Ealing Learning Disability Commissioning Strategy 2023 – 28

A joint strategy for all ages and including people with learning disabilities and autism.

September 2023

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Please note that all statistics and other figures referred to in this strategy were based upon available data at the time it was produced and were accurate at the time the strategy was prepared.

Foreword

Welcome to Ealing's new joint commissioning strategy for learning disabilities. If you would prefer to read the Easy Read version, please see the last section of this document. This strategy addresses the needs of our residents with learning disabilities of all ages. It includes people who are also autistic. It dovetails with a range of other local plans and strategies. Whilst it sets out what our shared ambition as the Integrated Care System and Council, it is also a call to action for the wider community to do their bit to make Ealing a better place for people with learning disabilities to live meaningful lives. Following the creation of the new Integrated Care System across North West London in April 2022 and the local elections in May, we approach this ambition with renewed vigour.

This new approach is timely given the disproportionate impact of the COVID-19 pandemic on people with learning disabilities which shone a harsh light on the health inequalities that they face. They experienced higher rates of death, many services that they rely upon were suspended, and many have sustained social isolation and continuing preventive measures since mandated measures were lifted. This strategy is an opportunity to learn from this experience and for a reset in how services are delivered to people with learning disabilities.

The strategy also sets out the framework for ensuring services provided are of the best value for money in both cost and quality. It is also expected to leverage additional external funding to Ealing through specific Government initiatives and voluntary sector bids for charitable funding. It will bolster initiatives by people with learning disabilities and their families to complement formal service delivery through the voluntary and community sector and mutual aid.

We could not have prepared this new strategy on our own and we would like to thank everyone who contributed to its creation. This includes everyone who responded to the consultation for the strategy by completing surveys and attending meetings, especially those with learning disabilities and their families. The Ealing Power Group, a group of residents with learning disabilities who represent the local learning disability community took a leading role in co-producing the priorities and actions, and we would like to thank them for their time and their careful consideration of some complex issues. We are grateful to the local community and voluntary sector organisations and service providers that helped by contributing feedback and ideas, and by helping us to reach out to as many people as possible with the consultation; a special mention in this regard goes to Ealing Mencap, Ealing Parent Carer Forum, Ealing ISAID, and St Anne's School.

Responsibility for implementation of the strategy is dispersed across several organisations and the wider community. The Community Team for People with Learning Disabilities (CTPLD), which brings together our adult health and social care specialists, the Paediatric Learning Disabilities Team based at the Children and Adolescents Mental Health Service (CAMHS), and the full range of service providers will be essential to this endeavour. Our integrated health and social care commissioning functions will take a leading role in co-ordinating and monitoring activity, and ensuring we have good value quality services in place. Other Council departments like Housing, and other public bodies like Transport for London, will have specific responsibilities. The wider community will be key, for example local business in creating jobs and making reasonable adjustments. And we look forward to working with a range of people to create new community led forms of provision. The Learning Disability Partnership Board, including representatives of the Ealing Power Group, will take the lead on holding the system to account for delivery.

We hope that you enjoy reading this strategy and feel inspired to make your mark in enabling our residents with learning disabilities to be treated just like everyone else.

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Neha Unadkat Borough Director – Ealing North West London Integrated Care System	Kerry Stevens Director of Adult Services Ealing Council

Summary

This is the new learning disability strategy for Ealing for the next 5 years through to 2027-28. It includes people with learning disabilities of all ages from infancy to old age. It includes people with learning disabilities who are also autistic.

Our ambition is to improve the lives of people with learning disabilities and to achieve our vision that in Ealing, people with learning disabilities, including people with learning disabilities and autism, will be treated just like everyone else. We recognise that this is only possible for some people if they have the right support and adjustments to their environment.

The context for this strategy is changing rapidly amid the continuing COVID-19 pandemic which has had a profound impact on people with learning disabilities, which has raised awareness of the health inequalities that they face. Ealing, London's third largest borough, has a growing population. The population of people with learning disabilities is expected to become older and there is expected to be greater acuity of need across all age groups for those who are eligible for health, social care, and additional needs educational services. The final report of the Ealing Race Commission sets out a series of challenges that this strategy must respond to.

We aim for coproduction and engagement to be fundamental to our practice. This strategy has been co-produced with the Ealing Power Group, a group of people with learning disabilities who advocate for the wider learning disability community, facilitated by Ealing Mencap. There was extensive consultation in preparation of the strategy including with people with learning disabilities, their families, the voluntary and community sector, and service providers.

The outcomes we aim to achieve against each of our priorities are:

Priority	The outcomes we aim to achieve
Meaningful Lives	People with learning disabilities will be socially connected in the way that suits them best including with family, with friends, romantically, and with neighbours and community. People with learning disabilities will have the choice of a range of day activities across the borough. The number of voluntary and paid work opportunities available for people with learning disabilities will increase. The range of support and guidance available to help people with learning disabilities to stay in a voluntary

	or paid job will increase. People with learning disabilities will have a home that suits their needs. Services for people with learning disabilities will:
	Be of a good quality Enable people to have choice and control Promote equalities in the way they are delivered Pay staff at least the London Living Wage
Feeling and keeping safe	People with learning disabilities will feel and be safe at home and in the community.
Transport	People with learning disabilities will have choice and control relating to transport.
Lifelong learning	People with learning disabilities will be able to access opportunities for lifelong learning.
Improving health and lives	Health inequalities and the gap in life expectancy between people with learning disabilities and the general population will reduce.
Transition from children to adults' services	Young people with learning disabilities will be prepared for adulthood.
Good networks, information, and communication	People with learning disabilities will be able to easily find out about services and opportunities available to them. Information and communications will be in formats that are accessible to people with learning disabilities.

The Ealing Borough Based Partnership will have responsibility for implementing this strategy. The Learning Disability Partnership Board will have primary responsibility for holding the Borough Based Partnership to account for delivery.

Due to significant overlaps with other areas of work it is envisaged that progress towards implementing aspects of the strategy will also be reported to other boards forming part of the Local Partnership such as the Health and Wellbeing Board, the Children and Young People with Additional Needs (SEND) Board, the Autism Partnership Board, and the Safer Ealing Partnership.

Our Vision

Ealing is ambitious about improving the lives of its residents who have learning disabilities and their families. That ambition is summed up in our vision that:

In Ealing, people with learning disabilities will be treated just like everyone else. This includes people with learning disabilities and autism. It is only possible for some people if they have the right support.

This vision is for people with learning disabilities of all ages.

We have identified our priorities to achieve this vision. Section 6 sets out the priorities, together with the outcomes we are aiming for and next step actions. More detailed action plans will be developed and monitored over the life of the strategy.

How we made this strategy

This strategy was coproduced with the Ealing Power Group. Work started in the autumn of 2021 when the Power Group identified its priorities. The Power Group is a group of residents who have learning disabilities and who advocate on behalf of the local community of people with learning disabilities. They are supported by Ealing Mencap. The Power Group took an active role in shaping the strategy through a series of in-depth discussions at their regular meetings and making their views known at the Learning Disability Partnership Board.

A stakeholder analysis identified the key stakeholders for the strategy as: Residents with learning disabilities

Parents and other family carers

Service providers, including independent third sector and for-profit providers, NHS trusts, primary care providers, and Ealing Council

Social care workers, clinicians and other staff who work with people with learning disabilities, their managers, and other commissioners.

The consultation was based upon priorities identified by the Ealing Power Group that are now the headings for Our Shared Priorities.

The consultation included:

Meetings with the Ealing Power Group

135 people completed an online survey for all stakeholders; 27 were people with learning disabilities, 33 were family carers, and 68 were people who work with people with learning disabilities

63 copies of an Easy Read version of the survey for people with learning disabilities were returned out of the 397 that had been distributed to service providers and voluntary sector organisations

Service providers held "Let's Have a Chat" conversations with some service users to help them to understand the issues covered by the survey

Young people were supported to complete the survey by Ealing I-SAID (voluntary sector) and by an apprentice in the Council's Family Information Service

A series of 10 focus groups for family carers of people with learning disabilities were held with Ealing Parent Carer Forum, Ealing Mencap, and

Ealing I-SAID, plus a workshop session with parents at St Anne's Special School

Meetings with independent sector service providers, special schools, and voluntary sector organisations

Meetings with relevant staff in the Integrated Care System, Borough Based Partnership, NHS Trusts, and the Council, including the GP Council of Members, a workshop for clinicians based at the CTPLD, and a discussion with the Learning Disability Social Work Team

The strategy sets out the shared commissioning priorities of the members of the Ealing Borough Based Partnership for services for people with learning disabilities in Ealing and provides an opportunity to work in a joint up way across the priority areas.

The Context

The national legal and policy context

This strategy needs to be flexible enough to respond constructively to potential changes to the UK's national political landscape over the next 5 years. There have been several national policy initiatives to improve the lives of people with learning disabilities over the last 30 years and this strategy sets out how we will build upon that legacy.

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.

The strategy is Ealing's response to the national context and will help the Integrated Care System (ICS) and the Council to comply with relevant legislation and national policy including the 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, and the Learning Disabilities Mortality Review

Programme. 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 this 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.

The local policy context

This strategy links with a range of other local strategies and policies. This includes the Integrated Care System's plans, the North West London Learning Disabilities and Autism Plan, the Strategy for Children and Young People With Additional Needs (SEND), Adult Social Care Better Lives Programme, the Ealing Autism Plan, Health and Wellbeing Strategy, Community Safety Strategy, Housing and Homelessness Strategy, and Transport Strategy.

The Council's priorities and values

The Council's priorities are shaped by Ealing Labour Party's Manifesto Commitments¹ from the local elections held in May 2022 and are reflected in our shared priorities for learning disabilities.

The Council's priorities are:

- 1. Creating good jobs
- 2. Tackling the climate crisis
- 3. Fighting inequality

Ealing Race Equality Commission published its report on 27 January 2022². The Council has committed to implementation of its

¹ Ealing Labour: Manifesto 2022 - Ealing Labour

² <u>ealing-race-equality-commission-final-report-27-january-2022.pdf</u> <u>(dosomethinggood.org.uk)</u>

recommendations. The starting premise of the report is that race inequality is a crisis that demands an urgent response. This strategy intends to respond to the priorities identified by the Commission which are:

Education – Ensure that no child is left behind. Our children are not under-achieving, they are being under-served.

Health – Use what we have learnt from the COVID-19 pandemic to reduce health inequalities. If we don't act now these inequalities are going to grow.

Participation and democracy – increasing representation

Policing – Build trust and end the disproportionate rate of stop and search that is harming our young people

Income and employment - build back fairer

Housing – Respect and empowerment

Keeping feet to the flames – What happens next?

The Council plans to set out a clear Equality Action Plan to reduce the inequalities faced by people and communities who face continued discrimination, and launch the "Ealing for Everyone" pledge, ensuring that all public spaces, businesses, and services are accessible, welcoming and empower people of all ages with physical and mental disabilities to lead independent lives.

The Council's Corporate Plan Commitments for Healthy Lives Out of the nine commitments the following six are pertinent to this strategy:4-year goals	22/23 deliverables
HL1: Ensure every care worker in Ealing is paid the London living wage, and work with homecare and care home providers to increase standards and quality	1. Invest £2m growth funding to implement more sustainable pricing models that move us towards implementing Real Living Wage (London) on homecare contracts 2. Work with the NHS and providers to offer bespoke and more accessible training programmes to local social care market. 3. Work with the NHS and Public Health to extend investment into local infection prevention

The Council's Corporate Plan Commitments for Healthy Lives Out of the nine commitments the following six are pertinent to this strategy: 4-year goals	22/23 deliverables		
	and control specialists to provide advisory support to the care market 4. Embed a new model of provider intelligence gathering and Director led risk review arrangements to enable us to respond to quality issues and concerns 5. Continue to gear our commissioning of home care services to providers who are CQC rated good or above 6. Work with the market to complete a cost of care exercise and develop a market sustainability strategy		
HL2: Empower people and families who receive financial support for social care to have greater freedom, control, and power over how that money is spent, bringing people, families and communities together through a mutual and cooperative approach to commissioning care.	1. Introduce new regulations set out in the Health and Care Act, including our offer of support to self-funders and changes to the level of financial assistance the council provides to people with eligible care needs (Q2 onwards to October 2023) 2. Conduct a series of engagement activities to review and reimagine how people who use services and local communities can be empowered to have more control over how support is provided. From this we will: 3. Produce an options appraisal for piloting alternative community based, mutual or cooperative models of care brokerage and/or delivery focused on user engagement, choice, control Develop proposals to extend the use of the Direct Payments offer		
HL3: Establish a new community-based support network to deal with social isolation and improve mental health resilience, ensuring that anyone on	1. Participate in the national consultation on the Mental Capacity and Liberty Protection Safeguards and prepare to implement these extended statutory reforms to provide more protection for people who require support with their care or treatment due to their mental capacity		

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The Council's Corporate Plan Commitments for Healthy Lives Out of the nine commitments the following six are pertinent to this strategy: 4-year goals	22/23 deliverables
the edge of mental crisis, suffering from loneliness and still recovering from the impact of pandemic lockdowns has the support they need.	 Extend the participation and engagement with people with mental health needs on the MH partnership board Establish local mental health champions Following consultation, commission a new round of grant funded voluntary sector services that offer support to reduce social isolation
HL4: Deliver 300 new state of the art, purpose built supported accommodation home, to enable older people to lead independent lives, and meet the need for affordable homes that also provide additional support.	1.Work with Housing departments to begin construction of 71 homes for older adults at Lexden Road, Acton 2. Work with Housing and DFG to create opportunities to shape more innovative and tailored housing solutions for older or vulnerable residents with a focus on extending Extra Care provision over the medium term 3. Extend and promote our strength based social work practice with partners to promote prevention and independence – supporting more people to draw on support in community settings for longer. 4. Shape the market for community-based support through procurement of new contracts for homecare and accommodation-based support for people of working age
HL5: Work to prevent older people needing to go into care homes, supporting 3,000 of the most vulnerable residents get the care they need in their own homes, and invest at least £20m in home adaptations	 Extend and promote our strength based social work practice with partners to promote prevention and independence – supporting more people to draw on support in community settings for longer. Shape the market for community-based support through procurement of new contracts for homecare and accommodation-based support for people of working age (reference new DPS timeframes) Increase the capacity and effectiveness of our in house reablement service to support

The Council's Corporate Plan Commitments for Healthy Lives Out of the nine commitments the following	22/23 deliverables
six are pertinent to this strategy: 4-year goals	
	people to regain independence to support living of healthy independent lives
	1. Embed a new model of provider intelligence gathering and Director led risk
	review arrangements to enable us to respond to quality issues and concerns
	2. Continue to gear our commissioning of home care services to providers who are CQC rated good or above
	3. Introduce new regulations set out in the Health and Care Act, including our offer of support to self-funders and changes to the level of financial assistance the council provides to people with eligible care needs
	4. Work with the market to complete a cost of care exercise and develop a market sustainability strategy
	5. Introduce new regulations set out in the Health and Care Act, including our offer of support to self-funders and changes to the level of financial assistance the council provides to people with eligible care needs 6. Work with Housing and DFG to create opportunities to shape more innovative and
	tailored housing solutions for older or vulnerable residents, with a focus on extending Extra Care provision over the medium term

The Council's Corporate 22/23 deliverables **Plan Commitments for Healthy Lives** Out of the nine commitments the following six are pertinent to this strategy: 4-year goals HL6: Take on the huge 1. Publish the Ealing Health & Wellbeing Strategy health inequalities within and Ealing Health of the Borough annual report & our communities that the agree priorities pandemic has highlighted, 2. Health and Wellbeing Board to take forward and ensure that we learn health and care elements of the REC report, including a publish COVID-19 Lessons Learned the lessons from COVID-19, investing £100m in the next Review and support to enhance the local system's approach to community engagement for four years to enable people to live healthy, active, and example through the Community Champions independent lives from programme. day one, and publish an annual 'Health of the Borough' report setting out how every part of the council contributes to reducing health inequality

Ealing's Strategy for Children and Young People with Additional Educational Needs and Disabilities (SEND) 2022-2026

A new strategy for children and young people with additional needs was being prepared at around the same time as this learning disability strategy³. It includes children and young people with learning disabilities, together with those with other kinds of additional needs such as physical disability, autism, and mental health. It's four draft priorities in July 2022 were:

To provide guidance, earlier identification of needs and support for children young people and their families, so that schools and settings feel supported to welcome every child and young person and set the highest expectations for them.

Every child and young person in Ealing are prepared for the transition to a purposeful adulthood with opportunities for training and meaningful employment.

- Ensure parents, young people and professionals work together to assess review and meet needs and improve the quality and timeliness of Education Health and Care plans through coproduction.
- 2. Ensure sufficiency of provision in settings, schools, and services so that children and young people can have their health, social care and educational needs met and feel part of the wider local community.

The Preparing for Adulthood agenda within the SEND framework is an opportunity consider the outcomes of young people with SEND as they transition into their adult lives, including young people with autism and learning disabilities. As children transition to adults and lead independent lives, they will require suitable travel training (priority 3) and be supported in experiencing a smooth transition from children's services to adult services (priority 6). The opportunity to lead meaningful lives will mean that there is a need to consider how health and care provision in the local area meets their aspirations (priority 1 & 5). Young adults with learning disabilities and autism will continue to access learning opportunities beyond 18 which may or may not include the support of an Education Health and Care Plan, but there is a need to consider how their lifelong learning needs will be met locally where they have the right support to feel safe and included (priority 2 & 4). Co-production and participation are at the centre of the SEND strategy which prioritises the

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³ Ealing's strategy for SEND (Special Educational Needs and Disability) and priorities | Ealing Directory (ealingfamiliesdirectory.org.uk)

importance of information and communication to ensure that young adults, including those with learning disabilities and autism can find and understand the opportunities available to them (priority 7).

NWL Integrated Care System's priorities and values

The creation of the NWL Integrated Care System in April 2022 is driving significant top-level change and local NHS priorities are likely to evolve accordingly during the life of the new Learning Disability Strategy. NWL CCG's current priorities⁴ are stated as:

Patients at the heart of everything we do. Our vision is to give every child and family a good start, to support people to live healthy lives, make sure there is care and support as local to where people live as possible, and if hospital care is required, we want patients to receive high quality care as soon as possible.

Its priorities are focused around three pillars:

Start Well	Live well	Age well
Giving every child and family the best possible start	Creating a positive place for people to live in and work	Building communities that support people as they grow older

NWL Integrated Care System has an annual Learning Disabilities and Autism Plan which sets out actions to improve health care across the subregion including reducing reliance on inpatient care for those with mental health needs and reducing premature mortality and preventable deaths. This strategy is consistent with that plan.

Ealing Health and Wellbeing Board's Priorities

The most recent Ealing Health and Wellbeing Strategy 2016-215, set out four priorities:

Ensure all key organisations work better together to improve health and wellbeing

Take every opportunity to improve health and wellbeing through contacts with residents and in key settings such as schools and the workplace

⁴ Our plans :: North West London Clinical Commissioning Groups (nwlondonccg.nhs.uk)

⁵ Health and Wellbeing Strategy | Health and Wellbeing Strategy | Ealing Council

Create and sustain an urban environment that helps people to make healthy choices

1. Support residents and communities to manage their health, prevent ill health and build resilience

Some of the specific actions in the Health and Wellbeing Strategy relevant to the learning disability strategy include:

- 1. Joint approach to integration and prevention for people with complex needs
- 2. Quickly identify people with common mental illnesses and improve quality and availability of appropriate support
- 3. Give children the best start in life and look for opportunities to improve the health of the whole household and that healthy behaviours are embedded in schools and further education
- 4. Increase the availability of healthy food and drink options
- 5. People at high risk of developing major physical health conditions are identified early and able to access appropriate support
- 6. Identify and support the skills, knowledge, connections, and capacity within communities to make them more resilient and to reduce inequalities
- 7. Easy access to the information and resources that allow citizens to make healthy choices and manage their own health

Ealing Carers Strategy 2018-23

Parents and other relatives, friends, work colleagues and neighbours play an important role in supporting and caring for people with learning disabilities. Our plan to support these carers is set out in the Carers Strategy⁶ which complements this learning disability strategy. The priorities for the carers are:

- Identifying carers of all ages at an early stage, recognising them as partners in care, ensuring they are aware of their rights to assessment and support, recognising their contribution and involving them in designing local care and in planning individual care packages.
- 2. Enabling carers of all ages to have a family and community life alongside caring, personalising support for carers by improving

⁶ Carers strategy | Ealing Council

choice and flexibility of support available and providing good quality information, advice, and support.

- 3. Supporting carers of all ages to stay healthy, mentally, and physically, providing respite from caring and offering training to support carers in skills to care and increase carer confidence.
- 4. Supporting carers of all ages to maximise their incomes and realise their potential in education, employment, and leisure.

A new provider for carer support services in Ealing started in 2022, YVHSC, to deliver against these priorities.

Ealing's Learning Disability Population

This chapter summarises what we know about our residents with learning disabilities and the services that they use. It updates some of the data in the learning disability JSNA 20167. Further detail about the population and its characteristics will be provided in a revised learning disability JSNA due to be published by March 2023.

Ealing is London's third largest London borough by population. Ealing's population recorded in the census in March 2021 was 367,100 people8. Of these, 22% were 15 years old and younger and 13% were 65 and over. Data on ethnicity has not yet been released; the 2011 census indicated that 58.7% of residents were from Black, Asian, and other minority ethnic groups9.

There are an estimated 6,000 adults with learning disabilities in Ealing¹⁰
¹¹. 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 that¹⁰ ¹¹:

 There will be a small increase in the total number of adults with learning disabilities

⁷ <u>Learning disabilities | Ealing Council</u>

⁸ How the population changed in Ealing, Census 2021 - ONS

⁹ Population - UTLA1 | Ealing | InstantAtlas Reports

¹⁰ Projecting Adult Needs and Service Information System (pansi.org.uk)

¹¹ Projecting Older People Population Information System (poppi.org.uk)

- 2. There could be a slight decrease in the number that need specialist support
- 3. There could be a slight decrease in the number of people with Down's Syndrome
- 4. 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.

People who use Ealing's learning disability adult social care services

On 31st March 2022, there were 730 people with learning disabilities who had been assessed as being eligible for adult social care support¹², and out of these:

290 were female and 440 were male

650 were in the 18-64 age range, and 80 were aged 65 and over

311 were White, 186 Asian or Asian British, 152 Black or Black British, 28 mixed, 2 Chinese, 31 Arab, 17 Other ethnicity, and 3 Not stated.

People on the GP learning disability register in Ealing

In March 2022 there were 1,473 GP patients aged 14 and over on the Learning Disability Register¹³. 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 health checks completed	Percent	Number Health action plans completed	Percent
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%

¹² MOSAIC, Ealing Council, Aug 2022

¹³ Copy of Learning Disabilities Report - Mar 22 v3 (003).xlsx (sharepoint.com)

The current national target is for 75% of people with learning disabilities to have a Health Check and a 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 2016-17¹⁴.

Based on the proportion of completed annual health checks and associated action plans for people with LD, Ealing is the best performing borough in Northwest London.

Nationally, there has been a decrease in the proportion of women with learning disabilities aged 50-69 who have had a breast cancer screening test. The proportion of patients on the Learning Disability Register who had been diagnosed with autism has increased from 19.8% in 2016-17 to 28.6% in 2020-21.

School pupils with additional educational needs and disabilities (SEND) in Ealing

Some children are diagnosed with a learning disability before birth or in early childhood. For others, their disability becomes apparent over time, and it can be difficult to diagnose sometimes because children develop intellectually at different rates. Therefore, it is difficult to say with certainty how many children have learning disabilities. Data about children with additional educational needs and disabilities can clarify how Ealing compares to other areas:

Pupils with SEN or an EHCP ¹⁵	Number in Ealing	Proportion in Ealing	Proportion in London	Proportion in England
Primary school	873	2.9%	3.0%	2.3%
Secondary school	525	2.3%	2.5%	2.2%
Special school	917	98.5%	97.2%	98.7%

Research into the needs of pupils at St Anne's Special School for the Telstar Post-19 project identified the following recommendations for service delivery for young people with severe learning disabilities in the 14-25 years age range:

1. Development of additional specialist residential care and supported living options.

Health and Care of People with Learning Disabilities Experimental Statistics 2020 to 2021 - NHS Digital

¹⁵ Ealing - Children and Young People - UTLA | Ealing | InstantAtlas Reports

- 2. Development of day opportunity services for the cohort with health and education.
- 3. Development of specialist short-breaks provision that includes specialist health input.
- 4. Engagement of the community in the co-design and commissioning of services.
- 5. A joint approach between social care, health, and education Assessment of individuals for Continuing Healthcare funding and a better coordinated approach to the market by health and social care commissioners.

Equalities

An equalities analysis and assessment were prepared for this strategy and is attached as an appendix. There is also an Easy Read version of it. The key points are:

Age: People with learning disabilities are living longer lives than in the past. One consequence is increasing numbers of children and young people with complex needs surviving beyond infancy. Another consequence is growth in the numbers aged 50 and over, and growth in the number of those experiencing early onset of age-related conditions.

Disability: People with learning disabilities are much more likely to also have one or more additional disabilities or long-term conditions, for example about 3 in 10 are also autistic.

Race: The proportion of people with learning disabilities receiving Adult Social Care services in Ealing who are Black is about 20%, compared to about 10% in the general population.

There is national data to indicate that learning disabilities are slightly more prevalent in South Asian communities, but this is not reflected in the profile of people who use Ealing Adult Social Care services.

Sex: The ratio of men to women with learning disabilities in Ealing is 6:4 which accords with national and global prevalence data.

We do not have much information about people with learning disabilities and the other protected characteristics.

Personalisation helps people with learning disabilities to exercise choices that may be informed by an individual's protected characteristics.

Generally, the strategy is intended to have a positive impact for people with a disability. The actions emerging from it are:

Reflecting the data about ethnicity and the findings of the Ealing Race Equality Commission, a specific action plan on race equality for people with learning disabilities is recommended.

- 1. The Learning Disability Mortality Review programme (LeDeR) and the impact of the COVID-19 pandemic have highlighted continuing health inequalities for people with learning disabilities that will need to be addressed.
- 2. Improvements in the collection of data about equalities will help with decision making in the future.
- 3. As we implement the strategy over the next five years this could lead to changes to some commissioned services for people with learning disabilities and there will be a requirement for further equalities analyses and assessments the data collected for the strategy will be helpful for this.

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 2022¹⁶ detailed the impact of the pandemic on our community and Ealing Power Group also published a report about the impact on residents with learning disabilities¹⁷.

In 2021 the rate of deaths of people with learning disabilities from COVID-19 was more than twice that in the rest of the population and it was the leading cause of death for them¹⁸. In 2020 the rate of deaths from COVID-19 was 3.6 times higher for people with learning disabilities than for the general population¹⁹. For those who were also Asian/ British Asian the rate was 4.5 times higher and for those who were also Black/ Black British it was 4.4 times higher. Deaths were more evenly spread across all age groups than for the rest of the population.

The numerous changes to COVID-19 related regulations and guidance were confusing and a source of anxiety to many people with learning

¹⁶ Annual public health reports | Ealing Council

¹⁷ Living Through Lockdown, Ealing Power Group, July 2021

¹⁸ Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR) (kcl.ac.uk)

¹⁹ COVID-19: deaths of people with learning disabilities - GOV.UK (www.gov.uk)

disabilities²⁰. People with disabilities were more likely to take actions to mitigate their risk of exposure to the virus that increased their risk of social isolation, for example social distancing and avoiding indoor socialising. People with disabilities were more likely to be worried or somewhat worried about the effect of COVID-19 on their life than other people. The Council for Disabled Children found that the pandemic had been a very demanding experience for many disabled children and their families²¹.

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

Preparation - being better prepared to respond to surges in new variants of the COVID-19 virus that may be more harmful to health, and to the risks of other similar pandemics.

- Communication keep in touch with people during times of uncertainty, be clear about what is going to happen and by when, check understanding and allow the person to ask questions, check with the person their preferred way of communicating, and use communication to build trust and confidence and to empower.
- 2. Support to understand rights, to continue to learn (including for children about things outside the core curriculum), to use technology, to have access to technology equipment, for technology that is inclusive of people with learning disabilities, to provide outdoor activities, and to ensure people have enough food.
- 3. Mental health and wellbeing create a culture where it is welcome to ask for support with mental health, ensure staff are trained to support with mental health, enable people to connect and spend time with friends and family, promote physical activity, and provide training on use of any new medical equipment.

Learning disability mortality reviews (LeDeR)

The Learning Disability Mortality Reviews Programme²² (sometimes referred to as LeDeR) was introduced from 2017 following the 2013 Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD)²³ to carry out a review each time a person with a learning disability dies and to identify opportunities to learn and improve

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²⁰ Wave 3 Results (warwick.ac.uk)

²¹ <u>Lessons Learnt From Lockdown: The highs and lows of the pandemic's impact on disabled children and young people (councilfordisabledchildren.org.uk)</u>

²² LeDeR - About LeDeR

²³ Reports | CIPOLD (Confidential Inquiry into Premature Deaths of People with Learning Disabilities) | University of Bristol

service delivery.

The national report²⁴ for the 2021 calendar year confirmed that people with learning disabilities are likely to die at an earlier age than other people with six out of every ten deaths being before the age of 65. COVID-19 was the leading cause of death, followed by diseases of the circulatory system and diseases of the respiratory system. 58% experienced good or excellent care, up from 54% in 2020. People with Black, Asian, and Mixed ethnicities were more likely to die at a younger age than White people. 49% of the deaths were identified as avoidable which compares to 22% in the general population.

The North West London LeDeR Annual Report 2020-21 includes a 7-page 3-year action plan organised under the following priorities:

- 1. Implementing LeDeR policy
- 2. Continued learning from LeDeR
- 3. Better support for children and young people
- 4. Improved uptake and quality of health checks
- 5. Increasing uptake of screening and immunisation
- 6. Better care in hospital
- 7. Reducing health inequalities
- 8. Improving the quality of care and support

A desktop analysis of 18 reviews completed in Ealing in 2020-21 identified several areas of good practice including:

- 1. Most had recent health checks and health action plans
- 2. Hospital passports worked well
- 3. Palliative care support at home was highly praised and highlighted strengths in person centred support
- 4. There was good quality care coordination by the CTPLD of multiple agencies
- 5. People who had consistent support from the same GP had personalised support and well led care

²⁴ <u>Learning from Lives and Deaths - people with a learning disability and autistic people</u> (LeDeR) (kcl.ac.uk)

- 6. People who are more independent have very individualised packages of care
- 7. During the COVID-19 pandemic, technology had been invaluable for helping people to video chat with friends and family.

Areas to learn and improve practice included:

- 1. Making sure everyone eligible for a health check and health action plan has one, and that they are accessible and meet the required standards.
- 2. The consistency with which hospital passports are used
- 3. Understanding of the Mental capacity Act 2005 in respect of resuscitation orders, medication reviews and Deprivation of Liberty Safeguards
- 4. Collaborative working between community and acute services Structured judgment reviews
- 5. Implementation of the STOMP (Stop Over-Medication of People with Learning Disabilities and Autism) initiative
- 6. Specialist epilepsy support and guidance
- 7. Use of the Accessible Information Standard
- 8. Take-up of cancer screening
- 9. Timeliness of Care Act reviews and assessments
- 10. Continuing Healthcare procedures, including fast track assessments
- 11. Provision of specialist equipment during the COVID-19 pandemic

The Financial Context

The financial context for the Council and NWL ICS is challenging largely due to inflationary pressures across the national economy and the impact of the COVID-19 pandemic. there remains an ongoing challenge about long term sustainable government funding for social care.

Adult social care budgets

The total (gross) Adult Social Care budget for learning disabilities in 2022-23 is £31.7M and this includes:

1. Residential care homes £20.4M

- 2. Nursing homes £0.4M
- 3. Direct Payments £3.4M
- 4. Supported Living £4.4M
- 5. Home care £1.0M
- 6. Day centres £2.1M
- 7. Residential respite £0.2M

The most significant trend in the budget in recent years is the growth in supported living and reduced spend on residential care and significant inflationary pressures on the cost of care for working age adults, linked to complexity of need and to economic factors.

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

Other uncertainties in the budget include:

- Non-recurring potential income and spend (for example, due to decisions about Ordinary Residence or eligibility for Continuing Healthcare funding)
- 2. Workforce issues, such as implementing the London Living Wage.

NWLI CS spend on LD in Ealing

The ICS spends around £10million a year on specialist services for people with learning disabilities. Its financial system does not provide a breakdown of the budget or spend by borough. It is not capable of stating how much is budgeted for or spent on learning disabilities across the system. Some of the information may be contained within the budgets of NHS Trusts operating in Ealing. Council recharges to the Integrated Care System for placement costs of adults with learning disabilities eligible for Continuing Healthcare in 2021-22 were £696,000 (this is an under-statement of the actual recharge because some people will be counted for in children's and older people's budgets).

The highlights of what people told us in the consultation:

Priority		People said:
Good networks, information, and communications	SUPPORT	It is hard to find out about things for people with learning disabilities.
Feeling and keeping safe		People are concerned about keeping safe. There needs to be more learning disability awareness in the community.
Transport		Travel training is important for all. They want to know about how transport for adults is funded.
Healthy lives	Train 10	A lot of ideas were mentioned to improve the health of people with learning disabilities. Annual health checks need to be easier to understand.
Learning	College	Learning is important at all ages. This includes learning independent living skills.
Employment	jobcentreplus Market Thanks	There should be more support to get a job, especially for adults. Employers need support to help people with learning disabilities work as well.

Accommodation – where you live	People want more information about housing options. People want more suitable houses in Ealing. Most people prefer supported living to residential care.
Day opportunities and activities	People want more activities to choose from. People want to access more in their community. There are not enough activities in Ealing at weekends and evenings.
Social connection – friends and family	People want support to make friends and have relationships. Some people want help to safely access social media to keep them connected.
Transitions	Work has started to improve how young people transition from children's services to adults' services. There is scope to improve handoffs between paediatric and adult specialist health services.
Cross-cutting	Technology could help more people to have a better life in the future.

There is more detail on what people said in the next section.

Priority 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

1.1 Social connection - friends and family

Introduction

People with learning disabilities are at high risk of social isolation and many will always need support to maintain the kinds of relationships with friends and family that most of us take for granted.

Aims and outcomes

People with learning disabilities will be socially connected in the way that suits them best including with family, with friends, romantically, and with neighbours and community.

What we know

- 1. One impact of the pandemic is that some people with learning disabilities have lost some of their social connections and/ or their ability to connect socially with other people.
- 2. It is a Council priority to reduce social isolation and the impact that it can have on mental health.
- 3. Some adults with learning disabilities live with an elderly family carer they may not be known to health and social care services, they may not have had the opportunity to learn skills to live independently, and they can require a service at short notice.
- 4. There may be a need for additional support for parents of people with learning disabilities of all ages.
- 5. The new carers centre contract is an opportunity to improve support and mutual aid for parent carers of people with learning disabilities.
- 6. There is a need to expand the quantity of and choice in respite provision.

- 7. Ealing has a new pathway to in support parents who have a learning disability.
- 8. Ealing Mencap has funded 2 specialist parent support workers and this new service started in 2022.
- 9. The contract for the carers centre transferred to YVHSC in April 2022 and provides for a range of advice, information, and other support to family carers.

Short Breaks

There is an adults Council-run short breaks service at Green Lane attached to the CTPLD's offices that can accommodate up to ten people. There is another overnight short-breaks service at Haymill Close commissioned from Certitude that can accommodate up to six people.

During the first two years of the COVID-19 pandemic there was a bottleneck in these two services due to challenges in making emergency placements into supported living and care homes. Some people stayed there much longer than they would have done before the pandemic. This bottleneck has now cleared but not everyone who regularly used the services before the pandemic has returned to their previous pattern of usage. Some people may be happy with the alternatives they have found to overnight stays. Therefore, it is not yet clear if there is the same level of demand as in the past.

A review of children's short-breaks services is currently underway.

What people told us

- 1. The most frequent comment was that there is a lack of social and leisure groups for people with learning disabilities in Ealing where they can make new friends or meet existing friends locally.
- 2. People with learning disabilities are at high risk of social isolation and its consequences for health and being a victim of crime. The COVID-19 pandemic has increased the risks and likelihood of social isolation.
- 3. Technology could help some people but people with learning disabilities may need additional support and guidance to access and manage the risks of social media.
- 4. Many people with learning disabilities will need continuing support to make and maintain friendships, to understand the difference between being a "friend" and being "friendly", to manage challenges in friendships, and to accept that some friendships end.
- 5. There appears to be no local sources of advice or support on romantic relationships for people with learning disabilities.
- 6. The role of staff in accommodation-based services in helping people with social connection is unclear, and whether they have time or the

skills.

- 7. The location of accommodation can hinder social connection
- 8. Better use could be made of Council and voluntary sector buildings for social activities.
- 9. Being a family carer of a person with learning disabilities, whether as a parent or sibling, can be very demanding with significant emotional and financial impacts for the whole family.

1.2 Day opportunities and activities

Introduction

Day opportunities and organised activities can be an essential part of the day for people with learning disabilities with care and support needs. They provide opportunities to meet other people and provide structure to the day. They can also provide a break for families and housemates.

Aims and outcomes

People with learning disabilities will have the choice of a range of day activities across the borough.

What we know

The COVID-19 pandemic had the impact of widening the day opportunities offer from building based activities to also include more activities in the community, remote support, and activity packs.

There are gaps in the market offer in:

- 1. After-school, weekend, evening, and school holiday activities for children with learning disabilities
- 2. Activities of interest to young people in the 14-25 age range
- 3. Activities for those who fall just beyond Adult Social Care's eligibility criteria.
- 4. Adult day opportunity services are not regulated and there is some concern about the quality and ethos of day centres run by some independent providers.
- 5. There is a role for technology in the provision of activities.

Day time services for adults

In January 2022, 169 people had a commissioned package of care that include day-time services²⁵. Others used their Direct Payment to purchase daytime services directly. There are about 20 providers

²⁵ MOSAIC, Ealing Council, January 2022

including NAS and Ealing Mencap, and a council-run service at the Cowgate Centre that caters for those with higher needs.

Day activities for children

This includes provision after school, at weekends and during school holidays. The Log Cabin has been established for a long time as the main provision aside from that provided by schools. A review is currently being carried out by Children's Integrated Commissioning with a view to creating additional market options and capacity.

What people told us

- 1. There are fewer activities available for people with learning disabilities in Ealing than in the past and that this is due largely to austerity but also to some extent due to fewer parents being able to volunteer in a mutual aid capacity than in the past.
- 2. There should be more options to choose from.
- 3. Employment and volunteering should be looked at as alternatives for some people.
- 4. Ideas for the types of activities that should be provided included arts, learning, physical activities, day trips and outings. People said that activities should be stimulating.
- 5. There are gaps in provision for those with challenging behaviour and for young adults in the 25-34 age range.
- 6. For children and young people there are concerns about the reliance on one specific provider for after school activities, and gaps in provision in the evenings, weekends, and school holidays.
- 7. For adults living in supported living and residential care there are concerns about the capacity of staff to provide meaningful activities.
- 8. For young people and adults there are very few social activities available within Ealing and access to these activities is only available to those who have a parent who is willing to do the research and provide transport.
- 9. There is some interest in mutual aid to plug gaps.

1.3 Employment

Introduction

Just as with anyone else, paid employment and volunteering can help people with learning disabilities to enhance their self-worth, provide social connection with work colleagues, give structure to the day, and give the chance to grow and develop. Some people with learning disabilities may never be able to work but many can when given the right support and opportunities.

Aims and outcomes

The number of voluntary and paid work opportunities available for people with learning disabilities will increase.

The range of support and guidance available to help people with learning disabilities to stay in a voluntary or paid job will increase.

What we know

- 1. It is a Council priority to increase the number of people with learning disabilities in employment.
- 2. There is a range of employment support initiatives for young people aged 18-25 who have special educational needs and disabilities, including work experience, supported internships, and apprenticeships.
- 3. Adults in the 25-65 age range do not have the same opportunities and achievement of paid employment outcomes is mixed.
- 4. The benefits system may be acting as a disincentive to employment, including the 16 hours per week cut-off and for some the impact on Housing Benefit for service charges under Exempt
- 5. Accommodation regulations creating a "benefits trap."
- 6. A bid has been made jointly with Brent for DWP funding for an employment support project, with S106 match funding.

The ASCOF learning disability employment indicator data for 2021-22 indicates that 1.8% of 18–64-year-olds with learning disabilities known to adult social care in Ealing are employed²⁶. In 2020-21 two other London boroughs had the equivalent proportion at 17%²⁷. There appeared to be a significant fall in performance over recent years which started before the COVID-19 pandemic, and we have agreed a new process with Ealing Mencap and the Shaw Trust to make sure that all those who are in employment are recorded:

Year	% employed
2016-17	6%
2017-18	5%
2018-19	5%
2019-20	1%
2020-21	1%
2021-22	1.8%

Employment Support

There are two employment support services operating in Ealing that

²⁶ MOSAIC, Ealing Council, August 2022

²⁷ Measures from the Adult Social Care Outcomes Framework - NHS Digital

work with adults with learning disabilities. The Shaw Trust is commissioned by the West London Commissioning Alliance to provide employment support to a range of people traditionally excluded from the employment market, including adults with learning disabilities, and operates from a base in Acton. Dare To Dream at Ealing Mencap provides employment support to individuals and the service is either spot purchased or micro-commissioned by people with a Direct Payment. A joint bid with Brent has been submitted to the DWP for funding for a pilot initiative to support an additional 40 people with learning disabilities and/ or autism into employment.

For young people with additional educational needs and disabilities the SEND employment pathway provides opportunities to learn about the world of work, work experience, supported internships, apprenticeships, and traineeships.

What people told us

- 1. Some people with learning disabilities will never be able to work.
- 2. Employment has numerous benefits for people with learning disabilities and their families.
- 3. If a person with a learning disability can work, they should be supported to do so.
- 4. Employment support is currently available to those aged under 25 and this should be extended to adults who are 25 and over.
- 5. Apprenticeships are a good route to employment.
- 6. There needs to be more long-term work opportunities.
- 7. Employers will need to be supported too.

1.4 Accommodation - where people live

Introduction

Having a secure place to call home is often a prerequisite for the other aspects of having a happy and meaningful life.

Aims and outcomes

People with learning disabilities will have a home that suits their needs.

What we know

1. A new Dynamic Purchase System and accreditation scheme from 2024 should provide the opportunity to improve the range of choice and the standard of quality in supported living.

- 2. The Council operates a quota system for social housing tenancies.
- 3. In the Adult Social Care learning disabilities budget, the biggest proportion of spend is on care homes but there is a continuing trend for this proportion to reduce as more new placements are into supported living.
- 4. Older people care homes are occasionally used to accommodate older people with learning disabilities.
- 5. It can be hard to source accommodation-based services for people with more complex needs and people with behaviour that challenges services and others.
- 6. Pipeline data on people awaiting a placement in 2021 shows a continuing steady demand for supported living.
- 7. The recent award of NHSE capital funding may go some way to meeting the ongoing need for additional specialist accommodation if a suitable site can be found.
- 8. A consequence of COVID-19 could be increased demand for adaptations.
- 9. Safeguarding alerts have been investigated in some unregulated supported living recently developed by new market entrants.
- 10. The learning disabilities element of the Adult Support (housing related support) budget is now included within the Adult Social Care learning disabilities care packages budget.
- 11. The Home Ownership scheme for people with long-term disabilities²⁸ could help some people with learning disabilities who have access to equity to buy their own home.
- 12. The Council's Adult Social Care priorities related to where people live include: improving the quality of care homes in Ealing, reduced admissions of people into care homes, increased people supported to live independently in their own homes.

Settled accommodation

The ASCOF learning disabilities settled accommodation indicator records the proportion of people with learning disabilities aged 18-64 who live in their own home or with their family²⁹. The most recent comparative data for 2020-21 indicates that 77% are in settled accommodation, compared to 77.7% for London and 78.3% for England. The two best performing London boroughs achieved 89%.

For women in Ealing the comparable proportion was 75.8% and for men 78.2%. This is the reverse of London and England.

Performance improved and then plateaued in recent years:

²⁸ Own Your Home | Home Ownership for People with Long-Term Disabilities (HOLD) - Own Your Home

²⁹ Measures from the Adult Social Care Outcomes Framework - NHS Digital

Year	%
2016-17	71
2017-18	72
2018-19	78
2019-20	77
2020-21	77
2021-22	77 ³⁰

Residential and nursing care homes

In January 2022, there were 163 adults with learning disabilities living in a residential care home³¹. 131 were aged 18-64, and 32 were aged over 65. The numbers placed in residential have remained steady over the last two years. "Short term residential" normally used for emergency placements increased during the first 18 months of the pandemic from 18 in April 2020 to 38 in August 2021 but then reduced back to 24 by January 2022; this change is explained by the difficulties in making placements whilst services had infection control policies in place. Some people with learning disabilities live in block contracted care homes for older people and these placements are relatively cost effective.

In January 2022 there was a total of 31 adults with learning disabilities living in a nursing home commissioned through the Council³². There were seven adults living in long-term nursing home placements, two were aged 18-64 and five were 65 or over. In addition, there were 24 in short-term nursing home placements, 18 aged 18-64 and six aged 65 or over.

Across the whole of adult social care, Ealing has the highest rate of placements into residential and nursing care in London. When it comes to learning disabilities only, Ealing has the 8th highest rate of placement in residential and nursing care per 100,00 in London. This indicates that more people could be living in supported living or their own flat if that option were available to them. Ealing pays a higher average weekly rate for its learning disability residential and nursing placement than the average for London, indicating possible greater potential for containing costs; alternatively, this may simply be due to different profiles of need.

The care home market has been under significant pressure due to high number of voids (around 20%). Financial viability has been supported by one off Infection Control Grants and NHS funding in 2020/21 and

³⁰ MOSAIC, Ealing Council, August 2022

³¹ MOSAIC, Ealing Council, January 2022

³² MOSAIC, Ealing Council, January 2022

2021/22 and now it has ended there is thought to be increased market risk of potential business failures in the care home sector.

Supported Living and Outreach

In January 2022 there were 232 adults with learning disabilities living in supported living³³, including shared houses, small blocks of flats, and people receiving support to live in their own flat. Eight people have their own flat with support in Extra Care housing. 14 people live in Shared Lives as a lodger in the home of a private householder who provides some support. Capital funding has been awarded, subject to identifying a suitable site, from the DHSC's Building the Right Support programme to develop additional housing capacity for 5 or 6 people due for discharge from an assessment and treatment unit or who are at high risk of admission. There are 41 people with learning disabilities whose supported living is part funded by Adult Support (formerly Supporting People) with block contracts that are due to end in 2023.

Housing Strategies

Ealing Housing and Homelessness Strategy 2022-27 was being prepared at around the same time as this learning disability strategy³⁴. The Council aims to prevent homelessness and increase the supply of homes in Ealing. It aims to create high quality homes and neighbourhoods that are sustainable, healthy, energy efficient, safe, and secure.

The Council plans to set up a new Housing Equality Steering Group and its responsibilities will include the following actions that may benefit people with learning disabilities:

- 1. Review the commissioning arrangements for supported housing
- 2. Build 300 new supported accommodation extra care flats for older people
- 3. Ensure at least 10% of new homes are suitable for wheelchair users and that the rest are visitable and adaptable
- 4. Provide disabled facilities grants (DFGs), floating support, tenancy sustainment and community alarms
- 5. Set up new community hubs to support residents to access Council services at a one-stop place that can support those most impacted by the cost-of-living crisis with wraparound support.

The GLA's London Housing Strategy 2018³⁵, Policy 5.2, Meeting London's Diverse Housing Needs, sets out the GLA's intentions to:

- 1. Improve accessibility for disabled Londoners in the housing stock
- 2. Invest in supported housing for disabled and older Londoners.

³³ MOSAIC, Ealing Council, January 2022

³⁴ Strategies, plans and policies | Ealing Council

³⁵ London Housing Strategy

Currently there is no new GLA investment in supported housing for people with learning disabilities in Ealing.

What people told us

- 1. People would like information about housing options and referral routes.
- 2. The consultation revealed a clear preference for supported living over residential care.
- 3. Sheltered housing and extra care housing could be good solutions for some older people with learning disabilities.
- 4. For people with learning disabilities who have a social housing tenancy there are concerns about repairs and anti-social behaviour.
- 5. Shortage of space or bedrooms came up several times for families living in social housing where there is one or more person with a learning disability. One person mentioned difficulties with toileting due to the lack of a ground floor toilet in the family home.
- 6. In some families there is scope to help a relative to buy their own home, but it is hard to find advice about this.
- 7. Some people will need specialist accommodation to meet additional needs including due to mobility, and challenging behaviours.
- 8. There were concerns about the supply of specialist accommodation and whether the Council takes a coordinated approach to planning and meeting this need.

1.5 Service delivery

Introduction

Ealing has a lot of good things happening for people with learning disabilities and it is always trying to improve what is on offer. Some people feel that they are not able to live as independent a life as the rest of the population and need help to achieve this. This sub-priority cuts across the other sub-priorities under Meaningful Lives.

Aims and outcomes

Services for people with learning disabilities commissioned by the Borough Based Partnership will:

- 1. Be of a good quality
- 2. Enable people to have choice and control
- 3. Promote equalities in the way they are delivered
- 4. Pay staff at least the London Living Wage

What we know

1. Phased implementation of the London Living Wage and the Council's

new Social Value Policy in the social care supply chain are priorities for the Council³⁶.

- 2. A range of options to improve equalities were identified in the equalities analysis and assessment for this strategy.
- 3. There is limited use of Technology Enabled Care³⁷ ³⁸ for people with learning disabilities in Ealing and the experience of the COVID-19 has shown that there are opportunities for technology to be part of the solution to some of the challenges that people face.
- 4. A new High Needs Commissioning Board is being established to improve the co-ordination of care packages for those aged 0-25 with the most complex needs.

Direct Payments

The number of adults with learning disabilities receiving a Direct Payment has reduced from 152 in April 2020 to 132 in January 2022, out of which 131 people were aged 18-64 and one person 65 or over³⁹.

Home Care

There has been little change in the number of people with learning disabilities receiving home care over recent years. In January 2022, there were 86 people with learning disabilities receiving home care, out of which 79 were aged 18-64 and seven were aged 65 and over⁴⁰. The home care market is relatively buoyant with a wide spread of risk in terms of the number of providers and relatively low unit costs compared to accommodation-based services.

Adult Social Care social work team

There is a specialist learning disabilities social work team based in the CTPLD. The average waiting time for assessments increased during the COVID-19 pandemic and actions have been taken to reduce the backlog, including recruitment of additional locum social workers.

Workforce

It is challenging to recruit those with specific skills such as social workers, occupational therapists, psychologists, and drivers. Some providers and voluntary sector organisations are facing challenges in recruiting support staff who can work with people with learning disabilities despite active involvement with recruitment fairs and other innovative approaches. Some people with a Direct Payment find it difficult to recruit the right people to support them. The Council has a new policy for its contracts for social care services to require that

³⁶ Ealing Social Value Policy 2022 | Ealing Council

³⁷ NHS England » Technology Enabled Care Services (TECS)

³⁸ TSA - the voice of TEC (tsa-voice.org.uk)

³⁹ MOSAIC, Ealing Council, January 2022

⁴⁰ MOSAIC, Ealing Council, January 2022

providers pay their staff at least the London Living Wage.

What people told us

- 1. People want services to be good quality.
- 2. People are concerned about staff and want them to have the right attitudes and skills, and to be paid at a rate that reflects their skills.
- 3. People with learning disabilities appreciate being given different options to choose from and services being personalised around them.
- 4. Equalities are important to people with learning disabilities. The additional challenges for families where English is a second language were raised by some parents.
- 5. A lot of people with a learning disability have access to computers and smartphones but they want support to get the most out of them and to be safe online.

Priority 2: Feeling and keeping safe

Introduction

Most of the time people are safe and do not have any problems when they are out and about but if something does happen to a person with learning disabilities it can be very scary and stressful.

Aims and outcomes

People with learning disabilities will feel and be safe at home and in the community.

What we know

- 1. Hate crimes against people with learning disabilities are thought to be under-recognised and under-reported⁴¹.
- 2. Cuckooing and other anti-social behaviour towards vulnerable adults is central to Ealing's Community Safety Strategy⁴².
- 3. DWP delays in paying Universal Credit and other benefits leads to informal borrowing by vulnerable adults that puts them at risk of abuse and exploitation.
- 4. Technology Enabled Care is not used much in Ealing to keep people with learning disabilities safe in their home and community compared to other client groups.
- 5. There is an opportunity to strengthen the link between the Learning Disability Partnership Board and the Safer Ealing Partnership.

^{41 &}lt;u>Learning disability and autism - True Vision (report-it.org.uk)</u>

⁴² Safer Ealing partnership strategy | Ealing Council

Community Safety Strategy

A significant focus of the Community Safety Strategy is about protecting vulnerable adults and families who live in social housing from harm and anti-social behaviour. This will include many people with mild learning disabilities who are not eligible for specialist learning disability care and support.

The Safer Ealing Partnership priorities are:

- 1. Focusing on Substance Misuse, Domestic Abuse and Mental Health
- 2. Preventing Exploitation and Victimisation
- 3. Managing Spaces Effectively
- 4. Strengthening Intelligence, Information Sharing and Resilience

What people told us

- 1. Parents and people with learning disabilities are concerned about risks of bullying and anti-social behaviour, regardless of age.
- 2. People with learning disabilities feel at most risk being out after dark.
- 3. There needs to be more awareness of learning disabilities among the general population.
- 4. There is a gap in the provision of support for people with learning disabilities to stay safe online.
- 5. Complaints processes need to be made more accessible.
- 6. Some parents need support (encouragement, advice, reassurance) to enable them to allow their adult child to make their own choices and take reasonable risks.

Priority 3: Travel

Introduction

Ealing is a large borough connected by good transport links, which allow people to travel easily. Sometimes the transport does not allow people with disabilities to use it as easily as everyone else and they find it difficult to move about the borough.

Aims and outcomes

People with learning disabilities will have choice and control relating to transport.

What we know

1. The Council has a Special Transport Team with officers responsible for arranging transport for people with learning disabilities assessed as needing it in their care package.

- 2. There has been a significant increase in demand for special transport for children with additional needs.
- 3. The provision of special transport is facing significant challenges from the increased cost of fuel and the shortage of drivers.
- 4. There is an opportunity for people with learning disabilities to be represented on a new Access Forum.
- 5. There are two Changing Places toilets in Ealing⁴³. As part of the National Disability Strategy, the Government has started a programme of grants to increase their availability⁴⁴.
- 6. The Council is setting up a new Dynamic Purchase System to procure special transport services.

What people told us

- 1. Many people with learning disabilities have faced difficulties when using public transport, including a lack of awareness of their needs, assumptions about "invisible disabilities", and harassment.
- 2. Some people with learning disabilities will never be able to use public transport on their own.
- 3. Following the pandemic, some people will need additional support and refreshed travel training to return to using public transport.
- 4. There is a gap in travel training for adults.
- 5. Travel training should not just be for routes to college or work.
- 6. The process to award travel support to adults with learning disabilities as part of their package of care is not clear, and assurance cannot be given that it is awarded in a way that is fair and consistent.
- 7. Difficulties can arise for individuals when there are changes to their regular special transport service.
- 8. More locally based services and activities may mitigate the need to travel further afield.
- 9. GPS technology could help some people.
- 10. Group travel from special schools to after school clubs should be arranged.

Priority 4: Learning

Introduction

Learning new skills and refreshing on existing knowledge is important for all age groups of people with learning disabilities. They may struggle more than other people with remembering what they have learnt and with taking on new information. Independent living skills can help people with learning disabilities to be less dependent upon others.

Aims and outcomes

People with learning disabilities will be able to access opportunities for

⁴³ Changing Places Toilets (changing-places.org)

⁴⁴ Changing Places Toilets (changing-places.org)

lifelong learning.

What we know

- 1. Whilst Ealing has a range of good special schools, there is a gap in places in-borough to meet demand.
- 2. There is a gap in the provision of training for independent living skills.
- 3. The key groups who need it are:18-25 years olds in transition, adults who live with a parent where there is a high risk of family breakdown, those adults who have lost skills and confidence due to socially isolating during the pandemic.
- 4. Since the Government reformed funding for adult education in 2016 for it to be work-related there has been a gap in the provision of specialist adult education for people with learning disabilities.

What people told us

- 1. Independent living skills learnt by young people with learning disabilities at school and college can be lost and then need to be relearnt if the young person does not have an opportunity to practice them.
- 2. Adult education has tilted towards a focus on helping people gain work-related skills and qualifications, but people with learning disabilities will continue to need to be able to access training in independent living skills including managing their money.
- 3. Some people with learning disabilities will never be able to understand information about benefits, the law and policy, and will always need support with them.
- 4. There is not enough funding, including for learning for leisure.
- 5. Lifelong learning does not end at 25.
- 6. Online learning suits some people with learning disabilities.
- 7. Teaching staff in mainstream schools may need additional training to identify and support pupils with learning disabilities.
- 8. People with learning disabilities would like more help with learning and maintaining digital technology skills.

Priority 5: Healthy lives

Introduction

People with learning disabilities are more likely to have health problems – both physical and mental health. Also, they are likely to find it more difficult than others to describe their symptoms and to understand how to prevent further illnesses.

Aims and outcomes

Health inequalities and the gap in life expectancy between people with learning disabilities and the general population will reduce.

What we know

- 1. The number eligible for Continuing Healthcare is increasing due to the ageing population and increased acuity of need in younger age groups.
- 2. Ealing performs well in managing risk of long-term hospital admissions.
- 3. Ealing GPs are high performing in the delivery of Health Checks and Health action Plans. In 2021-22, 83% of people with learning disabilities over the age of 14 had a Health Check and 82% had a Health Action Plan. However, there are concerns that Health Checks and Health Action Plans do not always deliver the expected improvements in health outcomes for people with learning disabilities. This may be down to whether the patient and those who support them understand the advice given to them, and the time clinicians spend to explain and check understanding.
- 4. The long-term impact on wellbeing from the pandemic is expected to be felt over the next few years including increased incidence of mental health issues and challenging behaviours, the breakdown of families no longer able to cope, and people with learning disabilities not coping.
- 5. There is likely to be increased rates of physical ill health affecting mobility and frailty.
- 6. There is an opportunity to improve service delivery by implementing the learning from the LeDeR mortality reviews programme.
- 7. Gaps in the promotion of physical activity are expected to be addressed through a joint project with Brentford Football Club.
- 8. There do not appear to be any local initiatives aimed at people with learning disabilities to promote healthy diets.
- 9. People with learning disabilities are at greater risk of poor oral and dental health than the general population⁴⁵. This is due to a range of factors including social deprivation and higher sugar consumption. Loss of teeth and oral health conditions have a wider impact on the health and wellbeing of people with learning disabilities.
- 10. There is a gap in provision of hydrotherapy.
- 11. The introduction of the learning disability Liaison Nurse service at Ealing Hospital has led to improvements in the patient experience there.
- 12. A dementia pathway for people with learning disabilities has been developed.
- 13. Challenges in information sharing between organisations is preventing people of all ages with learning disabilities from experiencing a holistic approach to the management of their health care. This is

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⁴⁵ Health Inequalities: Oral Health, Public Health England, 2019

largely due to the use of different IT systems that do not have functionality to share information with one another.

- 14. It is a Council priority to refresh commissioning strategies to reduce health inequalities in partnership with voluntary sector and health partners.
- 15. The Learning Disabilities Health Action Group was launched in May 2022.

Specialist health care provision

Based in the CTPLD the adult specialist health team shares a single point of access with the specialist social work team. The team provides the following health services to adults with learning disabilities:

- 1. Psychology (including family therapy, dialectical behaviour therapy, positive behaviour support, music therapy and art therapy) there are three positive behaviour support practitioners in the team
- 2. Psychiatry
- 3. Nursing (including mental health)
- 4. Speech and language therapy
- 5. Occupational therapy

Based in the CAMHS, the Paediatric Learning Disability Team provides assessments, psychology, and psychiatry to children with learning disabilities. There are significant ongoing challenges in staff recruitment to the CAMHS.

There is a learning disability nurse liaison service at Ealing Hospital.

Continuing Healthcare assessments and complex case management are provided by the Integrated Care System.

Transforming Care

Ealing's performance is good with low numbers of people with learning disabilities and autism in assessment and treatment units or in long-term hospital settings. Risks are well-managed in community-based settings. There have been zero mental health admissions in recent years with wraparound support provided to those at risk of admission and cases actively managed through the Dynamic Support Register. Capital funding has been awarded to develop additional housing capacity.

What people told us

- 1. The CTPLD is highly valued.
- 2. Awareness of Health Checks and their purpose appears to be mixed.
- 3. There was a lot of anger about the treatment of people with learning disabilities who had been hospitalised during the pandemic.
- 4. There should be increased effort to promote healthy lifestyles among people with learning disabilities including healthy eating, exercise and

physical activity, and mental wellbeing.

- 5. There were concerns based on personal experience about waiting times for assessment of a diagnosis of a learning disability and responsiveness to crises by the CAMHS.
- 6. Some young people had been discharged from specialist paediatric services at the age of 18 and not referred on to the equivalent adult service.
- 7. Various experiences were described outside of learning disability specialist services where clinicians did not provide reasonable adjustments for patients with learning disabilities in one focus group it was thought that changing the language to talking about "additional needs" might help professionals of all kinds to focus on solutions.
- 8. People with learning disabilities would like information about chaperone services and other reasonable adjustments that have been made for them in general healthcare settings.

Priority 6: Transitions

Introduction

Since a new transitions team was set up in 2021 a lot of improvements have been made in the way that young people are supported as they transition from Children's services to Adults' services. However, we know this is the start of the journey and there is more to be done.

Aims and outcomes

We aim for all young people with learning disabilities to be prepared for adulthood.

What we know

- 1. A new social care Transitions Team was set up from scratch in 2021, with new staff and new processes this is still work in progress.
- 2. About 70% of the Transitions Team's clients have complex needs.
- 3. An impact of COVID-19 is that many young people have had an extra year in education and consequently there is a spike in the number transitioning this year, and possibly next year.
- 4. Many young people with learning disabilities have grown up with digital technology and consequently the Transitions cohort may be best placed to make best use of Technology Enabled Care.
- 5. Social, emotional, and mental health (SEMH) is an important part of the curriculum for those with additional educational needs, including support to develop positive relationships and learning about sexual health. This includes checking that contraception is compatible with other medications a young person is taking.

6. Young people with undiagnosed learning disabilities are at risk of entering the youth justice system.

What people told us

- 1. People would like more information about what to expect of the transitions process and for it to start from the age of 14
- 2. There is a need to improve transitions systems in health to match the developments in social care.
- 3. There are concerns about support available to young people who have had an EHCP but who do not meet adult social care eligibility criteria.
- 4. Deputyship could be helpful for some families to manage their child's care beyond the age of 18, but many cannot afford the costs of applying for and maintaining it.
- 5. There were concerns about the availability of services that cater for younger adults including activities, home care and supported living.

Priority 7: Good networks, information and communication

Introduction

Ealing is a big area with many things happening for people with learning disabilities. Lots of the things are good and some could be better. Sometimes people don't know where to find out what's happening or how to raise issues. Sometimes people can't get involved because the communication isn't in the right way for them.

Aims and outcomes

People with learning disabilities will be able to easily find out about services and opportunities available to them.

Information and communications will be in formats that are accessible to people with learning disabilities.

What we know

- 1. The 2016 Accessible Information Standard requires all organisations that provide NHS care and publicly funded adult social care to meet the communication support needs of patients and service users with a disability⁴⁶.
- 2. The CTPLD has reviewed its written information to ensure it is consistent with the Accessible Information Standard. The Council is improving the accessibility of its website and is updating the Local Offer.
- 3. Ealing has a high proportion of families for whom English is not their first language.

⁴⁶ NHS England » Accessible Information Standard

- 4. There is increasing demand on the Ealing advice service from people with mild learning disabilities.
- 5. The CTPLD has commenced involving people with learning disabilities on recruitment panels.

What people told us

- 1. People, including professionals, find it hard to find information about services and activities for people with learning disabilities in Ealing.
- 2. Family carers often find information through informal networks, but many have limited access to such mutual support.
- 3. People search online for information, but search results are often not helpful.
- 4. The idea of online directories is valued but there are concerns about information being kept relevant and up to date.
- 5. Different online search results often signpost to each other.
- 6. Family carers would find a newsletter helpful.
- 7. Some people with learning disabilities cannot use Easy Read.
- 8. Makaton is taught in special schools but then pupils find there is limited use of it by others outside of school.
- 9. People with learning disabilities should be involved in recruitment of staff involved in their care and support.
- 10. People with learning disabilities should be involved in recruitment of staff who provide their care and support.

Next Steps

The strategic partners in the Ealing Borough Based Partnership will be responsible for implementation of the strategy. The Learning Disability Partnership Board will assure delivery.

The Borough Based Partnership's role will be managed by the Operational Delivery Group, the Adults Senior Management Team, and the Health and Wellbeing Board.

Governance

The table below shows the schedule of governance boards the strategy will be presented to, and comments/approval requested prior to publication. The Joint Strategic Needs Analysis (JSNA) chapter for Learning Disabilities is being developed in parallel with the commissioning strategy - the timetable for approval of the chapter is included below.

Governance Boards	Scheduled date
Scrutiny Committee (HASSP)	1.2.23
Health and Well Being Board	15.3.23
Cabinet member briefing	26.9.22
Adult Services Management Group (ASMT)	6.9.22
Operational Delivery Group (ODG)	23.9.22
Learning Disability Partnership Board (LD PB)	12.10.22
Learning Disability JSNA Steering Group	2 23
SEND Strategy & Inclusion Executive Board	6.10.22
High Needs Commissioning Group 0-25	24.11.22

Appendices1. Jargon buster

- 2. Background documents
- 3. Equalities analysis and assessment4. Easy Read version of the strategy

Appendix 1 - Jargon Buster

An appendix provides extra information for people who want it. This appendix explains some of the jargon and acronyms used in the learning disability commissioning strategy. We hope you find it useful.

Accessible Information Standard – sets out requirements for health and social care organisations to make documents and websites easier to understand. NHS England » Accessible Information Standard

Accommodation-based services - places where people live with care and support provided.

Adult Support – a funding stream for housing related support in some supported living schemes that for learning disabilities is now incorporated into Ealing's Adult Social Care budget.

ASCOF – Adult Social Care Outcomes Framework – the framework includes two outcomes for people with learning disabilities that measure the proportion in employment and the proportion who live in settled accommodation.

Building the Right Support – a government initiative to reduce admissions to and increase discharges of people with learning disabilities and autism from mental health assessment and treatment units that was part of the response to the Panorama report on abuse at Winterbourne View. Building the Right Support followed on from Transforming Care (see below).

Capital funding - money for buildings, land, and equipment

Care home – also called a registered care home – a place where a group of people live with care and support provided 24 hours a day and which is regulated by the Care Quality Commission. The cost of the accommodation is not eligible for Housing Benefit and the full cost is usually paid by Adult Social Care or by private individuals who have the financial means to pay.

Carer – a person who provides care and support to a disabled person in an unpaid capacity. This is typically a parent but could be a partner, another relative, a friend or a neighbour.

Care Quality Commission/ CQC – the national regulator for health and care services.

Children and young people with additional needs – in Ealing we are now using this phrase to describe children with special educational needs

as defined by the Children's Act 2014

Commissioning – the processes and function in local councils and NHS bodies to identify the needs of the local population, to make plans, to provide and purchase solutions to meet those needs, and to monitor and review services

Community alarm – a device or set of devices in the home that link to an emergency call centre through the telephone network. The devices can include for example panic buttons, pull cords, activity sensors and smoke detectors. When an alert is raised the call centre operator can call to check on the person and arrange for an emergency response if it is needed.

Continuing Healthcare – also referred to as CHC and Continuing Care in other documents – funding to meet care and support needs that are primarily required to meet an individual's healthcare needs outside a hospital. Requests for funding are assessed by individual case.

Coproduction - involves people who use services being consulted, included, and working together from the start to the end of any project that affects them.

COVID-19 – this the formal name for the disease caused by the SARS-CoV2 virus that led to the ongoing global pandemic and preventive health measures from 2020. It is also known as Covid and Coronavirus.

CTPLD – the Community Team for People with Learning Disabilities is the joint health and social care service located at a single site in Green Lane Hanwell and includes a range specialist health and social care staff for adults with learning disabilities.

Direct Payment – some people who are eligible for social care are given control over how the money is used and enabled to buy care and support services themselves.

DFG – Disabled Facilities Grant – capital funding for individuals with disabilities to have adaptations and equipment in their home.

DHSC – Department of Health and Social Care – the Government department that has main responsibility for services for people with learning disabilities. Its head is the Secretary of State for Health and Social Care who is a member of the Cabinet and reports to the Prime Minister.

DWP – Department for Work and Pensions – the Government department that has responsibility for welfare benefits and helping people to find work

Dynamic Purchase System – DPS – a cost-effective method of buying care and support services from service providers that have been vetted to join the system. The vetting includes checks on quality, past performance, and financial viability.

Dynamic Support Register – DSR – a list of people with learning disabilities and/ or autism who are in hospital or at risk of admission to hospital due to their mental health and/ or behaviours which is regularly reviewed to ensure individuals have the right support in the community.

Ealing Power Group – EPG – a group of people with learning disabilities who represent the local learning disability community at various meetings. The Council commissions Ealing Mencap to support them.

EHCP – Education, Health, and Care Plan for children with additional needs and disabilities

Equalities Analysis and Assessment – a form used by the Council to understand the impact of its policies, plans and any changes to services on different groups of people by protected characteristic. There are 9 protected characteristics include disability, race, and sex. Completion of the form helps the Council to check that it complies with the requirements of the Equalities Act 2010. Other public bodies, like the Integrated care System, use a similar form.

Exempt Accommodation Regulations – the DWP's rules for payment of enhanced rates of Housing Benefit to people who have a tenancy where support related to the accommodation is provided as a condition of the tenancy.

GLA – the Greater London Authority which is headed by the Mayor for London.

GP – General Practitioner – a medical doctor at your local community surgery

GPS – Geo Positioning System – a navigation system operated by satellite for mapping and location.

Health Action Plan – a plan that gives personalised advice to individuals with learning disabilities on how to look after their health after they have had a health check.

Health Check – anyone over the age of 14 who has a diagnosed learning disability is eligible for an annual health check at their GP surgery.

Home care – personal care provided to people with eligible health and social care needs by a paid care worker in their own home or their family home. It is regulated by the CQC.

IAPT – Improving Access to Psychological therapies for common mental illnesses.

Infection Control Grant – money that the Government gave to local councils and providers to help them to continue to provide care and support in the first two years of the COVID-19 pandemic.

Integrated Care System – ICS – regional bodies that from 2022 bring together all the health care commissioning bodies and health trusts in their region. Ealing is included in the North West London ICS.

JSNA – Joint Strategic Needs Analysis – a review of the health of the local population by the Public Health team at the Council. It is updated regularly and includes various themes such as one on learning disabilities that is due to be refreshed by March 2023.

Learning Disability Mortality Review Programme/ LeDeR – in response to the 2013 report of the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) the DHSC set up a system to review the circumstances when an individual with a learning disability dies to identify opportunities to improve care and support services and reduce the risk of premature death for others.

Learning Disability Partnership Board – LDPB – is a group of people that meets every three months to call to account services used by people with learning disabilities and to discuss issues that affect them. It includes members of the Ealing Power Group, and representatives from service providers, voluntary and community sector organisations, the NHS, and the Council. It is part of the wider local partnership structure in which it sits under the Health and Wellbeing Board.

Liberty Protection Standards – this will replace the Deprivation of Liberty Standards, the system to authorise care and support for individuals who lack the mental capacity to give their consent. We are waiting for the Government to announce when the new Standards will begin.

London Living Wage – a voluntary fair minimum wage that reflects the additional costs for workers living in London and which the Council plans to have in all its contracts for care and support services.

Nursing home – this is like a care home but with nursing care also provided as part of the service.

Ordinary Residence – rules about who is responsible for paying for a person's care when they move between different areas.

Outreach – unregulated support provided to someone who lives in their own home or with their family.

Personal Health Budget – this is like a Direct Payment and sometimes given to people who are eligible for Continuing Healthcare.

S106/ Section 106 – a legal power for councils to negotiate with developers for added benefits as a condition for granting planning permission. It can include things like new social housing and school buildings, and funding for projects to help the community.

SEND – children and young people with special educational needs and disabilities.

Settled Accommodation – this is a place someone lives that is either their family home, a home that they own, or a home where they have a tenancy agreement. It does not include care homes and nursing homes.

Short breaks – this is sometimes called 'respite', but that name is falling out of use. It is a range of services that enable a carer to have a break from their caring responsibilities. It can include short term stays in care homes, short-term 24-hour home care, and day opportunity services. **Social Value** – the Public Services Act 2012 enables councils to include a requirement in contracts for additional benefits above the main purpose of the contract. This can include, for example, apprenticeships for local young people, and measures to help the environment adapt to climate change.

STAMP – national campaign Supporting Treatment and Appropriate Medication in Paediatrics to ensure that children and young people with learning disabilities and/ or autism are not over-medicated.

STOMP – national campaign to Stop Over-Medication of People (adults) with learning disabilities and/ or autism.

Supported living – specialist housing for people with learning disabilities where they have a tenancy and are provided with care and support as a condition of the tenancy. It includes shared houses, small blocks of flats with shared facilities, and outreach support to people who have their own flat in the community. The landlord and the care and support provider should be separate organisations. When personal care is provided as part of supported living that part is regulated by the CQC.

Technology Enabled Care – includes community alarms and a range of other technology devices that help people to remain independent, take care of themselves, to learn, be entertained, and to keep in touch with others. It also includes technology equipment that helps staff to support people and for providers to manage their services effectively.

Tenancy sustainment – support, provided by social landlords to vulnerable tenants, to help people to comply with the conditions of their tenancy agreement.

Transforming Care – a government initiative to reduce admissions to and increase discharges of people with learning disabilities and autism from mental health assessment and treatment units that was part of the response to the Panorama report on abuse at Winterbourne View

Transitions – shorthand for the process for young people with learning disabilities aged 14-25 to transition from children's services to adults

Valuing People/ Valuing People Now – a government initiative from 2001, refreshed in 2009, to improve the lives of people with learning disabilities.

Appendix 2 - Background documents

Needs and statistical data.

Performance dashboard:

https://ealingperformance.inphase.com

NHS Digital:

Health and Care of People with Learning Disabilities Experimental Statistics 2020 to 2021 - NHS Digital

Workforce:

Skills for Care - Home

Local data:

Ealing Data - Health & Social Care - Map

https://data.ealing.gov.uk/health-and-social-care/#/view-report/5fc28856d17a46548e6f1b9f557fe1b5/ iaFirstFeature

PANSI and POPPI population projections for groups that may require social care services:

<u>Projecting Adult Needs and Service Information System (pansi.org.uk)</u> <u>Projecting Older People Population Information System (poppi.org.uk)</u>

JSNA, Learning Disabilities, 2016:

Learning Disabilities EalingJSNA 2016.pdf

JSNA Children 2021:

EALING JSNA Focus On CYP 2021 FINAL.pdf

Neurodiversity in the Criminal Justice System – A Review of Evidence, Criminal Justice Joint Inspection (HM Inspectorate of prisons, HM Inspectorate of Probation), 15 July 2021 – includes learning disabilities in their definition of neurodiversity:

Neurodiversity in the criminal justice system: a review of evidence (justiceinspectorates.gov.uk)

Workforce:

<u>Learning disability (skillsforcare.org.uk)</u>

Hate crime statistics collated by True Vision – their report for the year 2020-2021 includes crimes directed towards people with a disability, and trends over recent years: <u>Hate crime</u>, <u>England and Wales</u>, 2020 to 2021 - GOV.UK (report-it.org.uk)

They also have various resources for people with learning disabilities and

people who support them: <u>Disability Hate Crime - True Vision (reportion and vision</u>)

it.org.uk)

Health Inequalities: Oral Health, Public Health England, 2019:

Health inequalities Oral health.pdf

Local strategy documents

Ealing Council's Corporate Plan:

Council plan | Council plan | Ealing Council

Ealing Health and Wellbeing Strategy, 2016-21:

Health and Wellbeing Strategy | Ealing Council

Ealing Housing and Homelessness Strategies:

Housing strategy | Housing strategy | Ealing Council

The London Housing Strategy, GLA, 2018 (Policy 5.2 Meeting London's Diverse Needs, p146):

London Housing Strategy

SEND Strategy 2018-22:

<u>Ealing's strategy for SEND (Special Educational Needs and Disability) and priorities | Ealing Directory (ealingfamiliesdirectory.org.uk)</u>

Carers Strategy 2018-23:

Carers strategy | Ealing Council

Mental Health and Wellbeing Strategy 2017-22:

Ealing mental health and wellbeing strategy for adults | Ealing Council

Information about the CTPLD:

Learning disability :: West London NHS Trust

Final Report of the Ealing Race Equality Commission, January 2022:

Report - Do Something Good

National policy context

National Strategy for Autistic Children, Young People and Adults, 2021-26:

National strategy for autistic children young people and adults 2021 to 2026

National Disability Strategy 2021:

<u>Public services: National Disability Strategy explained - The Disability Unit</u> (blog.gov.uk)

Learning disability mortality reviews

National: <u>LeDeR - About LeDeR</u>

LeDeR annual report for 2021, Kings College London:

<u>Learning from Lives and Deaths - people with a learning disability and</u> autistic people (LeDeR) (kcl.ac.uk)

LeDeR annual report for 2020, Bristol University: LeDeR - About LeDeR

NW London annual LeDeR report for 2020-21: <u>Commissioning Strategy - OneDrive (sharepoint.com) permission to access?</u>

Ealing Analysis of Mortality Reviews, 2020

Also, from 2013: Reports | CIPOLD (Confidential Inquiry into Premature Deaths of People with Learning Disabilities) | University of Bristol

Building the Right Support:

NHS England » National plan – Building the right support

Transforming Care:

NHS England » Homes not hospitals

Supplementary Guidance for commissioners, 2019:

ld-serv-model-oct15.pdf (england.nhs.uk)

NHS 10-Year Plan:

NHS Long Term Plan

Stopping Over-Medication of People with Learning Disabilities and Autism (STOMP):

NHS England » Stopping over medication of people with a learning disability, autism or both (STOMP)

Supporting Treatment and Appropriate Medication in Paediatrics (STAMP): NHS England » Supporting Treatment and Appropriate Medication in Paediatrics (STAMP)

Learning Disabilities Health Check Scheme:

<u>Learning disabilities - Annual health checks - NHS (www.nhs.uk)</u> Learning Disabilities Health Check Scheme - NHS Digital

Changing Places:

Changing Places Toilets (changing-places.org)

Technology Enabled Care:

TSA - the voice of TEC (tsa-voice.org.uk)

The Real Tenancy Test 2015:

The Real Tenancy Test - NDTi

Valuing People/Valuing People Now:

<u>Improving outcomes for people with learning disabilities - GOV.UK</u> (www.gov.uk) is link working?

Learning Difficulties and Ethnicity, The Centre for Research in Primary care - Leeds University, 2012:

Learning Difficulties and Ethnicity | www.basw.co.uk

Learning Difficulties and Ethnicity – A Framework for Action, Second Edition 2011, The Foundation for People with Learning Disabilities:

<u>Learning difficulties and ethnicity: updating a framework for action | Foundation for People with Learning Disabilities</u>

The Bradley Report 2009 – the criminal justice system and people with learning disabilities:

The Bradley Report: Executive Summary (Iscft.nhs.uk)

Legal framework

People at the Heart of Care White Paper, December 2021:

<u>People at the Heart of Care: adult social care reform white paper -</u>
GOV.UK (www.gov.uk)

Green paper on SEND reforms 2022:

<u>SEND and AP green paper: responding to the consultation - GOV.UK (www.gov.uk)</u>

Health & Social Care Act 2022

The Down Syndrome Act 2021

Mental Capacity (Amendment) Act 2019

Care Act 2014

Children and Families Act 2014

Health and Social Care Act 2012

Equalities Act 2010

Mental Capacity Act 2005

Impact of COVID-19 and Recovery

Ealing Annual Public Health Report 2020-21, COVID Health Inequalities: Annual public health reports | Ealing Council

How has the Covid-19 Pandemic affected people with a disability and their carers in Ealing, Ealing Healthwatch, October 2021

Living Through Lockdown, Ealing Power Group, July 2021

The Covid-19 Pandemic Should be Last Orders for Poor Care of People with Neurodevelopmental Disorders, Andre Strydom, Elizabeth Corcoran, Anne-Sophie Rebillat, The British Journal of Psychiatry, 2021

Report by Public Health England, November 2020, on deaths of people with learning disabilities from COVID-19:

COVID-19: deaths of people with learning disabilities - GOV.UK (www.gov.uk)

Report by the ONS on the impact of COVID-19 on the wellbeing of people with disabilities:

<u>Coronavirus and the social impacts on disabled people in Great Britain - Office for National Statistics (ons.gov.uk)</u>

Coronavirus and the social impacts on Great Britain: Headline indicators by disability and clinically extremely vulnerable (CEV) status - Office for National Statistics (ons.gov.uk)

Warwick University study into the impact of COVID-19 on people with learning disabilities, March 2021:

Wave 3 Results (warwick.ac.uk)

National guidance on safe delivery of care (periodically updated): Delivering safe, face-to-face adult day care (scie.org.uk)

Final Report: National advisory group: People with Learning Disabilities and Autistic People, 2020:

Social Care Sector COVID-19 Support Taskforce: People with Learning Disabilities and Autistic People Advisory Group report and recommendations (publishing.service.gov.uk)

National research on impact of COVID-19 on disabled children:

<u>Lessons Learnt From Lockdown: The highs and lows of the pandemic's impact on disabled children and young people</u>
(<u>councilfordisabledchildren.org.uk</u>)

Report on "creating the new normal" for disabled children:
Real Support for Real Futures.pdf (councilfordisabledchildren.org.uk)

Co-production and consultation

Consultation Feedback Report for the Joint All-Age Learning Disability Strategy, Report to Ealing Learning Disability Partnership Board, 13 July 2022

Barriers to Employment, Ealing Power Group report to the Learning Disability Partnership Board, 13 April 2022

Ealing Parent and Carer Forum survey 2021 on parent carer satisfaction.

Include Me SEND Conference October 2021, reports.

Appendix 3 Equalities Analysis and Assessment

1.Proposal Summary Information

EAA Title	Ealing Joint Learning Disability Strategy	
Please describe your proposal.	Policy	
Is it HR Related?	Yes □No □	
Corporate Purpose	Officer Decision	
1. What is the Polic	y looking to achieve? Who will be affected?	
	to improve the lives of people with learning disabilities who Iraft vision statement is:	
like everyone else.	Ealing people with learning disabilities will be treated just This includes people with learning disabilities and autism. or some people if they have the right support.	
	intersectionality of disability and multiple other protected entral to this strategy.	
coproduced with the 1. Good networks,	omes have emerged from the 6 priorities that were e Ealing Power Group: information, and communication ngful life in the community safe	
Meaningful lives inc Day opportunities Accommodation Employment Social Connection	:lude:	
I — — — — — — — — — — — — — — — — — — —	trategy there will also be outcomes related to: ildren's to adult services	
	Cross-cutting themes in the strategy ne impact of Covid-19	

- 5. Workforce
- 6. Coproduction

The services affected are used by people with learning disabilities, primarily those who are eligible for additional support with their education, health, and social care.

- 1. Adults with learning disabilities may be eligible for support funded by the Council under the Care Act 2014 services provided include short breaks (respite), home care, supported living, Shared Lives, care homes, day services, and employment support.
- 2. The NHS provides a range of specialist health care services for children and adults with learning disabilities in addition to universal primary care provision. People with learning disabilities over the age of 14 are eligible for an annual health check and there is a programme of reviews of deaths of people with learning disabilities (LeDeR) to identify opportunities to improve services across the health and social care system.
- 3. The Council budgeted to spend over £31.7M to support adults with learning disabilities in 2021-22.
- 4. This strategy will complement the SEND strategy which addresses the needs of children with additional needs, including learning disabilities who are eligible under the Children and Families Act 2014 for an Education, Health, and Care Plan (EHCP), and services provided include special schools, home care and short breaks.
- 5. The strategy will build upon recent actions to improve the experience of young people with learning disabilities as they transition from children's to adults' services.
- 6. Around 30% of people with learning disabilities are autistic; this strategy will complement the Ealing Autism Plan and the requirements of the Autism Act 2009.
- 7. The strategy will promote personalisation, choice, and control.
- 2. What will the impact of your proposal be?

The strategy will provide a framework for implementation of actions to improve service delivery to people with learning disabilities and their experience of living in Ealing. It will impact on service improvement in specialist learning disability services and influence improvements in accessibility for people with learning disabilities to services for the whole community. It will impact primarily on health and social care services provided by North West London Integrated Care Partnership - Ealing Borough Based Partnership and Ealing Council. It will also impact on education, housing, leisure, community safety, criminal justice, public transport, voluntary and community sector, and other services in the Borough used by people with learning disabilities. It will impact on employers and universal service providers in the wider local economy.

There are different estimates of the number of people who will be affected:

1. Estimates by Oxford Brooks University based upon census data from the

Office of National Statistics indicate that there are about 6,000 adults with learning disabilities in Ealing - of these, about 1,300 are estimated to have moderate or severe learning disabilities and the remainder mild learning disabilities (PANSI and POPPI).

- 2.There are about 1,500 people aged 14 and over on GP Learning Disability Registers in Ealing. Just under 800 are supported by Adult Social Care 56% Black, Asian, and other minority ethnic (BAME) groups 60% male, 40% female 12% aged 65 and over.
- 3. The data about the number of children with learning disabilities is unclear because whilst for some the disability is diagnosed during pregnancy, for others a diagnosis may not be made until they are approaching adulthood.
- 4. Those who do not receive formal support directly due to their learning disability are more likely to be users of other services for people who are vulnerable
- 5. Most people with learning disabilities will rely on family carers to advocate for and to support them for much of their life. There is a cohort of people who are supported by their family with little or no intervention from statutory authorities until a crisis occurs. This includes older people with learning disabilities living with older family carers. The size of this cohort is not clear.
- 6. Covid-19 has had a disproportionate impact on people with learning disabilities. The rate of death from Covid-19 was estimated to over three times higher than the general population between March and June 2020, and higher for those of Black and South Asian ethnicities. Measures to contain the spread of Covid-19 have increased existing problems with social isolation and have led to the loss of confidence and independent living skills among people with learning disabilities. The strategy will aim to address these issues across each of the themes.
- 7. The continued promotion of personalisation, choice and control will potentially benefit people against all the protected characteristics.

Impact on Groups having a Protected Characteristic

AGE: A person of a particular age or being within an age group.

State whether the impact is positive, negative, a combination of both, or neutral: Positive

Describe the Impact

The strategy will have a positive impact across all age groups.

Children and young people

The number of children and young people with learning disabilities is unclear because whilst for some the disability is diagnosed during pregnancy, for others a diagnosis may not be made until they are approaching adulthood. They may be assessed as having additional needs without the

label of learning disability being attached to them. The difference in approach by age group reflects the different statutory frameworks for meeting the health and social care needs of children and adults. Children with severe or profound and multiple learning disabilities can be expected to have an Education Health and Care Plan (EHCP) regardless of whether their learning disability has been formally diagnosed. The consultation has identified concerns about access to diagnostic services when it is suspected that a child may have a learning disability.

This strategy will complement the Ealing SEND strategy and action plan. The four priorities of the SEND strategy are:

- 1. Support Schools and other educational settings to embed the highest expectations for children & young people/adults with SEND, reducing the variation in the quality of provision & outcomes.
- 2. Develop clear transitions and improve progression pathways through the curriculum to support better preparation for adulthood.
- 3. Improve the quality and timeliness of the statutory assessment process, co-production of EHC plans and establish a new funding model for all children and young people with SEND.
- 4. Ensure the local offer is developed further to meet current and future needs of our children and young people.

For young people (14-25), there will be plans to build upon recent improvements in the transition from children's to adults' services and ensure that they are equipped to live as independently as they are able. This is likely to include preparation for work and development of independent living skills and confidence. The consultation identified that when young people with LD reached the age of 18, they and their parents were not always informed that their case was closed to paediatric health services, and they were not consistently referred on to the equivalent service for adults

Working age adults

Out of the 778 people supported by Adult Social care with a primary care need of learning disability, 683 or 88% were aged between 18 and 64. The comparable percentage for whole adult population is 82.8%.

The age at which people with learning disabilities first need assistance with their accommodation varies. Some will need it from the age of 18 but many continue to live with parents, often until a crisis occurs that leads to family breakdown.

Younger adults (18-45) with learning disabilities have grown up in a culture shaped by the 2001 Valuing People initiative and the 2014 SEND reforms. Typically, they expect to live an ordinary life just like anyone else. The strategy is likely to benefit younger adults by including plans to enhance opportunities to take up opportunities to be independent, for paid work and

to have their own tenancy.

Adults aged 45 and over will also have felt the benefit of the Valuing People initiative but may have spent much or all their formative years living in institutional settings. For some the resulting institutionalisation has had a lifelong impact on their ability to successfully live in more independent settings and reach their full potential.

Older adults

Out of the 778 people supported by Adult Social Care with a primary care need of learning disability, 95 or 12% were aged 65 or over. The proportion of the whole adult population aged 65 and over is 17.2%. People with learning disabilities experience lower life expectancy due to the greater risks to health associated with some types of learning disability, a greater prevalence of co-morbidity with other disabilities and health conditions, historic inequalities in the treatment of learning disabilities, and the intersection with other social factors such as poverty.

People with learning disabilities are typically living longer lives than in the past due to increased opportunities to live an "ordinary life" in the community and improvements in health care. The consequence has been a significant increase in the proportion of the population of people with learning disabilities aged 40 years and over. Covid-19 infections caused an increase in the rate of mortality among people with learning disabilities across all age groups, but this is unlikely to significantly change the underlying long-term trend for life expectancy of people with learning disabilities. Austerity is another factor that may influence mortality rates over the coming years, due to the cumulative impact of increased poverty and reduced opportunities for households that include a person with learning disabilities. In 2016 a programme of mortality reviews (the LeDeR programme) of the circumstances surrounding the death of people with learning disabilities started, and the learning from these reviews has led to improvements in health care and other services that is benefiting the health of the wider community of people with learning disabilities. Also, the STOMP campaign (Stop Over-Medication of People with Learning Disabilities) is likely to have contributed to increased length of life. Therefore, for the purposes of this strategy it is wise to assume that the trend for people with learning disabilities to live a longer life will continue for the near future. It would be timely to review the local implementation and impacts of LeDeR and STOMP.

Generally, people with learning disabilities are at greater risk of age-related health conditions, typically due to the association of learning disability with other life-long conditions and/ or physical disabilities. Some types of learning disability are associated with specific age-related conditions, for example, the association between Down's Syndrome and increased risk of early onset dementia. Among the cohort of older people with learning disabilities, there will continue to be a proportion who spent a formative part of their life in a

specialist learning disability hospital prior to implementation of community care and hospital closures programmes in the 1990s; some have remained institutionalised which has inhibited their potential for more independent living.

There is an unknown number of older adults with learning disabilities who live with an elderly parent or other family carer. In these families the person with a learning disability may not have had the opportunity to develop skills and confidence for independent living. In these circumstances, when the parent is no longer able to continue in a caring capacity, there can be an increased risk of a requirement for residential care instead of more independent accommodation settings. Whilst this kind of family arrangement can be found across all ethnicities, it is more prevalent in South Asian families.

These factors, taken together, will have significant consequences on the pattern of services that will need to be commissioned. The considerations for commissioning of services include:

For some individuals care and support needs related to age may come to surpass those related to learning disability which may lead to situations when an age-related service is likely to be more appropriate than a learning disability specific service, for example nursing homes and residential care homes with a dementia specialism.

Health and other services that specialise in conditions associated with older age will need to make reasonable adjustments to meet the needs of older people with learning disabilities.

Some people will need to move from their current accommodation if it is not viable to adapt it to their changing physical needs as they age. Some older people in shared accommodation may need to move because of challenges in filling vacancies caused by the death or increased needs of the people they share with.

There is likely to be additional demand for extra care and retirement housing schemes from older people with learning disabilities.

This in turn is expected to have a positive impact for older people with learning disabilities.

Proposed actions that could be considered to improve equalities for people with learning disabilities by age

- 1. Review the provision of LD diagnosis services for children
- 2. Ensure the provision of local special schools keeps pace with changes in demand
- 3. Refresh the transitions action plan, including health
- 4. Improve understanding of the number and needs of people with LD who live with an older parent
- 5. In older people services consider the need for reasonable adjustment to

meet the anticipated growth in demand from older people with LD 6. Include the needs of people with LD in proposals to develop additional extra care housing.

Alternatives and mitigating actions which have been considered in order to reduce negative effect:

Describe the Mitigating Action

The strategy is expected to have a positive impact for people with learning disabilities of all ages, with specific actions for different age groups. Therefore, alternatives and mitigating actions have not been considered at this stage. As the actions set out in the strategy are implemented over the next five years there will be further EAAs when required that will further consider the impact by age.

DISABILITY: A person has a disability if s/he has a physical, mental or sensory impairment which has a substantial and long-term adverse effect on their ability to carry out normal day to day activities¹.

State whether the impact is positive, negative, a combination of both, or neutral:

Describe the Impact

The strategy is concerned with improving the lives of people with learning disabilities and their experience of living in Ealing. Therefore, its impact is likely to be positive for people with a disability that is a learning disability and for people with learning disabilities that have multiple disabilities. Making reasonable adjustments for people with learning disabilities is likely to benefit people with other kinds of disability and indeed the wider community.

Data on the number of people with learning disabilities in Ealing is set out in section 1.2 above of this analysis.

Data recorded in the Mosaic Adult Social Care database on conditions indicated that over three quarters of people with learning disabilities eligible for adult social care also had one or more other conditions:

Learning disability only	162	23%
LD + 1 other condition	321	45%
LD + 2 other conditions	179	25%
LD + 3 or more other conditions	50	7%

The most recorded other conditions were:

Learning/Developmental - Autism	198
Physical - Other	157

Neurological - Other	107
Mental Health Condition - Other	84
Sensory Impairment - Visually Impaired	61

A high proportion of those recorded as "Neurological – Other" are likely to be people with epilepsy. The number recorded under "Mental Health Condition – Other" does not include dementia; the number recorded as having dementia is 9. Cross referencing this with the data about ageing indicates that prevalence of dementia among people with learning disabilities is likely to increase.

The 2016 JSNA contains a range of data about learning disabilities and other conditions, and states the following about mental health:

- 1. Between 25 and 40% of people with learning disabilities also suffer from mental health problems
- 2. 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 learning disabilities. 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.
- 3. People with learning disabilities demonstrate the complete spectrum of mental health problems, with higher prevalence than found in those without learning disabilities
- 4. 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+)
- 5. 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.
- 6. Prevalence rates for schizophrenia in people with learning disabilities are approximately three times greater than for the general population (3% vs 1%)
- 7. 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
- 8. 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.

The strategy will include a range of outcomes and actions that will help to improve the lives of people with learning disabilities, including:

- 1. Provision of specialist services
- 2.Reasonable adjustment and adaptations to universal services and places to make them more accessible to people with learning disabilities
- 3. Information and communications in formats that can be easier to understand
- 4. Raising awareness about people with learning disabilities, what they are capable of, and what people need to think about when they encounter someone who may have learning disabilities.

Consultation with parents of people with learning disabilities highlighted that for some people their learning disability/ LD and autism can be an invisible disability that leads to their needs not being recognised or met. It also pointed up how reframing "special needs" as "additional needs" could help professionals and service provider organisations to create reasonable adjustment solutions for their patients/ clients/ customers with learning disabilities.

Proposed actions that could be considered to improve equalities for people with learning disabilities by disability

- 1. Enable more people with LD to take up paid employment
- 2. Require and advocate for reasonable adjustment in universal services and places used by people with LD
- 3. Provide information and communications in formats that are easier to understand, and encourage others to do so too
- 4. Raise awareness of people with LD

Alternatives and mitigating actions which have been considered in order to reduce negative effect:

Describe the Mitigating Action

The intention of the strategy is to improve the lives of people with learning disabilities who will all have the protected characteristic of disability. Therefore, alternatives and mitigating actions have not been considered at this stage. As the actions set out in the strategy are implemented over the next five years there will be further EAAs when required that will further consider the impact by disability.

GENDER REASSIGNMENT: This is the process of transitioning from one sex to another. This includes persons who consider themselves to be trans, transgender and transsexual.

State whether the impact is positive, negative, a combination of both, or neutral:

Describe the Impact

There is very little information available about gender reassignment and learning disabilities. The 2021 Census asked an optional question about

gender identity; the results have not yet been published.

Easy Read guidance about gender reassignment was published in 2019: Transgender-easy-read-guide-For-Web.pdf (choicesupport.org.uk)

Stonewall runs Rainbow Friends, a social group for LGBT Londoners with learning disabilities.

The strategy is likely to include an affirmation of the NW ICP – Ealing Borough Based Partnership and Council's approach to personalisation in health and social care services, improve access to services provided by the NHS, and proposals to improve signposting to community organisations. This is expected to have a positive impact for people with learning disabilities who are considering, are undertaking, or have completed gender reassignment.

Alternatives and mitigating actions which have been considered in order to reduce negative effect:

Describe the Mitigating Action

The strategy is expected to have a positive impact for people with learning disabilities who are considering, are undertaking, or have completed gender reassignment, and therefore alternatives and mitigating actions have not been considered at this stage. As the actions set out in the strategy are implemented over the next five years there will be further EAAs when required that will further consider the impact by gender reassignment.

RACE: A group of people defined by their colour, nationality (including citizenship), ethnic or national origins or race.

State whether the impact is positive, negative, a combination of both, or neutral:

Describe the Impact

Introduction

The strategy is being prepared following the publication of the final report of the Ealing Race Equality Commission which was set up in the context of Black Lives Matter and the murder of George Floyd. The Council has signalled its intention to implement the report's recommendations. The Covid-19 pandemic resulted in greater risk of Covid-19 related illness and death for both BAME people and people with learning disabilities, with a compounded impact for those at the intersection of being both BAME and learning disabled. This context gave rise to a renewed interest at a national level into the experience of BAME people with learning disabilities including a briefing paper by the Race Equality Foundation, more in-depth analysis of race in the annual report of the learning disability mortality programme (LeDeR), and three projects commissioned by Learning Disability England.

Local data

GLA 2020 Estimates - Ethnicity of the whole population:

Ethnicity	Number of people identifying in Ealing	Percentage of the borough of Ealing
Arab	12700	3.5
Bangladeshi	2223	0.6
Black African	17830	4.9
Black Caribbean	12362	3.4
Chinese	5254	1.5
Indian	49188	13.6
Other Asian	42813	11.8
Other Black	8275	2.3
Other Ethnic Group	11734	3.2
Other Mixed	5322	1.5
Other White	64816	17.9
Pakistani	14460	4
White & Asian	5088	1.4
White & Black African	2776	0.8
White & Black Caribbean	4370	1.2
White British	92495	25.6
White Irish	10129	2.8

In December 2021, of the 778 people with learning disabilities who had been assessed as being eligible for adult social care support their ethnicity was recorded as:

Ethnicity	Number of people	Percentage
White	335	43%
Asian or Asian British	226	29%

Black or Black British	157	20.2%
Mixed	33	4.2%
Chinese	17	2.2%
Arab	6	0.8%
Unknown	3	0.4%
Not stated	1	0.1%

Asian or Asian British – the proportion of ASC clients with learning disabilities (29%) is similar to the overall population (30%). Given higher prevalence of learning disabilities in South Asian communities across the country (see below), it might be expected that the proportion of Adult Social care client with learning disabilities of South Asian ethnicity would be higher. This may indicate issues with fair access to services for people who are South Asian and learning disabled.

Black or Black British – the proportion of Adult Social Care clients with learning disabilities (20.2%) is double that in the general population (10.6%). The higher rate of use of learning disability and mental health services is reflected in national data, (see below). This is likely to be explained by a combination of factors including inequalities and unconscious bias in maternity care, poverty, school exclusions, and criminal justice. There could be a recording issue and it would be worthwhile checking the ethnicity recorded when a social care case review is carried out.

Arab – the proportion of ASC clients with learning disabilities (0.8%) is significantly lower than for the whole population (3.5%). This might be explained by a younger age profile for Arab communities in Ealing compared with the whole population, and by relatively recent migration to the UK from Arab countries.

National data

In November 2020 Public Health England reported that the rate of deaths from Covid-19 was 3.6 times higher for people with learning disabilities than for the general population, that for those who were also Asian/ British Asian the rate was 4.5 and for those who were also Black/ Black British it was 4.4.

NHS Digital published an analysis into the use of NHS mental health, learning disability and autism services in England in May 2021 <u>Use of NHS mental health, learning disability and autism services - GOV.UK Ethnicity facts and figures (ethnicity-facts-figures.service.gov.uk)</u>. The analysis did not delve into differences between primary care needs. It found:

Black Caribbean people were most likely to use the services – people from the Chinese ethnic group were least likely.

People in the Any Other, Mixed Other and Black Other ethnic groups had the highest rates for using the services – but these rates are considered to be

overestimates because 'Other' categories may have been used for people whose specific ethnicity wasn't known

The Chinese, Indian, and Mixed White and Asian ethnic groups were the 3 ethnic groups with the lowest rate of people using the services in the 3 years to March 2020

An analysis published by Lancaster University indicated that there is increased prevalence of learning disabilities in South Asian communities (Emerson and Hatton, Institute for Health Research, Lancaster University, 2004). The higher prevalence of learning disabilities in South Asian communities has been linked to increased levels of material and social deprivation, combined with poor access to maternal health care and higher rates of environmental or genetic risk factors (Mir, G., Nocon, A., Ahmad, W., et al, Learning Difficulties and Ethnicity, Department of Health, 2001).

The Race Equality Foundation's Learning Disability Briefing Paper In June 2021 the Race Equality Foundation published a Learning Disability Briefing Paper Layout 1 (raceequalityfoundation.org.uk). Some of the key points were:

People with learning disabilities were six times more likely to die from Covid and 40 percent of these deaths were people from Black and Pakistani communities.

The available data does not give a definitive answer as to how many people with learning disabilities are from BAME communities.

According to Lancaster University's Centre for Disability Research, between 2011 and 2020, 25% of new entrants to adult social care with learning disabilities were from minority ethnic communities. However, higher rates of identification of more severe forms of intellectual disability are recorded among children of Pakistani and Bangladeshi heritage.

The intersection of race and (dis)ability, two stigmatised identities in society, results in a double discrimination experienced for BAME people with learning disabilities.

Families and professionals have shared experiences of how a lack of time and cultural understanding can lead to inappropriate care decisions around the person with learning disability, particularly around supported living.

It can be said, from the review of the literature, that what we are observing in the lives of people with learning disabilities in general and those from BAME communities in particular, is overt institutional racism and disablism in action.

It is more common for BAME families to care for people with additional needs within the family home. Therefore, BAME people with learning disabilities may be more likely to be living in overcrowded households and therefore exposed to this increased risk.

Prior to the Covid-19 pandemic, The Learning Disability Mortality Review reported the overuse of DNRs for people with learning disabilities, and 22% of these were reviewed as inappropriately completed and followed. There is a disproportionate burden of poor health on people with learning

disabilities and particularly those with learning disabilities from BAME communities.

The following questions give rise to an urgent need for us to ensure that social justice becomes part of the narrative in the lives of people with learning disabilities:

- 1. How can we better understand the needs of the local community, particularly those with learning disabilities from BAME communities? What can be done to make links to ensure that referral rates reflect the population and reasonable adjustment are made?
- 2. How can we commit, train, and plan to talk about inequalities, implicit bias, systemic institutional disablism and racism? Should this training be mandatory, regular, and underpinned by human rights?
- 3. How do we talk to people with learning disabilities about racism and provide a therapeutic space to manage these experiences?
- 4. What can be done to better understand the impact of implicit institutional racism/disablism and its impact on all our practices from strategic development, policy and practice at all levels?
- 5. What should be put in place to develop a commissioning process that listens, knows its population, plans, and measures impact, and is guided by community, equality, and inclusion? What is needed so that prevention and early intervention is at the heart of the commissioning process as well as antiracist, disablism and institutional discrimination?
- 6. How can research create understanding about this population and their experiences across health and social care settings, to further inform policy, training, and practice?

The LDE project

Learning Disability England, working in partnership with the Race Equality Foundation and commissioned by NHSE, is currently running a project due to report later in 2022, Equal Treatment: Challenging racism and health inequalities through strengthening self-advocacy and peer support Equal Treatment: Challenging racism and health inequalities through strengthening self-advocacy and peer support — Learning Disability England. The project is seeking to challenge racism to reduce mortality and health inequalities by race and ethnicity by funding three local initiatives:

- 1. Self-advocacy by minority ethnic people with learning disabilities to raise awareness and challenge racism
- 2.Training resources to enable peer support between minority ethnic family carers
- 3. Work with community organisations for or led by minority ethnic communities to help them to understand barriers faced by people with learning disabilities and their families, and support them to overcome those barriers

Some of the learning may be applicable to Ealing and consideration could be given to local replication of the initiatives.

The 2020 LeDeR Annual Report

The national 2020 LeDeR (Learning Disability Mortality Reviews) report had a specific focus on the experience of minority ethnic groups: <u>LeDeR-bristol-annual-report-2020.pdf</u> (england.nhs.uk)

The report includes detailed analysis of cause of death be ethnicity. Key points relevant to this analysis were:

- 1. The number of deaths of people from different minority ethnic groups is too small for analysis by individual ethnicities and data is therefore less robust. Fewer than 5% of adults who died were of Asian/Asian British ethnicity (3% of those who died in 2018; 3% in 2019; 4% in 2020), but this was the case for a quarter of children (26% of those who died in 2018; 22% in 2019; 25% in 2020).
- 2. People from minority ethnic groups were more likely than others to live in their own or their family home.
- 3. There was an increased likelihood of being prescribed antipsychotic medication if a person was from a Black/African/Caribbean/ Black British ethnic group (1.9 times greater than someone of white British ethnicity).
- 4. Several variables were significantly associated with the likelihood of dying aged 18-49 years:
- 5. Being of Asian/Asian British ethnicity (the likelihood was 9.2 times greater than a white British person).
- 6. Being of mixed/multiple ethnicities (3.9 times greater than someone of white British ethnicity).
- 7. Being of Black/African/Caribbean/Black British ethnicity (3.6 times greater than someone of white British ethnicity).
- 8. In 2020, the condition-specific leading cause of death in people with learning disabilities from age 35 and over for males, and age 20 and over in females was COVID-19. The cause of death as underlying conditions related to COVID19 were more frequently reported in people from minority ethnic groups.
- 9. The proportions of deaths where there were problematic aspects of care were higher in each of the minority ethnic groups than in the white British group. The biggest disparity was in relation to concerns about the death, which were raised about 24% of deaths of people from mixed/multiple ethnicities but 11% of deaths of white British people.
- 10. One of the report's recommendations was that the local JSNA should collect and publish data on the health needs of people with learning disabilities by ethnicity, and Integrated care Systems and Primary Care Networks to publish to take actions to reduce any disparities.

Consultation feedback from statutory sector employees involved in delivery or planning of services for people with learning disabilities (Ealing Council, North West London CCG and West London NHS Trust)

This element of the consultation for the strategy provided anecdotal evidence of:

- 1. A tendency among South Asian families (possibly also for some other ethnic minority families) for the adult child with LD to remain living in the family home
- 2. First generation immigrant families not having equal access to learning disability services due to different cultural understandings of learning disability, unfamiliarity with English health and social care systems, and parents being primarily focused on work that is often insecure and nonstandard working hours.
- A potential link between school exclusions and over-representation of black people in adult LD services
- 4. Gaps in the provision of Responsible Adult and Appropriate Adult services in custody suites may be linked to the over-representation of people with LD in the criminal justice system and the over-representation of Black people in LD services
- 5. A relationship between levels of poverty experienced in some ethnic groups and the use of adult social care LD services by ethnicity.

The strategy

Given the strength of the evidence and the political will, the strategy must contain various actions that will have a positive impact on the health, mortality, and wellbeing of BAME people with learning disabilities. During consultation with parents of people with LD about the strategy various concerns were raised about the availability of information about services for and processes affecting people with LD, and it was pointed out that if you do not have access to IT or English is not your first language then it can be much harder to find out what's available.

Proposed actions that could be considered to improve equalities for people with learning disabilities by race

- 1. Carry out a review based upon Learning Difficulties and Ethnicity: A Framework for Action by the Foundation for People with Learning Disabilities, 2011. Whilst in some respects it is dated, it remains the most up to date national guidance for health and social care commissioners and includes a Local Checklist that could be used to inform action planning.
- 2. Prepare a race equality action plan for LD that includes: Fair access to services.

Evaluate local provision against the Learning Difficulties and Ethnicity Local Checklist.

Consider the applicability of learning from the LDE Equal treatment project to Ealing.

The LD Health Action Group will consider health inequalities for BAME people with LD.

Review the impact of potential unconscious bias in care package decisions. Provision of information to family carers in community languages.

Review of GP LD health checks by ethnicity.

Review recording of ethnicity of people with LD.

The next LD JSNA to collect and publish data on the health needs of people with LD by ethnicity.

Alternatives and mitigating actions which have been considered in order to reduce negative effect:

Describe the Mitigating Action

The strategy is expected to have a positive impact for people with learning disabilities of all races and therefore alternatives and mitigating actions have not been considered at this stage. As the actions set out in the strategy are implemented over the next five years there will be further EAAs when required that will further consider the impact by race.

RELIGION & BELIEF: Religion means any religion. Belief includes religious and philosophical beliefs including lack of belief (for example, Atheism). Generally, a belief should affect a person's life choices or the way you live for it to be included.

State whether the impact is positive, negative, a combination of both, or neutral:

Describe the Impact

Religion	Number of people identifyin g as this religion	Percenta ge for the borough of Ealing	Number of people identifyin g as this religion in whole of London	Percenta ge for the whole of London	Number of people identifyin g as this religion in whole of England	Percenta ge for the whole of England
Buddhis t	4228	1.2	8206	1	238626	0.5
Christia n	148055	43.7	3957984	48.4	3147987 6	59.4
Hindu	28915	8.5	411291	5	806199	1.5
Jewish	1131	0.3	148602	1.8	261282	0.5
Muslim	53198	15.7	1012823	12.4	2660116	5
Sikh	26778	7.9	126134	1.5	420196	0.8
Other religion	1987	0.6	47970	0.6	227825	0.4

No	50848	15	1694372	20.7	1311423	24.7
religion					2	

Data held by Adult Social Care about religion and belief in January 2022 is:

Religion/ belief	Percentage recorded
Buddhist	0.3%
Christian	44.8%
Hindu	5.5%
Jewish	0.5%
Muslim	16.8%
Sikh	7.6%
Other religion	0.6%
No religion	1.1%
Not known/ not stated	22.8%

This data should be treated with caution as it may reflect a parent's religious belief rather than that of the person with learning disabilities. In some cases, it may be based upon a professional's assumptions about the person. Also, the proportion of not known/ not stated gives scope for misinterpretation of the other percentages.

The data raises a question about the accuracy of the number of people with learning disabilities who are recorded as Hindu. This adds richness to the data about South Asian ethnicity and supports the view that South Asian people may be under-represented in users of Adult Social care services for people with learning disabilities.

The strategy is likely to include an affirmation of the CCG and Council's approach to personalisation in social care services and signposting to community organisations. This is expected to have a positive impact by enabling people with learning disabilities to practice their religion or belief.

Alternatives and mitigating actions which have been considered in order to reduce negative effect:

Describe the Mitigating Action

The strategy is expected to have a positive impact for people with learning disabilities to practice their religion or belief and therefore alternatives and mitigating actions have not been considered at this stage. As the actions set out in the strategy are implemented over the next five years there will be further EAAs when required that will further consider the impact by religion or belief.

SEX: Someone being a man or a woman.

State whether the impact is positive, negative, a combination of both, or neutral:

Describe the Impact

GLA Estimates for Ealing 2020 Female 174,833 Male 177,976

GLA Estimates for Ealing 2030 Female 193,631 Male 202,407

In December 2021 there were 778 people with learning disabilities who had been assessed as being eligible for adult social care support out of which 310 were female and 468 were male.

The proportion of men to women with learning disabilities aged 18 and over in the UK is estimated to be 59% to 41%. For Ealing Adult Social Care, the proportions are very close at 60% and 40% respectively. This is consistent with Global prevalence rates.

For some people there will be a requirement for single sex services. This may arise due to preference and is a specific consideration in respecting choice, for example when people are placed into accommodation-based services. For some individuals, with behaviours that challenge that manifest as sexualised behaviours, there may be a need for placement in single sex services to manage their own and/or others' risks and safety. Taken together this is expected to have a positive impact for the sex of people with learning disabilities.

Alternatives and mitigating actions which have been considered in order to reduce negative effect:

Describe the Mitigating Action

The strategy is expected to have a positive impact for people with learning disabilities regardless of their sex, and therefore alternatives and mitigating actions have not been considered at this stage. As the actions set out in the strategy are implemented over the next five years there will be further EAAs when required that will further consider the impact by sex.

SEXUAL ORIENTATION: A person's sexual attraction towards his or her own sex, the opposite sex or to both sexes, covering including all LGBTQ+ groups.

State whether the impact is positive, negative, a combination of both, or neutral:

Describe the Impact

The Office of National Statistics in 2019 reported that 2.7% of people over the age of 16 in England and 3.8% in London describe themselves as lesbian, gay or bisexual (LGB), <u>Sexual orientation</u>, <u>UK - Office for National Statistics</u> (ons.gov.uk).

There is no data nationally or locally on the proportion of people with learning disabilities that are LGB. A range of research into sexuality and learning disabilities has been carried out over the last two decades, along with development of accessible sex education materials: Royal Mencap's website includes a range of useful references: Research references | Mencap Social isolation is an issue for LGB people and for people with learning disabilities, and therefore LGB people with LD are at high-risk of social isolation even in London which has one of Europe's most visible LGB communities. Stonewall runs Rainbow Friends, a social group for LGBT Londoners with learning disabilities.

The strategy is likely to include an affirmation of the Borough Based Partnership and Council's approach to personalisation in social care services, actions to reduce the risk of social isolation, and signposting to community organisations. This is expected to have a positive impact for the sexual orientation of people with learning disabilities.

Alternatives and mitigating actions which have been considered in order to reduce negative effect:

Describe the Mitigating Action

The intention of the strategy is to improve the lives of people with learning disabilities regardless of their sexual orientation. Therefore, alternatives and mitigating actions have not been considered at this stage. As the actions set out in the strategy are implemented over the next five years there will be further EAAs when required that will further consider the impact by disability.

PREGNANCY & MATERNITY: Description: Pregnancy: Being pregnant. Maternity: The period after giving birth - linked to maternity leave in the employment context. In the non-work context, protection against maternity discrimination is for 26 weeks after giving birth, including as a result of breastfeeding.

State whether the impact is positive, negative, a combination of both, or neutral:

Describe the Impact

There is a lack of comprehensive data about people with learning disabilities, and pregnancy and maternity. The number of people with learning disabilities who are pregnant or who are parents and who receive adult social care in Ealing is not known but is thought to be in single digits. Nationally, there are estimates that up to 7% of people with learning disabilities may be a parent but are mostly people with mild learning disabilities (for example with an IQ

in the range of 60 to 70) who are unlikely to be eligible for adult social care. There are many others who fall just outside the definition (IQ in the range of 70 to 85) for whom there would be benefits to them and their child from system wide reasonable adjustments.

Good practice guidance in supporting parents with learning disabilities was published by the Department of Health in 2007 and updated by Bristol University in 2016 (Microsoft Word - 2016 WTPN UPDATE OF THE GPG - finalised (bristol.ac.uk)). A person's learning disability by itself is not a barrier to good parenting. The most significant indicator of success in parenting was found in the strength of social support networks from families and communities that existed prior to pregnancy. For families with at least one parent with a learning disability the most common significant issue is poverty. The provision of learning disability awareness training to staff in maternity services and the provision of information in accessible formats is recommended.

The University of Surrey published in 2019 a range of resources on maternity services for people with learning disabilities as part of an ongoing research project, The Together Project, funded by Health Education England (<a href="The Together Project: Supporting the delivery of good practice in maternity services for parents with learning disabilities | University of Surrey |). The strategy will set out the joint vision between the Council and the CCG to improve health care services for people with learning disabilities, including the experience of using maternity services. The Community Team for People with Learning Disabilities has recently developed guidance for pregnant women with learning disabilities and those that have recently become parents, and the strategy is likely to include the next steps in the development and promotion of this good practice. Taken together this is likely to have a positive impact on pregnancy and maternity for people with learning disabilities.

Proposed actions that could be considered to improve equalities for people with learning disabilities by pregnancy and maternity

1. Implement the CTPLD's guidance on supporting pregnant women with LD and those who have recently become parents.

Alternatives and mitigating actions which have been considered in order to reduce negative effect:

Describe the Mitigating Action

The intention of the strategy is to improve the lives of people with learning disabilities during pregnancy and maternity. Therefore, alternatives and mitigating actions have not been considered at this stage. As the actions set out in the strategy are implemented over the next five years there will be further EAAs when required that will further consider the impact by pregnancy and maternity.

MARRIAGE & CIVIL PARTNERSHIP: Marriage: A union between a man and a woman. or of the same sex, which is legally recognised in the UK as a marriage

Civil partnership: Civil partners must be treated the same as married couples on a range of legal matters.

State whether the impact is positive, negative, a combination of both, or neutral:

Describe the Impact

ONS Census 2011:

Status	Numbe r of people in Ealing	Percentag e of Ealing populatio n	Numbe r of people in London	Percentag e of London populatio n	Number of people in England	Percentag e of people in England
Divorced or formerly in a same-sex civil partnership which is now legally dissolved	18356	6.8	484106	7.4	3857137	9
In a registered same-sex civil partnership	993	0.4	27425	0.4	100288	0.2
Married	11896 6	44.1	260834 5	39.8	2002936 9	46.6
Separated (but still legally married or still legally in a same- sex civil partnership)	7978	3	211500	3.2	1141196	2.7
Single (never married or never	10957 5	40.6	288894 4	44.1	1488992 8	34.6

registered a same-sex civil partnership)						
Widowed or surviving partner from a same-sex civil partnership	13704	5.1	328853	5	2971702	6.9

The Council and CCG do not collect data on the marital status of people with learning disabilities in a format that enables comparative analysis with the general population. Most people with learning disabilities on GP health registers or in receipt of adult social care are single. There is some anecdotal evidence of an increase in the number of marriages and civil partnerships between people with learning disabilities.

Over the last two decades various guidance has been published for people with learning disabilities, their families and support workers to support people with learning disabilities to have healthy adult romantic and/ or sexual relationships. For example: Relationships and Sex and Learning Disability | Mencap

There is a dating agency for people with learning disabilities based in West London that was set up in 2017 by a relative of a person with a learning disability, www.happilydating.co.uk

The strategy is likely to include an affirmation of the CCG and Council's approach to personalisation in social care services and signposting to community organisations. This is expected to have a positive impact on marriage and civil partnership for people with learning disabilities.

Proposed actions that could be considered to improve equalities for people with learning disabilities by marriage and civil partnership

1. Support people with LD to make and maintain friendships and romantic relationships

Alternatives and mitigating actions which have been considered in order to reduce negative effect:

Describe the Mitigating Action

The intention of the strategy is to improve the lives of people with learning disabilities regardless of marital status. Therefore, alternatives and mitigating actions have not been considered at this stage. As the actions set out in the

strategy are implemented over the next five years there will be further EAAs when required that will further consider the impact by marriage and civil partnership.
3. Human Rights
4a. Does your proposal impact on Human Rights as defined by the Human Rights Act 1998? Yes ⊠ No □
The effect will be to protect and promote the Human Rights of people with learning disabilities. The following Articles of the United Nations convention on Human Rights are highlighted: Article 8, Right to Respect for Private and Family Life, is relevant regarding
the provision of medical treatment and social care, dealing with families and children, and in the provision and management of housing. Article 14, Prohibition of Discrimination, is relevant especially regarding protection of people from discrimination based on disability.
In mitigation, as the specific actions in the strategy are implemented further consideration may need to be given to Human Rights impacts of some specific actions.
4b. Does your proposal impact on the rights of children as defined by the UN Convention on the Rights of the Child? Yes \square No \square
(If yes, please describe the effect and any mitigating action you have considered.) The strategy will enable the Council and the CCG to demonstrate compliance with the Convention.
4c. Does your proposal impact on the rights of persons with disabilities as defined by the UN Convention on the rights of persons with disabilities? Yes \square No \square
(If yes, please describe the effect and any mitigating action you have considered.) The strategy will enable the Council and the CCG to demonstrate compliance with the Convention.

4. Conclusion

- 1. Generally, the strategy is intended to have a positive impact for people with disabilities, specifically learning disabilities
- 2. The strategy will support implementation of the recommendations of the Ealing Race Equality Commission
- 3. The data on mortality rates for people with learning disabilities, including

related to Covid-19, indicates that attention needs to be paid to reducing health inequalities for Black and South Asian people with learning disabilities.

- 4. Improvements in the collection of data about equalities characteristics would help with decision making in the future
- 5. As the strategy is implemented over the next five years this could lead to changes to some commissioned services for people with learning disabilities and there may be a requirement for further equalities analyses and assessments the data collected for the strategy will be helpful for this
- 4a. What evidence, data sources and intelligence did you use to assess the potential impact/effect of your proposal? Please note the systems/processes you used to collect the data that has helped inform your proposal. Please list the file paths and/or relevant web links to the information you have described.

(Please list all sources here: i.e., local consultation, residents' survey, census etc.)

Evidence cited includes analysis of data held in the Council's Mosaic social care database.

Other evidence was sourced from the following:

- GLA population projections 2020, <u>Ealing Population UTLA GLA | Ealing |</u>
 InstantAtlas Reports
- 2. JSNA, Learning Disabilities, 2016, Learning Disabilities EalingJSNA 2016.pdf
- 3. Learning Disability Death Reviews (LeDeR) programme, Bristol University 2020, LeDeR-bristol-annual-report-2020.pdf (england.nhs.uk)
- 4. NHS Digital, <u>Use of NHS mental health, learning disability and autism</u> <u>services GOV.UK Ethnicity facts and figures (ethnicity-facts-figures.service.gov.uk)</u>, <u>Health and Care of People with Learning Disabilities</u> Experimental Statistics 2020 to 2021 NHS Digital
- 5. Office of National Statistics, <u>Sexual orientation, UK Office for National Statistics (ons.gov.uk)</u>
- 6. PANSI and POPPI population projections, Institute for Public Care at Oxford Brooks University, Projecting Older People Population Information System (poppi.org.uk)
- 7. Public Health England, November 2020, report on deaths of people with LD from Covid-19, COVID-19: deaths of people with learning disabilities GOV.UK (www.gov.uk)
- 8.Race Equality Foundation, Learning Disability Briefing paper, <u>Layout 1</u> (raceequalityfoundation.org.uk)
- 5. **Action Planning**: (What are the next steps for the proposal please list i.e., when it comes into effect, when mitigating actions linked to the protected characteristics above will take place, how you will measure impact etc.)

Action	Outcomes	Success	Timescales/	Lead Officer
		Measures	Milestones	(Contact

				Details)
Work with the Learning Disability Partnership Board to develop detailed action plans for each of the strategic priorities with each plan considering opportunities to enhance equalities		Will be defined		Commissioner
Conduct further EAAs when significant changes are proposed to services used by people with LD	Will be defined	Will be defined	Will be defined	LD Joint Commissioner

Additional Comments: None

6. Sign off: (All EAA's must be signed off once completed)

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Completing Officer Sign Off:	Service Director Sign Off:	HR related proposal (Signed off by directorate HR officer)			
Signed: Name (Block Capitals): Date:	Signed: Name (Block Capitals): Date:	Signed: Name (Block Capitals): Date:			
For EAA's relating to Cabinet decisions: received by Committee Section for publication by (date):					