

Harrow Joint Commissioning Strategy for People with Learning Disabilities and Autistic People: 2022 to 2026

September 2022

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EXECUTIVE SUMMARY

The Harrow Joint Learning Disabilities and Autism (LDA) Strategy 2016-2020 led to significant achievements and there has been the development of the Integrated Care Partnership (ICP) which brings equal partnership between people with learning disabilities (LD) and autistic people (ASD) and their families and carers, health, local authority services i.e., early years, education, housing, public health etc., and voluntary sector organisations to work together towards improving outcomes and quality of life for residents with LD or ASD.

In October 2021 engagements with people with LD and ASD, families, carers, professionals, and other stakeholders were carried out to facilitate the development of this new joint all age Learning Disabilities and Autism Strategy 2022-2026.

Some of the feedback was reflective of the support and joint working which was experienced during the COVID-19 pandemic most notably during the 2020 to 2021 lockdowns.

Feedback from stakeholders was wide-ranging:

What worked well:

- ***All family members were assisted, that is individuals, siblings, and parents.***
- ***Peer support groups and up to date information sessions were particularly valued.***
- ***Joint working was demonstrated, with accounts of services directing to, or liaising with others.***
- ***The specialty of different organisations is respected and appreciated.***

What could be improved:

- ***People say they lack basic awareness of the services on offer.***
- ***Accessibility is questioned by some, who cite a lack of adjustments (requirement to use the phone), language barriers and insufficient written/leafleted information.***
- ***Communication - when accessing or leaving services could be better.***
- ***On referrals, we were told that pathways can be confusing and difficult, with insufficient information on what is available, or what the offer consists of.***
- ***Opportunities for greater independence with proper support***
- ***Sustained employment opportunities***
- ***Enhanced social inclusion***

People shared what was needed to make a difference to their lives:

- ***Greater training and awareness - in the community and the workplace.***
- ***Access to preventative information and advice for wellbeing***
- ***Greater focus on Preparing for Adulthood for young people***
- ***Timely needs assessments and services.***
- ***Autism specific areas in parks, slots at supermarkets and exercise facilities, at reasonable times***
- ***Very few have utilised behavioural or emotional support, possibly because there is a real lack of support for distress/stress behaviours if children and young people do not have a learning disability.***

Feedback from residents indicated that to have a meaningful life the journey starts from the womb, by ensuring mothers are supported effectively, children and young people are given tools to enable and empower them to live independent lives from early years through education, ensuring there is holistic and equitable transition into adulthood support.

Ensuring there is an inclusive short break offer which includes SEND support. Outside educational establishments to continue; and people living independently receive support to retain and make friendships, build safe relationships including sexual relationships, getting into employment, and retaining their jobs, ensuring that the community is inclusive, and the environment plus services are accommodating of their needs e.g., leisure activities to facilitate a move away from building-based day centre activities to meaningful outcome based activities, suitable housing, social care placements in Harrow, even for those with complex needs etc., the criminal justice system understands people's needs to ensure residents do not live in fear of persecution.

This feedback provides learning, opportunities for innovative partnership working and most importantly identifies and directs where improvements in the system can be made to ensure citizens are put first by enhancing their experience as Harrow residents.

Through this Strategy, the aim is to ensure citizens recognise and or are supported to identify the positive outcomes they want to achieve to enable them to be independent and included in the community.

Through partnership working health and the local authority are keen to continue working together to identify solutions that improve lives with greater emphasis on crisis prevention, early intervention and crisis support to ensure people are supported before their situation becomes worse and requires medical intervention or hospital admission.

From the data analysis and feedback from stakeholders, five key priorities have been identified which will be focused on throughout the Strategy. The priorities are all driven by an overarching guiding principle of tackling health and social inequalities for people with a learning disability and autistic people.

These include:

- Personalised care and support
- Appropriate information, referrals and support
- Living in local communities
- Responsive health care
- A skilled workforce

In addition to the five key priorities, the following items will be a focus to address specific needs highlighted by the feedback from stakeholders:

- Transition Services
- Mental Health Support Services
- Support for Carers

Each priority will set out the outcomes and recommended actions to be taken by the Integrated Care Partnership (ICP) which includes health, the local authority services e.g., education, public health, housing, social care, etc., to jointly improve people with a learning disability and autistic people's lives, so that they are able to enjoy fulfilled lives with equal access to their community and health services.

This Strategy is aspirational and to achieve the outcomes for residents it requires joint working across the system to collaboratively manage the finite financial resources whilst meeting the increased needs.

It will be important that services work together with citizens and in partnership to devise and deliver innovative interventions to improve citizens' lives with greater focus on citizens' strength-based positive outcomes approach, quality, efficiency, transparency, and sustainability.

The implementation of this Strategy will ensure prevention, early intervention, facilitation in community connection; and be driven by measurable positive improvement outcomes for Harrow citizens.

The first of these will be to ensure that partnership working between, primary, secondary, social, voluntary sector and care acknowledge and address the health inequalities of people with learning disabilities and autistic people. There are over 1.2 million people in England who have a learning disability who face significant health inequalities compared with the rest of the population. In Harrow, there are over 1200 people with learning disabilities.

Autistic people have a lifelong condition and is part of daily life for around 600,000 people in England. It is estimated that 20-30% of people with a learning disability also have autism.

Primary care has a key role in identifying early signs of serious ill-health and agencies like Community ConneX has been providing encouragement to people with learning disabilities in the community to attend their GP practice to have a health check on an annual basis. People with learning disabilities and autistic people are at greater risk of ill-health and both often experience poorer access to healthcare.

The Strategy will build on the Learning Disabilities Mortality Review Programme (LeDeR) that commenced in 2017, which found that 31% of deaths in people with a learning disability were due to respiratory conditions and 18% were due to diseases of the circulatory system. As part of the 2021 LeDer Policy, we will ensure professionals working in all parts of the health and social care system understand what is required in delivering LeDeR within their roles. We will also focus on the LeDeR initiative to identify common themes and learning points and provide targeted support to local areas. There will be continued focus and implementation of the Learning Disabilities Mortality Review Programme (LeDeR), where Harrow Borough based partnership will work collaboratively with cares and citizens to ensure a programme of improvements to the lives of people with learning disabilities.

Across the Harrow based partnership, we will do more to ensure that all people with a learning disability, autistic people, or both can live happier, healthier, longer lives. We will ensure that reasonable adjustments are made so that wider NHS services can support, listen to, and help improve the health and wellbeing of people with learning disabilities and autistic people, and their families.

Over the last number of years, we have focused on ensuring only the appropriate level and use of psychotropic medicine is prescribed to people with a learning disability or autistic people. This was also expanded to the Stopping Over Medication of People with a learning disability, autism, or both and Supporting Treatment and Appropriate Medication in Paediatrics (STOMP-STAMP). This is of great importance and will continue through education and monitoring.

During 2022/23 Harrow will be working to reduce its waiting list for assessments and workforce shortages across both learning disability and services for autistic people.

CHAPTER 1: INTRODUCTION

To prepare for the new *Harrow Joint Commissioning Strategy for People with Learning Disabilities and Autistic People 2022 to 2026*, a 'Learning Disability and Autism Strategy Working Group' was set up to oversee the task of co-developing the Strategy. A key function of the Working Group was to 1) ensure that progress made following the implementation of the 'Harrow Joint Commissioning Strategy for People with Learning Disabilities & People with Autistic Spectrum Conditions 2016-2020' was captured and 2) to reflect and reference any new relevant local and national policy/strategies, and changes in language and knowledge concerning learning disabilities and autism. The Working Group was made up of members from Voluntary Sector Organisations (VSO) Harrow Council and the Integrated Care Board (ICB) previously known as the Clinical Commissioning Group (CCG).

A clear aspiration of the Working Group was that partners would collectively work to improve the quality of life for people with a learning disability and autistic people, reduce stigma, and combat health and social inequalities. It was agreed that this would remain as an all-age Strategy to ensure no one is left behind when planning and commissioning services within the Borough and to support smooth transitions across the life course. It was recognised that to achieve the aspirations, joint working across the system would ultimately be required from other partners such as education, housing, local employers, police, transport, faith organisations etc., to work alongside health, social care and voluntary sector providers. As such, a commitment to reaching out to these partners would be core to the delivery and implementation of the Strategy over the next five years.

Following several engagement sessions, it was acknowledged that although people with a learning disability and autistic people have some distinct differences, they have many similarities in relation to expressed needs and the available desired offers to meet these needs. To reflect this the approach taken was to include a joint 'Outcome Framework' chapter to outline 'what people said matters' and 'how it will be achieved' as well as have a chapter specifically dedicated to learning disabilities and autism which would focus on the key issues for each group.

1.1 Vision:

For Harrow to be a place where people with learning disabilities and autistic people of all ages live as equal citizens in a community that treats them with dignity and respect, and provides access to high quality services, that supports people to realise their ambitions.

1.2 Approach:

The approach taken to gather data to inform the Strategy included several strands. There was a review of the 2016-2020 Strategy to measure progress, engagement of key stakeholders, analysis of relevant data, and space to reflect and link into local and national policies and strategies to reduce duplication and align to national standards. This section will focus on the progress made in the 2016-2020 Strategy, the methods of engagement used to gain feedback from stakeholders, as well as the local and national policies and strategies which were critical to the development of this Strategy.

1.3 Review of the 'Harrow Joint Commissioning Strategy for People with Learning Disabilities & People with Autistic Spectrum Conditions 2016 - 2020':

In the 'Harrow Joint Commissioning Strategy for People with Learning Disabilities & People with Autistic Spectrum Conditions: 2016-2020', six areas were identified, which health and social care partners agreed to focus on during the lifespan of the Strategy to make improvements in the quality and access to services. Table 1 illustrates a summary of progress which was made during this period.

Table: 1 Areas to Improve – Actions

	Areas to Improve	Action
1	Improve Data Recording and Collection to Consistently Inform Service Commissioning	<ul style="list-style-type: none"> Established GP Learning Disability Register to offer annual health checks to people with a learning disability over the age of 14 years Local Authority Mosaic data system introduced to ensure consistent recording across the Local Authority
2	Identification and Pathways to Support	<ul style="list-style-type: none"> Developed Learning Disability (LD) Newsletter to share information Reinstated Learning Disability & Autism (LDA) Health and Social Care Focus Groups Carers and advocates key members of the LD & Autism Health and Social Care Focus Groups and LDA workstream meetings Easy read documents available within hospital settings Harrow Parents Carers Forum set up a Coffee morning for Parent engagement Health App put in place with links to Local Authority services including local offer information
3	Support	<ul style="list-style-type: none"> GP outpatient appointments began to introduce reasonable adjustments Additional LD & Autistic Spectrum Disorder (ASD) nurse funding to support in hospital settings Health Passports for LD and Autism patients were rolled out Community ConneX formerly Harrow Mencap developed a video to promote Health Passports

		<p>and developed toolkits around Annual Health Checks for GPs, individuals, and support workers</p> <ul style="list-style-type: none"> • Family Support Worker role established - linking schools with parents and carers • LD and ASD pathways have been rolled out for adults - further work required for children and transition • An all-age Dynamic Risk Register set up and led by health colleagues to support those most at risk of placement breakdown • Community Education Treatment Reviews (CETR) & Local Area Emergency Protocol (LAEP) introduced and led by health colleagues to support people with a learning disability and Autistic people who are at risk of going into an inpatient setting or already in an inpatient setting
4	Access to the Community	<p><u>Employment</u></p> <ul style="list-style-type: none"> • Second Internship Programme is in progress • Shaw Trust Work and Health Programme • Prince's Trust courses • Developed links with Job Centre Plus • Developed links with Work and Health Programme • Exploring other employment options and models <p><u>Housing and Support</u></p> <ul style="list-style-type: none"> • Housing and needs assessment carried out in 2019/20 • Applied for Transforming Care Programme (TCP) funding for respite - unsuccessful • Task & Finish Group was set up with Social Care Supported Accommodation. This group considered social care processes and the benefits and disadvantages of residential care vs supported living
5	Autism Specific	<ul style="list-style-type: none"> • Harrow has a clearly identified strategic lead - Assistant Director - Specialist Learning Disabilities Care and CYAD Services • Training is currently rolled out to social care staff in children and adult services • GP Master Class training available • External service has been commissioned to support early years and adults • CAMHS ADHD Service - nurse led, working closely with Centre for ADHD and Autism Support
6	Learning Disabilities Specific	<ul style="list-style-type: none"> • LD pathway in place and is monitored by the LD Health and Social Care Focus Group • Coordinate My Care in place • Formal Crisis Pathway completed and launched • Learning Disability Mortality (Death) Review introduced in Harrow to support learning and improve services

<p><i>Other Highlights</i></p>	<ul style="list-style-type: none"> • Integrated LD Health Service was established in November 2019 • LDA Enablement Project Pilot implemented December 2020
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1.4 Methods of Engagement:

The Learning Disability and Autism Strategy Working Group used two main methods to engage key stakeholders - questionnaires and online workshops. Three separate questionnaires were developed in June 2020: 1) professionals, 2) people with a learning disability and 3) autistic people. As it was an all-age Strategy each questionnaire included a question which allowed respondents to indicate one of three age categories. The age range was used to enable the Working Group to know whether there was a representation across the life span responding.

The questions in the questionnaires were approved by members who attended either the Harrow Learning Disability Health and Social Care Focus Group or the Harrow Autism Health and Social Care Focus Group. Once they were signed off, colleagues from Community ConneX formatted them into Survey Monkey and they were sent out to stakeholders during August and September 2021. Questionnaires were returned by: 44 professionals and 122 local people (41 (aged 16), 20 (aged 16 to 25), and 61 (aged 25 and over)). The questionnaire results were then analysed by Community ConneX colleagues.

Following the questionnaires, four online stakeholder sessions were held in October 2021 over a two-day period. A morning and evening session was held for people with a learning disability and autistic people to enable stakeholders to have time to attend e.g. carers or those in education or employment. 64 participants attended across the two learning disability workshops and 51 participants attended across the two autism workshops. Valuable insights from these workshops combined with the questionnaires supported the development of the first draft priorities which were shared with both Focus Group members for comment and sign off in December 2021 (see Appendix 1 and 2 for the themes that developed the draft priorities).

In February 2022, the National Development and Training Inclusion Team (NDTi) were commissioned by the Local Authority due to their expertise in supporting local areas in developing strategies. NDTi supported the process in the following ways 1) further engagement with stakeholders to ensure everyone had a chance to feed into the process 2) refining of the outcomes and measurements for the Strategy 3) co-designing a workshop to support with the prioritising of the activities to focus on over the duration of the Strategy.

Feedback from stakeholders was wide-ranging across all platforms; and a snapshot of some of the key points are listed below:

What worked well:

- All family members were assisted, e.g. individuals, siblings, and parents
- Peer support groups and up to date information sessions were particularly valued
- Joint working was demonstrated, with accounts of services directing to or liaising with others
- The specialty of different organisations is respected and appreciated

What could be improved:

- Lack of basic awareness of the services on offer
- Accessibility e.g., lack of adjustments (requirement to use the phone), language barriers and insufficient written/leafleted information
- Communication - when accessing or leaving services
- Referrals - pathways can be confusing and difficult, with insufficient information on what is available
- Provisions and consideration for the needs of Children Looked After (CLA), individuals who did not meet eligibility criteria for Special Education Needs (SEND), those presenting with behaviour that challenges or receiving other neurodiversity diagnosis such as ADHD

To make a difference to their lives, what was needed included:

- Greater training and awareness in the community and the workplace
- Timely needs assessments and services
- Autism specific areas in parks, slots at supermarkets and exercise facilities at reasonable times
- Very few have utilised behavioural or emotional support, possibly because there is a real lack of support for distress/stress behaviours if children and young people do not have a learning disability

1.5 National and Local Strategies:

Statutory guidance and national strategies that have informed this Strategy include:

- **Building the right support for people with a learning disability and autistic people (2022)** An action plan to strengthen community support for people with a learning disability and autistic people to reduce reliance on mental health inpatient care.
- **Autism Strategy (2021-2026):** This strategy is a refreshed national strategy for improving the lives of autistic people of all ages and their families and carers. It replaces the adult autism strategy, Think Autism, which was published in April 2014.

- **Reforming the Mental Health Act (White Paper 2021)** Plans to reduce the reliance on specialist inpatient services via alternative community provisions
- **NHS Long Term Plan (2019-2024):** NHS Long term plan has put forward key proposals for people with learning disabilities and autism which help to drive down health inequalities in access to physical health care and improve access to crisis services.
- **Care Act (2014):** The Care Act puts greater emphasis on a strength-based approach to consider people`s own strengths and capabilities from birth to older age.

Local strategies and plans identified as having an important role that align with this Strategy to ensure its success include:

- Harrow Carers Strategy (in development)
- Harrow Enablement Strategy 2020 for Citizens with Learning Disabilities and Autism
- Harrow Adult Social Care Strategy 2020-2023
- Harrow Vision for Community Services July 2020
- Harrow SEND Strategy 2019 – 2024
- Harrow Accommodation, & Support Needs Assessment 2019/20

1.6 The Impact of COVID-19

Since 2020, Harrow senior leaders have reviewed several commissioned research reports and worked with local providers to understand the local impact of COVID-19. It was well recognised that the COVID-19 pandemic exacerbated inequalities and difficulties such as, social isolation, anxiety, and loneliness for both groups. For those in education there was also a negative impact on learning across the board. Access to health and social care was also adversely affected e.g. access to GPs and cancellation of health and care appointments due to the pandemic. Nationally there was an expressed wish for more specific information and advice for people with a learning disability and autistic people. Locally initiatives were put in place to shape and improve the system`s ability to respond appropriately.

In the face of challenges, there were also some benefits expressed by people with a learning disability and autistic people. For example, the availability of virtual spaces increasing their involvement in some meetings and reduced sensory and social overload. These new insights, both positive and negative, will not be lost, but will be considered in relation to any new developments within the Strategy to help create a Borough which is learning disability and autism friendly.

CHAPTER 2: HARROW LEARNING DISABILITIES AND AUTISM STRATEGY OUTCOMES FRAMEWORK 2022-26

Our Vision – 5 Priority Areas

Our vision is for Harrow to be a place where people with learning disabilities and autistic people of all ages live as equal citizens in a community that treats them with dignity and respect, and provides access to high quality services, that supports people to realise their ambitions

To achieve our vision, we will work on five key areas:

1. Work with communities to ensure that people can have good lives and be active and connected in their communities. Citizen's will get and keep jobs and aspirations will develop as they learn new skills.
2. Put plans and systems in place to ensure that support is personalised to individuals and their families. Support will enable greater independence.
3. Ensure that people have the information they need, support and or diagnosis when they need it.
4. Ensure our health services offer preventative support and make the reasonable adjustments people need.
5. Develop the workforce across health, social care, education, and community to be connected and skilled. The workforce will be coordinated, connected, and share information and learning.

To achieve our vision, we will undertake the following:

Partnership Working

This Strategy will involve several different partners working together to make it happen. These include:

- Social care services and providers
- Health services
- Education
- Community organisations
- Housing departments and organisations
- Local businesses
- Local transport providers

Coproduction and Inclusion

We are committed to working with people with learning disabilities and autistic people and families in the implementation of the plans; and to ensure progress is happening. We will:

- Review the existing Strategic Boards to ensure we have the correct representation from key stakeholders
- Develop surveys for people to feedback what has changed and what else they would want to see; and hold forums with citizens to gather their feedback directly
- Ensure community groups from across our diverse Borough have seen our plans and can contribute feedback on progress
- All system partners commit to collect and monitor protected demographics data to ensure plans do not systematically directly or indirectly discriminate against any vulnerable groups

Links to other work

This Strategy will link to other strategies, such as

- Building the right support for people with a learning disability and autistic people (2022)
- Autism Strategy (2021-2026):
- NHS Long Term Plan (2019-2024):
- Care Act (2014)
- Harrow Carers Strategy
- Harrow Enablement Strategy 2020 for Citizens with Learning Disabilities and Autism
- Harrow Adult Social Care Strategy 2020-2023
- Harrow Vision for Community Services July 2020
- Harrow SEND Strategy 2019 – 2024
- Harrow Accommodation, & Support Needs Assessment 2019/20

The Outcome Framework

For each of the five priority areas that make up our future vision, people told us about the outcomes and things that mattered to them. This section describes the things people said matter, what we will work together toward and how we will check if progress is being made.

Part 1: Support that is personalised to people and their families

Important Outcomes	Things we will work on to achieve outcomes	How we'll know if we are progressing
Support is personalised and people can make decisions about how support is provided	<ul style="list-style-type: none"> Ensure we have advocacy available for people who need support to put their wishes across Review our support for personal budgets and personal health budgets so people can use these as direct payments or ISF if they wish 	<p>Count people accessing advocacy and their outcomes and check this is available to people from all communities</p> <p>Count take-up of PBs and PHBs and reviews from eligible clients</p>
<p>People share their story once</p> <p>Support enables independence</p>	<ul style="list-style-type: none"> Improve how we do person-centred planning with people Work across services so people have one plan that is person-centred, based on their aspirations and strengths and shared between those who need it 	<p>Quality check person-centred planning</p> <p>Customer surveys</p>
People can get support in a crisis	<ul style="list-style-type: none"> Review and improve support available for people in a crisis Ensure Care and Support plans include contingency plans 	<p>Details of crisis placements</p> <p>Feedback on quality of support</p>
Families and unpaid carers have the support they need	<ul style="list-style-type: none"> Care and Support Planning and EHCPs consider carer's needs This Strategy is linked to the Carers Strategy so carers can have assessments, support 	Feedback from carers and carer strategy leads locally

	and personal budgets if they need	
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Part 2: People have good and active lives in their local communities

Important Outcomes	Things we will work on to achieve outcomes	How we'll know if we are progressing
People are part of and connected in their communities	<ul style="list-style-type: none"> Work with people with lived experience to raise awareness in businesses, communities and transport, to build autism and learning disability friendly communities. People have good and active lives in their local communities 	<p>Monitor training offered</p> <p>Encourage and monitor partnerships with leisure, business, and transport</p> <p>Quality check people's sense of living in a learning disability and autism friendly community</p>
People have their own aspirations and can develop and learn new skills throughout their lives	<ul style="list-style-type: none"> All planning with people from childhood onwards is focused on their aspirations and strengths Ensure that education, health and social care work well together and that Education Health and Care Plans (EHCPs) include life outcomes as well as educational goals Ensure adults have access to college or other learning and colleges are learning disability and autism friendly Ensure people with profound and multiple 	<p>Quality check people's plans and reviews</p> <p>Count how many children and young people are in education or training</p> <p>Quality check any plans put into place to mitigate against children and young people (statutory school age) being out of education</p> <p>Quality check EHCPs</p>

	learning disabilities are included	
People will get and keep meaningful jobs that are sustainable	<ul style="list-style-type: none"> • Vocational profiles offered to all young people with SEND as part of their education and planning for adulthood • Review and develop our supported employment services for young people and adults • A whole systems approach across social care, health and voluntary sector • Link up all employment providers and services 	<p>Count the number of people in different types of work (paid, unpaid, part time, full time, or ad hoc) and the numbers staying in work for what length of time</p> <p>Creation of extra opportunities for young people and adults</p>
People have homes and live where and with whom they wish	<ul style="list-style-type: none"> • Social care and housing will work together to make a plan for people to get the homes they need • EHCPs ask about homes and housing • Leads for Housing invited to be core members of the local Dynamic Support Register to aid system wide support to those at risk of placement breakdown 	<p>Review who needs to find a home, and who moves each year</p> <p>Feedback from system wide partners and families about the effectiveness of the Dynamic Support Register</p>
People have friends and relationships	<ul style="list-style-type: none"> • Education and social care and community peer support will plan with people to support them with the skills they need to build and keep friendships and relationships 	<p>Check about friendships and relationships in reviews</p>

Part 3: People have the information, support and or diagnosis when the need it

Important Outcomes	Things we will work on to achieve outcomes	How we'll know if we are progressing
<p>People can get the support they need when they need it, with or without a diagnosis</p> <p>People can find the information they need about referrals and support</p>	<ul style="list-style-type: none"> • Robust and clear pathways for autism diagnosis, ADHD and learning disability in children and adults' services • Develop more local community support options for people before diagnosis and after • Put a Preparing for Adulthood (PfA) Strategy in place • Develop our information hub so it includes the information people need from SEND through to adult support • Work with social prescribing link workers to ensure that people with learning disabilities and autistic people have access to this offer 	<p>Waiting list times and diagnosis data</p> <p>Feedback from people and families</p> <p>Website usage and feedback</p> <p>Monitor uptake of social prescribing by people with learning disabilities and autistic people</p>

Part 4: Health services offer preventative support and make the reasonable adjustments people need

Important Outcomes	Things we will work on to achieve outcomes	How we'll know if we are progressing
<p>People can get the support from specialist and community mental health services when needed</p> <p>People are understood and supported with the reasonable adjustments they need</p> <p>People have preventative health support and screening to help them stay well</p> <p>Most complex needs get good support locally</p>	<ul style="list-style-type: none"> • Mental health services to ensure they can meet the needs of people with a learning disability and Autistic people • Those with lived experience and partners to work with GP practices to support them to be learning disability and autistic friendly • Promote and check the use of Health Passports • Annual Health Checks and Health Action Plans offered to everyone over 14 who is autistic or has a learning disability • Provide Local Emergency Protocol Meetings (LAEP) and Community Education Treatment Reviews (CETR) for people with a learning disability and Autistic people to support them to stay well in the community and out of hospital 	<p>Training carried out with mental health services on learning disability and autism</p> <p>Feedback from people with a learning disability and autistic people using mental health services</p> <p>Primary care data on health checks</p> <p>Hospital feedback and complaints</p> <p>Quality checking of Annual Health Checks and Health Action Plans</p>

Part 5: Developing the workforce across health, social care, education, and community

Important Outcomes	Things we will work on to achieve outcomes	How we'll know if we are progressing
<p>All staff across health, social care, community and education have a good understanding of learning disabilities and autism and how to support people</p> <p>The workforce across different organisations are coordinated, connected and share information and learning</p>	<p>Commission training for staff in schools, social care and health services on learning disabilities and autism which is co-delivered by local people with lived experience</p> <p>Ensure the workforce has the skills to meet the outcomes in this Strategy and offer additional training as needed</p> <ul style="list-style-type: none"> • Information sharing agreements between commissioned services • Develop champions networks between services • Health and social care to work closely with key services such as inpatient services, emergency services and the criminal justice system to ensure they are adequately trained to support people with a learning disability and autistic people in their places of work 	<p>Training carried out</p> <p>Info sharing agreements</p> <p>Workforce data</p> <p>Details of champion networks and their activity</p>

CHAPTER 3: PEOPLE WITH A LEARNING DISABILITY

3.1 Definition - 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. There are different types of learning disability that is; mild, moderate, severe, or profound. In all cases a learning disability is lifelong. A learning disability which you are born with is different to a learning difficulty which is where an individual faces a problem in learning e.g., dyslexia.’¹.

3.2 What the data is telling us

Health

Nationally people with a learning disability tend to have shorter life expectancy compared to the general population and more complex health conditions. On average, women with a learning disability have a life expectancy gap of 18 years when compared to women in the general population and it is 14 years shorter for men when compared to men in the general population (NHS Digital 2017). In line with national guidance, Harrow GPs offer annual health checks to address this health inequality. There are around 1,351 people aged 14 years and over, registered on the GPs learning disability register who are eligible for an annual health check by their GP (WSIC, 2022). At least 75% access their health checks yearly. Of the 1351 people registered for health checks most of them fall within the 18-64 age category. They are relatively evenly split across gender. The three largest ethnic groups are White, Asian/Asian British, and Black/Black British respectively. Although 75% of those eligible receive a health check, feedback from stakeholders is to focus on the quality of the checks.

In, 2020/2021 Harrow, 15 deaths of people with a learning disability were reported using the Learning Disability Mortality (death) Review process (LeDeR). The main cause for death reported were related to respiratory conditions. LeDeR process has helped local systems collectively learn from avoidable deaths and will be a key part of the Strategy to continue.

Support

As of December 2021, there were 128 children and young people aged 2 to 18 with learning disabilities, Autism or Asperger’s needs allocated to a Harrow Social Worker. People receiving support has marginally increased since 2017/2018,

¹[What is a learning disability? | Mencap](#)

although the number of people receiving part direct payments reduced from this same period.

Employment

In 2019/20 the number of people with learning disabilities in Harrow who were in employment was significantly lower at 2.8% than other local authorities in the region which is 7.0% and England average of 5.6%.

Education

In 2021, there were 2,180 Harrow resident children and young people with learning disabilities or autism needs as pupils/students. Of these, 1,661 were attending Harrow schools, 356 were attending out of borough settings and 163 were attending Harrow non-state settings. Transition: 682 (31%) of these 2,180 children and young people were aged 14 to 18 (school years 9-13 used as a proxy where age not available).

Housing

124 citizens (85 males and 39 females) under the age of 65 were in registered care homes.

Table 2: Projected Population Trend 2020 – 2040

Data source: www.pansi.org.uk

People in Harrow aged 18-64 predicted to have a learning disability by age

Age Group	2020	2025	2030	2035	2040
18-24	465	436	478	493	461
25-34	886	829	787	804	859
35-44	911	880	818	778	748
45-54	758	778	806	790	746
55-64	664	682	685	699	718
Total population aged 18-64 predicted to have a learning disability	3,684	3,605	3,574	3,565	3,532

If the current trends continue the number of people with a learning disability will decrease in Harrow marginally by 2040.

CHAPTER 4: AUTISTIC PEOPLE

4.1 Definition - Autism

Autism is a spectrum condition and affects people in different ways. It can affect how people perceive, communicate, and interact with others. Like all people, autistic people have their own strengths and weaknesses. Some autistic people will need little or no support in their lives, and others will need high levels of care. Autistic people may have social or communication differences, repetitive and restrictive behaviours, and sensory differences. Many will have high levels of anxiety. They may need support with navigating friendships, education, or the workplace. Ultimately, autistic people want the same opportunities as their non-autistic peers². With an estimated 700,000 autistic adults and children in the UK – approximately 1% of the population – most people probably know someone who is autistic. In addition, there are an estimated 3 million family members and carers of autistic people in the UK³.

4.1.2 Definition - Neurodiversity

'Neurodiversity aims to encourage people to view neurodevelopmental differences such as Attention Deficit Hyperactive Disorder (ADHD) or dyslexia as variations of the human condition. ADHD affects about 3-5% of children and 2% of adults and is more common in males than females 4:1'⁴.

4.2 What the data is telling us

Health

The British Medical Society reported that approximately 700000 people have a diagnosis of Autism with one in 100 children in the UK have a diagnosis of autism spectrum disorder⁵. In Harrow there are 450 people over the age of 18 who are diagnosed with autism and registered with a GP. Health and Social Care Commissioners recognise that this reported number is probably lower than the actual need due to people not obtaining a diagnosis. The health data also shows that ADHD is a growing priority, which is supported by feedback that it needs more attention from statutory services from stakeholders who attended the Workshop sessions in October 2021 and June 2022.

² [What is autism](#)

³ [The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK \(www.gov.uk\)](#)

⁴ [GMCA Guidance Delivering Effective Services \(england.nhs.uk\)](#)

⁵ [Autism spectrum disorder \(bma.org.uk\)](#)

Support

There is currently very little data for adult social care regarding Autistic citizens accessing and receiving support.

Employment

The Disability Employment Gap is wide, with around half of disabled people in work, compared to over 80% of non-disabled people; and the autism employment gap is even wider, with just 22% of autistic people reported in paid work nationally. Autistic people seem to have the worst employment rate; and although not all autistic people can work, evidence suggests that most want to. ⁶

Education

The number of pupils with ASD has increased year on year, increasing from 420 pupils in 2019 to 427 pupils in 2020 and to 445 pupils in 2021. A significant proportion of the pupils with ASD continue to be males, with over 83% in each of the years from 2019 to 2020. Over 60% of the pupils with the primary need ASD do not have a secondary need. In 2021, of the pupils with a secondary need, a fifth of the pupils with ASD have the secondary need of speech, language and communication, as can be seen in the table below. the majority of pupils with ASD in 2021 were of White British ethnic origin (20.2%), Indian ethnic origin (18.9%), Asian Other origin (16.6%) and Other White ethnic origin (9.0%).

Just over two thirds of Harrow school's resident pupils with ASD have an Education Health Care Plan and a third are on SEN support - this has remained consistent over the last three years. Of Harrow's children with an Education Health, Care Plan (EHCP) or a Statement with the primary need of Autistic Spectrum Disorder, 243 pupils were attending an out of borough setting between the period of 1st January 2020 to 11th May 2021.

The proportion of Harrow's 243 children with ASD attend an out of borough setting and the majority of the children attended settings in Hillingdon (31.7%), Hertfordshire (21.0%) and Brent (12.8%). Most of the ASD pupils are not eligible for Free School Meals. However, the percentage of pupil's eligible for FSM increased from 16% in 2019 to 18.7% in 2021.

⁶ [New shocking data highlights the autism employment gap](#)

Housing

The majority of pupils with ASD in 2021 were resident in the following wards – Roxbourne (9.0%), Pinner South (6.7%) and Wealdstone (6.7%). The proportion of pupils with ASD by ward of residence have stayed similar over the last three academic years.

Table 3: Projected Population Trend 2020 – 2040

Data source: www.pansi.org.uk

People in Harrow aged 18-64 predicted to have an autistic spectrum disorder by age

Age Group	2020	2025	2030	2035	2040
18-24	180	167	185	189	179
25-34	372	351	334	338	360
35-44	377	365	346	331	319
45-54	316	328	340	335	320
55-64	289	295	299	308	317
Total population aged 18-64 predicted to have autistic spectrum disorders	1,533	1,507	1,503	1,501	1,495

If the current trends continue the number of people with a diagnosis of autism will decrease in Harrow marginally by 2040.

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- **Deven Pillay** (Chief Executive & Company Secretary), Community ConneX
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Appendix 1 - LD Themes for the LDA Strategy December 2021

The following themes were developed from the stakeholder event in October 2021, and the stakeholder questionnaires September – October 2021.

Themes for Learning Disabilities
<p>Improving pathways to diagnosis and pre / post diagnostic support</p> <p>Areas:</p> <ul style="list-style-type: none"> • Access - person centred, suitable environment, coordination/integration (info sharing) between services, consistent information to stakeholders about what services are available, communication/ information to be more accessible and jargon free e.g., language, easy read • Diagnosis - accessible services for those with diagnosis and without a diagnosis, eligibility, reduce wait times and waiting list, promotion of health passport & health checks • Carer's support - promote carers register, refer for support, support wider health needs • Workforce & Training - training for staff on ADHD support and the difference between learning disabilities and learning difficulties, more services & capacity e.g., emotional support, mental health support, personal care, physiotherapy, reasonable adjustments being standard practice
<p>Building the right support in the community and preventative care</p> <p>Areas:</p> <ul style="list-style-type: none"> • Access - person centred, transition between services, provide consistent information to stakeholders, more LD representation on comms within the local authority, less virtual and more face to face, out of hours services, pricing of services - affordability • Carer's support – promotion of care act assessments, respite, support, informed of rights, advocacy • Crisis support – robust services in place to support people with learning disabilities and their families/carers at the point of or in crisis • Housing - provision of good quality local housing options, a register/list of residential and supported accommodation for carers & clients to review, regular monitoring of LD housing support provisions • Life skills - Education and life skill opportunities including during transition, social support/opportunities in the community • Respite/Personal budgets – good access to personal budgets, respite, short breaks • Transport – available transport to access support in the community, blue badge spaces • Workforce & Training - issues in relation to more staff to provide services and advocate, provisions for people with Downs Syndrome, mental health and personal care support, additional support/ early help akin to Kooth for moderate/ severe LD children
<p>Improving people with a learning disability access to education, employment and supporting positive transitions into adulthood and Improving support within the criminal and youth justice systems</p> <p>Areas:</p> <ul style="list-style-type: none"> • Access - accessibility including for physical health needs, person centred, more face-to-face support, appropriate options to meet the needs of the individuals, with appropriate support where required • Support provided- demystify the EHCP process, support daily living skills, more support and options located within Harrow • Life skills - employment, educational, life skills, sex education and social opportunities – daytime and evening access, peer support, mentoring • Workforce & Training - To understand the issues of people with learning disabilities and their families/carers, more support from staff in schools, better understanding about the transition into adulthood support, improving support and partnerships within the criminal and youth justice systems
<p>Improving understanding and acceptance of learning disabilities within society</p> <p>Areas:</p> <ul style="list-style-type: none"> • Access - Respect, visibility, inclusion, opportunities in the community, more Changing Places Toilets, more disability friendly parks, cafes and activity places, safe spaces • Workforce & Training - awareness training for public settings / shops etc.
<p>Strands to underpin the Strategy</p> <ul style="list-style-type: none"> • Addressing stigma • Provision of culturally competent services • Reaching underserved communities

Appendix 2 - ASD Themes for the LDA Strategy December 2021

The following themes have been developed from the stakeholder event in October 2021, and the stakeholder questionnaires (September – October 2021).

Themes for Autism
<p>Improving pathways for diagnosis and pre / post diagnostic support</p> <p>Areas:</p> <ul style="list-style-type: none"> • Access - person centred, information shared, reasonable adjustments, good communication, convenient appointment times, knowledge of services • Diagnosis - not based on a tick box exercise, simpler pathways, clarity on what information is needed, reduce wait times and waiting list, pre and post diagnosis support, access to the right professionals e.g., SALT • Carer's support – promote carers register, refer for support, support wider health needs, support for carers/families whilst on the waiting list • Workforce & Training – anxiety/OCD and other mental health awareness for staff involved in the care/ support e.g., GPs. Autism training for professionals to better understand autistic adults – particularly late diagnosis, reasonable adjustments being standard practice, access to the right health professionals e.g., OT's, Therapist (adapted therapies autistic people need), physical and mental health needs considered,
<p>Building the right support in the community and preventative care</p> <p>Areas:</p> <ul style="list-style-type: none"> • Access - person centred, transition between services, provide consistent information to stakeholders • Housing - provision of good quality housing with access to outdoor space, consider the needs of autistic people e.g., sensory needs, a register/list of residential and supported accommodation for carers & clients to review • Carer's support – promotion of care act assessments, respite, support, informed of rights, advocacy • Crisis support – robust services in place to support autistic people and their families/carers at the point of or in crisis • Life skills - education, employment, vocational and life skill opportunities including during transition, mentoring service, peer support, improved support for 18–25-year-olds (consider those coming from residential school settings back into the community) • Respite/Personal budgets – good access to personal budgets, respite, short breaks • Transport – available transport to access support in the community • Workforce & Training - mental health awareness, autism awareness and other relevant training for staff involved in the care, more staff available to provide general services and advocate, hub
<p>Improving autistic people's access to education, employment and supporting positive transitions into adulthood</p> <p>Improving support within the criminal and youth justice systems</p> <p>Areas:</p> <ul style="list-style-type: none"> • Access - person centred, transition between services, provide consistent information to stakeholders • Support provided- support for those autistic children without an EHCP, support with executive functioning / daily living skills • Life skills – Education, employment, vocational and life skill opportunities, mentoring service, peer support • Workforce & Training - To understand the issues of autistic people and their families/carers, more support from staff in schools, better understanding about the transition into adulthood support for those with no LD, improving support and partnerships within the criminal and youth justice systems
<p>Improving understanding and acceptance of autism within society</p> <p>Areas:</p> <ul style="list-style-type: none"> • Access - better community understanding of sensory needs, more accessible leisure/community activities, activities that autistic children and siblings can attend together, better transport provision, safe spaces • Workforce & Training - awareness training for public settings / shops etc.
<p>Strands to underpin the Strategy</p> <ul style="list-style-type: none"> • Addressing stigma • Provision of cultural competency services • Reaching underserved communities

Appendix 3 - Glossary of Terms

ADHD	Attention Deficit Hyperactive Disorder
ASD	Autistic Spectrum Disorders, also referred to as Autistic Spectrum Conditions
CAMHS	Child and Adolescent Mental Health Service
CCG	Clinical Commissioning Group
CETR	Community Education Treatment Reviews
CLDT	Community Learning Disability Team
CNWL	Central and North West London NHS Foundation Trust
EHCP	Education, Health and Care Plan
GP	General Practitioner
ICB	Integrated Care Board
ICP	Integrated Care Partnership
JSNA	Joint Strategic Needs Assessment
LA	Local Authority
LAEP	Local Area Emergency Protocol
LD	Learning Disability
LeDeR	Learning Disability Mortality (Death) Review
MH	Mental Health
NDTi	National Development Team for Inclusion
NHSE	NHS England
NWL	North West London
SEN	Special Educational Needs
SEND	Special Educational Needs and Disabilities
TCP	Transforming Care Programme
VSO	Voluntary Sector Organisations
WSIC	Whole Systems Integrated Care