



**HARROW JOINT COMMISSIONING STRATEGY
FOR PEOPLE WITH LEARNING DISABILITIES &
PEOPLE WITH AUTISTIC SPECTRUM
CONDITIONS**

2015 - 2020

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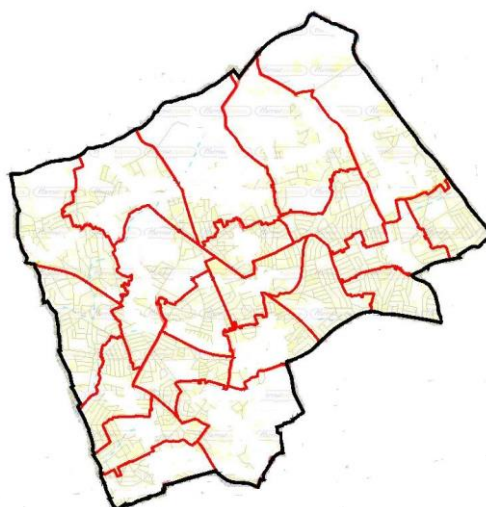
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Learning Disabilities
Local CQUINN (2016-1

Preface – Harrow’s Strategy

The aim of this strategy is that Harrow residents with learning disabilities, autistic spectrum conditions and challenging needs receive high quality health and social care throughout the whole course of their life.



This strategy will encompass a ‘whole life’ or ‘life course’ approach to supporting and commissioning services for children, young people and adults with Learning Disabilities, autistic spectrum conditions or challenging behaviour needs in the London Borough of Harrow.

A ‘life course’ approach encompasses all age groups from pregnancy and birth through childhood, adulthood and older adulthood. Many of these people have contact with services and providers from an early age and through this strategy we seek to promote positive outcomes for health and independence at all stages. This approach entails commissioning and planning services that ensure the following:

- Seeing the person 'in the whole' - a commitment to building services around the person and their life, meaning that success is not judged in terms of outcomes of a particular service - but seeing impact on 'whole lives'
- Services work better together – holistically for the person and their community, but also to ensure the intent and impact of children's and adults services are aligned at a policy and operational levels
- Equitable allocations of resource where needed, not linked to categories of need or diagnosis
- Services that draw on individual and community resources and invest in and strengthen these resources available locally in Harrow.
- Services that promote connectivity between individuals - and not separation/isolation - supporting the creation of stronger communities that will in turn support individuals.

This strategy is informed, amongst others, by the following statutory guidance and local strategic plans:

- The Care Act 2014 sets out five statutory duties for the delivery of services for vulnerable groups, with a focus on prevention, development of facilities or resources to prevent delay in service provision, focus on community engagement and co-production
- Autism Act 2009, ‘Think Autism’ and associated guidance which sets out five key objectives in delivering services for people with autism.
- The Transforming Care Plan (TCP) with actions to change the way services are provided for people with learning disabilities and or autism and challenging behaviour
- The children and families Act 2014 and associated SEN reforms sets out a number of changes in the system for children and young people with disabilities to ensure the

best outcomes including a focus on co-production and joint working with families and the third sector on Education, Health and Care Plans.

- Harrow's Strategic Plan which includes a wide vision for a whole systems integrated care to improving the quality of Health and Social Care for individuals, carers and families
- Joint Health and Wellbeing Strategy for Harrow 2016-20
- Harrow SEND Strategy 2015-2020
- Harrow Children and Families Strategic Plan 2013-18
- Pan London and Harrow Safeguarding Children and adults strategies - Working together to safeguard children and adults is paramount. Harrow has well developed systems in place that seek to prevent abuse and neglect and stop it quickly when it happens as well as Safeguarding Adults and children Boards, which carry out review when someone with care and support needs dies as a result of neglect or abuse and independent advocates to represent and support a person who is the subject of a safeguarding enquiry or review if required.

This commissioning plan is based on analysis of current resource, performance and service mapping information, needs assessments including Harrow's Joint Strategic Needs Assessment (JSNA), consultation with carers and service users partners and stakeholders.

It is well known that outcomes experienced by people with learning disabilities and or autism tend to be poorer than in the general population. Many people with learning disabilities and or autism also have complex health needs and often suffer from potentially preventable conditions which are often left untreated due to barriers accessing services in a timely and effective way and insufficient support to enable lifestyle change. The average age of death of someone with a moderate learning disability and or autism is 20 years less than the general population.

Harrow Council and Harrow Clinical Commissioning Group (CCG), as nationally, face serious financial challenges now and in the next five years and focusing limited resources to achieve value for money and maximise benefits for the most vulnerable groups and their families is challenging. Therefore we believe that working jointly with partner agencies using a whole system approach will be the critical success factor in achieving the outcomes in our strategic plan.

We look forward to working together to ensure our commissioning plans lead to improvements in service delivery and quality of life for Harrow service users their carers and families.

Section 1 - Introduction and background

This strategy for Harrow residents with learning disabilities, autism or challenging behaviour has been produced jointly by service users, carers, Harrow Council and Harrow Clinical Commissioning Group and voluntary sector organisations.

This 'whole life' or 'life course' strategy represents considerable progress in the planning and commissioning of services where joint working arrangements already work well in practice. This will be further enhanced through the joint action plan that will be developed from this strategy and shared commitments to commissioning high quality services for people in all age groups.

It is important that even though there is an overlap in the population, the needs of people with autistic spectrum conditions or learning disabilities should not be assumed to be the same. There is a wide range of needs and issues that relate to each condition.

The aim of this strategy is that Harrow residents with learning disabilities, autism and challenging needs receive high quality health, education and social care throughout the whole course of their life.

1.1. Objectives

The strategy is intended to support partnership working to achieve the following objectives:

- Set out the strategic direction of NHS Harrow CCG and the London Borough of Harrow for children, young people and adults with a learning disability, autism and people with behaviour that challenges.
- Build on existing good practice and continue to improve health, education and social care outcomes.
- Work with people using services, carers and families to ensure a more positive experience of care.
- Ensure health and social care services are commissioned appropriately within available resources
- Improve access to a greater range of support that is responsive to the individual needs and achieve the best outcomes.
- Ensure there are pathways to adulthood that build on foundations of education to help people to be independent and part of their community.
- Develop pathways into paid and voluntary employment opportunities to maximise young people's independence wherever possible.
- Ensure that the safety and wellbeing of children, young people and adults with learning disabilities, autism and challenging needs are protected.

1.2. Key Priorities

Four key priorities have been identified:

1. Ensure easier access to assessment, diagnosis and ongoing support for children, young people and adults with learning disabilities and/or autism and their carers.
2. Services are co-produced and meet local needs
3. Services commissioned will promote personalisation, independence and choice

4. Ensuring a seamless transition for young people moving in to adulthood and for older people.

1.3. What is a Learning Disability?

A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. People with learning disabilities have significant and widespread difficulty in learning and understanding. They will have had this difficulty since childhood.¹

Learning disability diagnosis tends to be on 4 main levels;

- Mild - A person who is said to have a mild learning disability is usually able to hold a conversation, and communicate most of their needs and wishes
- Moderate - People with a moderate learning disability are likely to have some language skills that mean they can communicate about their day to day needs and wishes.
- Severe - People with a severe learning disability often use basic words and gestures to communicate their needs. Many need a high level of support with everyday activities such as cooking, budgeting, cleaning and shopping, but many can look after some if not all of their own personal care needs
- Profound- People with profound intellectual and multiple disabilities, or profound and multiple learning disabilities (PMLD) which means that their intelligence quotient (IQ) is estimated to be under 20 and therefore they have severely limited understanding. Some people with profound learning disabilities (LD) may have additional impairments which can include impairments of vision, hearing and movement as well as other challenges such as epilepsy and autism

The term 'learning disabilities' is different to specific learning difficulties such as dyslexia, specific social/communication difficulties such as Asperger's syndrome or significant and widespread difficulty in learning and understanding that are acquired in later life.²

1.4. What is Autism?

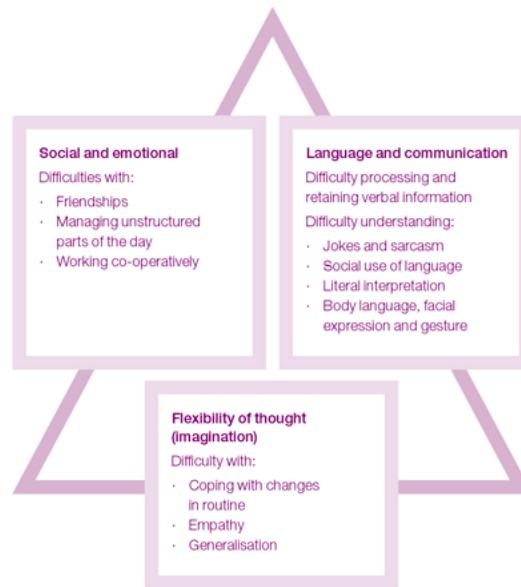
Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.³

¹ Mencap website <https://www.mencap.org.uk/definition>

² What Councils Need to Know about People with Learning Disabilities, A Local Government Knowledge Navigator Evidence Review - Review Number One, Dr Paula Black, January 2014

³ National Autistic Society website <http://www.autism.org.uk/about/what-is/asd.aspx>

The Autism 'Triad of Impairments'



Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

1.5. Why we need a strategy

There are both national and local drivers that underpin the requirements for a Strategy. Nationally there is a long history of policy reviews highlighting poor care for people with learning disabilities and autism. In some cases abuse has also been uncovered. This has both influenced, but also reflected the prevailing views on what is the best and most efficient means of providing care. The most recent reviews cover policy in: Special Educational Needs (SEN), health and premature deaths; social care; the Winterbourne View cases. The context for the implementation of these is also shaped by the local implementation of the government's vision for health and care transformation in Harrow and other local authority developments. Further details of national and local policy context are detailed below:

Valuing People Now 2009

This national strategy for people with learning disabilities reaffirms the four guiding principles set out in the original Valuing People Strategy (2001):

- Rights – people with learning disability and their families have the same human rights as everyone else.
- Independent Living – people should have greater choice and control over the support they need to live their daily lives and greater access to housing, education, employment, leisure and transport opportunities.
- Control – people should be involved in and in control of decisions made about life.
- Inclusion – people should be able to participate in the community.

Autism Act 2009

The Autism Act 2009 sets out the direction of national strategy. 'Think Autism' is an update to the 2010 adult autism strategy and reaffirms the importance of the five areas for action identified in the strategy:

- Increasing awareness and understanding of autism

- Developing clear, consistent pathways for the diagnosis of autism
- Improving access for adults with autism to services and support
- Helping adults with autism in to work
- Enabling local partners to develop relevant services

In particular, 'Think Autism' has a new focus on:

- Building communities that are more aware of and accessible to the needs of people with autism, on promotion innovative local ideas, services or projects that can help people in their communities
- How advice and information on services can be joined up better for people

'Think Autism' can be found at <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

Winterbourne View Concordat

As a response to the 2013 review of the Winterbourne View care home the Department of Health (DH) issued the 'Winterbourne View Concordat': a nationally agreed programme of action addressing imminent changes in provision of services for people with a learning disability and mental health issues: The Department of Health issued a set of actions to improve services in the document – *Transforming Care: A national response to Winterbourne View Hospital*. The key expectations of *the Concordat*

- The person and their family must be at the centre of all support across health and social care: this support must be individualised; person centred; and designed around them with their full involvement;
- Intensive community services should be designed and commissioned to prevent in-patient admission and support people to stay in their own home in their own locality;
- When someone needs to be in hospital for a short period, this should be in small inpatient settings as near to their home as possible.
- Focus on development of early intervention services
- Better use should be made of existing Mental Health services with the right reasonable adjustments;
- Shifting settings of care to ensure the majority of people are supported in their own home.

Transforming Care Plan

The vision of the North West London (NWL) Transforming Care Partnership for improving the care and support available for the people of North West London with a learning disability and/or autism who also have, or are at risk of developing, a mental health condition or behaviours described as challenging. This is an all ages plan to address the needs of people with a learning disability, people with autism (including those with Asperger's syndrome) who do not also have a learning disability, and people with a learning disability and/or autism whose behaviour can lead to contact with the criminal justice system.

This plan provides a shared picture of:

- The North West London area
- The services currently commissioned and provided across our area
- Our shared vision for how future services will be commissioned and provided
- What we need to change to achieve our vision and how we intend to do this

Across North West London, there is agreement to continue to collaborate on knowledge sharing and working towards the same strategic vision rather than having a preconceived set solution in place to deliver care.

This plan contains a broad over-arching vision, developed through extensive discussion with the learning disability, disability, children's and mental health commissioning leads, housing teams, and finance colleagues in Clinical Commissioning Groups (CCGs) and Local Authorities across the 8 North West London boroughs. This builds on work at a local level to understand the views of service users and their families/carers.

The vision is realised through developing pathways and services that:

- Are community based where appropriate, with a reduced reliance on inpatient facilities;
- Have staff with the right skills and experience to manage complex cases, including managing the complexity of competing demands across health and social care;
- Provide respite for families and carers to maintain, wherever possible, at home placements and strong family relationships;
- House people with a learning disability and/or autism locally wherever possible and appropriate;
- Meet the needs of people of all ages – not defining support by age but instead responding to care and support needs and reducing the differences in services for children, young people and adults.

The plan supports all ages and follows the life course. As such, it does not put emphasis on the differences between children and young people, adults, and older adults. Instead it describes services, systems, and pathways that meet the needs of all people, regardless of age.

These services and pathways will help to achieve:

- Timely access to assessment and treatment for learning disability and/or autism;
- Reduced numbers of admissions to hospitals (both secure and non-secure), and shorter stays when admitted;
- Improved health and educational outcomes;
- Improved quality of life;
- Improved experience of services.

The North West London plan builds on the progress already made in each of the boroughs; it brings together best practice and shared learning and where it makes sense brings together resources, capabilities and expertise to develop collaborative solutions. Where there are differences and local nuances, these are outlined in each borough's local annex (attached to this plan). However, across North West London we are aligned on our plans to commission:

- **Community support**, including the utilisation of more skilled staff to manage more complex/challenging behaviour. This may involve moving or outreaching staff from inpatient facilities into community services, and vice versa, to share learning.
- **Crisis care**, available 24 hours a day, 7 days a week that ensures that people with a learning disability and/or autism who display behaviour that challenges, and their families and carers, receive care and support that meets their needs in times of crisis, including when this crisis occurs outside of standard working hours.
- An **all ages offer** that responds to the care and support needs of people regardless of their age and reduces the differences between services for children, young people and adults.
- A North West London level **service for people with a forensic history** or Asperger's to provide the specialised psychological support required and manage the smaller number of cases over a larger geographical area;

- Education and support to encourage the use of **education, health and care (EHC)** plans and **personal budgets**, working with parents, carers, and people with a learning disability and/or autism who display behaviours that challenge to develop guidance and support to use these budgets to personalise and self-manage their care.
- **Co-ordinated care** across the health, social care and housing pathways, ensuring that primary care clinicians, teachers, social care and housing staff are involved in early identification and signposting, and all partners are engaged in on-going care and support.

Children and Families Act 2014 (including Special Educational Needs Reforms)

Since September 2014, the Act has underpinned changes to the system for children and young people with special educational needs and disabilities so that services consistently support the best outcomes for them. Changes include:

- Local authorities have a duty to set out clear and searchable information on services available to parents and carers, children and young people
- Education, Health and Care Plans (EHCP) for children and young people with special educational needs from birth to age 25: Replace Statements of Special Educational Needs, and Learning Difficulty Assessments for post 16 education
- Places a requirement on local authorities and health services to jointly commission services for young people and families with SEND
- The need to involve children, young people, parents and carers at the heart of the process in a more person centred way
- Work with partner agencies and organisations to ensure that plans are in place to support young people to have a good transition and plan for future opportunities that will result in more choices for people enabling them to live a full life.

SEND Strategy 2015-2020

In addition, to the SEND reforms, the government is also changing the funding for special education and locally Harrow has increasing pressure on places for pupils with special educational needs. A Special Educational Need and Disability (SEND) Strategy was developed by a representative group of headteachers and officers to focus on key strategic priorities and agreed by Cabinet in April 2015. Cabinet received an up-date report in July 2016 that highlighted progress and wider developments and agreed 4 strategic priorities focussing on:

- Sufficiency and appropriate in-borough school places across early years to post 16 provision
- A continuum of provision and support for children, young people and young adults with social, behaviour and mental health
- Improving local education and social care opportunities for post-16 provision working in partnership with other agencies
- Improving outcomes for children and young people (0-25) with SEND and ensure appropriate staff skilled and qualified in all provision.

The Care Act 2014

The Care Act sets out the following service provision duties for local authorities:

- To provide or arrange for the provision of services, facilities or resources that contribute towards preventing or delaying the development of care and support needs.
- To increase early intervention services by providing information, advocates, guidance and signposting on to alternative services, support, groups who might help.
- To ensure that people's wellbeing is promoted with more about prevention and health promotion
- A focus on engagement of people and communities through co-production
- To work together with partner agencies to improve people's health and wellbeing

The Care Act strengthens the areas identified for action in 'Think Autism' for people with autism, Valuing People Now for people with learning disabilities and the Winterbourne Concordat.

In addition, revisions in the latest Mental Health Act Code of Practice broaden the remit with specific reference to certain groups, including children and young people, people with learning disabilities and / or autism.

Section 2 - People with Learning Disabilities

National picture

This section considers the health and social care needs of people with learning disabilities in Harrow. The national picture of the needs of people with learning disabilities has shown key factors which affect their health and wellbeing. Studies undertaken by the Local Government Knowledge Navigator 2013 outline the following prevalence of people with learning disabilities in England;

- In 2011 approximately 20 people in every thousand had a learning disability.
- Of these people, 4.6/1000 are likely to be known to health and care services and 3.6/1000 are likely to receive social care.
- An estimated 286,000 children and young people under the age of 18 (180,000 boys, 106,000 girls) had learning disabilities while an estimated 905,000 adults (530,000 men, 375,000 women) had learning disabilities of whom only 189,000 (21%) were known to learning disability services.
- Over 70,000 children in England have a Statement of Special Educational Needs (SEN) and a primary SEN associated with learning disabilities. Of these, just over half have a moderate learning disability; one third have a severe learning disability and just over one in ten have a profound multiple learning disabilities.

Ethnicity

Studies have shown that a higher rate of white British pupils tend to present with various forms of learning difficulties than any other ethnicity, followed by pupils of Asian origin. However, Pakistani pupils tend to present with high rates of learning disability classed as severe.

Gender

The National SEN data collated by the Department for Education (DfE) indicate that there is a higher percentage of girls compare to boys in groups of pupils with a Moderate, Severe and Profound & Multiple Learning Disabilities. Boys tend to present with behavioural, emotional and social difficulties 17.3% compared to 6.2% in girls.

Physical health

People with learning disabilities continue to have high levels of physical ill health, shorter life expectancy and increased risk of early death when compared to the general population.

- Those with less severe learning disabilities and limited access to services are more likely to be exposed to common 'social determinants' of health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination
- People with learning disabilities are 2.5 times more likely to have health problems than the rest of the population. Co-existing conditions may include mental illness, epilepsy, challenging behaviours, and sensory disabilities.⁴
- The leading cause of death recorded is respiratory disease followed by cardiovascular disease related to congenital heart disease.
- Four times as many people with learning disabilities die of preventable causes as people in the general population

⁴ Health Needs Assessment of Learning Disability in Harrow, Dr Anandhi Nagaraj (NHS Harrow), July 2009

Risk factors

- Social deprivation and limited maternal education are strongly associated with mild to moderate degrees of learning disability.
- Low birth-weight and premature birth are associated with learning disability.
- Children with learning difficulties have a higher risk of having learning disabilities - 36%, compared to 8% among children without learning difficulties.
- Children with learning disabilities account for 14% of all British children with a diagnosable psychiatric disorder who often require specialist interventions.

Local picture in Harrow

Early years (0-4 years)

In Harrow and generally there is limited data for analysis and understanding of early years learning disabilities and or autism, their needs or gaps in service provision. National studies have shown that there tends to be difficulties determining whether or not a child under the age of 4 with delays in development has a learning disability, therefore the term global development is often used during the early stages of a child's life.

School children and young people

Emerson at al⁵ calculated prevalence in children and young people with learning disabilities for different age groups as follows:

- 5 to 9 years: 0.97%
- 10 to 14 years: 2.26%
- 15 to 19 years: 2.67%

The table below indicate the numbers of children with learning disabilities might be expected in Harrow when Emerson's prevalence rates are applied. The rates for different age groups reflect the perception that as children get older, more are identified as having a learning disability.

Estimated number of children with a learning disability in Harrow in 2012

	Children with a learning disability		
	aged 5-9	aged 10-14	aged 15-19
Harrow	145	325	410

Source: Office for National Statistics mid-year population estimates for 2012

Harrow's schools have experienced a growth in demand for children with special educational needs requiring support in an additionally resourced mainstream school or special school place. The number of statements, now ECHPs has increased since 2007 continues to rise. The percentage of the school population has remained fairly stable at 2.6%. The increase in ECHPs for post-16 is an area of increase under the SEND reforms. To meet this demand locally 151 additional places for pupils with SEN have been opened in Harrow schools. This includes the expansion of three special schools. There is further projected unmet demand and the need for an additional 120 place special school, for children with severe and complex needs with autism has been identified. Opportunities to increase provision for young children in early years provision are also being explored.

Children with learning disabilities and other health conditions

⁵ Harrow Learning Disabilities Needs Assessment, 2014

People with learning disabilities are more likely to experience mental health problems.⁶ The Foundation for People with Learning Disabilities (2002) estimates an upper estimate of 40% prevalence for mental health problems associated with learning disability, with higher rates for those with severe learning disabilities.

The table below shows the estimated prevalence of children with learning disabilities who also experience a mental health disorder by age group and sex in Harrow.

	Estimated number of children with LD & a mental health disorder								
	<u>Aged</u> <u>5-10</u>	<u>Aged</u> <u>11-16</u>	<u>Aged</u> <u>5-16</u>	<u>Boys</u> <u>aged</u> <u>5-10</u>	<u>Boys</u> <u>aged</u> <u>11-16</u>	<u>Boys</u> <u>aged</u> <u>5-16</u>	<u>Girls</u> <u>aged</u> <u>5-10</u>	<u>Girls</u> <u>aged</u> <u>11-16</u>	<u>Girls</u> <u>aged</u> <u>5-16</u>
Harrow	1,350	2,050	3,400	920	1,180	2,100	440	865	1,305

Source: Harrow Joint Strategic Needs Assessment 2015

Data show that in Harrow over the five years to 2009 the average number for hospital admissions for people with learning disabilities was around 40 per year. Reasons for admissions included

- fractures of neck of femur,
- wounds,
- epilepsy,
- bronchial asthma,
- inflammatory lung diseases
- urinary tract infections
- skin inflammation,
- neoplasm,
- gastrointestinal diseases,
- difficulties in swallowing and volume depletion

Many children and young people with learning disabilities may also have autism as well as developmental disorders including;

- hyperactivity
- co-ordination disorders
- speech and language disorders
- epilepsy

We know that a good preventative measure to reduce hospital admissions is to ensure that children and young people with learning disabilities have a health passport and regular health checks.

⁶ Harrow Learning Disabilities Needs Assessment, 2014

Transition planning for young people

There are key transitions periods which require planning and support for young people's futures which include post-compulsory education and/or training; employment; independent life (including housing, finances, social life).

National studies have found historic weaknesses in transition arrangements for young people with special education needs, disability and Learning Difficulties and or disabilities which often result in young people being systematically unprepared for adult life. Studies also show that life chances for children and young people with SEND are disproportionately poor with a higher incidence of mental health needs, offending behaviour, and higher levels of financial deprivation when compared to the general population.

Young people with learning disabilities transitioning to adult services trend

Year	Number of young people in transition (18 years old)
2011-12	27
2012-13	32
2013-14	Figs not available
2014-15	35
2015-16	50 est. include dual diagnosis of LD and autism. At least 20 of the 50 will have complex care needs

Children and families data/adult social care transition team figures

The figures above suggest year on year increase in the numbers of young people transitioning to adult social care in Harrow and crucially an increase in the numbers requiring high level interventions. Early interventions and planning must be a focus.

During Harrow Council's wider corporate restructure and the formation of the new People Services Directorate, it was recognised that there was an opportunity to improve service delivery for children and adults with disabilities. In particular to provide a joined up, integrated specialist service or model for all children and young people with disabilities.

The model is underpinned by the Children & Families Act 2014. This led to the implementation of Education, Health and Care plans (also known as EHC plans) to ensure seamless pathways for young people as part of the Special Educational Needs and Disability reforms (SEND). The Care Act 2014 also promotes a 'no gap' transition between children's and adults services.

To achieve this, People Services Directorate has a newly formed children and Young Adults Disabilities Services (CYAD) since April 2016, for people aged between 0 to 25. The adoption of this lifelong disabilities pathway is considered nationally as best practice. It offers a responsive, 'no-gap' transition between childhood and adulthood and fosters early intervention support for Harrow's most disabled children and young adults.

The aims of the new service are to;

- Deliver better outcomes through commissioning clear pathway of support across children and adult services
- Focus on supporting young people to be as independent as possible
- Accommodate young people in borough so that they remain close to their families and local networks

- Provide early intervention across health and social care to reduce long term dependency on services
- Better manage the cost pressures arising from the growing number of younger people with learning disabilities, autism and those who challenge services.

Adults aged 18 and over

National predictions of the number of people with a learning disability as at year 2020 are:

- 2.02% of 65-69 year olds
- 2.33% of 70-74 year olds
- 2.08% of 75-79 year olds
- 1.93% of people aged 80 and over

Projected demand in Harrow

- A total of **3,782** people aged 18+ have a learning disability in 2014 and this number is expected to increase by 176 in 2020.
- The population of people with mild learning disability will increase by over **30 per year**.

Projected Population age 18 -64

2014	2015	2020	2025	2030
3782	3816	3958	4080	4208

- There will be **additional 8 to 10 cases** of moderate to severe learning disability per year
- At least **20 transition cases** per year will have complex care needs

Projected population age 65+

Learning disability estimates and projections 65+ for Harrow	2014	2015	2020	2025	2030
People aged 65 -74 predicted to have a learning disability	409	415	470	512	571
People aged 75 - 84 predicted to have a learning disability	248	252	271	318	360
People aged 85 and over, predicted to have a learning disability	95	99	121	146	17

The highest increase will be in the 65-74 years age group.

Around 1 in 9 adults with a learning disability is likely to have a moderate or severe disability, around 970. This is predicted to increase by 14% to around 1,110 therefore most likely to be in receipt of services⁷. This group is most likely to be in receipt of health and social care services.

It is estimated that approximately 75 people aged 18-64 with a learning disability are predicted to display challenging behaviour.

Number of Adults in Harrow with a Learning disability known to GPs

Period	Number of Adults	Harrow	London	England Average
2010-11	736	3.92	3.19	4.33

⁷ POPPI and PANSI data

2011-12	760	4.35	3.36	4.54
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Source: QOF Age specific prevalence 2010-11

The figures above, whilst underreporting compared with projections, suggest year on year increase in the number of adults known to GPs / on GP registers by 2020, an estimated total of 952.

The increase in demand is due to:

- Growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood
- A sharp rise in the reported numbers of school age children with autistic spectrum disorders, some of whom will have learning disabilities
- Increases in the life expectancy of people with disabilities – many more living into older age due to improvements in healthcare

It must be noted that not all people will be known to or indeed require support from adult social care or NHS services.

2.1. Current service provision

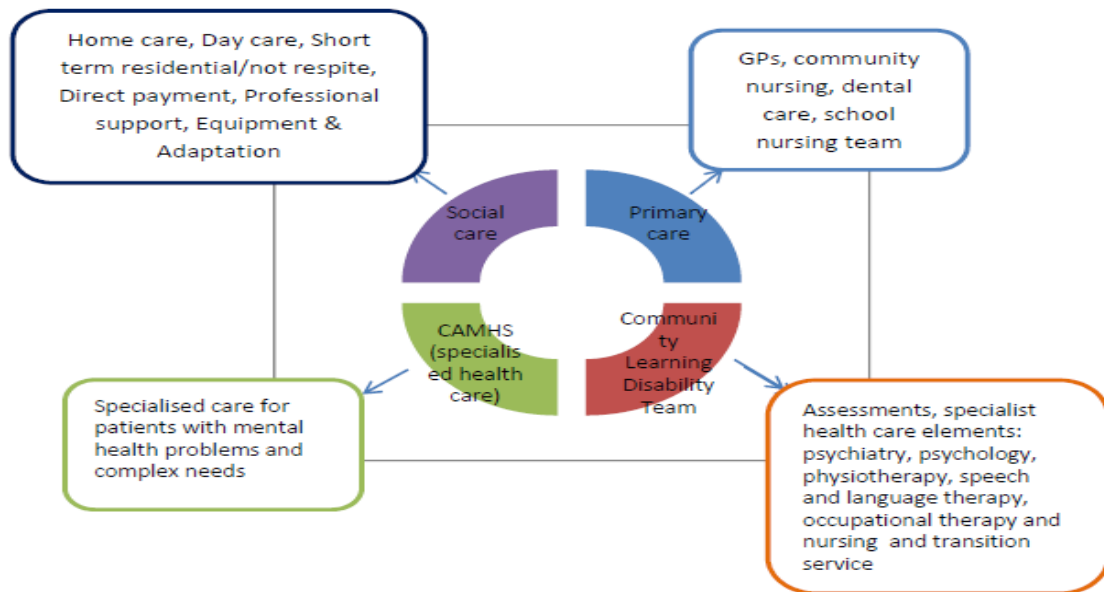
Harrow learning disabilities service and other social care and health services support people with learning disabilities into a range of services including social work, care brokerage, continuing health care, nursing and residential care home placements, supported accommodation, day services and specialist health care.

People with complex and severe learning disabilities will require specialist support to meet their health and/or social care needs.

Support may consist of accommodation based services for specialist nursing, residential and supported placements, assessment and treatment beds, and specialist in-patient or day patient services.

Cases are assessed by local care-co-ordinators and/or Social Workers and presented to complex care panels held individually or jointly with the CCG and Local Authority. All cases to specialist providers are reviewed on a case by case basis to ensure services meet the individual's needs.

Harrow Service Delivery Model for Health and Social Care



Health, education and social care services for children and young people

There are a wide range of specialist health and social care services available for children and young people with special educational needs and disabilities in Harrow. These services have been commissioned by Harrow Council and Harrow Clinical Commissioning Group to support people to stay healthy and live as independently as possible. More information can be found at <http://www.harrow.gov.uk/localoffer/info/2/health>

The North West London Hospitals (NWLH) Child Health Team is an integrated team of health professionals including: Consultant Paediatricians and medical staff, Community Children's Nursing team; Occupational therapists, Physiotherapists, Speech & Language Therapists and Dieticians

The Dual Diagnosis Team provides mental health service to patients in a general medical hospital, inpatients, outpatients & attenders at the A&E Department. The team assess patients exhibiting psychiatric or behavioural symptoms and those with learning disability.

Community Dental Service - provide community dental care specialist dental care for children under 5 with special needs and act as assessment for referrals to secondary care. The service is for children and adults with special needs including those with learning disabilities and autism.

School nurses - provide public health functions to local schools (56), including four special schools for children with a disability: Woodlands School, Kingsley High School, Alexandra School and Shaftesbury High School.

Harrow Child and Adolescent Mental Health Service accept children with moderate to severe learning disabilities, with challenging behaviour or with psychiatric co-morbidities such as severe depression. Referrals are accepted from GPs, Health Visitors, School Nurses and Community LD team

Where ever possible pupils with special educational needs attend local schools and there are four special schools in Harrow making provision for pupils with moderate and severe

and complex needs. Three of the four schools have been increased in size to accommodate increasing numbers of pupils. Some pupils attend out-borough day and residential provision where their needs cannot be met within Harrow.

Health and Social Care Services for Adults

Enhanced support from GPs

GPs in Harrow undertake the following services as part of an enhanced service agreement

- Attend a multi-professional education session which will provide support and advice around learning disabilities for GP practices
- Carry out a health check for patients on the learning disabilities register on an annual basis
- Meet with the community learning disability team on a 6 monthly basis to review and discuss the patients on the learning disabilities register.
- Familiarise themselves with information and easy read leaflets to make their service more accessible to patients with an LD.
- Submit an audit detailing the outcomes of their health checks

Community Learning Disability Team (CLDT)

- The Community Learning Disability Team (CLDT) is provided by CNWL and is the primary specialist LD service for adults in Harrow. Service users include:
- People with a diagnosis of learning disability, aged 18 or over and young people transitioning into adult services, who have: a moderate to severe learning disability and complex health needs or a mild learning disability where there are additional complex needs and high levels of risk.
- CLDT provides elements of specialist care, such as psychiatry, psychology, physiotherapy, speech and language therapy, occupational therapy and nursing as part of a combined health and social care approach. However there are reported gaps in specialist occupational and physiotherapy services. For details on other services for people with learning disabilities see
- Harrow focus team provide specialist community forensic services to those in the community who have offended and those at risk of offending. The team provides case management, assessment, liaison and diversion to the courts, police stations and probation teams.

Social Care

The majority of adults with learning disabilities known to adult social care use community based services, residential care, day services, direct payments, home care and other services.

Access to social care is determined by social services eligibility criteria. The Care Act 2014 makes sure that access to an assessment of need and resource allocation is fair for all service user groups.

Average weekly unit costs (£) of LD social care services in 2014/15

Shared lives	LD residential	LD nursing	Personal budget	Home Care
400	1122	1381	280	<i>Approx.</i> 280

Source: Harrow social care management records

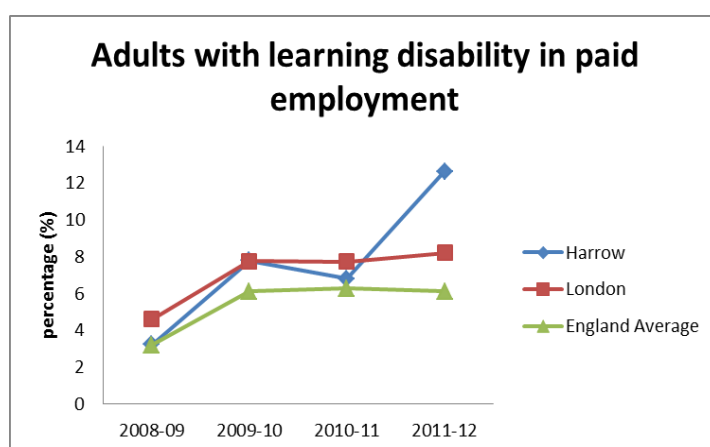
Community based services for adults - Day provision

- Neighbourhood Resource Centres deliver day services for adults with learning disabilities.
- Harrow Wiseworks Community Resource- provides support primarily to adults with mental health problems to develop confidence and skills for employment. This has recently expanded to support people with learning disabilities

Employment, advice, support and opportunities

It is well recognised that paid work provides recognition of a valued social role. Useful day time occupation helps to support people's health and wellbeing. Government policy has emphasised the importance of maximising work opportunities for people with learning disabilities since the publication of *Valuing People Now* (2009).

In Harrow the percentage of adults with learning disabilities in employment rose dramatically in 2011-12 to 12.64% compared to 6.82% in 2010-11 as shown in the graph below.



Source: NHS Information centre

The Adult Social Care Outcomes Framework (ASCOF) performance indicator shows at the end of March 2015, 16.5% of adults with a learning disability were placed into paid employment against a target of 16.9%. Harrow is committed to implement further plans to improve on this performance over the next five years with a focus on supporting people into more long term employment.

Accommodation related services

How people with learning disabilities are accommodated in Harrow:

- 38% with family and friends
- 22% in a registered care home
- 16% in supported accommodation
- 12% as tenants in social housing
- 3% in private rented accommodation

Social care support people with learning disabilities into;

- Residential and Nursing Care and supported living schemes
- Harrow Shared Lives Scheme - members of the public share their lives and homes with a vulnerable adult in order to support them to live full and satisfying lives.

- Floating Support services support people in their own homes or with their own tenancies.
- Transition team in place to support young people into adult services
- The local authority work with the NHS to provide support into Specialist residential and nursing and other health care settings (Inc. independent hospitals and Out of Area Hospital Placements).
- A CYAD (0-25) team in place to support Children and young people into adult services
- As at March 2014 approximately 68 service users 18+ were accommodated out-borough.

Exploring opportunities to increase local supported living accommodation / independent living options and moving away from traditional residential units must be a priority area

2.2. Where we are now

- ✚ Harrow's has an Action Plan to meet Winterbourne Concordat recommendations was 'signed off' by the Winterbourne Task and Finish Group and the National Winterbourne Joint Improvement Programme. Harrow's work-plan is jointly monitored by the council and CCG governance arrangements. People in inpatient care will continue to be tracked and monitored via joint panels.
- ✚ There is an all age disability team in People Services to support people with learning disability and or autism
- ✚ Personalisation system and care management process in place in Adult Social care
- ✚ GPs training in awareness and supporting people with learning disability undertaken, plans to roll out training for other patient facing staff are in place.
- ✚ There is an 'Improving access to healthcare' working group in place to implement a range of health programmes for people with learning disabilities including implementation of the 'Greenlight' tool kit, a tool for learning disabilities service provider to ensure 'reasonable adjustments' are made to mainstream pathways ensuring improved access for people with learning disabilities and mental health dual diagnosis
- ✚ Review of day and residential care undertaken, an accommodation strategy for vulnerable people being developed to develop more flexible independent living accommodation for vulnerable groups including for people with Learning disabilities and autism
- ✚ People with learning disabilities champions in place in the Central and North West London (CNWL) provider services
- ✚ Child and Adolescent Mental Health Service Learning Disabilities contract in place, lead and monitored by the CCG
- ✚ In-depth training delivered to staff providing day opportunities for people with learning difficulties in the council's Neighbourhood Resource Centres. Training covered areas such as sensory considerations, challenging behaviour and support planning. Further training planned for other frontline staff via care management teams
- ✚ Harrow adult mental health services care pathways protocol for people with dual diagnosis of learning disability and mental health in place
- ✚ Personalisation is embedded in adult social care, care management process.

2.3. What people with learning disabilities and carers are telling us

Harrow Mencap consulted people with learning disabilities on the strategy in February 2015. Users and carers identified the following gaps in services.

- ✚ There needs to be more support and diagnosis for parents of preschool children this includes access to peer support groups.
- ✚ There needs to be a central point for information and advice both a physical and virtual space.
- ✚ There needs to be training in communication and respect for health professionals.
- ✚ Health passports need to be available to everyone with a learning disability.
- ✚ Materials including social care assessments should be available in an easy read format.
- ✚ There needs to be earlier involvement of adult social care at transition.
- ✚ There needs to be more training for social workers and for care and support staff so they understand the needs of people with more complex needs.

- # Access to an advocate is essential to support people voices being heard.
- # Access to advice, information and guidance should be available
- # There needs to be more services that support people with employment. This includes CV writing, job searches, support during interviews and support to settle into employment.
- # There needs to be more choice and opportunities for daytime, evenings and weekend activities. Somewhere they could do things with their peers.
- # High dissatisfaction suggests there needs to be more involvement in the design and development of services.
- # Respite for carers and support for older carers is needed
- # More access to leisure centres including accessible transport to get to the leisure centres.

Section 3 - People with Autism

This chapter considers the health, social care needs and wellbeing of people with autism in Harrow. This includes people who have learning disabilities and people who do not, such as those with conditions such as Asperger Syndrome.

3.1. What the data is telling us

The following section looks at current and future trends in the prevalence of autism, both nationally and in Harrow. A more detailed analysis can be found in the Draft Health Needs Assessment for Children and Adults with Autism (Public Health, Harrow Council, 2014).

National picture

A survey by Baron-Cohen et al (2009)⁸ using Special Educational Needs (SEN) registers alongside a survey of children in schools aged 5 to 9 years produced prevalence estimates of autism of 157 per 10,000, so 1.57% of children.

Analysis of the prevalence of autism in adults published by the NHS Information Centre estimated national prevalence to be 1.1% (The NHS Information Centre for Health and Social Care 2012).

Some caution should be used when using prevalence data as many services do not routinely collect data on the number of clients with autism. The issue of “diagnostic overshadowing” means that some clients with learning disabilities or mental health problems accessing services may also be suspected of having autism, but are not diagnosed. In addition, a number of clients with conditions such as Asperger syndrome may not be accessing statutory services and not known to agencies.

The rate of autism among men (1.8%) is higher than that among women (0.2%), which fits with the profile found in childhood population studies.⁹ This disparity is believed to be due in part to the under identification of the condition in women.

Other conditions

Evidence also suggests that people with autism are particularly vulnerable to mental health problems. Often, it is due to mental issues why some people with autism but no LD may access services.

- An estimated 20 - 33% of adults with a learning disability also have autism (Learning Disability Observatory 2010).
- 84.1% of children with Autism meet the full criteria of at least one anxiety disorder (Research Autism 2012).
- approximately 6.7% of people with Asperger syndrome experience depression
- 8-10% of children with autism but no learning disability, such as Asperger syndrome, were diagnosed with Obsessive Compulsive Disorder.

⁸ Prevalence of autism-spectrum conditions: UK school-based population study, Simon Baron-Cohen, Fiona J. Scott, Carrie Allison, Joanna Williams, Patrick Bolton, Fiona E. Matthews, Carol Brayne, The British Journal of Psychiatry May 2009, 194 (6) 500-509

⁹ Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007 was published by the Health and Social Care Information Centre in September 2009

Local picture in Harrow

In Harrow, as nationally, there is no central database of adults with autism. The data is held on many different systems and many services do not routinely collect data. Therefore it is not possible to provide an accurate figure on the current prevalence of autism in Harrow. However, using the studies mentioned above, we are able to estimate the prevalence of autism in the local population.

Estimated prevalence in children and young people

There is little data on the numbers of preschool children with autism. Using the previous study by Baron-Cohen et al, there is an estimated prevalence of 300 children aged 5-9 years old in Harrow.

Estimates from Harrow CCG have used General Practice (GP) registered patient counts in practices that record autism aggregated up to CCG level. These show that there were an estimated 255 children aged 5-9 and 110 children aged 9-10 with autism in 2012. This is in the region of the estimated prevalence using the Baron-Cohen et al study.

Although the figures are much lower than the estimates of children with autism, we can look at trends using school census data on pupils with a Special Educational Need (SEN) School Action Plus or a Statement. There has been a steady increase in the number of pupils with the primary need of autism in Harrow's schools between 2010 and 2014. This increase is despite a drop in the number of pupils with School Action Plus or a Statement in Harrow overall. This system has now changed under new Special Educational Needs and Disabilities legislation.

Estimated prevalence in Harrow adults

Using national prevalence rates of between 1 and 1.1%, approximately 1,900 to 2,057 adults aged 18+ in Harrow have autism. This figure includes both diagnosed and undiagnosed individuals; research suggests that for every three known cases, there are two undiagnosed individuals who might need a diagnosis at some point in their lives (Baron-Cohen et al 2009). The table below shows the predicted number of adults in Harrow aged 18 and over to have autism, projected to 2030. This is predicted to increase by 4% by 2020.

Adults in Harrow predicted to have autism, by age, projected to 2030

Autistic spectrum disorders by age	2015	2020	2025	2030
People aged 18-24	203	189	193	215
People aged 25-34	417	427	420	408
People aged 35-44	367	403	429	440
People aged 45-54	316	327	350	383
People aged 55-64	263	288	304	315
People aged 65-74	186	210	230	254
People aged 75 and over	161	179	211	245
Total population aged 18 and over	1,912	1,992	2,137	2,260

Source: Projecting Adult Needs and Service Information System (PANSI) and Projecting Older People Population Information, Figures may not sum due to rounding. Crown copyright 2014

Overall the highest demand will be in the 25-54 age group and males 18-64. The ratio of men to women with the condition is reported as approximately 9:1. However, we need to bear in mind the effect of under-diagnosis in females. Epidemiological research for Autistic Spectrum Disorders suggests that the ratio should be closer to 4:1.

Adults in Harrow predicted to have autism, by gender, projected to 2030

Autistic spectrum disorders by gender	2015	2020	2025	2030
Total males aged 18-64	1,409	1,472	1,532	1,593
Total females aged 18-64	156	161	164	168
Total males aged 65+	306	344	391	443
Total females aged 65+	41	45	50	56
Total population aged 18 and over	1,912	1,992	2,137	2,260

Source: *Projecting Adult Needs and Service Information System (PANSI) and Projecting Older People Population Information (POPPI)*, Figures may not sum due to rounding. Crown copyright 2014

The statutory guidance *Implementing Fulfilling and Rewarding Lives* (Department of Health 2010) recommends that service planning and provision locally should reflect local needs and priorities, generally identified through the Joint Strategic Needs Assessment (JSNA). Harrow’s data has now been incorporated in to the JSNA. However, the JSNA does not look at the needs of older people with autism and this should be addressed.

Addressing the lack of data collected at service level on people with autism is still a key priority and would improve future estimates and planning, particularly around the areas of accommodation and employment.

It must also be noted that not all people will be known to or indeed require support from adult social care or specialist NHS services.

3.2. Current service provision - health and social care

Harrow has defined diagnostic and care pathways for both children and adults with autism.

Support for Children and Young People

In Harrow, concerns about a child’s development, communication or social interaction are often picked up in education or early years settings. The lead professionals in those settings would initiate where necessary, special educational needs support and referral for paediatric assessment.

The range of health and social care services in the borough include the following:

Accommodation	<ul style="list-style-type: none"> Respite services
Health and Mental Health	<ul style="list-style-type: none"> NWLH Child Health Team: an integrated team of health professionals providing services to children and young people with a learning disability :

	<ul style="list-style-type: none"> • Child and Adolescent Mental Health Service • Child and Adolescent Mental Health Service (LD) • Speech and Language Therapy
Education	<ul style="list-style-type: none"> • 5 additionally resourced provisions in mainstream schools • 4 Special Schools • Special Educational Needs and Disability (SEND) http://www.harrow.gov.uk/info/200220/special_educational_needs_and_disabilities
Support for parents and carers	<p>Many of the services for children with autism are based around skills to enable parents.</p> <ul style="list-style-type: none"> • Early Bird (preschool) and Early Bird+ (4-8 years) from National Autistic Society • Portage support (pre-school only?) • Supporting Carers of people with Autism through Training (SCATT)
Voluntary sector	<ul style="list-style-type: none"> • Voluntary sector run coffee groups, workshops and courses for parents. • Advocacy services

Support for Adults

Adults who have autism and a learning disability are diagnosed and then supported by Learning Disabilities Service. Assessments for social care needs are carried out by Adult Social Care. Adults with autism and no learning disability are mainly diagnosed by the specialist Autism Diagnostic Service, although it is also possible to access diagnostic services from a range of private providers. The service uses specialist assessment tools following referral from mental health services or GPs across London with commissioner agreement to fund the assessment. Assessments for health and social care needs are carried out by the Central and North West London NHS Trust Mental Health (CNWL).

Where a Care Act eligible need for care and support is identified, community based services can be accessed by a Personal Budget. There are a range of services that support adults with autism in Harrow. Some are health or social care funded, others may be provided by the voluntary sector or need to be directly funded by the individual. People who are assessed as being eligible for social care and support by adult social care may be supported to find appropriate residential or nursing care or receive a personal budget to give them choice and control over their community services.

National estimates suggest that the number of adults with autism and no learning disability who are living at home, on their own or with family members in private accommodation is 79%, 5% live in supported accommodation, and 16% live in residential care.¹⁰

Residential and Nursing Care	<ul style="list-style-type: none"> • The majority of residential homes for people with learning difficulties support those who also have autism. • Harrow Council has a specialist 5 place residential
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¹⁰ Knapp et al 2007 cited in National Institute for Health and Clinical Excellence guidance 2012.

	<p>scheme specifically for people with autism.</p> <ul style="list-style-type: none"> • On reaching 65 years old, people with autism who have residential care needs are often supported in settings primarily for older people.
<p>Specialist residential, nursing and other health settings (including independent hospitals and Out of Area Hospital Placements)</p>	<ul style="list-style-type: none"> • Kingswood Assessment and Treatment Unit • The Cygnet Health Care Springs Wing Rehabilitation service is a highly specialist service which provides a recovery focus programme for people with very particular and complex mental health needs and co-morbidities (including autism spectrum disorders).
<p>Supported living schemes</p>	<p>These are building based schemes which support people who do not need the level of care provided in residential care homes. Schemes often work with people for up to two years to help them prepare for greater independence and to live in their own homes.</p>
<p>Shared Lives</p>	<p>Harrow Shared Lives Scheme - members of the public share their lives and homes with a vulnerable adult in order to support them to live full and satisfying lives, encouraging independence. Many of the people who use these services would otherwise live in residential settings.</p>
<p>Housing Support</p>	<p>Floating Support services can support people in their own homes and with their own tenancies.</p>
<p>Day services</p>	<p>As well as opportunities to access the community with support from a personal budget:</p> <ul style="list-style-type: none"> • Harrow Council's Neighbourhood Resource Centres deliver day services for adults with learning disabilities and autism. Staff are well trained in working with people with learning disabilities and autism and the centres are low arousal environments. • Wiseworks supports adults to develop skills to build confidence and gain employment.
<p>Voluntary sector</p>	<p>Local voluntary sector organisations run services to support individuals and their carers including:</p> <ul style="list-style-type: none"> • social skills support • employment support • counselling • coffee groups, • workshops and support for carers • advocacy services • support with nutrition and financial planning

3.3. Where we are now

This strategy is updating the Harrow strategy for Adults with Autism 2012-2014, under which:

- ✚ The Autism Task and Finish Group implemented a range of programs to increase awareness and improve services for people with autism.
- ✚ A clear pathway for autism diagnosis and care and a responsible senior commissioning manager are in place.

- ✚ A Health Needs Assessment on Autism in Harrow was carried out by Public Health in order to inform this strategy.
- ✚ Autism has been included for the first time as a topic in the Joint Strategic Needs Assessment (JSNA) for 2015.
- ✚ Autism has been included as a mandatory category in the development of the social care client record system (Frameworki). This means that Harrow Council are now able to report on the number of people that they support.
- ✚ Harrow CCG have increased the capacity for autism diagnosis for adults in Harrow
- ✚ Harrow CCG now monitors the data for people receiving support from the diagnostic service.
- ✚ Training needs assessment undertaken identifying gaps in workforce awareness in Harrow.
- ✚ Autism Awareness training rolled out for Social Workers, Harrow Council Customer Service staff and Housing, with over 100 staff trained in the first 18 months. This training is ongoing.
- ✚ Harrow Council worked with CNWL Mental Health and voluntary sector advocacy providers to organise Autism Awareness training jointly.
- ✚ Harrow Council commissioned training for community care assessors from the National Autistic Society from 2014 onward.
- ✚ In-depth training delivered to staff who provide day opportunities for people with learning difficulties in the council Neighbourhood Resource Centres. Training covered areas such as sensory considerations, challenging behaviour and support planning. The TEACH programme is also delivered to support people with autism.
- ✚ Harrow Council in-house residential services have dedicated staff members to deliver training to other residential homes.
- ✚ Harrow adult social care has a dedicated Transition Team that works with Children with disabilities and SEN services to plan young people's transition to adult support services appropriate to their needs.
- ✚ Harrow Council's residential home for people with autism & complex needs has been accredited by the National Autistic Society and has had a good rating by recent CQC inspection.
- ✚ Voluntary sector partners have been successful in bidding for Department of Health funding to support people with autism in nutrition and financial planning
- ✚ Harrow Council foster carers have received autism awareness training
- ✚ JSNA health needs assessment undertaken to inform the strategy
- ✚ LD and autism specialist services are rolling out training for staff in community LD/autism services.
- ✚ Successful funding bids for voluntary sector and user-led projects around dealing with financial hardship, budgeting and healthy eating and developing a website for support with autism.

3.4. What people with autism and their carers are telling us

Between December 2014 and February 2015, Harrow Mencap carried out a consultation with people with Learning Disabilities and Autism in order to inform this strategy. In addition, members of the Autism Task and Finish Group have provided input in to the strategy. The group is led jointly by Harrow Council and Harrow CCG and has representation from a range of stakeholders. Some of the key points that have emerged are detailed below:

Identification and diagnosis - it is very difficult to get autism recognised and diagnosed for both children and adults.

Getting services that meet needs - people with autism felt that even after diagnosis, many people were still not offered any help or support or signposted to someone who could support them .

Social care Assessment - people with autism who were assessed by mental health staff had a less positive experience of the social care assessment process than people with learning disabilities. Assessors did not appear to understand autism and were not aware of how best to communicate with people to carry out an appropriate assessment.

Information and advice - people with autism and carers reported that it was difficult get the information they needed. Many reported that information was often contradictory and could cause anxiety if it wasn't correct and that they were often sent from one place to another. People stated that the thing they found most difficult was to get information on benefits.

Health and Mental Health - people with autism expressed dissatisfaction with health services. They felt that health professionals did not understand autism. A lack of health services for people with autism was identified, in particular, only being able to access short term therapy was seen to be unhelpful. A need for specific mental health services for people with autism and mental health needs was identified by both people with autism and carers

Making a complaint - there did not appear to be a good understanding of how to make a complaint about health or social care services among people with autism. Where complaints had been made, people felt that the complaints procedure was very long and complicated and they would be unable to do this unsupported.

Transition to adult services – people identified difficulties when they were leaving education. People without a learning disability were often left without anything to do or any support.

Employment and training – many people found that they had no structure or activities to do during the day which was bad for their physical and mental health. There was also a lack of support to find and maintain work.

Criminal Justice System – adults with autism who have had contact with the criminal justice system, either as a suspect or a victim, have reported a lack of awareness. People were sometimes deemed fit for interview by people with no understanding of autism. In addition, increasing difficulties getting appropriate adults for people with autism have been reported.

4. Section 4 - Challenging Needs

Some people that have a learning disability or autism may have behaviours that are more complex to support and challenges services.

‘Behaviour that can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others, and is likely to lead to responses that are restrictive, aversive or result in exclusion.’¹¹

The National Institute for Health and Care Excellence describes challenging behaviour as ‘problem behaviour’ or ‘difficult behaviour’ or ‘socially unacceptable behaviour’. But in recent years, the term challenging behaviour reflects the fact that some of the behaviours are a challenge to professionals, teachers, carers and parents.

Prevalence

The prevalence rates are around 5–15% in educational, health or social care services for people with a learning disability. Rates are higher in teenagers and people in their early 20s, and in particular settings (for example, 30–40% in hospital settings). People with a learning disability who also have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems (including dementia) may be more likely to develop behaviour that challenges.

Policy context

In October 2015, the government published 'Building the right support'¹². This new framework for commissioners outlines a new national service model based on a whole system response and for people of all ages. The aim is to deliver more community based services for people with learning disabilities or autism, including people with challenging behaviour.

Harrow

Harrow CCG and Council’s joint response to the improvements required nationally as a result of the Transforming Care agenda included work on a local understanding of and approach to better supporting people with challenging needs. This covers:

- Understanding changing needs throughout an individuals lifetime
- Developing the capacity of families and professionals in the community
- Sharing appropriate information to develop responsive support
- Working in partnership and using a holistic approach to service development
- Reviewing services and pathways

Harrow CCG and Harrow Local Authority have ensured there are healthcare professionals, educational staff, social care practitioners to develop care pathways for people with a learning disability and challenging behaviour and the transition between services.

¹¹ Challenging Behaviour: A Unified Approach, Royal College of Psychiatrists, 2007

¹² Building the right support, a national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition, published: 30 October 2015.

The Kingswood Centre (CNWL) provides assessment of the person, their environment and any biological predisposition including functional assessment. The service provides early identification of the emergence of challenging needs and has a dedicated specialist. Risk assessment and regularly reviews for suicidal ideation, self-harm, harm to others, self-neglect is undertaken.

Harrow CCG also commission an independent counsellor for specific cases whose approach to the challenging behaviour in a non-judgemental and who works together with the client to analyse considering the consequences and bigger picture in relation to the challenging behaviour. This allow them to address all the information, both the counsellor and the client can set choices and together attempt to develop the strategy to change the mal-adaptive behaviour.

5. Section 5 - Recommendations

5.1. Growing levels of demand

The projected increase in levels of demand for support for people with learning disabilities and autism in Harrow will mean increase pressure on budgets over the course of this strategy. There has been an increase in the number of pupils with special educational needs and in particular those requiring a place at a special school which is creating pressure on education budgets. The expected 20 complex care transition cases alone is expected to be a pressure on social care budgets of approximately £1.2m per year

The Care Act, other legislative changes and users and carers expectations about the scope and quality of services for people with learning disabilities and autism have also increased significantly. We expect this 'whole life approach' to commissioning of services will provide opportunities to;

- Improve joint working between children and adult services and health partners
- Improve planning to manage demand.
- Increase early intervention services

This will enable us to progress our overall strategy of improving services through:

- Improving pathways between services
- Enabling people to make fuller use of universal services
- Increase the effectiveness of services by increasing service users choice and control about the support they receive
- Ensure people received the right support after assessment of needs
- Focus across all services on helping people to be as independent as possible
- Reducing our reliance on traditional and more costly residential and nursing accommodation
- Manage the significant financial pressure cause by increasing level of needs and growing demand

5.2. Recommendations – what is needed to improve services

This section sets out the key recommendations for service development over the next five years as a result of estimated and predicted future demand. As well as the specific areas, there are also some cross-cutting themes across learning disabilities and autism.

Learning disabilities recommendations

- Improve data collection and recording to provide more reliable data set in particular for children with learning disabilities aged under 5 years old, carers and young people in transition to support 'whole life' planning and service reviews.
- Joint working between the Council and the CCG to ensure GP data on lifestyle and screening for those with LD can be monitored and compared with the general population.
- Ensure learning disabilities data is included in Harrow's JSNA
- Explore the development of the local day services as hubs to provide advice and information on training and employment and support to access day and evening leisure activities and community services.
- Explore opportunities to increase employment and training opportunities for people with learning disabilities.

- Joint working between the Council and the CCG to review, develop and improve pathways/ access to health screening programmes and ensure health passports are available to people with LD who needs them.
- Continue to review Learning Disability and Adult Mental Health placement processes with the Local Authority to ensure good outcomes and value for money services are delivered.
- Continue to work with providers to improve access to psychological therapies for people with learning disabilities

Autism recommendations

- Continue to extend autism awareness training across health and social care, particularly in primary and mental health care.
- Increase the number of health and social care staff with specialist autism training across all appropriate statutory agencies.
- Increase the uptake of diagnosis and support for parents of preschool children
- Ensure that people with autism are supported well as they move into adulthood
- Develop services that support people with employment that is accessible and appropriate for people with autism.
- Develop access to local daytime, evening and weekend activities to improve access for people with autism.
- Ensure professionals in the criminal justice system receive autism awareness training.
- Promote the need for reasonable adjustments to public mainstream services for people with autism.
- Explore opportunities to improve housing options and support for people autism
- Ensure that there is appropriate access to counselling services provided by staff who are trained to support people with autism.
- Improve the recording of autism by statutory organisations and other services
- Explore how a variety of health professionals can be maintained through out a person's life, by skilling up IAPT and other key health professionals
- Review the quality of support provided to people aged 65 and over

Cross cutting recommendations for learning disabilities and autism

- Harrow Council and the CCG to ensure diagnostic, assessment and integrated care pathways are in place for people with learning disability, autism and complex and challenging behaviour.
- Ensure access to clear accurate and consistent information and advice. Ensure materials are produced in easy read format.
- Improve the involvement of people with autism and learning disabilities and their carers in the design, delivery and development of services
- Improve support for people with autism and leaning disabilities who have contact with the criminal justice system, in particular better access to an appropriate adult.
- Work jointly to implement the 'Green Light Tool Kit' to ensure providers make 'reasonable adjustments' to their practices that will make them accessible and effective for people with learning disabilities or autism.
- Implement plans to develop adequate supply of supported/independent living accommodation locally moving away from more costly traditional residential and residential nursing care.
- Explore assistive technology and telecare options as part of a package of support

- Work jointly to review and update Transition Protocol and pathways. Ensure the transition process commences early and is seamless for both the young person and their families and carers.(children to adults and adults to older people’s services)
- Develop more robust transition pathway, strengthen the way education, children’s and adult services plan together.
- Support implementation of the SEND transformation plans to prepare young people for adulthood and improve transition by ensuring full involvement of young people with autism and learning disabilities and their families in multi-agency transition planning. http://www.harrow.gov.uk/info/200220/special_educational_needs_and_disabilities
- Continue regular review of need and service provision, including local community facilities and access through out the life of the strategy.

5.3. How progress will be measured

Although there are no specific national targets for learning disability or ASCs, there are a number of initiatives which aim to drive up standards in access and care management e.g. introduction of a local enhanced service for annual health checks.

Harrow Council and Harrow CCG will use the following initiatives to measure performance.

- Harrow CCG CQUIN performance assessment
- Social Care national and local performance data
- Adult Social Care Outcomes Framework indicators on employment of people with Long Term Conditions, as a measure of enhanced quality of life
 - The proportion of people with a learning disability who are in paid employment
 - the proportion of people in contact with secondary mental health services in paid employment
- Consultation with users and Carers
- Children and Young People Commissioning Executive Board
- The Green Light Toolkit to measure how accessible mental health services are for people with learning disabilities.
- Development of an LD and Autism work plan addressing ten priority areas
- Winterbourne JIP local area action plan – Harrow’s Winterbourne plan for the delivery of services to people with learning disabilities was signed off in October 2014. The plan is jointly monitored and updated by the LA and CCG.
- LD and Autism self assessment, as required.

Outcomes

We expect the strategy activities will support good quality care for people with learning disabilities and autism and contribute towards achieving a number of health, social care and individuals outcomes.¹³

Adult Social Care Outcomes	NHS Outcomes	Public Health Outcomes
<ul style="list-style-type: none"> • Enhancing the quality of life for people with care and support needs • Delaying and reducing the need for care and support 	<ul style="list-style-type: none"> • Preventing people from dying prematurely • Enhancing quality of life for people with 	<ul style="list-style-type: none"> • Improving the wider determinants of health • Health improvement

¹³ Adult Social Care Outcomes Framework <https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-ascof-2015-to-2016>

<ul style="list-style-type: none"> • Ensuring that people have a positive experience of care and support • Safeguarding adults who are vulnerable and protecting them from avoidable harm 	<p>long term conditions</p> <ul style="list-style-type: none"> • Helping people to recover from episodes of ill health or following injury • Ensuring that people have a positive experience of care • Treating and caring for people in a safe environment and protecting them from avoidable harm 	<ul style="list-style-type: none"> • Health protection • Healthcare public health and preventing premature mortality
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Individual's outcomes

We want people with learning disabilities and autism to have positive experiences of services they receive. Think Local Act Personal - Making it Real¹⁴ and 'Think Autism' include a number of 'I statements' that people want to see and experience. The table below show how we will use the "I" Statements to monitor our progress on achieving outcomes for individuals.

Making it real	What people with learning disability and or autism say
Information, advice, guidance and advocacy	<ul style="list-style-type: none"> • I have the information I need when I need it to remain as independent as possible. • I have opportunities to train, study, work or engage in learning activities that match my interests, skills, abilities
Active supportive communities	<ul style="list-style-type: none"> • I have access to a range of support that helps me to live the life I want and remain a contributing member of my community • I regularly see my friends and family
Health and wellbeing	<ul style="list-style-type: none"> • I know who my GP is and where to go when I feel unwell • I have access to sport and leisure activities
Flexible care and support	<ul style="list-style-type: none"> • I can decide the care and support I need and when, where and how to receive it • I am in control of planning my care and support • I have care and support that is directed by me and responsive to my needs • I can live independently and have control of how I live my life
Work force	<ul style="list-style-type: none"> • My support is coordinated, cooperative and works well together and I know who to contact to gets things changed • I have help to make informed choices if I need and want it
Personal budget and self funding	<ul style="list-style-type: none"> • I know the amount of money available to me for my care and support needs and I can determine how this is used. • I have support to claim benefits I am entitle to.
Risk enabled	<ul style="list-style-type: none"> • I feel safe, I can live the life I want and I am supported to manage any risks including the risk of discrimination and abuse • I can plan ahead and keep in control in a crisis

¹⁴ Think local Act Personal –Making IT REAL –marking progress towards personalised, community based support, 2012

Joint Commissioning Plan for people with Learning Disabilities or Autism 2016-2020

The following commissioning plan is a result of findings from Harrow's Learning Disabilities and Autism JSNA, service reviews, feedback from consultation with users and carers, Winterbourne and Autism task and finish groups' outcomes and legislative and local priorities. This plan will be formally reviewed on an annual basis throughout the life of the strategy to ensure it remains relevant and up to date.

Priority	Activity	Measures of success	Lead	Timescale	
Learning disabilities and autism					
1 Improve data recording and collection to consistently inform service commissioning					
1.1	<p>Ensure data collection and recording are improved to provide more detailed analysis of local needs, In particular improve data collection for children with learning disabilities or autism aged under 5, carers and young people in transition.</p>	<ul style="list-style-type: none"> • Joint working between the Council and the CCG to review and ensure GP data on lifestyle and screening for people with LD can be monitored and compared with the general population • Ensure GPs record patients with autism and retain a list in their practices • Develop mechanisms for the collection of data for children with LD and autism, particularly under 5s, carers of people with LD and young people in transition to adult services • Develop the learning disabilities and autism data included in Harrow's JSNA 	<p>Data collection and recording is improved to provide more consistence reliable data set in particular for children with LD, under 5s, carers and young people in transition to support 'whole life' planning</p> <p>Learning disabilities and autism data is consistently included in Harrow's JSNA</p> <p>Services commissioning is consistently based on adequate population data.</p>	<p>CCG and LA Commissioners</p> <p>Children with Disabilities Service Managers</p> <p>Public Health</p>	<ul style="list-style-type: none"> • 2016/17 • 2016/17 • 2017/18 • 2016/17

2. Identification and pathways to support					
2.2	Ensure diagnostic, assessment and integrated care pathways are in place for people with learning disability, autism and complex and challenging needs	<ul style="list-style-type: none"> Review pathways currently in place, develop and implement. Ensure easy read versions are in place. Ensure staff, service users, carers and families are aware of the pathways 	Positive feedback is received from service users, carers and professionals	Harrow CCG	<ul style="list-style-type: none"> 2016/17 → 17/18 2017/18
2.3	Support implementation of the Special Educational Needs and Disabilities (SEND) Strategy to prepare young people for adulthood, into training, employment and volunteering opportunities	<ul style="list-style-type: none"> Work jointly to review and update transition protocols and pathways. Ensure the transition process commences early and is seamless for young people, their families and carers and older adults Ensure the SEND preparing for adulthood plans and protocols are aligned to this plan. 	Young people with SEND their families and carers have access to information and support in their preparation for adulthood	LA commissioners Children with Disabilities Service Managers SEN service managers	<ul style="list-style-type: none"> 2016/17 2017/18 2017/18
2.4	Ensure transition process pathways are in place, transition commences early and is seamless for young people, older adults, their families and carers.	<ul style="list-style-type: none"> Review, update and implement transition protocols and pathways including development of easy read versions 	Protocols and pathways are in place to support early planning for transition into services General transition for all ages and condition is improved		<ul style="list-style-type: none"> 2017/18 → 18/19
3. Support					
3.1	Ensure access to clear accurate and consistent information and advice. Ensure materials are produced in easy read format	<ul style="list-style-type: none"> Clear accurate information and advice is available including in easy read format and signposting to existing services 	People with LD or autism have the information they need when they need it to remain as independent as possible.	LA and CCG Commissioners Voluntary sector partners	<ul style="list-style-type: none"> 2017/18

	Signposting to autism aware/specific services/provision must be in place.				
3.2	Improve the involvement of people with autism and learning disabilities and their carers in the development of services	<ul style="list-style-type: none"> Develop mechanisms to improve how we engage and involve learning disability and autism service users and carers for co-production, shaping and service design 	LD and autism services commissioning and service development is consistently informed by service users, carers and families' views.	LA and CCG Commissioners Voluntary sector partners	<ul style="list-style-type: none"> 2017/18
3.3	<p>Work with the CCG and providers to improve access to psychological therapies (incl. counselling) for people with learning disabilities or autism</p> <p>Ensure the pathway into specific counselling for people with autism are available and easily accessible</p>	<ul style="list-style-type: none"> Continue to work with providers to increase access to services for depression, anxiety, counselling, CBT etc. for children young people and adults Work jointly to deliver 'Children in Mind' local plan and priorities Develop and implement clear pathways into services Review clinical psychology support services for children and young people with ASD and behavioural issues. Make data available on the numbers of people with learning disability and autism accessing psychological therapies, so that access can be monitored. 	<p>Support is available. People are informed and are able to access services in a timely way</p> <p>CCG Children's Commissioner</p> <p>Psychology resource is available to provide advice on the management of psychological issues and behavioural difficulties.</p>	LA and CCG commissioners Providers	<ul style="list-style-type: none"> 2017/18 → 18/19 2016/17 2017/18 2017/18 2017/18 → 18/19
3.4	Develop adequate supply of supported and independent living accommodation locally for people with LD and autism	<ul style="list-style-type: none"> Implement Harrow's Supported Housing strategic plan and the NHS National Transforming care Plan to develop more local supported 	Reduced reliance on costly traditional residential or nursing placements	LA Commissioners Service	<ul style="list-style-type: none"> 2017/18 → 18/19

		<p>housing and independent living provision for people with LD, autism and low level needs. Develop in partnership with housing, voluntary sector & private providers</p> <ul style="list-style-type: none"> Explore the range of appropriate assisted technology and telecare as part of a package of care available and increase take-up 	<p>A good range of supported/independent living accommodation options are available locally to support people to move through services as their needs change</p> <p>More people with LD and or autism are supported to remain within and feel part of their community.</p> <p>Increased housing options are available for people with LD and autism</p>	<p>managers Housing managers</p>	<ul style="list-style-type: none"> 2016/17 → 18/19
4. Access to the community					
4.1	<p>Work jointly to ensure services make 'reasonable adjustments' to their practices that will make them accessible and effective for people with learning disabilities or autism</p>	<ul style="list-style-type: none"> Work with health commissioners and providers to implement and monitor the Green 'Light Tool Kit' to ensure providers make reasonable adjustments to their practices to improve access. Support local community and leisure services and other services such as GP surgeries, Job centre plus and employment agencies to apply reasonable adjustments to ensure people with LD and autism are able to access services 	<p>More people with LD and autism will say access to services have improved</p> <p>Positive feedback from service users and carers</p>	<p>Commissioners</p> <p>Community providers</p> <p>LD and autism services providers</p>	<ul style="list-style-type: none"> 2016/17 → 18/19
4.2	<p>Identify opportunities to increase employment and training for people with autism or learning disabilities to promote independence</p>	<ul style="list-style-type: none"> Develop local hubs to provide information, advice, guidance training and support into employment 	<p>More people with LD and autism accessing training and employment opportunities</p>	<p>Commissioners</p> <p>Community providers</p>	<ul style="list-style-type: none"> 2016/17 → 18/19

		<ul style="list-style-type: none"> • Develop a plan to increase access to resources to support people into employment including: <ul style="list-style-type: none"> ○ Job coaches ○ Voluntary sector support ○ Providers ○ LA employment support ○ Job centre plus. • Put employment at the forefront of day opportunities and care management • Develop and agree an approach on developing employment opportunities within the council and externally. 		<p>Job centre plus</p> <p>LA employment support</p>	<ul style="list-style-type: none"> • 2016/17 → 18/19 • 2017/18 • 2017/18
4.3	Improve support for people with autism and learning disabilities who have contact with the criminal justice system, in particular better access to an appropriate adult	<ul style="list-style-type: none"> • Work with criminal justice sector to improve awareness of learning disabilities and autism. • Identify and develop a pool of trained appropriate adults. 	People with learning disabilities and autism say they feel safe	<p>LA and CCG</p> <p>Safeguarding Hub</p>	<ul style="list-style-type: none"> • 2017/18 • 2017/18
4.4	Improve access to community health initiatives	<ul style="list-style-type: none"> • Health promotion information and advice for smoking cessation, sexual health, exercise, substance and alcohol abuse, and wellbeing initiatives are available, suitable and clear. 	People are aware of and are able to access health promotion initiatives to improve general health and wellbeing.	Public Health commissioner	<ul style="list-style-type: none"> • 2016/17

5 Autism Specific					
5.1	Continue to extend autism awareness training across health and social care, particularly in primary and mental health care	<ul style="list-style-type: none"> Review current programme. Undertake audit of trained providers who could undertake training i.e. voluntary sector PPGs 	Increased numbers of staff in health and social care receive autism awareness training	LD and autism Service Managers.	<ul style="list-style-type: none"> 2016/17 → 17/18
5.2	Increase the number of health and social care staff with specialist autism training across all appropriate statutory agencies	<ul style="list-style-type: none"> Identify funding and develop and implement a training programme to increase training to GPs, staff in acute settings, community health services and other front line specialist health services. 	Specialist staff are increasing autism aware and are able to deliver improve assessments and support	CCG and LA commissioners LA service providers ** NOTE: this must include CNWL**	<ul style="list-style-type: none"> 2016/17 → 17/18
5.3	Increase the uptake of diagnosis and support for parents of preschool children with autism	<ul style="list-style-type: none"> Ensure the parents of pre-school children with autism are on the pathway for diagnosis and available support 	Early identification and support in place	CCG and LA commissioners	<ul style="list-style-type: none"> 2017/18
5.4	Develop access to local daytime, evening and weekend activities for people with autism.	<ul style="list-style-type: none"> Map local resources and identify existing local centres which could be adapted and extended to provide appropriate activities resources. Identify and train supporters for adults with autism into mainstream provision/places 	Access to local community resources and activities for people with autism are increased	LA commissioners	<ul style="list-style-type: none"> 2017/18 2017/18
5.5	Ensure professionals in the criminal justice system receive autism awareness training	<ul style="list-style-type: none"> Scope and develop a list of autism awareness trained appropriate adults. Circulate list to relevant services in the LA, voluntary sector and CCG 	Pool of trained appropriate adults are available to support those who come in contact with the criminal justice system		<ul style="list-style-type: none"> 2017/18 2016/17

5.6	Ensure the LA has clearly identified strategic autism lead who has an interest in autism and that they are able to be contacted.	<ul style="list-style-type: none"> Ensure role is maintained in the LA 	Autism lead in place		<ul style="list-style-type: none"> 2016/17
5.7	Ensure smooth transition to appropriate older people's services	<ul style="list-style-type: none"> Map the types and quality of support provided to people aged 65 and over. Develop a strategy to improve transition 	<p>Transition process is smooth and improved</p> <p>People aged 65 and over with LD or autism receive appropriate support</p>	<p>Social care management</p> <p>LA commissioners</p> <p>Service providers</p>	<ul style="list-style-type: none"> 2017/18 2017/18
6. Learning Disabilities Specific					
6.1	Joint working between the Council and the CCG to review, develop and improve pathways/ access to health screening programmes and ensure health passports are available to people with learning disabilities	<ul style="list-style-type: none"> Develop & implement clear diagnosis pathways into specialist services for people with LD and specifically for people with mental health issues which is an identified gap Increase uptake of health checks and health plans with specialist teams to prevent hospital admissions 	<p>Pathway in place for children, young people and adults with learning disabilities and with or without mental health issues</p> <p>Screening and referral to assessment services are undertaken in a timely manner ensuring individual needs are identified at the earliest point possible.</p>	<p>Harrow CCG Commissioners</p> <p>Service providers</p>	<ul style="list-style-type: none"> 2017/18 2017/18
6.2	Provide respite for eligible carers and support for older carers	<ul style="list-style-type: none"> Identify carers with learning disabilities and older carers and arrange for carers assessments. Ensure information on carers support is available in easy read format Ensure that care assessments and reviews look at planning for the future 	Carers are supported in their caring roles and enabled to have a life outside of caring	LA Service Managers	<ul style="list-style-type: none"> 2017/18 2017/18 2017/18

6.3	Ensure good outcomes and value for money services are delivered for people with learning disabilities and mental health issues	<ul style="list-style-type: none"> Continue to review Learning Disability and Adult Mental Health placement processes with the Local Authority. 	Services are continuously improved	Harrow CCG Commissioners	<ul style="list-style-type: none"> 2016/17
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An implementation plan with timescales and a strategic group will be developed to drive the activities of the plan and monitor progress.

Acronym Buster

ASCOF	Adult Social Care Outcomes Framework
ASD	Autistic Spectrum Disorders, also Autistic Spectrum Conditions
CCG	Clinical Commissioning group
CWD	Children with Disabilities
ASC	Adult Social care or Autistic Spectrum Conditions
CAMHS	Child and Adolescent Mental Health Service
CLDT	Community Learning Disability Team
CNWL	Central and North West London NHS Foundation Trust
DAOC	Delayed Acceptance of Care
DH	Department of Health
DTOC	Delayed Transfer of Care
EHCP	Education, Health and Care Plan
GLA	Greater London Authority
JSNA	Joint Strategic Needs Assessment
LA	Local Authority
LD	Learning Disability
MH	Mental Health
NHSE	NHS England
NWL	North West London
SCATT	Supporting People with Autism Through Training
SAF	Self Assessment Framework
SEN	Special Educational Needs
SEND	Special Educational Needs and Disabilities
TCP	Transforming Care Plan
WLMHT	West London Mental Health Trust