

# Final for Harrow Board

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

		<ul style="list-style-type: none"> <li>Family Support Worker role established - linking schools with parents and carers</li> <li>LD and ASD pathways have been rolled out for adults - further work required for children and transition</li> <li>An all-age Dynamic Risk Register set up and led by health colleagues to support those most at risk of placement breakdown</li> <li>Community Education Treatment Reviews (CETR) &amp; 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</li> </ul>
4	Access to the Community	<p><u>Employment</u></p> <ul style="list-style-type: none"> <li>Second Internship Programme is in progress</li> <li>Shaw Trust Work and Health Programme</li> <li>Prince's Trust courses</li> <li>Developed links with Job Centre Plus</li> <li>Developed links with Work and Health Programme</li> <li>Exploring other employment options and models</li> </ul> <p><u>Housing and Support</u></p> <ul style="list-style-type: none"> <li>Housing and needs assessment carried out in 2019/20</li> <li>Applied for Transforming Care Programme (TCP) funding for respite - unsuccessful</li> <li>Task &amp; 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</li> </ul>
5	Autism Specific	<ul style="list-style-type: none"> <li>Harrow has a clearly identified strategic lead - Assistant Director - Specialist Learning Disabilities Care and CYAD Services</li> <li>Training is currently rolled out to social care staff in children and adult services</li> <li>GP Master Class training available</li> <li>External service has been commissioned to support early years and adults</li> <li>CAMHS ADHD Service - nurse led, working closely with Centre for ADHD and Autism Support</li> </ul>
6	Learning Disabilities Specific	<ul style="list-style-type: none"> <li>LD pathway in place and is monitored by the LD Health and Social Care Focus Group</li> <li>Coordinate My Care in place</li> <li>Formal Crisis Pathway completed and launched</li> <li>Learning Disability Mortality (Death) Review introduced in Harrow to support learning and improve services</li> </ul>
<i>Other Highlights</i>		<ul style="list-style-type: none"> <li>Integrated LD Health Service was established in November 2019</li> <li>LDA Enablement Project Pilot implemented December 2020</li> </ul>

#### **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 (see Appendix 3 Workshop Presentation, June 2022).

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



### 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
2. Put plans and systems in place to ensure that support is personalised to individuals and their families
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

## 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"> <li>Ensure we have advocacy available for people who need support to put their wishes across</li> <li>Review our support for personal budgets and personal health budgets so people can use these as direct payments or ISF if they wish</li> </ul>	<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"> <li>Improve how we do person-centred planning with people</li> <li>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</li> </ul>	<p>Quality check person-centred planning</p> <p>Customer surveys</p>
People can get support in a crisis	<ul style="list-style-type: none"> <li>Review and improve support available for people in a crisis</li> <li>Ensure Care and Support plans include contingency plans</li> </ul>	<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"> <li>Care and Support Planning and EHCPs consider carer's needs</li> <li>This Strategy is linked to the Carers Strategy so carers can have assessments, support and personal budgets if they need</li> </ul>	<p>Feedback from carers and carer strategy leads locally</p>

## 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"> <li>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</li> </ul>	<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"> <li>All planning with people from childhood onwards is focused on their aspirations and strengths</li> <li>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</li> <li>Ensure adults have access to college or other learning and colleges are learning disability and autism friendly</li> <li>Ensure people with profound and multiple learning disabilities are included</li> </ul>	<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>
People will get and keep meaningful jobs that are sustainable	<ul style="list-style-type: none"> <li>Vocational profiles offered to all young people with SEND as part of their education and planning for adulthood</li> <li>Review and develop our supported employment services for young people and adults</li> </ul>	<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>

	<ul style="list-style-type: none"> <li>• A whole systems approach across social care, health and voluntary sector</li> <li>• Link up all employment providers and services</li> </ul>	Creation of extra opportunities for young people and adults
People have homes and live where and with whom they wish	<ul style="list-style-type: none"> <li>• Social care and housing will work together to make a plan for people to get the homes they need</li> <li>• EHCPs ask about homes and housing</li> <li>• 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</li> </ul>	<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"> <li>• 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</li> </ul>	Check about friendships and relationships in reviews

### 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"> <li>• Robust and clear pathways for autism diagnosis, ADHD and learning disability in children and adults' services</li> <li>• Develop more local community support options for people before diagnosis and after</li> <li>• Put a Preparing for Adulthood (PfA) Strategy in place</li> </ul>	<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>

	<ul style="list-style-type: none"> <li>• Develop our information hub so it includes the information people need from SEND through to adult support</li> <li>• Work with social prescribing link workers to ensure that people with learning disabilities and autistic people have access to this offer</li> </ul>	
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**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 most complex needs</p>	<ul style="list-style-type: none"> <li>• Mental health services to ensure they can meet the needs of people with a learning disability and Autistic people</li> <li>• Those with lived experience and partners to work with GP practices to support them to be learning disability and autistic friendly</li> <li>• Promote and check the use of Health Passports</li> <li>• Annual Health Checks and Health Action Plans offered to everyone over 14 who is autistic or has a learning disability</li> <li>• 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</li> </ul>	<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"> <li>• Information sharing agreements between commissioned services</li> <li>• Develop champions networks between services</li> <li>• 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</li> </ul>	<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.'<sup>1</sup>

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

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<sup>1</sup>[What is a learning disability? | Mencap](#)

## 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](http://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 peers<sup>2</sup>.

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 UK<sup>3</sup>.

#### 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'<sup>4</sup>.

### 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 disorder<sup>5</sup>. 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.

#### Support

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

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<sup>2</sup> [What is autism](#)

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

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

<sup>5</sup> [Autism spectrum disorder \(bma.org.uk\)](#)

## 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. <sup>6</sup>

## 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.

## 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.

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<sup>6</sup> [New shocking data highlights the autism employment gap](#)

**Table 3: Projected Population Trend 2020 – 2040**

Data source: [www.pansi.org.uk](http://www.pansi.org.uk)

People in Harrow aged 18-64 predicted to have a autistic spectrum disorders 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.

## ACKNOWLEDGEMENTS

The Strategy was completed with the help of several contributors who came together to champion the same vision of improving the lives of people with learning disabilities and autistic people. Contributors included those with lived experience, families, carers and professionals.

We would therefore like to acknowledge members of the **Learning Disability and Autism (LDA) Strategy Working Group**:

- **Oasis Azeez-Harris** (Strategic Commissioning Manager), Harrow Council
- **Safron Simmonds** (Programme Delivery Manager), NWL ICB (Harrow)
- **Lennie Dick** (Head of Joint Commissioning for Mental Health, Learning Disabilities and Autism), NWL ICB (Harrow)
- **Santokh Dulai** (Assistant Director), Harrow Council
- **Mital Vagdia** (Senior Strategic Commissioning Manager), Harrow Council
- **Deven Pillay** (Chief Executive & Company Secretary), Community Connex
- **Marie Pate** (Business Manager Corporate Services), Community Connex
- **Lynne Laverty** – (Managing Director Autism), Centre for Autism and ADHD Support (CASS)

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- All members of the Harrow Learning Disability Strategic Partnership Group and the Harrow Autism Strategic Partnership Group formerly known as Harrow Learning Disability Focus Group and the Harrow Autism Focus Group respectively
- **David House** (Advocate), Community Connex
- **Helen Fleetwood** (Adult Services Manager), Centre for Autism and ADHD Support (CASS)
- **Vicky Leech** (Steering Group Member Chair), Harrow Parent Carer Group
- **Patricia Penfold** (Carer Representative, Carer Facilitator, Co-Chair)
- **Elizabeth Hugo** (Self Advocate), Aspergers Syndrome Access to Provision (ASAP)
- **Beatrice Cingtho-Taylor** (Interim Head of Housing Needs), Harrow Council
- **Meghan.Zinkewich-Peotti** (Housing Strategy Project Manager), Harrow Council
- **Jonathan Kilworth** (Business Intelligence Partner), Harrow Council
- **Madeline Cooper** (Programme Lead), National Development Team for Inclusion (NDTi)
- **Lyn Griffiths** (Development Lead – Learning Disability), National Development Team for Inclusion (NDTi)

Although it is not possible to mention everyone by name, we would like to say a big thank to everyone who participated in the workshops and shared comments directly or via a membership organisation with members of the Learning Disability and Autism (LDA) Strategy Working Group.

## 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><b>Improving pathways to diagnosis and pre / post diagnostic support</b></p> <p><b>Areas:</b></p> <ul style="list-style-type: none"> <li>• <b>Access</b> - 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</li> <li>• <b>Diagnosis</b> - accessible services for those with diagnosis and without a diagnosis, eligibility, reduce wait times and waiting list, promotion of health passport &amp; health checks</li> <li>• <b>Carer's support</b> - promote carers register, refer for support, support wider health needs</li> <li>• <b>Workforce &amp; Training</b> - training for staff on ADHD support and the difference between learning disabilities and learning difficulties, more services &amp; capacity e.g., emotional support, mental health support, personal care, physiotherapy, reasonable adjustments being standard practice</li> </ul>
<p><b>Building the right support in the community and preventative care</b></p> <p><b>Areas:</b></p> <ul style="list-style-type: none"> <li>• <b>Access</b> - 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</li> <li>• <b>Carer's support</b> – promotion of care act assessments, respite, support, informed of rights, advocacy</li> <li>• <b>Crisis support</b> – robust services in place to support people with learning disabilities and their families/carers at the point of or in crisis</li> <li>• <b>Housing</b> - provision of good quality local housing options, a register/list of residential and supported accommodation for carers &amp; clients to review, regular monitoring of LD housing support provisions</li> <li>• <b>Life skills</b> - Education and life skill opportunities including during transition, social support/opportunities in the community</li> <li>• <b>Respite/Personal budgets</b> – good access to personal budgets, respite, short breaks</li> <li>• <b>Transport</b> – available transport to access support in the community, blue badge spaces</li> <li>• <b>Workforce &amp; Training</b> - 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</li> </ul>
<p><b>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</b></p> <p><b>Areas:</b></p> <ul style="list-style-type: none"> <li>• <b>Access</b> - 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</li> <li>• <b>Support provided</b>- demystify the EHCP process, support daily living skills, more support and options located within Harrow</li> <li>• <b>Life skills</b> - employment, educational, life skills, sex education and social opportunities – daytime and evening access, peer support, mentoring</li> <li>• <b>Workforce &amp; Training</b> - 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</li> </ul>
<p><b>Improving understanding and acceptance of learning disabilities within society</b></p> <p><b>Areas:</b></p> <ul style="list-style-type: none"> <li>• <b>Access</b> - Respect, visibility, inclusion, opportunities in the community, more Changing Places Toilets, more disability friendly parks, cafes and activity places, safe spaces</li> <li>• <b>Workforce &amp; Training</b> - awareness training for public settings / shops etc.</li> </ul>
<p><b>Strands to underpin the Strategy</b></p> <ul style="list-style-type: none"> <li>• Addressing stigma</li> <li>• Provision of culturally competent services</li> <li>• Reaching underserved communities</li> </ul>

## 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><b>Improving pathways for diagnosis and pre / post diagnostic support</b></p> <p><b>Areas:</b></p> <ul style="list-style-type: none"> <li>• <b>Access</b> - person centred, information shared, reasonable adjustments, good communication, convenient appointment times, knowledge of services</li> <li>• <b>Diagnosis</b> - 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</li> <li>• <b>Carer's support</b> – promote carers register, refer for support, support wider health needs, support for carers/families whilst on the waiting list</li> <li>• <b>Workforce &amp; Training</b> – 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,</li> </ul>
<p><b>Building the right support in the community and preventative care</b></p> <p><b>Areas:</b></p> <ul style="list-style-type: none"> <li>• <b>Access</b> - person centred, transition between services, provide consistent information to stakeholders</li> <li>• <b>Housing</b> - 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 &amp; clients to review</li> <li>• <b>Carer's support</b> – promotion of care act assessments, respite, support, informed of rights, advocacy</li> <li>• <b>Crisis support</b> – robust services in place to support autistic people and their families/carers at the point of or in crisis</li> <li>• <b>Life skills</b> - 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)</li> <li>• <b>Respite/Personal budgets</b> – good access to personal budgets, respite, short breaks</li> <li>• <b>Transport</b> – available transport to access support in the community</li> <li>• <b>Workforce &amp; Training</b> - 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</li> </ul>
<p><b>Improving autistic people's access to education, employment and supporting positive transitions into adulthood</b></p> <p><b>Improving support within the criminal and youth justice systems</b></p> <p><b>Areas:</b></p> <ul style="list-style-type: none"> <li>• <b>Access</b> - person centred, transition between services, provide consistent information to stakeholders</li> <li>• <b>Support provided</b>- support for those autistic children without an EHCP, support with executive functioning / daily living skills</li> <li>• <b>Life skills</b> – Education, employment, vocational and life skill opportunities, mentoring service, peer support</li> <li>• <b>Workforce &amp; Training</b> - 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</li> </ul>
<p><b>Improving understanding and acceptance of autism within society</b></p> <p><b>Areas:</b></p> <ul style="list-style-type: none"> <li>• <b>Access</b> - 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</li> <li>• <b>Workforce &amp; Training</b> - awareness training for public settings / shops etc.</li> </ul>
<p><b>Strands to underpin the Strategy</b></p> <ul style="list-style-type: none"> <li>• Addressing stigma</li> <li>• Provision of cultural competency services</li> <li>• Reaching underserved communities</li> </ul>

## Appendix 3 - Harrow Strategy Meeting Presentation June 2022 – Main Slides

Community CONNEX Strategy for people with learning disabilities and autistic People of all ages who live in Harrow

Centre for ADHD & Autism Support

Harrow COUNCIL LONDON

NHS North West London

Welcome

- 1 ~~~~~
- 2 ~~~~~
- 3 ~~~~~
- 4 ~~~~~
- 5 ~~~~~

### Agenda:

- How the strategy has been developed so far
- What people said matters
- Group Conversation: Have we missed anything?
- Priorities for what is worked on first
- Group Conversations: How shall we involve people well going forward?



Developing the Strategy so far

Plan



Working group with partners set up in June 2021

#### Stakeholder questionnaires

- 44 professionals
- 122 local people
  - 41 (aged 16),
  - 20 (aged 16 to 25)
  - 61 (aged 25 and over)

Survey results were analysed by Community Connex



Developing the Strategy so far

Plan



4 online meetings with people with lived experience and supporters were held in October 2021

- 64 people joined the 2 meetings about what matters to people with learning disabilities
- 51 people joined the 2 meetings to talk about what matters to autistic people



NDTI have visited some people in their homes

Some people including young people have sent their thoughts in writing



We want to keep listening and hear more voices!



Developing the Strategy so far

Plan



Some things we heard about what is going well

Some things need to improve

#### Next steps

Lots of people- in education, health, social care and communities- will need to work together to ensure people have a good life



Some big themes

Personalised care and support for people and families

Information, diagnosis, referrals and support when people need them

People have good and active lives in their local communities

Health care is preventative, responsible and reasonably adjusted

A skilled, connected and supported workforce



Personalised care and support for people and families



People said its important:

- They make decisions about their own support
- To share their story once
- People or Families are confident they could help someone take on a personal budget
- Families get the support they need
- People can get support when they need- including in a crisis
- Support enables people to be independent



Things that can be done to improve personalised care and support

Plan

Join: [vevox.app ID: 186-298-752](https://vevox.app/join/186-298-752) **POLL OPEN**

### What 3 things do you think are most important?



Information, diagnosis and referrals available when people need them

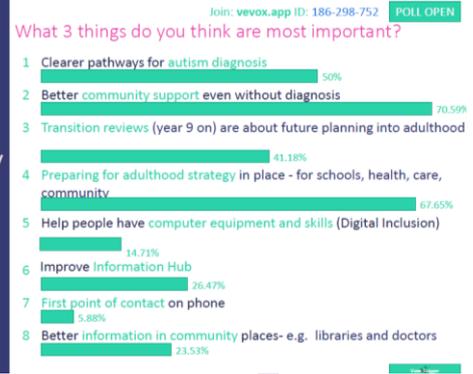


People said its important:

- They can get support at the right time, even if they don't have a diagnosis
- They can get a diagnosis if they want one
- People and supporters can find the information they need to get support



Things that could be done to improve people getting information, diagnosis and support when they need it



People have good and active lives in their local communities

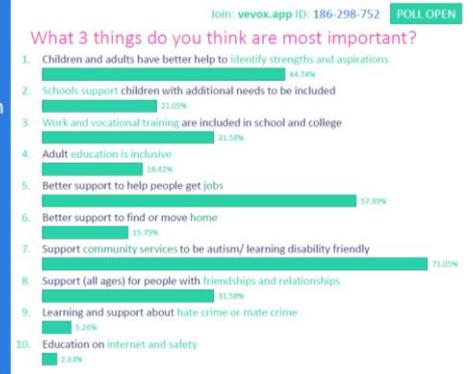


People said they want:

- opportunities to learn new skills – from childhood and through life
- paid jobs
- to be connected and visible in their communities
- friends and relationships
- to feel safe
- homes where and with whom they wish



Things that could be done so people have good and active lives in their local communities



Healthcare is preventative, responsive and reasonably adjusted

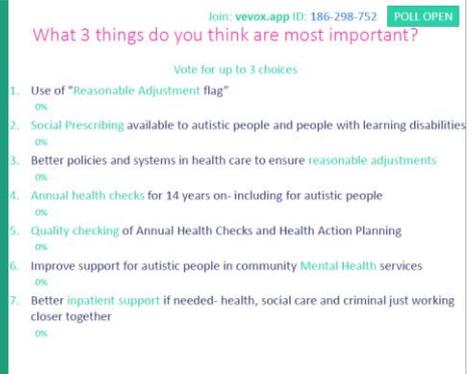


People said its important:

- they are understood and supported with the reasonable adjustments they need
- That healthcare and screening helps people to stay well
- they can get specialist mental health support when they need it
- People with the most complex needs get good support locally (including people in touch with criminal justice or mental health systems)



Healthcare is preventative, responsive and reasonably adjusted



A skilled, connected and well supported workforce

For people have good support in health, education care and community it will be important that:

- Different teams work well together
- All staff have a good understanding of autism, learning disabilities and how people experience those



## Appendix 4 - Glossary of Terms

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

## Appendix 5 - Glossary for Parents, Carers and Professionals (Courtesy of Harrow Parent Carer Forum)

# The useful SEND Glossary



A guide to understanding the words and terms you may come across in relation to special educational needs and disability.

**Additional Needs:** Another term for Special Education Need and/or Disability (SEND).

**ADHD:** Attention Deficit Hyperactivity Disorder is a group of behavioural symptoms that include inattentiveness, hyperactivity and impulsiveness.

**Adult Social Care and Support/ASC:** For Adults who need extra help to manage their lives and be care independent, This includes residential care homes, home care, personal assistants, day centres etc

**Advocacy:** Helps to enable you to get the care and support you need that is independent of your local council. They can help you find services, make sure correct procedures are followed and challenge decisions made by councils or other organisations.

**Aids and Adaptations:** Help to make things easier for you around the home. You may also need changes to your home to make it easier and safer to get around e.g. grab rails, ramps, walk-in showers, stair lifts etc.

**Annual Review:** A review plan which the Local Authority must undertake at least every 12 months (EHCP, care plans etc.)

**APD:** Auditory Processing Disorder

**ARMS:** Additionally Resourced Mainstream School

**ASD/ASC:** Autistic Spectrum Disorder or Condition is a 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.

**Assessments:** The process of working with you to identify what your needs are and how to go forward to get the best outcome. For a child, this would be with a parent/carer/social worker. For an adult this would be with an Adult Carer/Parent Carer. This is an all age process ie. Parent/Carer assessment, Adult Carer assessment, Young Carer assessment etc.

**Benefits:** Payments from the Government that you may receive because of your age, disability, income or caring responsibilities.

**Broker (also called 'Care Navigator'):** Someone whose job it is to provide you with advice and information about services available in your area.

**CAMHS:** Child and Adolescent Mental Health Services: These services assess and treat children/young people with emotional, behavioural or mental health difficulties.

**Care Plan:** A record of the health and/or social care services that are being provided to a person to help them manage a disability or health condition.

**Carer:** A person who provides unpaid support to a partner, child/young person, family member who could not manage without this help.

**Caseworker:** A named officer of the local authority who will deal with your child's case and who will talk to you if you have an enquiry or concern.

**CCG:** Clinical Commissioning Groups. They are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. After a national programme of restructuring, Harrow now comes under North West London CCG. CCGs are led by an elected governing body made up of GPs, other clinicians and lay members. They are responsible for the majority of spending on the NHS in England and commissioning healthcare for their populations including mental health services, urgent and emergency care, elective hospital services, and community care.

**CETR - Care, Education & Treatment Review:** A Care, Education and Treatment Review (CETR) or Care and Treatment Review (CTR) is for anyone with a learning disability, autism or both; and is at risk of admission to/or who is already in a specialist learning disability or mental health hospital.

There are two different types of meetings both with its own code and toolkit:

1) children and young people - Care, Education and Treatment Review (CETR); and

2) adults Care and Treatment Review (CTR).  
Care, education and treatment reviews fall part of

## The useful SEND Glossary



a greater scheme called the 'Transforming Care Programme'. The programme is 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 and improve outcomes for them.

**CHC:** See NHS Continuing Healthcare.

**Citizen:** a person who is a member of a particular country and who has rights because of being born there or because of being given rights, or a person who lives in a particular town or city.

**Client Contribution:** The amount you may need to pay towards the cost of the social care services you receive. Whether you need to pay, and the amount you need to pay, depends on your local council's charging policy.

**Commissioner:** A person or organisation that plans the services that are needed by the people who live in the area the organisation covers and ensures that services are available.

**Community Mental Health Teams (CMHTs):** These teams provide support to people with mental illness who are living in the community. They are made up of a range of professionals including psychiatrists, community psychiatric nurses, occupational therapists and support workers.

**Community Services:** Services that are delivered in a wide range of settings such as homes, community clinics, community centres and schools. They commonly include adult community nursing, specialist long-term condition nursing, therapy services, preventive services such as sexual health and smoking cessation clinics, and child health services including health visiting and school nursing. These services aim to keep people well, treat and manage diseases and support people to live independently in their own homes. This can also include voluntary organisations.

**Community Services are divided into:**

- 1. Community Care Services:** Social care services that can help you live a full, independent life and to remain in your own home for as long as possible.
- 2. Community Health Services:** Health Services that are provided outside hospitals, such as district nursing.

**Community Paediatricians:** Specialist children's doctors who are trained and contribute to pathways of care of children with a range of conditions and needs. They will co-ordinate services for those with neuro-disability, chronic illness and other special needs, including intellectual disability, Autism and ASD.

**Community Mental Health Teams Services (CMHTs):** These teams provide support to people with mental illness who are living in the community. They are made up of a range of professionals including psychiatrists, community psychiatric nurses, occupational therapists and support workers.

**Comorbidity:** Comorbidity is the simultaneous coexistence of multiple disorders alongside a primary disorder. Common comorbid conditions are depression, anxiety, schizophrenia and addiction. In children, we often see comorbid conditions of ADHD, learning disabilities and others.

**Co-production:** When you as an individual are involved as an equal partner in designing the support and services you receive. Co-production recognises that people who use Council, Services social care services, health Services (and their families) have knowledge and experience that can be used to help make services better, not only for themselves but for other people who need social care.

**CYAD:** Children and Young Adults 0-25 Disabilities Services. (NB. This is a service name used within the Borough of Harrow and may differ for other local authorities.)

**Deprivation of Liberty Safeguards (DoLS):** An amendment to the Mental Capacity Act 2005 that is only applicable in England and Wales introduced these safeguards. They ensure that people who can't consent to their own care arrangements in a care home or hospital are protected if those arrangements deprive them of their liberty. Authorisation is given by a local authority and is subject to an independent assessment that the arrangements are necessary and in the person's best interests.

**DfE:** Department for Education

**DFG:** Disabled Facilities Grants issued by your local council if you're disabled and need to make changes to your home.

**Direct Payments/DP:** Money that is paid to you (or someone acting on your behalf) on a regular basis by your local council so you can arrange your own support, instead of receiving social care services arranged by the council. Direct payments are available to people who have been assessed as being eligible for council funded social care. They are not yet available for residential care. This is one type of personal budget.

**Disagreement Resolution:** This is a statutory service commissioned by local authorities to provide a quick and non-adversarial way of resolving disagreements between parents or young people and bodies

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responsible for providing education, whether the child or young person has an EHC plan or not, or health and social care in relation to EHC assessments and plans.

**DLA/Disability Living Allowance:** This is a benefit for children under 16 years with a disability.

**DSA:** Disabled Students Allowance: Financial support for undergraduate or post-graduate students who have SEN/disability or long-term health condition, mental health condition or specific learning difficulty which affects their ability to study. It can be used to pay for things such as special equipment, a note-taker or transport costs.

**DTocS:** Delayed transfers of care (from hospital to home or another care setting).

**EBD:** Emotional and Behavioural Difficulties

**EHCP / Education, Health and Care plan:**  
An EHC plan details the education, health and social care support to be provided to a child or young person who has SEN or a disability. It is drawn up by the local authority after an EHC needs assessment of the child or young person has determined that an EHC plan is necessary.

**Eligibility:** When your needs meet your council's criteria for council-funded care and support.

**EP/Educational Psychologist/Ed Psych:**  
Educational Psychologist: Helps in assessing your child's special educational needs and giving advice to schools.

**EYS / Early Years Settings:** All pre-school education provision such as nursery classes and schools, day nurseries and play groups.

**FE / Further Education college:** A college offering continuing education to young people over the compulsory school age of 16.

**Gifted and Talented:** This can be in different fields e.g. Education, Sport and Arts

**Healthwatch England:** An independent consumer champion, gathering and representing the views of the public about health and social care services in England.

**HE:** Higher Education meaning University

**HI:** Hearing Impairment

**Home Care:** Care provided in your own home by paid care workers to help you with your daily life. It is also

known as domiciliary care. Home care workers are usually employed by an independent agency, and the service may be arranged by your local council or by you (or someone acting on your behalf).

**IEP/Individual Education Plan:** this is a school plan to help with the child's or young person's education needs.

**IHP:** Individual Health Plan this is a school plan to help with the child's or young person's health needs.

**Inclusion:** Mainstream school can use this word as another word for SEND so they may have an Inclusion Leader/Manager instead of SENCO meaning to make education all inclusive.

**Independent living:** The right to choose the way you live your life. It does not necessarily mean living by yourself or doing everything for yourself. It means the right to receive the assistance and support you need so you can participate in your community and live the life you want.

**Independent school:** A school that is not maintained by a local authority and is governed by an elected board of governors.

**IS / Independent Supporter:** An individual who is independent from the local authority and is trained to provide advice and support for families with children with SEND through the statutory assessment and EHC process.

**Integrated Care:** Joined up, coordinated health and social care that is planned and organised around the needs and preferences of the individual, their carer and family. This may also involve integration with other services for example education, housing etc.

**Integrated Care Systems (ICSs):** Partnerships that bring together providers and commissioners of NHS services, across a geographical area with local authorities and other local partners, and voluntary sector to collectively plan and integrate care to meet the needs of their population - Kings Fund, 2020.

**Integrated Care Partnerships (ICPs):** Comprised of local health, care and voluntary sector organisations that deliver care to a local place based population. Coming together and working collaboratively to improve the health and care of a local population and include the NHS, Local Authority and the voluntary sector organisations.

**LA / Local Authority:** The council.

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**Local Offer:** Local authorities in England are required to set out in their Local Offer information about provision they expect to be available across education, health and social care for children and young people in their area who have SEN or are disabled.

**Learning Difficulties:** Where a child has a significantly greater difficulty in learning than the majority of others of the same age, or has a disability which prevents or hinders him or her from making use of educational facilities.

**Learning Disabilities:** A learning disability affects the way a person learns new things throughout their lifetime and the way they understand information and how they communicate.

This means they can have difficulty:

- understanding new or complex information
- learning new skills
- coping independently

**Multi Agency Safeguarding Hub (MASH):** Has been set up to enable sharing of information between services so risks to children can be identified at an early stage.

**Mediation:** A statutory service commissioned by local authorities which is designed to help settle agreements between parents or young people and local authorities over EHC needs assessments and plans.

**Mental Health Support Teams (MHST):** working in schools with a focus on early intervention. Working in partnership with the school community and other wellbeing services to develop a whole school approach to mental health and wellbeing, building on what is being done already in the local area.

**National curriculum:** This sets out clear, full and statutory entitlement to learning for all pupils, determining what should be taught and setting attainment targets for learning.

**NEET:** Not in Education, Employment or Training.

**NHS Continuing Healthcare:** To qualify for Continuing Healthcare funding, it must be proven that you have a 'primary health need'. This means that your care requirements are primarily for healthcare, rather than social or personal care needs. This is usually judged via a two-step assessment process; a Checklist followed by a Full Assessment. There is more information on the .GOV website.

**NHS England:** An independent body which aims to improve health outcomes for people in England by driving up the quality of care.

**Non-Maintained Special School:** Schools in England approved by the Secretary of State as special schools which are not maintained by the state but charge fees on a non-profit-making basis. Most non-maintained special schools are run by major charities or charitable trusts.

**OFSTED/ Office for Standards in Education:** A government department taking responsibility for the inspection of services providing education and skills for learners of all ages. They also inspect and regulate services that care for children and young people.

**OT / Occupational Therapy:** Aims to improve your ability to do everyday tasks if you're having difficulties.

**Outcomes:** Refers to an aim or objective you would like to achieve or need to happen – EG. continuing to live in your own home, or being able to go out and about. You should be able to say which outcomes are the most important to you and receive support to achieve them.

**Paediatrics:** Relating to the medical/health care of children so paediatric health services covers the range of medical and health provision for children.

**Parent Carer Forum:** A group of parents and carers of disabled children who work with local authorities, education, health and other providers to make sure the services they plan and deliver meet the needs of disabled children and families.

**PCN:** Primary care networks (PCNs) enable general practices to work together at scale leading to coordinated approaches around locality practices - including improving the ability of practices to recruit and retain staff; to manage financial and estates pressures; to provide a wider range of services to patients and to more easily integrate with the wider health and care system. There are currently 5 PCNs in Harrow, each covering between 3 and 11 general practices.

**Personal Assistant:** Someone you choose and employ to provide the support you need, in the way that suits you best. This may include cooking, cleaning, help with personal care such as washing and dressing, and other things such as getting out and about in your community. Your personal assistant can be paid through direct payments or a personal budget.

**Personal Budget/PB:** An amount of money identified by the local authority to deliver provision set out in an EHC plan where the parent or young person is involved in securing that provision. The funds can be held directly by the parent or young person or may be held and managed on their behalf by the local authority.

**PIP/Personal Independence Payment:** Payment that



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can help with some of the extra costs if you have a long term physical or mental health condition or disability.

**PMLD/Profound and Multiple Learning Disability:**

This diagnosis is used when a child has more than one disability, with the most significant being a learning disability. Many children diagnosed with PMLD will also have a sensory or physical disability, complex health needs, or mental health difficulties.

**Post 16:** Next options are full time Education e.g. School or College and or apprenticeships, training or Internships.

**Portage:** Planned, home-based educational support for pre-school children with special educational needs. Local authorities usually provide Portage Services. There is an active and extensive network of Portage Services in the UK.

**PRU / Pupil Referral Unit:** A specially organised school which provides education for pupils who would otherwise not receive suitable education because of illness, exclusion or any other reason.

**PT/Physiotherapy/Physio**

**PVIs:** Private, Voluntary and Independent setting/ organisations.

**Referral:** A process of making an application for someone to be seen by an organisation. That organisation can be statutory or voluntary and it can be for an assessment, information, support and/or guidance.

**Residential Care:** Care in a care home, with or without nursing, for older people or people with disabilities who require 24-hour care. Care homes offer trained staff and an adapted environment suitable for the needs of ill, frail or disabled people.

**Respite Care (Children):** (also known as **Short Breaks**): Identified package of support to give parent/carers a break from caring. Short breaks can be overnight care for the child/young person with disabilities, activities or a carer. Families may also be receiving support from the Children with Disabilities Service.

**Respite Care (Adults):** A service giving carers a break, by providing short-term care for the person with care needs in their own home or in a residential setting. It can mean a few hours during the day or evening, 'night sitting', or a longer-term break. It can also benefit the person with care needs by giving them the chance to try new activities and meet new people.

**Review:** When you receive a re-assessment of your

needs and you and the people in your life look at whether the services you are receiving are meeting your needs and helping you achieve your chosen outcomes. Changes can then be made if necessary.

**Risk assessment:** An assessment of your health, safety, wellbeing and ability to manage your essential daily routines.

**Safeguarding:** The process of ensuring that children, young people and adults at risk are not being abused, neglected or exploited, and ensuring that people who are deemed 'unsuitable' do not work with them.

**SEMH:** Social Emotional Mental Health

**Self-funding:** When you arrange and pay for your own care services and do not receive financial help from the council.

**SEND:** Special Education Needs and or Disability

**SENARS:** Special Educational Needs Assessment and Review Service. (NB. This is a service name used within the Borough of Harrow and may differ for other local authorities.)

**SENCO / Special Educational Needs**

**Co-ordinator:** The teacher with responsibility for the planning and monitoring of the special educational provision within your child's school.

**SEN Code of Practice:** A government document which provides practical advice to those carrying out their statutory duties to identify, assess and make provision for children's special educational needs.

**SEND IASS/SENDIAS:** Special Educational Needs and Disabilities Information, Advice and Support Service. Provides information and support to parents/carers whose children have special educational needs.

**SEN Support:** The additional or different help/support given to children with special educational needs, designed to help them access the National Curriculum.

**Short Breaks:** See Respite Care.

**Signposting:** Directing parents / carers to other sources of information, support and services.

**SLD:** Severe Learning Disabilities.

**SLT / Speech and Language Therapy / SaLT:**

Speech and language therapy is a health care profession, the role and aim of which is to enable children, young people and adults with speech, language and communications difficulties to reach their

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maximum communication potential.

**Social Worker:** A professional who works with individual people and families to help improve their lives by arranging to put in place the things they need. This includes helping to protect adults and children from harm or abuse and supporting people to live independently. Social workers support people and help them find the services they need. They may have a role as a care manager, arranging care for service users. Many are employed by councils in adult social care teams; others work in the NHS or independent organisations.

**Special School:** A school that is organised to make special educational provision for pupils with SEN and available for children with Statements of Educational Needs/EHC plans.

**Statutory Assessment:** A detailed assessment of a person's needs that a Local Authority must undertake. For children this relates to the child's special educational needs, which informs the EHC plan.

**Transition:** Significant change in a person's life E.g. primary to High School, College, University or child to

adult.

**Transition Plan:** A plan drawn up after the Year 9 Annual Review of a statement/EHC plan that draws together information from a range of individuals to plan for the young person's transition to adult life.

**Tripartite Panel:** Harrow Children's Tripartite Panel is the mechanism for deciding on funding for treatment and care of Harrow's children and young people (C&YP) aged 0-18 years, with complex needs, through Harrow Local Authority and NHS Harrow Clinical Commissioning Group. The panel will decide if there are education and care and /or health needs or a combination of these needs that does not fall into already commissioned services and agree funding splits across education, care and health.

**VI (Visual Impairment):** Those with problems with their vision who need support.

**Wellbeing:** Being in a position where you have good physical and mental health, control over your day-to-day life, good relationships, sufficient money, and the opportunity to take part in activities that interest you.

[www.harrowparentforum.org](http://www.harrowparentforum.org)  
[info@harrowparentforum.org](mailto:info@harrowparentforum.org)  
07928 577 689

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