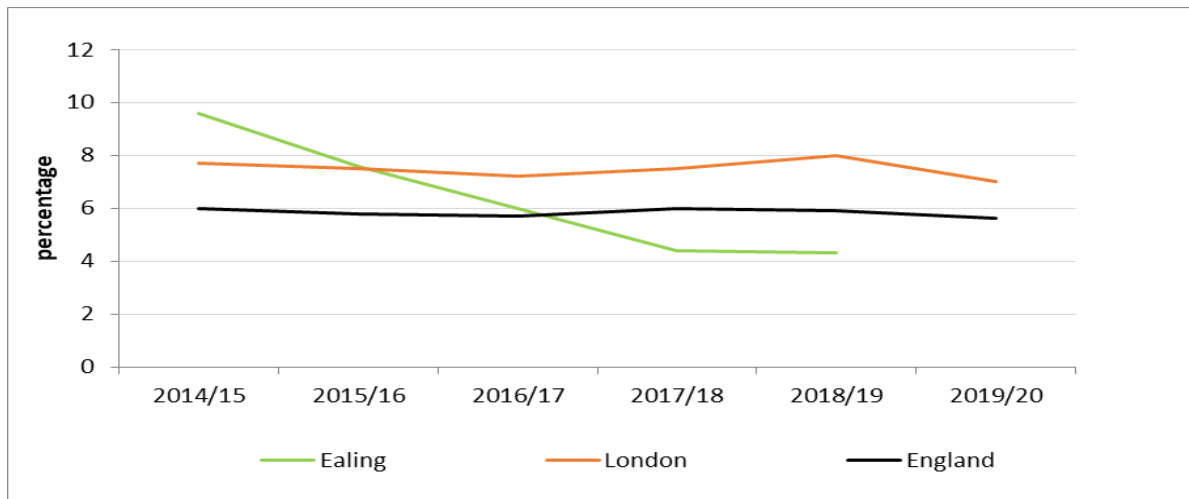
The National Autistic Society estimates that only 15% of adults with autism are in full-time paid employment. Gaining paid employment is a crucial part of tackling social exclusion as well as having obvious benefits to health and wellbeing.

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

Period	Ealing	London	England
2014/15	9.6	7.7	6.0
2015/16	7.6	7.5	5.8
2016/17	6.0	7.2	5.7
2017/18	4.4	7.5	6.0
2018/19	4.3	8.0	5.9
2019/20	*	7.0	5.6

Source: NHS Digital, Adult Social Care Activity and Finance Report, Short and Long-Term Care Statistics (OHID, Learning Disabilities Profiles, 2021);*value suppressed for disclosure control due to small count

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



Source: Source: NHS Digital, Adult Social Care Activity and Finance Report, Short and Long- Term Care Statistics (OHID, Learning Disabilities Profiles, 2021)

Rate (per 1000) of referrals to adults' social care safeguarding teams of people with LD (all ages)

There were 50 referrals to adults' social care team in 2021/22 (rate of 123.5 per 1000 referrals). 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 NHS Digital data, in 2018/19 there were 30 referrals and in both 2019/20 and 2020/21, there were 35 vulnerable individuals who were referred in Ealing.

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

Period	Ealing	London	England
2018/19	84.5	102.9	105.5
2019/20	102.9	101.5	101.8
2020/21	78.7	89.1	87.2
2021/22	123.5	91.5	92.1

Source: Safeguarding Adults – data tables for each year, experimental statistics, NHS Digital

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



Source: Safeguarding Adults – data tables for each year, experimental statistics, NHS Digital

Learning Disabilities Expenditure by London Local Authorities

Estimated net total cost (current expenditure) on people with LD by councils in London was £889.9 million in 2021/22⁵⁷. Net total cost on all adult social care by councils in London in 2021/22 was £2.74 billion, therefore net total cost on people with LD represents 32.5% of all adults' social care spend. This is similar to 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

	2019/20	2020/21	2021/22
Long term support (18 – 64)	£26,046,000	£23,841,000	£26,396,000
Long term support (65+)	£3,578,000	£3,189,000	£3,447,000
Short term support (18 – 64)	£706,000	£1,411,000	£1,659,000
Short term support (65+)	£221,000	£254,000	£168,000
Total spend	£30,551,000	£28,695,000	£31,670,000

Source: Ealing Council, Adult Social Care Finance return 2022

In Ealing, the total (gross) Adult Social Care budget for learning disabilities in 2022-23 is £31.7million and this includes:

- Residential care homes £20.4million
- Nursing homes £0.4million
- Direct Payments £3.4million
- Supported Living £4.4million
- Home care £1.0million
- Day centres £2.1million
- Residential respite £0.2million

There are significant inflationary pressures on the cost-of-care for working age adults, which are linked to increasing complexity of need

The most significant trend in the budget in recent years is the growth in supported living and reduced spend on residential care

The COVID-19 pandemic has disrupted normal patterns of spend with reduced spend on daytime activities offset by increased spend on accommodation-based

⁵⁷ Source: [Local authority revenue expenditure and financing England: 2021 to 2022 budget individual local authority data - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/statistics/local-authority-revenue-expenditure-and-financing-england-2021-to-2022-budget-individual-local-authority-data)

services and short-term injections of additional central government grants that have now ended. The long-term impact of this disruption remains to be seen.

NHS budgets

In 2021-22 the Ealing Borough CCG contributed £7.9million to the Pooled Better Care Fund on services that they commission for people with learning disabilities and complex needs. This included funding for the CTPLD, Continuing Healthcare, and specialist inpatient services.

Evidence of what works/Good practice

Building the Right Support Action Plan (2022) was published by the government on 15th July 2022 and the plan brings together into one document key elements from existing reports, recommendations and announcements from across government and public services aimed at improving care and support for people with a learning disability and autistic people, to provide a clear view as to what must be delivered.

The first section of the plan sets out what the government wants to achieve, learnings from work in this area so far and what is being done differently as a result, and analysis of latest data to understand progress to date on original national plan published in 2015 by NHS England (NHSE)⁵⁸.

The key areas of focus set out in the action plan are:

- ensuring that people with a learning disability and autistic people of all ages experience high quality, timely support that respects individual needs and wishes and upholds human rights;
- understanding that every citizen has the right to live an ordinary, self-directed life in their community;
- keeping each person at the centre of our ambitions and ensuring that we consider a person's whole life journey;
- collaborating across systems to put in place the support that prevents crisis and avoids admission;
- ensuring that, when someone would benefit from admission to a mental health hospital, they receive therapeutic, high quality care, and remain in hospital for the shortest time possible;
- making sure that the people with a learning disability and autistic people who are in mental health hospitals right now are safe and that they are receiving the care and treatment that is right for them;
- working together to ensure that any barriers to an individual leaving a mental health hospital when they are ready to do so are removed.

As set out in the 'Partnership Statement'⁵⁹, adults, children, and young people with a learning disability and autistic adults, children, and young people should be equal citizens in their communities. People with a learning disability and autistic people should live in their own home and have the right support in place to live an ordinary life. This includes access to education, employment, and other opportunities which help people to fulfil their aspirations. Building the Right Support seeks to make this a reality through strengthening community support and thereby reducing the overall reliance on specialist inpatient care in mental health hospitals.

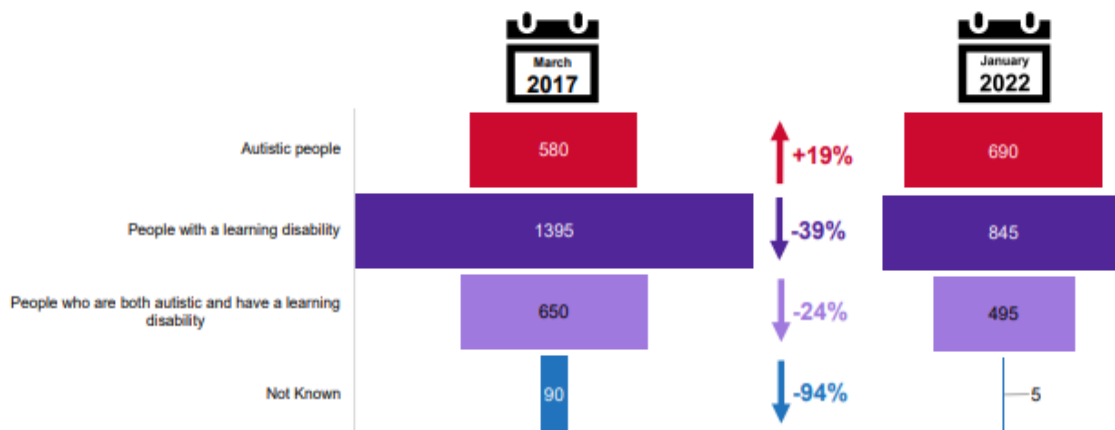
This action plan brings together, in one place, the commitments that have been made by different organisations to realise this aim.

⁵⁸ [47232_next-day-briefing-building-the-right-support-action-plan-july-2022.pdf \(nhsproviders.org\)](#)

⁵⁹ [Building the Right Support for People with a Learning Disability and Autistic People Action Plan - July 2022 \(publishing.service.gov.uk\)](#)

Since the national plan was published, a progress has been made on reducing the number of people with LD in mental health hospitals and more people have been supported to live in the community. The inpatient total in England at the end of May 2022 was 2,010: this is a 30.7% net reduction since March 2015, when there were 2,900 people with a learning disability and autistic people in mental health hospitals. This drop in inpatients total (over a slightly different period) is also illustrated in the figure below:

Figure 12: People by patient category, March 2017 compared to January 2022



Source: NHS Digital, Assuring Transformation (AT) dataset, January 2022

Guiding principles

The plan sets out the following principles to act as a guide and seek to create a common vision across all commitments⁶⁰ outlined in the action plan:

- Keeping people safe
- Personalised care and support
- Working together towards improvement and integration of care and support
- Holding ourselves and others accountable
- Inclusive decision-making

⁶⁰ [Building the Right Support Action Plan - Table of Commitments \(Annex A\) \(publishing.service.gov.uk\)](https://publishing.service.gov.uk)

Current Interventions and Assets

The Community Team for People with Learning Disabilities (CTPLD) is a team made up of professionals from multiple disciplines who are co-located. 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 9-5pm.

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. 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' is defined as a purposeful and planned process of supporting young people as they move from children's to adult services (Department of Health and Social Care, 2006). The years approaching adulthood are a time when there are many changes taking place in young people's lives, and these changes include opportunities to consider their own future. Transitioning into adulthood can be a difficult, but exciting time for many young people with SEND, neurodiversity and complex disabilities. Every young person should be at the centre of preparing for approaching adulthood, and supported to proactively plan for their future, and have a good experience as they leave children's services and become adults.

Since June 2021, the newly created Transition's Team (14-18 years) provides transition preparation and planning support to young people with complex needs arising from their disability to prepare for adulthood, and to help young people and families move into independence and/or receive support from adult services. Young people will be supported to develop a timely and effective transition's plan, building upon a young person's strengths and aspirations, and should involve all services working with the young person and family. The Transition's Team aligns education, health, and social care resources; taking in to account the Department for Education's Preparation for Adulthood outcomes which include employment, independent living, health, and community inclusion. This is delivered through our multi-agency partnership of health, education and social care services designed to provide integrated services to meet the needs of young people with disabilities.

There is a virtual multi-disciplinary meeting that is convened bi-weekly for the purposes of early identification for young people who may require on-going support to transition to adult services, and to determine the most appropriate pathway into adulthood. There is improved joint working across children's and adults' health services with input from clinical psychologists, who are able to provide learning disability diagnostic assessments. During Autumn 2022, a Transitions protocol is being created to outline what our ambitions and aims are for making improvements to our support during the period of transition, detailing what we know about the young people who might need support when they transition and to provide an overview of actions which need to be taken in order to improve the lives of young people and their families.

Identified Gaps

- 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
 - prevention and self-management awareness of long-term conditions

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)⁶¹ and mainstream services are reasonably adjusted for people with LD;
- As AHCs are now at 83% (2021/22), work is required to ensure that people undergoing AHC are aware of the process;
- Officers from the Council and NWL Integrated Care System - Ealing Borough to work alongside key stakeholders to ensure 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;
- Officers from the Council to work alongside key stakeholders to increase the numbers of people with learning disabilities who have to transport training to increase their independence and choice;
- Improve access to information about services and opportunities and services available for people with learning disabilities;
- Officers from the Council to work alongside key stakeholders to further develop suitable housing option for people with learning disabilities;
- Identify carers who have learning disabilities and support them. According to the Survey of Adult Carers (SACE) 2021/22⁶², 6.2% (with margin of error $\pm 3\%$) of adult carers in Ealing had a learning disability or difficulty.

⁶¹ NHS England.

<https://www.england.nhs.uk/ourwork/patients/accessibleinfo/#standardImplementationofthestandardBy1September2015allorganisationshatprovideNHSorpubliclyfundedadultsocialcaremusthavebeguntoprepareforimplementationoftheAccessibleInformationStandard.Thisincludes:Assessingcurrentsystemsandprocesses>

⁶² [Microsoft Power BI](#) – slide 9, question 24