

# Ealing Autism Partnership Board

## Strategic Action Plan for Autistic People 2023 - 2028

In Ealing, we want autistic people and their families and friends to be able to live their lives as they wish, and to be able to contribute to and benefit from their communities. Every autistic person is different. For autistic people's lives to improve the lead must come from autistic people themselves and their families and friends.

Our Autism Partnership Board aims to bring together everyone who shares this aim to plan and ensure delivery of real changes and improvements in Ealing.

Not everyone likes the term 'autistic people', preferring 'people with autism'. We recognise both as valid, and for simplicity, have followed the National Autistic Society in using Autistic People.

While developing this Strategic Action Plan we have had input from a range of people, including autistic adults and children and their families.

**We will continue to talk with autistic people and their families and friends. This Plan will be a living document as we learn more about people's experiences and needs and part of our commitment is to ensure this happens.**

This Plan includes autistic people who have other conditions, including a learning disability (whose needs are addressed in the Ealing Strategy for People with Learning Disabilities), other neurodevelopmental conditions, and mental health needs.

### This Document

This document sets out the Strategic Vision of the Ealing Autism Partnership Board, identifying what we want to achieve in Ealing over the next five years for autistic people of all ages and their families.

**The document starts with what we have decided are the priorities for action over the next five years. The rest of the document describes how we decided and what influenced and supported our thinking. The Board decided they wanted to see the actions at the start of the document to show our commitment to real changes.**

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## **1. Action Plan**

**This Plan is not set out as a conventional action plan. It shows what we want to do and to achieve. The Working Groups described below will turn these ambitions into actions.**

The table set out here is about our ambitions for improving the lives of autistic people in Ealing.

We have linked our ambitions to the themes of the National Strategy for autistic children, young people and adults 2021 – 2026 (published July 2021) and the North West London NHS Integrated Care Board Learning Disability and Autism Programme Principles developed through co-production during 2022. These principles are outlined later in this document and the action plan is shared in Appendix 1.

Each proposal will be developed, implemented, and monitored alongside autistic people, their families and friends, across our diverse communities. These ideas for action all came from the working groups and others interested in improving autistic people's lives and experiences in Ealing.

**It is important to acknowledge and thank everyone involved with the Partnership Board so far for their work in developing this Plan.**

### **Working Groups**

The next step for all of us is to make the Plan happen. To do this we have established new Working Groups, one for each theme:

- Understanding autism
- Education
- Getting a job or accessing training or volunteering
- Equal access to healthcare
- The right support in the community and in hospital
- Criminal and Youth Justice systems

The groups each have the job of starting the delivery of the Plan on one themed area, and will be answering the following questions:

How will we know we are making changes? How will we measure success?

Who will lead and who will be involved?

When will we achieve what we have planned?

What will it cost?

**Are there any quick wins we can do straightaway?**

## What will we do?

### Understanding autism

We want people everywhere to understand autism and welcome autistic people. We want to live our lives as we wish, choose our friends and how we spend our time - and get support if we need it.

**Training** to raise awareness and increase understanding of autism

- Mental health services
- GPs and Primary Care
- Local businesses
- Schools and colleges
- Universities
- Community services and organisations
- Autism Education Trust – expect teachers and school leaders to take part in training on exclusion, anxiety, distressed rather than challenging
- Understanding of how a 'spikey profile' can affect perceptions of autism

Public information campaign and talk about the positives!

Target specific ethnicity groups in Ealing where Autism is considered a taboo.

Develop a localised social media campaign during Autism Awareness Week March 2023.

Link with Learning Disability Partnership Board and proposed interactions with Transport for London to raise awareness of hidden disabilities.

Make an Autism card which people can use to explain that they are autistic when accessing services.

Support for autistic people and their families to understand autism.

Becoming an adult – training and support to understand what people need as they grow up.

### Education

Whatever our age, we want to be able to learn, go to school or college, follow our dreams and aspirations, choose to go to university. We want to learn life and independence skills such as 'home management' as well as academic subjects.

### Inclusion

Outreach to support schools with strategic plans for inclusion in addition to individualised approaches. Share documents regarding law.

Examine exclusions data and address underlying causes.

[SEND and inclusion key documents | Ealing Grid for Learning \(egfl.org.uk\)](#)

Build on school age Autism Champions (launched Summer term 2022)

Change Occupational Therapy pathway to be inclusive of Early Years. Workshops run by Occupational Therapists when people are waiting for assessments to include Early Years.

Employ autistic teachers.

## What will we do?

### **Families**

'Incredible Years' capacity building training for parents.

One Stop Shop for parents (Early Years) where they can access/discuss Occupational Therapy, Speech and Language Therapies.

Separate eligibility for support to meet needs from diagnosis.

Help for parents with specific challenges around their child's sensory needs, behavioural needs, feeding or sleep outside of school.

### **Support and training in schools**

Recognising when girls might be autistic and understanding experiences of autistic girls.

How autism affects children, young people and their families from Black, Asian and Minority Ethnic communities.

Identify and share school age IAPT (Improving Access to Psychological Therapies) services and other mental well-being initiatives in schools.

Increase awareness within services of needs of autistic people as they become adults.

Find out what people want support with!

Include home management skills, life and independence skills as well as academic subjects.

### **Support for adults in going to college and university**

Appropriate flexible support at college or university – when needed

Advice and support for aspirations and plans for education

Diagnostic pathways for adults to include follow up to signpost for education and training advice

### **Getting a job**

We want to be able to contribute to our communities, find the right employment as individuals, and be supported if needed to give our best in the workplace. We want our skills and experience to be valued.

Training for employment support services to work with autistic people.

Develop Apprenticeships for autistic people.

Support for schools to increase opportunities for work experience.

Promote and use Autism Education Trust transition into employment toolkit:  
<https://www.autismeducationtrust.org.uk/site-search?keys=employment+toolkit>

## What will we do?

Reviews with autistic people to include looking at what they aspire to, and should be ambitious. Include skills for independence.

Training and communication with voluntary and community sector. Encourage groups to offer volunteering opportunities that act as a springboard into work

Learn through positive experiences of autistic people about what works and offers of reasonable adjustments.

Training for employers led by autistic people.

## Equal access to health care

When we need health care we want to be able to get what we need at the right time – from GPs, from physical and mental health services – and understanding of autism from professionals. We need to be able to access what will keep us well.

Set up a small multiagency team (can be virtual) with expertise in autism for autistic adults and older young people) without a learning disability who experience or are at risk of experiencing crisis and distress.

Mental Health Integrated Network Teams and Improving Access to Psychological Therapies (IAPT) to improve access and experience for autistic people.

Develop services to support autistic people who have hazardous substance use in partnership with treatment services.

Understand and share research and information about how to make reasonable adjustments in healthcare. For example, article here: [Autism: making reasonable adjustments in healthcare | British Journal of Hospital Medicine \(magonlinelibrary.com\)](https://magonlinelibrary.com)

Extend regular physical health checks with GPs to autistic adults without a learning disability.

Psychological support for autistic people and their families to understand autism.

Work with those providing sexual health services to support making these more accessible to autistic people.

## The right support in the community

We need to know it is there and how to get it. Some of us will need support to live our lives as we wish and in the place that we want to live.

**We will make information** about what is available to autistic people and their families, friends, carers accessible and easy to find, in a range of different ways (online, leaflets, videos), mapping of existing support services, including scope, inclusion/exclusion, identification of gaps in support.

Wider promotion of National Autistic Society:

## What will we do?

[www.autism.org.uk](http://www.autism.org.uk) and Autism Education Trust: [www.autismeducationtrust.org.uk](http://www.autismeducationtrust.org.uk) as sources of information

Link to local community and voluntary sector services (Centre of ADHD and Autism Support and National Autistic Society) who are creating an information platform for Ealing.

Support for autistic people in developing social skills. This can be difficult, but can be learnt. Use safe, supervised environments to develop skills, mix with neurotypical people. Voluntary Sector good place for this.

Set out guidance for Autistic people using Social Media.

Accommodation with specialist support for autistic people who do not have a learning disability and have been in hospital for a long time, or who need a high level of support to avoid crisis and admission to hospital.

Refurbishment/redesign of specialist supported housing to be autism friendly, with housing-related support as a stepping-stone for people wanting more independence.

Develop respite care for all ages, where this is needed to make it possible for people to stay out of hospital.

Training for providers of residential care and supported living in autism and how to improve their support for autistic people.

### **The right support in hospital**

Advocacy for those in hospital.

Build on input to inpatient wards to support staff teams.

Input from people with lived experience into making ward environments more autism friendly.

### **The criminal and youth justice systems**

We want the right help to prevent us getting involved in crime and the right support if we do come into contact with the criminal justice system.

Work with the police to plan approach and collect data re race equality.

Work with Youth Offending Service.

Appropriate Adults.

Develop preventative approach.

Develop links with Criminal/Youth Justice Service at school age and work collaboratively.

Education for young autistic people at school about criminal justice system, consequences of behaviour and responsibility. Autistic adults with experience lead conversations and share learning.

Learn from HMP Parc's good practice. In January 2022 it became the first prison to achieve the National Autistic Society's Advanced Autism Accreditation award, after being recognised as a 'beacon of autism best practice'

## **2. The Ealing Autism Partnership Board**

To develop a Strategic Action Plan and Vision, the Ealing Autism Partnership Board started by setting up four working groups based on life stages, and one group to work on the way people can access an assessment and diagnosis across all ages.

The life stages groups were:

- Early Years
- School Age
- Young Adults
- Adults

Each working group included autistic people as well as others with lived experience including families and carers. The groups have met regularly and have identified the most important areas where change is needed. These have been used as the basis for the Strategic Action Plan.

The Partnership Board is co-chaired by an Expert by Experience and the Assistant Director of Adult social care. Partners on the Board are those with lived experience (parents, families, friends and carers as well as autistic people themselves) from all age groups, and those working with autistic people of all ages including from the voluntary sector and community services, the NHS, social care, SEND, schools, children's services, housing and mental health services.

### 3. What our Working Groups said matters most

These are some of things people brought to the working groups during 2022.

'What about people over 25?'

'We need more about positive perceptions and high aspirations'

'Better communication needed'

'Inequalities and discrimination'

'Many autistic adults without a learning disability are not eligible for social care under the Care Act'

'Too many autistic people are in prison and hospital'

'Housing: we need somewhere to live with the right support and the right environments for individuals'

'Autistic young people can be invisible at home'

'Support managing money, benefits and debt'

'More emphasis on opportunities and aspirations'

'Preventing crisis and supporting people when they are in crisis'

'Support with accessing the right benefits and opportunities'

'Physical health'

'Autistic people may experience crisis as they become an adult: support through education and children's mental health services often lost'

'Need for specialist support for autistic adults'

'End of life'

'Access to mental health services and therapies'

'Leisure and social opportunities and contributing to my community'

'Access to educational psychology'

'Importance of parental understanding and involvement'

'Race inequality – double discrimination in criminal justice system; understanding of autism; understanding and appropriate responses to actions'



## **4. Information about Autism**

### **What is Autism?**

The National Autistic Society defines Autism as follows:

Autism is a spectrum condition and affects people in different ways. Like all people, autistic people have their own strengths and weaknesses. Below is a list of difficulties autistic people may share, including the two key difficulties required for a diagnosis.

#### **1. Social communication and social interaction challenges**

Autistic people have difficulties with interpreting both verbal and non-verbal language like gestures or tone of voice. Some autistic people are unable to speak or have limited speech while other autistic people have very good language skills but struggle to understand sarcasm or tone of voice. Other challenges include: taking things literally and not understanding abstract concepts; needing extra time to process information or answer questions; repeating what others say to them (this is called echolalia)

Autistic people often have difficulty 'reading' other people - recognising or understanding others' feelings and intentions - and expressing their own emotions. This can make it very hard to navigate the social world. Autistic people may: appear to be insensitive; seek out time alone when overloaded by other people; not seek comfort from other people; appear to behave 'strangely' or in a way thought to be socially inappropriate; find it hard to form friendships.

#### **2. Repetitive and restrictive behaviour**

With its unwritten rules, the world can seem a very unpredictable and confusing place to autistic people. This is why they often prefer to have routines so that they know what is going to happen. They may want to travel the same way to and from school or work, wear the same clothes or eat exactly the same food for breakfast. Autistic people may also repeat movements such as hand flapping, rocking or the repetitive use of an object such as twirling a pen or opening and closing a door. Autistic people often engage in these behaviours to help calm themselves when they are stressed or anxious, but many autistic people do it because they find it enjoyable. Change to routine can also be very distressing for autistic people and make them very anxious. It could be having to adjust to big events like Christmas or changing schools, facing uncertainty at work, or something simpler like a bus detour that can trigger their anxiety.

### **Living with Autism**

In a world where autism is not well understood, autistic people face barriers in many aspects of life, such as health services, education, social life, employment and housing. There are many positive attributes of being autistic and some autistic people see their autism as a positive identity rather than a 'condition'. However, we have information which suggests that autistic people and their families do not have access to the support they need to live their lives as they wish. For example:

- Two out of three of autistic adults say they do not get the support they need
- Autistic adults without a learning disability have the highest suicide rate of any group
- Autistic children can struggle in and out of school, are more often excluded
- There are long waits for assessment – in Ealing waits are variable. For adults it is around three months. For children, it can be very much longer at different ages

- 2,055 autistic people and people who are autistic, have a learning disability or both are currently inpatients in mental health hospitals in England
- Average life expectancy for autistic people is 54 years
- A wealth of talent is not available to our communities
- Only 24% of autistic adults are in employment

## Local Population Data

There is not enough information available about how many autistic people there are in Ealing, or about their ethnicity or other demographics such as their social class.

Based on population and the national prevalence of autism, in Ealing there are at least 3,500 autistic people.

This is thought to be a significant underestimate. The following tables show some of what we know about Ealing.

**Table 1: number of people identified as autistic at 13/12 2022 in their GP records**

Primary Care Network	0-17 years			18 + years			Total			Grand Total
	Without Learning Disability	With a Learning Disability	0-17 years Total	Without Learning Disability	With a Learning Disability	18 + years Total	Without Learning Disability	With a Learning Disability		
Acton	79	30	109	89	39	128	168	69	237	
Greenwell	47	17	64	64	39	103	111	56	167	
NGP	79	18	97	93	32	125	172	50	222	
North Southall	53	17	70	28	20	48	81	37	118	
Northolt	57	32	89	23	18	41	80	50	130	
South Central Ealing	60	8	68	68	22	90	128	30	158	
South Southall	57	21	78	34	21	55	91	42	133	
The Ealing Network	75	11	86	96	28	124	171	39	210	
<b>Grand Total</b>	<b>507</b>	<b>154</b>	<b>661</b>	<b>495</b>	<b>219</b>	<b>714</b>	<b>1002</b>	<b>373</b>	<b>1375</b>	

**Table 2: ethnicity of children and young people (R-Y13) attending Ealing schools who are diagnosed with autism, Spring census 2021**

Ethnicity	ASD	% of ASD total	No. of Pupils	% of total of pupils
Asian/Asian British	210	24.88%	16543	30.24%
Black/Black British	166	19.67%	7607	13.91%
Mixed	87	10.31%	4959	9.07%
White	239	28.32%	15743	28.78%
Other	127	15.05%	8935	16.33%
Unclassified	15	1.78%	916	1.67%
<b>Total</b>	<b>844</b>		<b>54703</b>	

**Table 3: referrals to Ealing Adult Autism Assessment Service by ethnicity (as people described)**

How people described their ethnic background	Number of people referred
Black British	10
Asian	20
Middle East	3
Polish	1
Japanese	2
European	2
White British	79

Ealing Adult Autism Assessment Service had 120 referrals in total between January and December 2021.

62 were female and 58 male. Of these, 80% of the women referred were diagnosed as autistic, and 75% of the men.

Information about how many children have been referred for an assessment and diagnosed with autism is difficult to collect as the services carrying out this work include a broader range of assessments and diagnoses, including ADHD and Tics as well as speech and language, communication and mental health issues. The following information snapshots include children and young people referred to the Neurodevelopmental Team whatever the reason and so does not give us an accurate picture of the number of autistic young people.

It is known that there are long waiting times for CAMHS Neurodevelopmental Services which West London NHS Trust are working with partners to improve. Between April 2021 and August 2022, the average wait time to a second appointment across the three boroughs served by West London NHS Trust reduced from 623 days to 273 days. Referrals received by Ealing CAMHS Neurodevelopmental Team in August 2022 was 60. In the same month 59 referrals were screened and accepted.

The percentage of children and young people referred to Neurodevelopmental Teams across the three boroughs served by West London Trust recorded as White British was 31%, and as White Other backgrounds was 11%. 56% of children and young people referred were recorded as Black, Asian, or from Mixed backgrounds, with the highest percentage (7% of total) recorded as Caribbean.

Autism is not always routinely 'flagged' on people's health and social care records. It may not be considered as the primary issue the person is facing. We know that autistic people are more likely than neurotypical people to experience mental health difficulties, especially anxiety, depression, compulsive disorders and eating disorders. However, we do not know how many autistic people are known to mental health services. GP records, as shown above in Table 1, do not capture the number of people we would expect according to national prevalence (at least 3.500 people in Ealing).

In social care, the numbers are even lower, which does not represent the actual number of autistic people who have social care, but only those who are flagged on the recording system.

**Table 4: autistic people known to social care**

	Recorded with Asperger's Syndrome	Recorded as autistic	Total
<b>Female</b>	=<5	20	25
<b>Male</b>	10	40	50
<b>All</b>	15	60	75

30 of the 75 people recorded are aged between 25 and 34 years old.

20 people identified as Asian or Asian British, 10 identified as Black or Black British and 8 as 'Mixed'. 30 people identified as White

44 people of the 75 were having support for a learning disability as well as autism and 16 have support for mental health needs.

The following table shows the information from West London NHS Trust about autistic people known to them in community and hospital mental health services. The diagnostic definitions are not comprehensive so this is not a full picture of how many autistic people receive mental health support.

**Table 5: autistic people with mental health services**

Diagnosis	0 TO 17 years	18+	Grand Total
<b>Asperger syndrome</b>	6	16	22
Atypical autism	2	5	7
Childhood autism	72	28	100
<b>Grand Total</b>	80	49	129

We acknowledge the local difficulties in data collection in regards Autism diagnostic services, and overall prevalence data for Ealing.

**It is important that this is addressed so that we can understand the needs of people in Ealing and whether access to assessment and support for people from the range of ethnicities and backgrounds differs.**

The aim is to improve the information we have about autistic people and their access to assessment, diagnosis, education and support. The data we currently have is not helpful in understanding what we have, what we need and where the gaps are. Data, even good data, never tells the whole story.

**To better understand what will help autistic people, their families, friends and carers we need to talk to them directly.**

**We commit to:**

- Working across the system to access the information we need to understand how many autistic people there are in Ealing, which services they use, what are the important outcomes are for them
- Working with schools to understand information about number of autistic people excluded in schools and number of autistic children excluded
- Carrying out a survey of autistic people's experiences, working with the community and voluntary sector

## 5. Inequalities

People who are autistic face discrimination and stigma in society and have many barriers to overcome to live their lives as they wish. There are particular challenges faced by some groups of people when it comes to being diagnosed with autism, or living with autism.

Women and girls:

The National Strategy describes and addresses the inequalities and barriers faced by autistic people in relation to autism and looks at some information about gender and the ways girls and women's experiences differ from those of men and boys. Autistic girls are frequently overlooked when receiving a diagnosis of autism or are misdiagnosed. Diagnostic and screening tests do not consider the variation in females' presentation of autism, instead it is developed based upon the typical characteristics of males with autism. Autistic females are more likely to camouflage their autism symptoms, through masking or compensating their difficulties. Non-diagnosis or a misdiagnosis can have a significant impact on females' development and outcomes.

When the correct autism diagnosis is finally received this often happens significantly later in life when they are teenagers or adults.

This article from 'Ambitious about Autism' gives one young woman's experience of being autistic.

[Autistic females flying under the radar | Ambitious about Autism](#)

Black, Asian and Minority Ethnic people:

There is very little information about or research about the experiences of being autistic and a from a Black, Asian, Minority Ethnic backgrounds. The data from different countries varies. For example in the US Black people are less likely to be diagnosed as autistic, while in the UK this has recently changed to suggest that Black people are more likely to be diagnosed as autistic when children. The National Autistic Society carried out research into the experiences of Black Asian and Minority Ethnic people who are autistic in 2014. The report can be found here [Autism and BAME people](#) and makes strong recommendations for local services and commissioners to include the perspectives and experiences of Black Asian and Minority Ethnic people and communities in planning and delivering services.

The studies which have been carried out are clear that autistic people from Black, Asian and Minority Ethnic communities need to be listened to and services must be designed to understand the different ways that autism is understood within different communities.

The Council has established an Ealing Race Equality Commission which reported in January 2022, sharing its findings with residents, community and voluntary sector, the Council and the NHS. The full report can be found here: <https://erec.dosomethinggood.org.uk/report/>

The Commission concluded that to bring about change, those responsible for commissioning, delivering and co-designing services must:

- Build trust with communities. We must seize this opportunity now and start to rebuild that trust with those who feel these conversations have not resulted in change in the past. Too many distrust those who have power and responsibility.
- Listen to the experiences of residents and understand their challenges, recognising the differences between groups and their histories.
- Use data and insight to ensure the tenacious pursuit of narrowing inequality.

The priorities identified relate to education, health, participation and democracy, policing, income and employment, housing and 'keeping the feet to the flames' – what happens next. The plans being developed to tackle these issues are very important to this Strategic Action plan as Black, Asian and Minority Ethnic people who are autistic face discrimination and barriers because they are autistic or have a learning disability and additionally because of their race. Services and support may not be culturally appropriate for people from Black and Asian Minority communities, access may be poor for a range of reasons, and how autism and learning disability are viewed and understood varies across faith groups and cultures.

LGBTQ+ people:

People who identify as lesbian, gay, bisexual, non-binary and transgender experience discrimination and face barriers in their lives. It is important to understand how being autistic changes these experiences and can add another layer of discrimination. We also need to understand how LGBTQ+ spaces can be made autism friendly and welcoming to autistic people. Autistic people may have a different understanding of identity and a different approach to relating to their sexuality than neurotypical people.

- **Each workstream will have a responsible officer for inequalities to ensure that all action plans consider impact on different population groups and address inequalities.**

**Our commitment is to:**

Women and Girls

- Talk with women and girls about autism.
- Listen to the experiences of autistic women and girls.
- Find out more information about how many with women and girls access assessment, diagnosis and support including healthcare.
- Work with individuals, families and communities to improve the experiences of women and girls who are, or might be, autistic.
- Build on understanding in schools about autistic girls.

Black, Asian and Minority Ethnic people

- Talk with people from the diverse communities across our Borough about autism.
- Find out more information about how many autistic people from Black, Asian and Minority Ethnic communities access assessment, diagnosis and support, including healthcare.
- Listen to autistic Black, Asian and Minority Ethnic people about their experiences
- Work with individuals, families and community and faith groups to improve the experiences of Black, Asian and Minority Ethnic people who are, or might be, autistic, based on their knowledge and relevant to the way they wish to live their lives.

LGBTQ+ people:

- Talk with LGBT+ people about autism
- Find out more information about how many autistic LGBT+ people access assessment, diagnosis and support, including healthcare
- Listen to autistic LGBT+ people's experiences

- Work with individuals, families and communities to improve the experience of LGBT+ people who are, or might be, autistic

Make sure that training for health and social care professionals, communities and schools includes talking about protected characteristics as defined in the Equalities Act 2010 and how these affect people's experiences of being autistic.

## **6. National Strategy for autistic children, young people and adults 2021 - 2026**

In July the government published its National Strategy for improving the lives of autistic people and their families and carers in England, and the implementation plan for 2021 to 2022 that goes with this. A range of organisations and autistic people were involved in developing the Strategy. The Strategy builds on existing legislation, but does not replace it. The following legal framework and guidance still applies:

- The Autism Act (2009), followed by Fulfilling and Rewarding Lives (2010), placed a number of obligations on public bodies to improve opportunities for people with autism.
- Think Autism (2014) published detailed consultation and research into the views of people with autism and their families.
- 2015 'Statutory guidance for Local Authorities and NHS Organisations to support implementation of the Autism Strategy'
- The NHS Long Term Plan (2018) identifies autism as a priority. Actions include tackling preventable deaths in autistic people, reducing waiting times for specialist services and reducing the need for inpatient provision.
- Special Educational Needs and Disability (SEND) Code of Good Practice 2015

The National Strategy now covers all ages and is across government. It sets out a vision for the next five years.

The National Strategy identifies changes across six areas that would have a significant impact on autistic people's and their families' lives.

### Key themes of the Strategy

- Improving understanding and acceptance of autism within society
- Improving autistic children and young people's access to education, and supporting positive transitions into adulthood
- Supporting more autistic people into employment
- Tackling health and care inequalities for autistic people
- Building the right support in the community and supporting people in inpatient care
- Improving support within the criminal and youth justice systems

[National strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026)

The government published a new report on 14<sup>th</sup> July 2022 which describes the ongoing work to reduce the number of people who are autistic or have a learning disability or both who are in mental health hospitals, and to build up how people are supported in communities.

[Building the Right Support for People with a Learning Disability and Autistic People Action Plan - July 2022 \(publishing.service.gov.uk\)](https://publishing.service.gov.uk/government/consultations/building-the-right-support-for-people-with-a-learning-disability-and-autistic-people-action-plan-july-2022)

## **7. Ealing Council and NHS priorities**

Ealing Council's overarching priorities are:

- Creating good jobs
- Tackling the climate crisis
- Fighting inequality

Within this are pledges to:

- Enable everyone to get a decent living income, that can support genuinely affordable homes for all, securing what is great about our seven towns through good growth.
- Sustaining our environment, taking firm climate action to protect our future, foster civic pride and inclusion in thriving communities, and use our financial power to support a more inclusive economy.
- Ensure every child and young person gets a fairer start in life, where everyone can enjoy long and healthy lives, tackling crime and inequality that holds too many people back from fulfilling their dreams and aspirations

All these areas are relevant to our Autism Plan, in particular the pledges for a fair start for children and young people, tackling inequality, and enjoying healthy lives.

Ealing's priorities for children and young people with Special Education Needs and Disability (SEND) include

- Improving access to assessment and diagnosis for autism as well as building integrated support for families (with or without a diagnosis)
- Reducing admissions to hospital for young people with a learning disability and/or autistic people
- Improving the information provided to families about health, education and support as well as leisure, employment and community groups (the Local Offer)

In Ealing, our Borough Based Partnership includes people from across health, education and social care. The Partnership is developing at time of writing (December 2022) and has the following priorities for Ealing:

- Children and Young People, including access to early help and addressing assessment waiting times.
- People with complex needs, which includes those who are autistic, including training for staff and supporting people at the last phase of life.

Integrated Network Teams working within Primary Care Networks and developing Multidisciplinary Teams to meet local needs. Working across systems and with the Community and Voluntary sector on:

- Population health and inequalities
- Social prescribing
- Peer support
- Wellbeing checks
- Vaccinations
- Care coordination
- Mental Health link workers



- Urgent and emergency care, including preventative approaches working to address fuel poverty, alcohol use.

Prioritising work on the drug and alcohol treatment pathway within emergency care, First Response (including Psychiatric Liaison) and the use of Places of Safety.

For all these priorities it will be important to make sure that autism is part of the picture. For example, post diagnostic support for children and young people, training for staff supporting people at the last phase of life to include autism, mental health integrated teams to be able to support autistic people in distress, Places of Safety and emergency response to take into account the needs of autistic people in crisis.



The North West London Integrated Care Board came into being on 1<sup>st</sup> July 2022, and North West London Clinical Commissioning Group ceased to exist. The Board is the legal entity which oversees the North West London Integrated Care System (ICS). The ICS has three overarching aims: people are able to ‘Start well, live well and age well’.

At North West London the Learning Disabilities and Autism Programme is working to improve the experiences and lives of people who are autistic, have a learning disability, or both. The Programme has mapped the assessment and diagnosis pathways for all ages, and looked at the support available across the area. The programme oversees work to prevent people going to hospital who are autistic, have a learning disability, or both, and work to make sure these people leave hospital as soon as possible.

It has run co-design workshops about the pathways for diagnosis and support with autistic people to find out what is working well and what needs to change. The emerging principles from this work are shown here and there is a detailed action plan in Appendix 1:

Actions from the workshop and breakout groups have been categorised in to five key areas with targeted aims

Autism Partnership Board	Awareness and Profile	Waiting Well	Workforce Development	Service Design & Delivery
<ul style="list-style-type: none"> <li>• Improve collaboration and oversight of autism provision within the borough.</li> <li>• Amplify the voice of autistic people.</li> </ul>	<ul style="list-style-type: none"> <li>• Reduce stigma associated with autism.</li> <li>• Increase understanding of autism and support available.</li> </ul>	<ul style="list-style-type: none"> <li>• Increase access to information and support in a more timely way.</li> <li>• Better manage expectations.</li> </ul>	<ul style="list-style-type: none"> <li>• Increase understanding of autism and necessary skills.</li> </ul>	<ul style="list-style-type: none"> <li>• Reduce waiting times.</li> <li>• Increase capacity of services.</li> <li>• Increase delivery and uptake of VCSE provision.</li> </ul>


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As part of this work Ealing borough has received funding to pilot a pre-diagnostic Hub for people of all ages who are referred for assessment. This is now underway and supports the referral process, support referrers in identifying the right people, find the right help for people whether they are diagnosed as autistic or not. The Hub is mostly staffed by Experts by

Experience (either autistic people or parents of autistic people) who are available to support those who are referred in navigating and understanding the processes. One Expert by Experience said 'I am providing families with the support I could not get myself when my children were waiting for assessment and support'.

The Community and Voluntary Sector services for autistic people have received additional financial support through the North West London programme, and Ealing is now part of an NHS funded Key Working for all young people at risk of admission (under 25) to hospital who are autistic and/or have a learning disability.

Implementing the NHS Long term plan includes a commitment to improve the lives of autistic people with or without a learning disability, as outlined in this extract:

**'Across the NHS, we will do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives. This means that we will provide timely support to children and young people and their families. We will do more to keep people well with proactive care in the community. 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 autism, and their families.'**

There are work programmes delivered at North West London ICS level designed to:

- Reduce hospital admissions for autistic people
- Reduce suicide
- Reduce waiting times and waiting lists for diagnosis of autism
- Reduce the use of psychotropic medication
- Increase opportunities in employment, education and leisure
- Increase health checks and follow ups and include people who are autistic and do not have a learning disability
- Increase the use of Personal Health Budgets

## **8. Assessment and diagnosis**

We want people to be able to access an autism assessment when needed, delivered as a high quality comprehensive assessment of needs alongside early interventions as appropriate for age and other needs the person may have.

This will support building capacity across the whole system by enabling experts (professionals and by lived experience) to provide consultancy and advice to others, including referrers.

Early Intervention, or early help as it sometimes known, is support given when a difficulty first emerges, rather than waiting until things escalate. The aim of early intervention is to improve the outcomes for the child or adult. It can be provided at any stage in a child or adult's life.

Our commitment is to offer comprehensive, supportive and timely diagnostic pathways for children, young people and adults.

### **Comprehensive**

Children, young people and adults should be able to access a comprehensive neurodevelopmental assessment under one umbrella. This would include consideration of

factors that might influence the presentation of autism and the conditions known to be associated with autism.

- Services for all age groups contain the right skill mix to offer comprehensive assessment for neurodevelopment and mental health needs
- One referral will be sufficient with no gaps or differences in rejection and acceptance criteria
- Joint pathways to provide seamless acceptance, assessment and transitions

### **Supported**

Children, young people and adults should be able to access support for difficulties with communication and relationships, academic and social difficulties, and support to understand the referral process and implications of a possible diagnosis

- Information on interventions available pre and during referral will be made available to referrers, to families and publicly accessible
- Liaison between health, education, health visiting and social care will enable support to be accessed holistically
- Transitions between pathways where needed will be seamless and coordinated by professionals
- Long term support post diagnosis will be available as and when needed

### **Timely**

Children, young people and adults should be able to access timely assessments at the right time in their journey and without excessive waits

- Early identification will be available at all life stages
- Referral pathways criteria will be clear and simple and achievable
- Services will adhere to NICE guidance for assessments to start within three months of referral to the autism teams
- Services will aim to complete autism assessment within 6 months of referral to autism team

## **9. Impact of Covid-19**

The National Strategy takes into account the impact of the Covid -19 pandemic on autistic people and their families' lives. In Summer 2020, the Government commissioned the Policy Innovation and Evaluation Research Unit (London School of Economics) to undertake rapid research to improve understanding of autistic people's experiences during this time, and everyone's ability to respond appropriately.

[The Impact of COVID-19 on Autistic People in the United Kingdom: Final Report \(piru.ac.uk\)](https://piru.ac.uk)

The conclusion of this research was that many of the barriers faced by autistic people were exaggerated or exposed by the Pandemic. The research acknowledged that autistic people are a diverse group and what is true for one person or family will not be true for others. Some autistic adults experienced a sense of relief from the stresses they experience through social contact and demands. Locally we know that some autistic children benefitted hugely from being able to attend

school in a small bubble of children and made great progress. Other children suffered by the lack of routine and opportunities caused by being unable to attend school in lockdown.

However, overall the research concluded that autistic people had been negatively impacted in terms of their experiences of:

- Communication from government:

Government communication regarding COVID-19 was difficult to understand and follow for many autistic people. Clear communication and transparency of decision-making from government are important and can help autistic people follow advice and guidance.

- Schools and education:

Access to education for autistic children during lockdown was not consistent. Continued input from schools and maintaining contact with parents and families are vital if schools need to be closed in the future.

- Grocery shopping:

Accessing groceries during lockdown was a struggle for many autistic people. Ensuring everyone has access to necessary grocery shopping, especially vulnerable groups like autistic people, must be a priority.

- Mental health and access to medical care:

COVID-19 and its consequences affected the mental health of autistic people in a range of ways. Mental and physical health care should be accessible to all members of the population. This is particularly the case for autistic people who are more likely to have mental health problems and may find it harder to access services.

- Caring responsibilities and respite:

Renewed support for family members and carers is needed. Many were exhausted during lockdown, especially when external support and respite care were stopped or reduced.

The research acknowledged that some autistic people struggle to have, or may never have, a voice in this and other discourses.

'Left Stranded' is a report produced in the Summer of 2020 by the National Autistic Society along with other autism-led organisations. Their surveys and engagement found that many autistic people and their families felt they had been 'left stranded' during the early part of the Pandemic, specifically in terms of isolation, loneliness, reduction in or stopping of services, anxiety, depression, access to education, difficulties getting out of the house, and mask wearing.

Autistic people with a learning disability and their families, or others who had regular care and support in place, experienced many of their day services being closed at least temporarily to protect people from infection. This caused huge disruption to people's routines, activities and socialising, as well as increasing the pressure on families, which some found close to intolerable.

[Left stranded: our new report into the impact of coronavirus \(autism.org.uk\)](https://autism.org.uk)

## **10. Making a start – what is already happening**

Our Plan for autistic people, their families, friends and carers as outlined in this document is ambitious. It has come directly from the views and ideas of people who know about living with autism and know what needs to change. While we have been developing the Plan work has continued in improving people's experiences and what is available. This final section of the Strategic Action Plan acknowledges some of the the work already being done, both locally in Ealing, and at North West London level.

### **Information:**

Local Offer for children, young people up to age 25, and families.

Centre for ADHD and Autism Support Ealing Information Board is being developed.

### **Voluntary and community groups:**

Some community and voluntary sector support for autistic adults, children, young people and families and plan to expand this.

Voluntary sector, the Council and the NHS are providing training for professionals and others.

Experts by Experience are developing a voice in Ealing.

Council training about autism is available to all the voluntary sector.

Day opportunities are available for autistic adults with a learning disability.

There are generic community services which can be made accessible to autistic people.

### **Schools and colleges:**

Autism training is available and promoted to all Ealing mainstream schools.

All mainstream schools have access to autism outreach service.

Newly launched Early Years Autism Champions.

All mainstream schools are obliged to provide appropriate support within:

Quality First Teaching (Universal)

Special Educational Needs (SEN) support (Targeted)

Education Health and Care Plans (EHCP) (Personalised)

### **Employment:**

Job Centre Plus disability advisors offer support to autistic people.

Employment Support Network (mental health based).

Brent 'Young Drivers' and BSM: young autistic people gave good feedback.

National Citizens Service.

**NHS and Social care:**

Transitions from children's to adults' services is improving for all autistic people.

Psychologist now part of Transitions Team.

Transitions for autistic people with a learning disability are working well.

Ealing Adult Autism Assessment Service provides training and consultancy for mental health teams and other professionals.

Autistic people with a learning disability can access Community Team for People with a Learning Disability.

Social work support is available when people are eligible.

Autistic people with a learning disability have access to mental health support through their Community Team and have regular physical health checks.

Child and Adolescent mental Health Service (CAMHS) offer a psychoeducational course for parents of newly diagnosed children and young people.

Transforming care social worker and NHS Complex Care Team (NHS funded).

Support and training from the crisis pathway Autism Specialist and Team in West London NHS Trust for inpatient teams when autistic people admitted to hospital.

Adjustments to environment in hospitals being led by Autism Lead (Robin Ward, West London NHS Trust).

Ongoing work across NHS providers to develop a diagnostic pathway for all ages.

Waiting list support initiative with Neurodevelopment Service. Families can access support from Ealing CONTACT.

Pre-diagnostic Hub for all ages starting – one year trial, currently running and making plans to expand.

Central North West London NHS Trust (CNWL) has funded pilot for sleep support family support worker and link to Centre for ADHD and Autism Support programmes to March 2023.

CNWL waiting list trial: funding used to commission Autism Clinic London, a private provider, for nine children within Ealing to have an assessment for autism. If successful, there is scope for higher number of cases to reduce waiting lists.