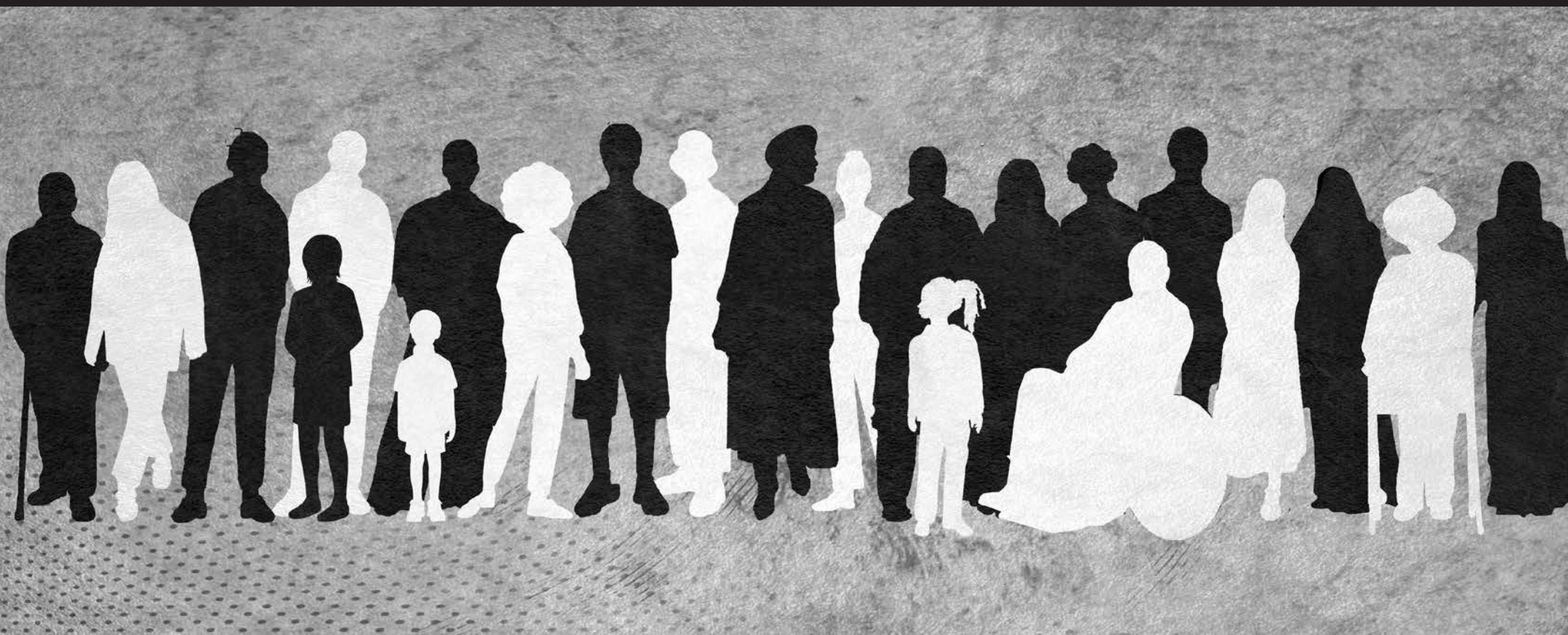


# Newham Autism Action Plan: Lets Talk Autism



# Glossary of Terms

Term	Description
Resident	Any autistic person who lives or studies in the London Borough of Newham.
Stakeholder	Any person, organisation or group whose work is relevant to the Action Plan, who have been involved in shaping the Action Plan and / or who will take part in the delivery of its Action Plan.

# Purpose of the Action Plan

In July 2021, the Government published a National Strategy for Autistic Children, Young People and Adults - replacing the Think Autism Strategy for Adults. The strategy aims to:

- improve understanding and acceptance of autism within society;
- improve autistic children and young people's access to education - and support positive transitions into adulthood;
- support more autistic people into employment;
- tackle health and care inequalities for autistic people;
- build the right support in the community and support people in inpatient care; and
- improve support within the criminal and youth justice systems.

The aims of the national strategy aligns with ours: Newham's autistic residents and our families; as well as the Council and its partners.

As such, this Newham Autism Action Plan details how these national aims will be met locally; and how additional, Newham-specific issues identified by us, our families and the stakeholders who support us will be addressed.

# Our Vision

Our vision is to provide meaningful change to make Newham a place where all autistic residents can be independent, achieve their potential and live well.

We recognise that making real, sustainable change takes time: the journey is likely to be challenging - and at times we will feel excited as some actions are delivered at pace whilst at other times, we will feel frustrated with some actions taking a longer time to achieve, but we, along with the Council and its partners are committed to working together to continually move forward - within the resources available.

# Autism: Strengths, Challenges and Prevalence



# What is Autism?

We view Autism as a lifelong cognitive difference that affects how we perceive, communicate and interact with others and the world around us.

We are as different from each other as anyone else, with different skills, talents, interests and challenges. As the impact of autism varies widely from one person to another, as does the level of support we may need in a particular environment and / or across our lifespan (from a child to a young person to an adult to an older adult).

Some refer to Autism as a 'hidden' disability as it isn't always visible or immediately obvious to others; and some do not consider it a disability at all.

# Autistic Strengths

Autism is a difference and not a deficit.

When you're autistic you think differently to people who are not autistic. This different way of thinking can make us very good at all kinds of activities and tasks; and often sets us apart from people who are not autistic in positive ways that allow us to make unique contributions to society. We call these our 'Autistic Strengths' - unusual talents, skills and qualities.

The National Autistic Society provides a list of some Autistic Strengths that scientific research has found to be common in autistic people. For example, we:

- not only see a greater intensity of colours, but can also read tiny text, like the small print on the back of products, from across a room!
- have acute hearing - allowing us to detect changes in pitch and in a melody;
- have Hyperfocus or Monotropism - an intense form of mental concentration or visualization on a subject, topic, or task; and for extended periods of times;
- solve problems up to 40% faster than people who are not autistic;
- think outside the box - generating creative and novel ideas (e.g. the typewriter, the iPod, the electric car; slopes from the pavement to the road, etc).

Getting to know our strengths can be both validating and empowering. Visit [autism.org.uk](https://www.autism.org.uk) for more information.

# Autistic Challenges

Like everyone, we find some things difficult too. When you're autistic, you think a little differently to people who are not autistic. This particular way of thinking means that some things are much harder for us than non-autistic people, such as:

- understanding and using verbal and non-verbal language (e.g. gestures and tone of voice, body language);
- understanding and recognising other people's feelings and managing our own;
- understanding and predicting other people's intentions and behaviour and adapting to new and unfamiliar situations;
- processing information - we can be over or under-sensitive to particular things such as smells, tastes, lights, colours, sound or touch;
- we often have repetitive and restrictive patterns of behaviour or interests (which can also be a strength).

However, many of these challenges are due to living in a world that is not Autism-Friendly and small adjustments often make all the difference.



# Intersectionality

## Gender

Evidence suggests that more men than women receive a diagnosis of autism. The reason why is unclear but is likely to be due to the way autism is defined and diagnosed, as opposed to biological differences. For more information visit: [neurodivergentinsights.com/autism-infographics/womenafab-and-autism](https://neurodivergentinsights.com/autism-infographics/womenafab-and-autism).

Evidence also suggests that Transgender people are three to six times more likely to be autistic. For more information visit: [neurodivergentinsights.com/autism-infographics/trans-autism](https://neurodivergentinsights.com/autism-infographics/trans-autism)

## Disability

The National Institute for Health and Care Excellence estimates that around 70% of autistic people have an additional condition, which is “often unrecognised”. The main conditions that co-occur more frequently in autistic people compared with the general population include: Mental Health (e.g. anxiety and depression), neurodevelopmental conditions (e.g. a Learning Disability or Learning Difficulty such as Dyslexia and Attention-Deficit Hyper-Activity Disorder) and Epilepsy.

## Ethnicity

Leeuw, Happe and Hoekstra (2020) advise there are cultural and contextual factors that often hinders the identification of autism in ethnic communities, such as ‘cultural norms of typical and atypical behaviour, culture-specific approaches to parenting, mental health literacy, cultural beliefs, attitudes and stigma, as well as the affordability, availability, accessibility and acceptability of services’. Newham is one of the most ethnically diverse boroughs in the UK, with around 75% of the population with a minority ethnic heritage. For more information visit: [pubmed.ncbi.nlm.nih.gov/32083402](https://pubmed.ncbi.nlm.nih.gov/32083402)

## Sexuality

Research from the University of Cambridge suggests that autistic people are less likely to identify as heterosexual and more likely to identify with a diverse range of sexual orientations. For more information visit: [cam.ac.uk/research/news/autistic-individuals-are-more-likely-to-be-lgbtq](https://cam.ac.uk/research/news/autistic-individuals-are-more-likely-to-be-lgbtq)

## Care Leavers

0.05% of Children in Care and Care Experienced Young People have an autism diagnosis - adding a further layer to the inequality that Care Experienced Young People face throughout their life.

# Health Inequalities

## GP Access

Research shows that around 80% of autistic adults report difficulty in access their GP, which could be made easier with small adjustments to the booking process and waiting areas. Autistic people experience poor physical and mental health along with reduced life expectancy compared with non-autistic people. 'Adverse outcomes include untreated physical and mental health conditions, not attending specialist referral or screening programmes, requiring more extensive treatment or surgery due to late presentations and untreated potentially life-threatening conditions'. Moreover, autistic people report 'difficulty asking for help' and 'discussing mental health' and note that unusual behaviour or stimming elicited negative reactions from other patients, reception or medical staff.' These barriers have a direct impact on an autistic persons life expectancy, and incidences of higher levels of physical and mental health conditions. For more information visit: [bmjopen.bmj.com/content/bmjopen/12/2/e056904.full.pdf](https://bmjopen.bmj.com/content/bmjopen/12/2/e056904.full.pdf)

## Education

Ambitious About Autism advises that more than one-third of autistic children have been out of education when they would have liked to have been at school, with some children out of school for years. Autistic pupils are more than twice as likely to be excluded from school than their peers. One in four autistic children wait more than three years to receive the support they need at school. For more information visit: [ambitiousaboutautism.org.uk/sites/default/files/resources-and-downloads/files/we-need-an-education-exclusions-report.pdf](https://ambitiousaboutautism.org.uk/sites/default/files/resources-and-downloads/files/we-need-an-education-exclusions-report.pdf)

## Mental Health

Evidence suggests that over 40% of autistic people have a mental health condition - this is often acute rather than chronic, and in most cases a direct reaction to living in a world that isn't Autism-Friendly, thus demanding a non-traditional therapeutic approach.

## Eating Disorders

Research suggests around 35% of people experiencing an eating disorder may be autistic. For non-autistic people, issues with weight or body image are often the reason they develop an eating disorder. For autistic people, the reasons are usually different and may include:

- sensory differences related to food (including food tastes, textures, temperature and smells or the inability to recognise being full or hungry, a.k.a. interception);
- counting calories and exercise becoming an intense interest or being used to manage general anxiety levels;
- developing strict routines and rules around food and exercise that are very difficult to change;
- a need for control and familiarity (such as restricted eating);
- a fear of consequences (including illness, choking and allergies);
- a genuine lack of interest in eating or food.

## Criminal and Youth Justice

Data shows there is a disproportionate representation of neurodivergent people in the Criminal and Youth Justice System - many of these will not have been assessed and diagnosed. There are several factors that may lead autistic people to un/willingly commit a crime or become a victim of crime. Similarly, both the Criminal and Youth Justice environment (e.g. loud, chaotic, etc) and processes are often triggering - causing further challenge for all involved.

## Suicide

Research suggests that 'autistic people on average die 20 years earlier than non-autistic people - and the two big causes are suicide and epilepsy'. In relation to suicide, the following factors play a part:

- late diagnosis and lack of post diagnosis support;
- Mental Health (e.g. anxiety and depression - studies have shown that psychosis, borderline personality disorder and depression increase the risk of suicidality);
- a gap in knowledge across Psychologists, Psychiatrists, Autism researchers and Diagnosticians to identify appropriate diagnosis support and treatment. For more information visit: [cam.ac.uk/research/news/study-reveals-high-rate-of-possible-undiagnosed-autism-in-people-who-died-by-suicide](https://cam.ac.uk/research/news/study-reveals-high-rate-of-possible-undiagnosed-autism-in-people-who-died-by-suicide) and [autism.org.uk/advice-and-guidance/professional-practice/autism-suicide](https://autism.org.uk/advice-and-guidance/professional-practice/autism-suicide)

# Newham's Autism Prevalence

Data collection and reporting across the Council (Adult Social Care and Children and Young People's Services); Education; and Health (including Primary Care, ELFT's Autism Diagnostic Service and Barts) varies with no universal Newham definitions and coding agreed. There is an action in the Action Plan to address this. As such, the data provided in this Plan captures the 'as is' position.

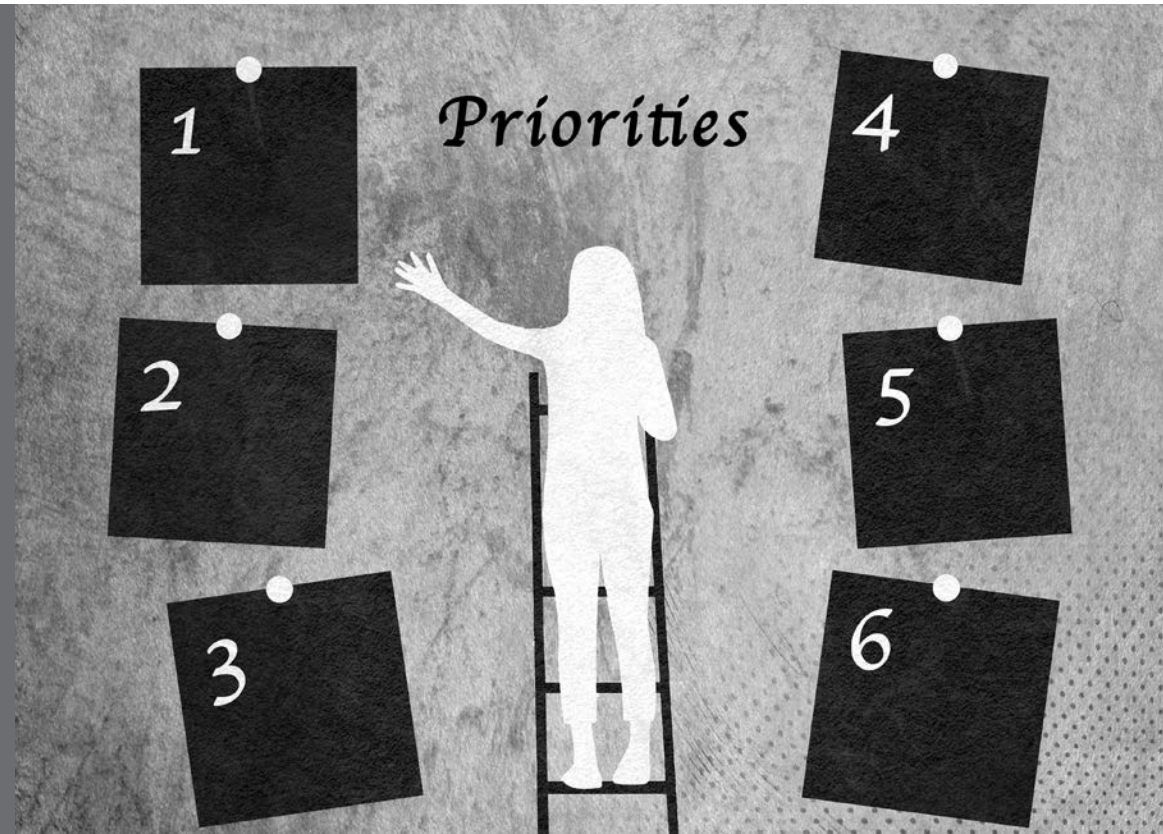
There are a number of ways to calculate the number of autistic people in Newham and measure their need (as of the 31.03.2024):

Source	Measure	Adults	Children
EMIS (GP database)	Number of autistic residents registered with a Newham GP.	561	2,664
School Census	Number of residents with Special Educational Needs support or an Education, Health and Care Plan where autism is the primary need.	N/A	1,840
Autism Diagnostic Service*	Number of residents given a diagnosis of autism.	120	664
AzeusCare (Social Care database)	Number of residents/children in receipt of Social Care. a snapshot taken in March 2024	206	236

Based on the EMIS figure, roughly 0.8% of Newham's population is autistic: the same percent as the UK's population (O'Nions et al., 2023).

The number of autistic residents in a Newham school has more than doubled since 2015 and is higher than both the London and England average; and is projected to increase further by 2027, to an estimated 2,000+ (Local Authority Interactive Tool). However, this is likely due to increased understanding of autism - leading to better recognition rather than the actual numbers increasing - noting many adults remain unrecognised.

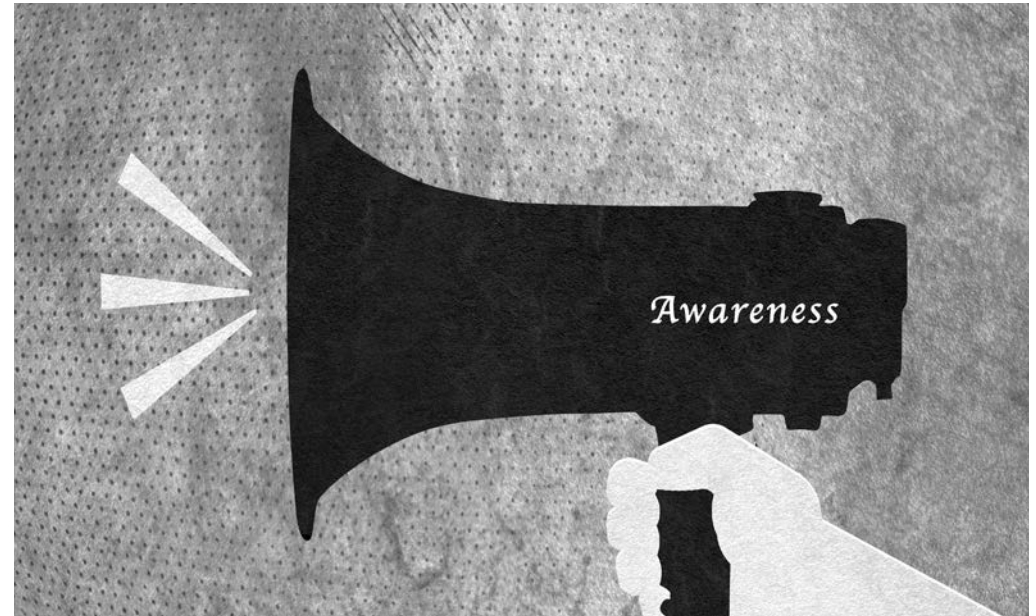
# Priorities



# Priority 1: Raising Awareness and Acceptance

The national aims of Priority 1 are to:

- improve public understanding and acceptance of autism so autistic people feel more included in their communities and less lonely and / or isolated;
- increase the number of organisations, businesses and public sector services to have become autism-inclusive, so that autistic people can engage in their communities, (e.g. taking part in initiatives like Autism Hour, the Autism Friendly Award or taking other steps to become more autism-aware);
- show autistic people feel more able to take part in their communities, including feeling more comfortable using public transport.



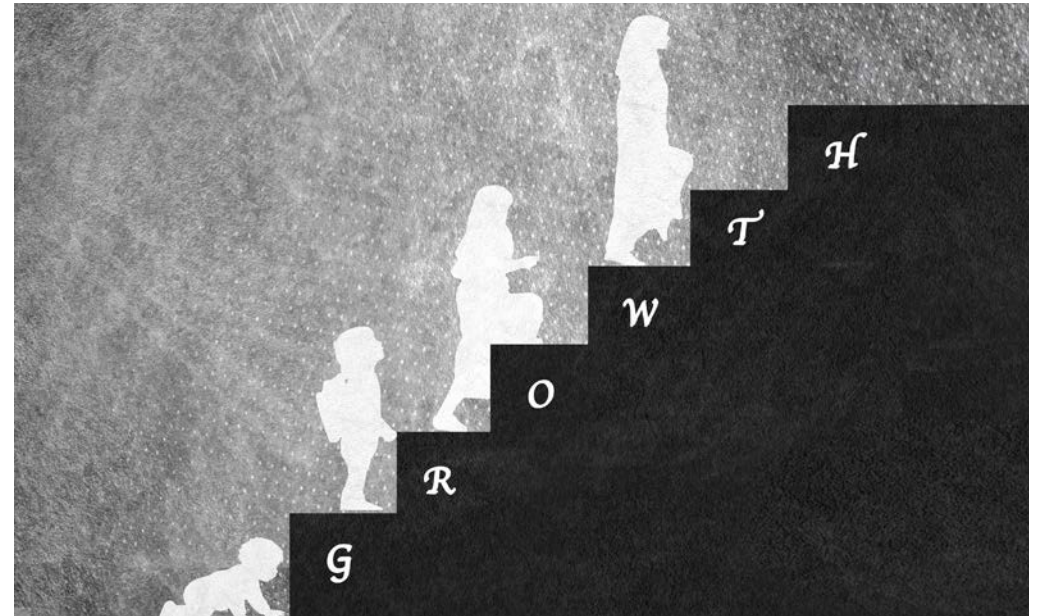
Locally, we aim to:

- agree Autism definitions and coding across Education, Health and Social Care to better understand Newham prevalence;
- deliver high quality training about Autism across all statutory frontline services;
- improve early diagnosis and timely information and support;
- improve the Newham population's understanding and acceptance of Autism - so we feel part of our communities;
- increase in the number of local Autism-Friendly services;
- have our views and experiences - and those of our Carers - heard and valued: and used to shape services.

# Priority 2: Improving Autistic Children And Young People's Access To Education, And Supporting Positive Transitions Into Adulthood

The national aims of Priority 2 are:

- for the SEND system to enable Autistic children and young people to access the right support, both within and outside of education settings;
- for education settings to provide better and more inclusive support to Autistic children and young people so that Autistic people are better able to achieve their potential, with more school placements sustained; and Autistic children having positive experiences in education;
- to improve transitions into adulthood so that more Autistic young people are able to live well in their communities, find work or higher education opportunities - resulting in fewer Mental Health crises and admissions into inpatient care.



Locally, we aim for Autistic residents to:

- strengthen early identification and early intervention pathways for autistic residents;
- build capacity within schools and settings from early years to Post 16 to deliver the graduated response through increased access to specialist services, including Speech and Language, CAMHS, Occupational Therapy and Educational Psychology Services;
- ensure all Newham settings and providers deliver high quality inclusive and Autism-Friendly environments;
- ensure all autistic residents receive a timely, well planned and person-centered transition plan as they move from one phase of education to another;
- strengthen community and employment pathways for autistic residents by focusing on Post 16 and Post 19 support;
- increase employment and training opportunities for autistic residents through improved engagement with local and national employers.

# Priority 3: Supporting More Autistic People Into Employment

The national aims of Priority 3 are to:

- close the employment gap for autistic people, drawing on the Labour Force Survey - supporting more autistic people who can and want to work to do so, and to ensure that those who have found a job are less likely to fall out of work;
- show that employers have become more confident in hiring and supporting Autistic people, and that autistic people's experience of being in work has improved;
- improve welfare support for autistic people who are unable to work, so they can get the support they need to live well in their communities.



Locally, we aim to:

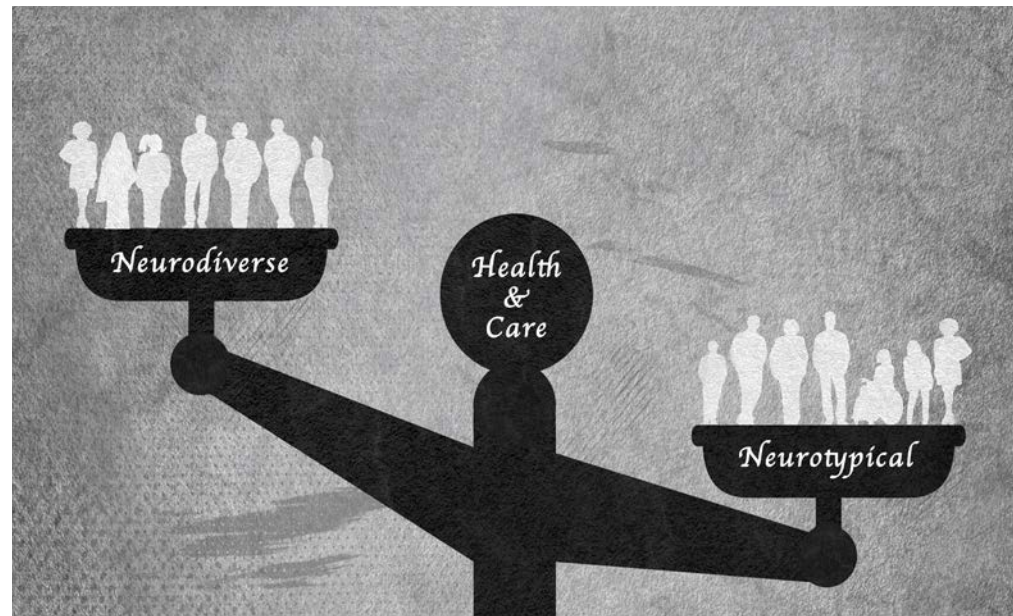
- acknowledge that there may be many autistic residents in employment, but undiagnosed;
- better inform autistic residents about their further education and employment options from Year 10 onwards;
- provide opportunities for autistic residents to obtain meaningful and enjoyable employment;
- increase the number of employment opportunities for Care Act eligible, working-age autistic residents;
- support local employers to understand the strengths that autistic employees may have and the issues that may affect them and how they can better support them: having more flexible interview processes and providing reasonable adjustments;
- ensure autistic residents who are unable to work receive all the financial benefits to which they are entitled.



# Priority 4: Tackling Health And Care Inequalities For Autistic People

The national aim of Priority 4 is to:

- make headway on reducing the Health and Care inequalities autistic people face, and show that Autistic people are living healthier lives - reducing the gap in life expectancy;
- improve diagnosis waiting times and diagnostic pathways for children, young people and adults across the country - providing access to high quality and timely diagnosis, as well as post diagnostic support;
- improve early identification of autism, so more children and young people can get the support they need at an early age.



Locally we aim to:

- improve diagnostic pathways and reduce diagnosis waiting times;
- ensure residents are supported whilst waiting for assessment / diagnosis - acknowledging that needs may still need to be met during this time;
- ensure autistic residents are provided with the support they need to live healthy lives following diagnosis;
- work with Health and Social Care service to adapt their practice to better engage and support autistic residents;
- better understand autism and intersectionality at a local level - and the impact this may have on autistic residents - with the aim of reducing stigma and isolation experienced by autistic residents and their families;
- recognise that autistic residents will access many universal services (e.g. Dementia Care) and that this Plan extends to beyond just specialist services.

# Priority 5: Building The Right Support In The Community And Supporting People In Inpatient Care

The national aims of Priority 5 are:

- to achieve the targets set in the NHS Long Term Plan for reductions in the number of autistic people who are Mental Health inpatients;
- modernise the Mental Health Act and bring forward changes which would mean that autistic people are only admitted to inpatient Mental Health settings if absolutely necessary. These changes would mean that autism alone is no longer a lawful basis for ongoing detention in inpatient care and would enable people in inpatient care to be discharged as soon as they are well enough to leave;
- improve the provision and quality of community support, including Social Care, Mental Health and housing support. - to prevent autistic people from reaching crisis point;
- for autistic people who really need care in inpatient settings, show this is of high quality, therapeutic and tailored to their needs, and as close to home as possible.



Locally we aim to:

- achieve the targets set out in the NHS Long Term Plan for reductions in the number of autistic residents who are Mental Health inpatients in Newham;
- better identify and support autistic residents at risk of crisis - via timely and effective Care and Treatment Reviews;
- ensure, when autistic residents do need care in an inpatient setting, this is of high quality, therapeutic and tailored to their needs; and multi-agency support is provided to enable successful and timely discharge.

# Priority 6: Improving Support Within The Criminal And Youth Justice Systems

The national aims of 6 are:

- to have made improvements in autistic people's experiences of coming into contact with the criminal and youth justice systems, by ensuring that all staff understand Autism and how to support Autistic people;
- for all parts of the criminal and youth justice systems, from the police to prisons, to have made demonstrable progress in ensuring that autistic people have equal access to care and support where needed;
- for autistic people who have been convicted of a crime to be able to get the additional support they may require to engage fully in their sentence and rehabilitation.



Locally we aim to:

- build on the work that has been done to both prevent young autistic residents offending and supporting those who are arrested on suspicion of committing a crime;
- ensure adult autistic residents who are arrested on suspicion of committing a crime receive the additional support they may require to engage fully in their arrest / charging, sentence and rehabilitation;
- reduce the number of autistic residents re-offending;
- reduce the number of autistic victims and witnesses of crime.

# Engagement



# Engagement - Adults

The table below summaries the engagement that has taken place with autistic adults and their families:

Activity	Description	Number of residents
Autistic Resident Survey	An online and paper-based survey asking adult autistic residents to share their views and experiences on what is working well and what could be improved within each of the six national priority areas was developed and promoted during the month of September 2023.	32
Carers Autism Survey	An online and paper-based survey asking parents / Carers of autistic adult residents to share their views and experiences on what is working well and what could be improved within each of the six national priority areas was developed and promoted during the months of July and August 2023.	68
Focus Group (Seldom Heard)	A Focus Group delivered by Voiceabilty with autistic residents who are seldom heard took place in July 2023 at Eastway Day Service and the Councils Day Service.	21
Autism Resident Advisory Group	Six face-to-face sessions took place with the Advisory Group - sharing views and experiences on each of the six national priority areas.	24
Carers Resident Advisory Group	A face-to-face session took place with the Advisory Group on what is working well and what could improved to support autistic residents.	13

# Engagement - Children and Young People

The table below summaries the engagement that has taken place with autistic children and young people and their families:

Activity	Description	Number of residents
Autistic CYP Survey	A paper-based survey asking autistic children and young people to share their views and experiences was shared at the Gr8Day 2Play; and online via the Local Offer website and the Inclusion Matters newsletter.	32
Great Day 2 Play	An event was held at Newham Leisure Centre in October 2023 for autistic children and young people to have their say about services in Newham and whether they want a forum. Voices were captured through a range of activities, including a weaving activity, Talkiokie and online survey.	78
Parent Carers Forum	A coffee morning for parent / Carers, organised by the Newham Parents Forum, was delivered in September 2023 with a focus on the Action Plan.	19
Parent / Carers Diagnosis Survey	Survey on the autism assessment and diagnosis pathway for children and young people.	25

# Engagement - Stakeholders

The table below summaries the engagement that has taken place with Stakeholders:

Priority 1	Priority 2	Priority 3	Priority 4	Priority 5	Priority 6
<ul style="list-style-type: none"> <li>• Adult Social Care</li> <li>• Care Providers Voice</li> <li>• Children and Young People's Services</li> <li>• East London Foundation Trust</li> <li>• Healthwatch</li> <li>• Integrated Care Board</li> <li>• Metropolitan Police</li> <li>• People Participation Liaison Service</li> </ul>	<ul style="list-style-type: none"> <li>• Children and Young People's Services</li> <li>• Connaught School</li> <li>• East London Foundation Trust</li> <li>• Educational Psychology Service</li> <li>• JFK Special School</li> <li>• Language, Communication and Interaction Service (LCIS)</li> <li>• Newham College</li> <li>• NewVic College</li> <li>• University of East London</li> </ul>	<ul style="list-style-type: none"> <li>• Adult Social Care</li> <li>• Ambitious about Autism</li> <li>• Barts NHS Health Trust</li> <li>• Children and Young People Services</li> <li>• Community Wealth Building Service</li> <li>• Connaught School</li> <li>• Department of Work and Pensions</li> <li>• JFK School</li> <li>• LCIS</li> <li>• Loughborough University</li> <li>• Newham College</li> <li>• NewVic College</li> <li>• Our Newham Money</li> <li>• Our Newham Works (inc: the Supported Employment Team)</li> <li>• Princes Trust</li> <li>• University of East London</li> </ul>	<ul style="list-style-type: none"> <li>• Adult Social Care</li> <li>• Children and Young People's Services</li> <li>• East London Foundation Trust</li> <li>• Healthwatch</li> <li>• NHSE Autism Lead</li> <li>• People Participation Liaison Service</li> </ul>	<ul style="list-style-type: none"> <li>• Adult Autism Diagnostic Service</li> <li>• Adult Social Care</li> <li>• Approved Mental Health Professional (AMHP) Service</li> <li>• Centre for Mental Health</li> <li>• Children's and Young People Service</li> <li>• Newham Health Team for Adults with Learning Disabilities</li> <li>• People Participation Liaison Service</li> <li>• SKIPS</li> <li>• Voiceability</li> </ul>	<ul style="list-style-type: none"> <li>• Adult Social Care</li> <li>• Appropriate Adults Service</li> <li>• Crown Prosecution Service</li> <li>• East London Criminal Justice Liaison Criminal Justice Liaison Service</li> <li>• Educational Psychology Service</li> <li>• Magistrates Court</li> <li>• Metropolitan Police</li> <li>• People Participation Liaison Service</li> <li>• Safeguarding Adults Board</li> <li>• Safeguarding Children and Young People Board</li> <li>• Speech and Language Therapy</li> <li>• Youth Offending Team</li> </ul>

# What's Working Well - Resident Views

The new autism centre that opened up is a good start.

Access to diagnosis. For me this was excellent and I as I understand it quite rare across the NHS and Local Authorities in England.

There is more awareness and understanding within Newham about SEN.

The Supported Employment Team supporting those who can work, into work.

Autistic children being in mainstream classrooms full or part time. Autism Awareness Week at school is really good as it allows children in school to better understand differences.

In Newham I find there is better acceptance generally for children on the spectrum especially those who have higher support needs.

Special Care Dentistry is good.

Headstart Programme works well.

My son gets an annual health review from our GP practice.

Speech and Language Therapy is good.

Newham Mencap and Newham Parent Carer Forum are fantastic, a wealth of knowledge!

There are colleges that cater for children with autism, e.g. Newham College. There are transition officers that explain what's on offer.



# Priority 1: What Could We Do Better - Resident Views

More awareness and acceptance for those who present well and have lower support needs.

Give lessons in schools about Autism and special needs so more people are aware of it.

I think designing spaces with more quiet areas.

Educating people in the borough about people with Autism and on different spectrums.

The voices of Autistic people heard in multiple settings. Highlighting both strengths, resilience and challenges. Supporting and promoting more organisations to become disability confident employers. Let Autistic people know about the in work support they can get. An Autistic voices social media site to break down stereotypes that highlights strengths.

Teach people about Autism correctly, how it varies in people, how it doesn't have one stereotypical image.

Extend information available to be more empathetic about Autistic people. We are blamed about not showing empathy, but all we see is that others don't show empathy towards us, just as we try so hard to be normal.

Speed up the assessment waiting list so families can get help sooner.

Have an Autism Service for Autistic adults, post-diagnosis, without Learning Disabilities! And let people self-refer for Assessment.

Autistic people who are perceived to be 'higher functioning' still have support needs that will continue lifelong. There seems to be a discontinuation of support when one reaches adulthood. Also those who have reached adulthood (especially women) who have not received diagnosis, have possibly masked there entire life. They are not receiving the right support for diagnostic assessment based on how they present or cope, but there are still challenges that are faced on a day to day. You cannot access the right support without first being assessed correctly through the right channels.

Autism awareness needs to be more obvious in the community by celebrating this and acknowledging that a variety of people could have this regardless of race, culture religion or ethnic background. As there is a lack of services within the local offer it already is difficult to access these services so by making these more available and advertised better could raise the profile of people with autism and increase the awareness amongst the community. More involvement with local centres offering drop in or workshops and links with local religious leaders would greatly help raise the awareness. Educating adults who may not have even heard of Autism is also key within the community.

# Priority 2: What Could We Do Better - Resident Views

Moving into adulthood is possibly the most difficult (i.e. there are rules to follow at school but as an adult it can be difficult cos they are not told what to do).

When children leave CAMHS, they are made to feel abandoned there is no support for families at that time either which leaves a gap, adults are not allowed to join the waiting list for adults services until their 18th Birthday. That gap should be filled.

Better education, ideally from someone who is autistic so they can see people with autism are just the same as others, they just experience things a little differently.

Specialist workers to support Autistic children in schools. More tailored and strength based learning that aligns to young persons preferences. More support is needed for autistic school refusers to re-engage them in education.

Let children with sensory issues be exempt from uniform - you would also be cranky and might act out if you feel like your skin is on fire. Give as much autonomy as possible - allow people to try things by themselves with supervision in the same way you would train any adult in stages, reducing how hands on the supervisor is until hopefully no supervision is needed.

Early identification and positive intervention where a young person with Autism is school refusing. Supportive strategies to help them re-engage with education positively. Pathways to supportive and informed employers with good employability opportunities. Too much is left to the parents with no direction, signposting or support. Parents are not experts on this.

Make sure funding is invested in providing a range of educational/social/leisure/employment activities in the borough - people I know look outside Newham.

There still does not appear to be an effective and robust transition pathway in Newham for children and young adults with complex autism and high support. Needs. Education in Newham schools is very poor for autistic children. Transition to adulthood starts very late and is not good enough.

Have appropriate support and programmes in school to allow access to appropriate education which will help Autistic children and young people. Be clear with parents over their choices for their children in terms of education settings and for those settings to be clear on the level of support and educational paths and outcomes available.

My personal experience was really bad. It was a long and hard journey to get to right people at Council and the uncovered gap between 16 and 18 years olds make parents job a living hell.

Promoting independence and understanding of non verbal to more able Autism and ADHD apprenticeship opportunities for 11-25 and how to set up your own business. Pathways for skills for life, mentoring, communication, trauma and support package for families and children being exploited, groomed, misled and teaching and understanding of the low arousal approach. School for 11-25 years old promoting physical exercise, communication, working in garden, cooking to self regulate having therapy and strategies available to parents and professional to work with multi agency approach.

# Priority 3: What Could We Do Better - Resident Views

Ensure every employer is given support to understand any Autistic person they may employ. Offer suitable well supported volunteering opportunities as a bridge. Work with a range of employers to offer different opportunities.

Employment skills need to start at primary school. Support them to create a job search plan which specifies certain activities on certain days / at certain times... Autistic people have many skills and talents that are not recognised.

I wasn't offered any support with employment and I feel I would benefit from some coaching to help me communicate and engage with other people at work.

Could support autistic people a bit more with career clarity focusing on strengths and taking into consideration the anxieties faced with applying for jobs.

Actually inform colleges and other places of education what you do as my son has never heard of any support being offered to find work.

Incentivising employers - case studies of Autistic employees and the benefits they offer. Getting employers who do well in this area to speak with other employers. Support individuals to complete applications and advocate for them the reasonable adjustments required at the interview stage and on the job.

I had to sign on at one point and the requirements while I was looking for a job were so confusing. The job centre was only concerned with me filling in a booklet to document jobs I'd applied for, there was no assistance about applying for jobs. I find it extremely difficult when I'm told to do things that don't fulfil the purpose for which I've gone to others for help.

Have events for employed Autistic people to mentor unemployed Autistic people. I would like to help.

Reduce stigmas in the society that the employers can provide suitable adjustments for Autistic people to work... once a routine is established the issue shrinks

There are no services actively and intensively engaged in supporting adults with complex Autism, severe Learning Disabilities and behaviours that challenge into employment; therefore one should be created.

Quicker identification and relevant intervention for school refusers - more focus on what can work for them rather than cost based assessment. Mentoring from industry, not recruitment agency. Work experience that has value, not just volunteering to plug job gaps at local/community events or organisations. Young people not in education have no access to work experience and need a better quality of support to prepare for and engage with this in the future. NCS, DOE or Prince's Trust type programme, minus the royalty or "government" connection.

# Priority 4: What Could We Do Better - Resident Views

People who have Autism with low support needs are not entitled to any Social Care support and often struggle to get their voices heard within the NHS. My son with complex Autism has not been able to access basic health care such as having a blood test, dental care, eye test and podiatry.

Better help for Autistic people to access services that know how to care for them better in places that are less triggering. For example, I struggle a lot with going to a dentist due to sensory issues that send me into a meltdown. I also massively struggle with anything touching or coming near to my face, so in the past have had to be given mild sedation to have work done, however it's a lengthy process for me to get to that point which could cause further damage. If I could just access these services from the start, a lot of time and money would be saved and I'd be able to grow my confidence with a dentist.

Waiting times need improvement, education, communication, access to services. I have access to mental health resources at the moment and, while well meaning, they can't account for the issues I'm facing. I'm not trying to be difficult, but suggesting a break to my routine and try something new to feel better is literally the thing that contributes to my stress levels and then I feel bad for not being normal enough to take the advice from the only service available to me.

Better understanding from health services (e.g. mental health reluctant to deal with Autistic people); more time may be needed for appointments; more creative approaches to empowering people to use health and care services and more attention to the need to maintain dignity - home visits may be necessary rather than appointments in busy settings; care provision needs to be individualised - not a one size fits all solution.

The people at the health services are still severely undereducated when it comes to dealing with autistic people. For example, I still need to call the GP to book an appointment on the day and talk to someone, they will still be annoyed when I ask for more clarity or I'm repeating what they told me. I still need to go in person to the pharmacy, as they would send medication at home only if I was bed ridden disabled. There is nothing to facilitate access for autistic people as would be for another physically disabled person.

Automatically provide robust mental health support with regular review and update. This will need to be lifelong and available as and when needed. It needs to recognise that the support may be light touch at times but also becomes in-depth and robust when needed the most. Young people with Autism will likely not self refer so monitoring must be regular by service. Better support and strategies around sleep and respite for working (single) parents that may not be full time carers but have a young person with a disrupted sleep routine. GPs and surgery to be aware young person with Autism may be reluctant to engage with health services and to set up a schedule of checking in/ monitoring. Support with taking regular or one off medication.

# Priority 5: What Could We Do Better - Resident Views

I'll just point out that no one should be living in a mental hospital because they're Autistic.

Better training and awareness for medical staff. The Autism Health Passport is a good idea but, medical staff need to be better trained and aware around Autism. Often this passport is not even looked at by medical staff who should address serious issues (e.g. impacts certain drugs can have on the individual, impacts of loud noises, smells and too many people around them). It is important for the primary Carer to be included as if anything happens to the person they are caring for, they are the one picking up the pieces not the services. Safeguarding also needs to be considered in hospital - ensuring human rights are upheld.

Listen to patients. Don't be scared of stimming. Sensory issues are more horrible for us than whatever minor adjustment we're asking for from you. We acknowledge how understaffed you are and appreciate your kindness. It can be difficult for us to convey our appreciation.

When I was in inpatient care for a week, I found it very stressful and hard because of sensory overwhelm and not being told what was going on with my care, as well as not being in charge of my medications. It accumulated in a lot of extra stress and I think that the doctor's saw the stress I was under and presumed it was the reason I was on the ward (which it wasn't), so I think it changed how I was cared for and the outcome. So understanding of Autism in the wider doctor community.

Inpatient care remains a nightmare for people in Newham with complex needs particularly if the admission is the result of a mental health need, as the wards do not seem at all well equipped to manage people with complex Autism.

Hospitals and treatment can be scary and overwhelming. Ideally inpatient treatment should occur in smaller settings if possible or extra time should be given to familiarise people to the surroundings / use of side wards should be routine to enable people to have a less overwhelming experience. Familiar adults should be able to remain with the Autistic person if both wish it, to help maintain routines and help with any anxiety; also to advocate if needed.

Early intervention. From my experience Newham professionals act only when there is an emergency. They take too long to put the right support in which ends up in the Autistic person and their family experiencing crisis and an extremely poor quality of life. Then when they get the support it is not effective as it takes lots of resources and time to bring the person back to their baseline.

# Priority 6: What Could We Do Better - Resident Views

There should be sufficient SEN provisions in mainstream schools. Sending SEN kids to PRU schools only emphasises the incorrect notion that we don't belong in society / we're difficult and need to be stuck with other difficult kids. If you treat people like criminals they become criminals

Provider better training and awareness for Police and Youth Justice System so they do not trigger individuals and make matters worse. With better training they will know how to engage with the individual in a dignified and more productive and positive way.

Stop exclusion and our children made to feel they are the problem.

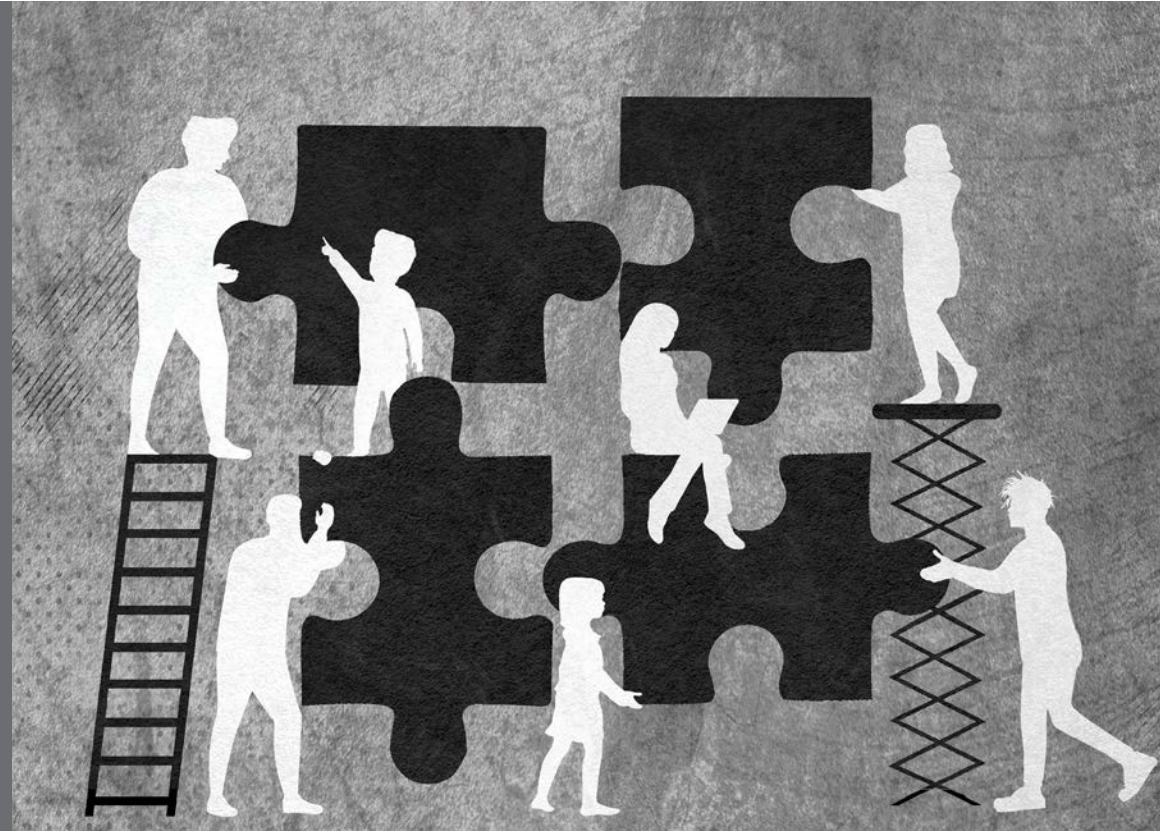
Ensure Appropriate Adult support is available. Provide training on Autism for all staff; and be flexible!

Those who are undiagnosed and have needs are being criminalised and put into the system.

Provide awareness training for all in the criminal and youth justice systems. Opportunities to become familiar with courts etc prior to appearing to help reduce anxiety; and opportunities to ask questions about the process, etc.

There are a high number of neurodiverse young people involved in criminal activity, as there is not much support or leisure activity for them to take part in or employment pathways.

# Delivery



# Delivery

A multi-disciplinary, multi-organisation Autism Strategic Delivery Board will be established to:

- oversee the delivery of the Action Plan;
- ensure appropriate resident and stakeholder contribution across the delivery of the Action Plan;
- identify synergies between the Action Plan and wider programmes across the Council, its partners and the North East London footprint;
- identify and address obstacles, dependencies and risks to the delivery of the Action Plan;
- identify and incorporate further related areas of work into the Action Plan, as appropriate.

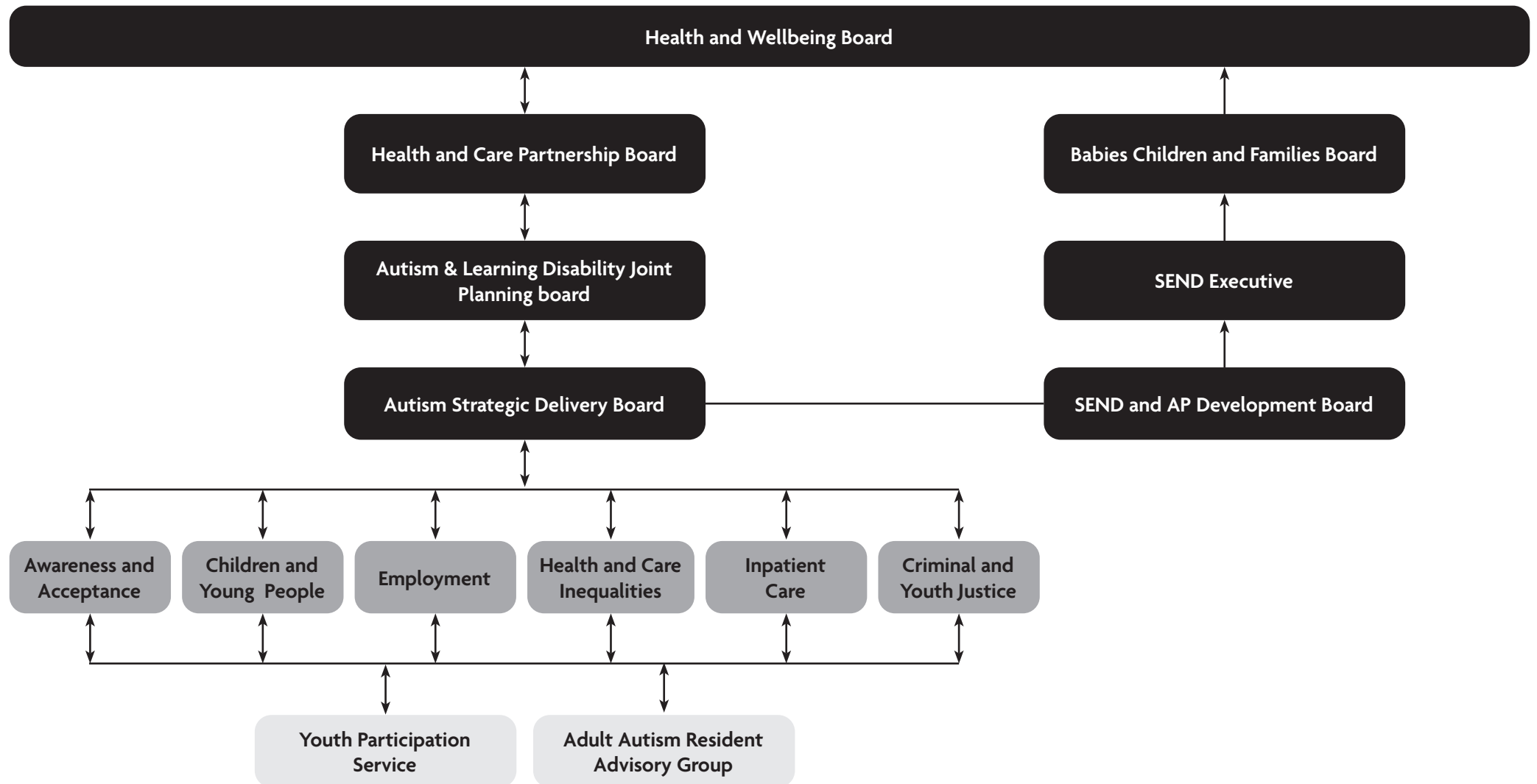
The Board may close, change or add actions to the Action Plan based on progress, learning - and resident and stakeholder feedback.

The adult Autism Resident Advisory Group will be asked to elect a resident to co-chair the Board on an annual basis. In line with the Council's Reward and Recognition Policy, the resident will receive a payment of the London Living Wage rate in exchange for their time.

A You Said, Together We Did document will be published by the Board on an annual basis to advise residents and stakeholders of the progress made toward the Action Plan.



# Governance



# Get Involved!

Join the adult Autism Resident Advisory Group which meets regularly to:

- share ideas and give views on the issues affecting adult Autistic residents in Newham and help shape services;
- co-design the activities, products and services agreed in this Action Plan;
- share information about activities, events and services that may be beneficial / of interest to adult Autistic residents;
- create a network of peer support.

To register visit: [newham.gov.uk/health-adult-social-care/autism/3](https://newham.gov.uk/health-adult-social-care/autism/3).

If you require support to register email: [autism.commissioning@newham.gov.uk](mailto:autism.commissioning@newham.gov.uk) or ring: 020 373 0731.

# Policies and Strategies

This Action Plan should be viewed in conjunction with the below national legislation and guidance and local policies:

## Legislation and Statutory Guidance

- [Children Act \(1989\)](#)
- [Equality Act \(2010\)](#)
- [Autism Act \(2009\)](#)
- [Care Act \(2014\)](#)
- [Children and Families Act \(2014\)](#)
- [SEND Code of Practice 0-25 \(2015\)](#)
- [National Strategy for Autistic Children, Young People and Adults: 2021 to 2026](#)
- [Working Together to Safeguarding Children 2023](#)
- [The Care Planning, Placement and Case Review \(England\) Regulations 2010](#)

## Local Policies

- [Building a Fairer Newham](#)
- [Newham Health and Wellbeing Strategy](#)
- [Newham Ageing Well Strategy](#)
- [Newham SEND and Inclusion Strategy](#)
- [Learning Disability Action Plan for Adults](#)

Recognising  
Diagnosing  
Accepting  
Understanding  
Embracing  
Supporting  
Celebration  
Talking Autism