

Camden All-Age Autism Strategy 2025 — 2030





Camden All-Age Autism Strategy 2025 – 2030

Contents

Thoughts from our partners4
By National Autistic Society4By Autism Hub4By Camden Disability Action5By National Autistic Taskforce5
Introduction6
Inclusive Statement
What we know about autism in Camden 10
Key concepts11Camden's autistic community13Co-production process – the story so far15

he principles for our Autism Strategy 22
Creating a culture change
nformation I need, when I need it 24 Theme 2 : Health, Wellbeing and independence –
Living the lifeI want, staying safe and well 26 Theme 3: Active and Supportive communities —
Keeping families, friends and connections 30 Theme 4: Flexible and integrated care & support –
My support, my own way
staying in control
Theme 6: Workforce
dentities
here to get support41
losing remarks
ppendix 43



Thoughts from our partners



By National Autistic Society

The new Camden All-Age Autism Strategy 2025-2030 is a piece of work which has co-production at its heart. Camden's commitment to ensuring that the local autistic community was involved from the start has been impressive, and it's obvious that residents' experiences and needs shaped the new strategy. The National Autistic Society provided support and advice throughout the process since 2023 and within various activities. Creating a society that works for autistic people is one of our aims, and we are pleased to see how, through this new Autism Strategy, the London Borough of Camden is contributing to this aim.



By Autism Hub

The Autism Hub has supported the Camden's co-production of the strategy to empower autistic residents to lead changes in Camden. The Autism Hub partners with Camden to address systemic inequalities that exist for autistic residents, ensuring that everyone has the opportunity to participate in the community.



Thoughts from our partners



By Camden Disability Action

Autistic and neurodivergent people have said clearly that change is needed. Change in how we are understood, how we are supported, and who holds the power to shape that support and our lives.

Camden Disability Action (CDA) is a peer-led organisation run by and for Disabled people. We work from lived experience, using the Social Model of Disability to challenge barriers and shift culture. As part of this autism strategy, we worked with Camden to co-produce trauma-informed training designed entirely by neurodivergent people. It is for those who support neurodivergent individuals, including Personal Assistants, and helps make culture change real in practice.

Trauma-informed approaches make support safer, more respectful, and more effective by shifting how we understand and respond to people's needs. Training helps people reflect on how their actions and systems can cause harm, and how trauma often comes not from someone's neurodivergence, but from how they are treated. Our role in this strategy is one part of a bigger commitment to hand power back to Disabled people and support lasting change.



By National Autistic Taskforce

We are pleased to see Camden engaging with autistic people in shaping this strategy. While there is always more to learn and improve, the emphasis on lived experience and cultural change is a constructive step towards a more inclusive borough.

Introduction



We want to create a culture change in Camden around autism.



Who's the strategy for?

This strategy is for both residents and professionals in the autistic community in Camden – it is a strategy for everyone working to improve things for Camden's autistic community. We acknowledge intersectionality and diversity, and we know that autistic individuals will have a range of different and varied experiences. That is why it is important to remember that "if you've met one autistic person you've met one autistic person". This strategy is for autistic people without an accompanying learning disability, as well as those with a learning disability. Autism is a form of neurodivergence, and we also know that autistic people often have other cooccurring neurodivergent conditions such as ADHD – this is why our vision is for Camden to be a neurodiversity - and autism-friendly borough. The strategy is also for people who don't have a formal diagnosis, or self-identify as autistic. This strategy sits firmly within the Council's wider commitment to an accessible and friendly Camden.

What we want to achieve

We want to make Camden a better borough for autistic people and their families, friends, carers, and support networks across all ages so they can start well, live well and age well. We want to create a culture change in Camden around autism, which is led by autistic people's experiences and understandings of autism. 'We Make Camden' sets out a commitment for the Council to play a leadership role in tackling structural injustice and inequality in all its forms. This includes challenging ableism - discrimination or prejudice against Disabled and autistic people - using our collective resources to tackle and address the systemic roots of inequality and ensuring that everyone has the opportunity to participate in the community.

Camden is home to huge opportunities, with sector-leading public services, a rich community of voluntary sector organisations and exciting global and local employers. But not all residents in Camden can access these opportunities due to structural inequalities. Camden autistic residents are also impacted by the national housing crisis, and the cost of living crisis. We want to ensure Camden's autistic residents have access to all that Camden has on offer, and reduce the impact of these challenges on our autistic residents.

How we'll get there

This Autism Strategy is our co-produced vision and strategy for how we will reduce the barriers faced by Camden's autistic community and create a culture change across the system. This all-age Autism Strategy is focused on autistic children, young people, and adults in Camden. Our residents have told us that "we need to take a life-span approach – autism is lifelong, and the right support should be too". Therefore, this strategy takes a life course approach, looking at how we can support autistic people to Start Well, Live Well and Age Well under 7 key themes which have come from co-production groups and meetings, and which have been adapted from Think Local Act Personal (TLAP) themes. Our Autism Strategy also complements other strategies and frameworks we have in Camden – our Supporting People Connecting Communities Strategy, our What Matters approach, our Planning Together work, The Big Plan 2025, our Coproduction Framework, our Education Strategy, our Relational Practice Framework, our Special Educational Needs and Disability Strategy, and our Adult Social Care and Children and Learning Workforce Strategies.

Introduction

Since Camden's 2016 – 2021 Autism Strategy, there have been a number of key achievements:

- We have created thriving community forums which bring autistic residents together, including the previous iteration of the Autism Partnership Board.
- We have secured funding for specialist roles including a Disability
 Job Hub Lead. This role provides autistic residents with tailored
 support to access employment and has included collaborating with
 Aspierations to deliver a pilot of Autism Pathways to Employment
 courses to autistic residents. Through this, we have learnt a lot about
 supporting autistic people into work.
- We have also invested in an Autism Lead Practitioner in Adult Social Care, a transitions post in Child and Adolescent Mental Health Services (CAMHS) and ensured we have a focus on autism within a range of council-commissioned services.
- Our autism education training offer has been delivered to schools and has been expanded to staff in early years settings and in the voluntary and community sector.
- The Camden and Islington Autism Hub has received a Better Care Fund grant to support their work.
- Camden's Exceptional Needs Grant offers non-statutory funding to meet high needs and 96.7% of Education Health and Care Plans are issued within 20 weeks.



There are some themes from our previous strategy that are still a priority for us. We know there is more to do to improve waiting times for diagnostic services, and to improve access to housing and employment. We also need to improve data collection around autism and ensure that universal services are accessible for autistic residents.



Introduction

This strategy outlines commitments in Camden from across the Council and our partners to support autistic residents. The strategy has been created in coproduction with children, adults, parents and carers. It outlines our shared vision for the culture change we want to create in Camden.

With huge thanks to:

- All of those generously shared their experiences through co-production
- All of the members and guest speakers at our Autism Partnership Board
- Autism Hub and ALAG (Asperger London Area Group)
- The Autistic Adult Choir
- Camden Autism Co-Researcher Group
- Synergy
- Camden SEND Parent Carer Forum
- Camden Carers
- Change Grow Live
- Autism Education Trust
- National Autistic Society
- National Autistic Taskforce
- Race Equality Foundation

- Camden Disability Action
- Camden Special Parents Forum
- Autism Partnership Board Autistic Adult Advisory Group and Parent/Carer Advisory Group
- Resources for Autism
- SAAIL (Supporting Autistic Adults' Intimate Lives)
- GIRES (Gender Identity Research and Education Society)
- Camden Disability Job Hub
- Aspierations
- British Association of Social Workers (BASW)
- Think Local Act Personal Making it Real
- Autism Education Trust
- Primrose Hill School and Autism Alternative Resource Provision
- National Autism Trainer Programme

Introduction

Inclusive Statement

Autistic residents, parents, family members and carers who have been involved in our work on autism have suggested that this Inclusive Statement lays the foundation of how we all agree to work together throughout the implementation of the strategy.

We will hold all of our identities, heritage, cultures and how we experience living in the world in our minds always – recognising and honouring what makes us all unique and special.

We will strive to remain present when others are talking and sharing, giving our fullest attention to the task at hand.

We will hold kindness, respect, dignity, and compassion in our actions and in our words.

We will be accountable for our words and actions and their impact.

We will seek to resolve conflicts, disagreements, and misunderstandings peacefully and respectfully.

We understand that productive conversation sometimes requires that we feel challenged or uncomfortable, but never unsafe, unheard, or abused – we will call in and call out if anyone feels those things.

We will be mindful of the space that we take and we will make space for everyone to express themselves and contribute.

We will do what each of us can to ensure the physical and emotional safety of ourselves and others.

All are welcome. Everyone is welcome here.



The inclusive statement has been adapted from the Centre for Liberatory Practices community agreement statement weaving values ϑ practices - Center for Liberatory Practice ϑ Poetry and the RYSE house agreements House Agreements — RYSE Center

Autism is a lifelong difference in how people think, perceive the world, and interact with others. It is usually thought to be neurodevelopmental.

An autistic person may see, hear, feel, and experience the world differently from non-autistic people. If you are autistic, you are autistic for life; autism is not an illness or disease and cannot be 'cured'.

Autism is not a single set of characteristics. Autistic people are very diverse, and each autistic person has their own strengths, interests, skills and challenges. This is why autism is called a 'spectrum'. Here is a link to the National Autistic Society's What is autism video.



What we know about autism in Camden

Key concepts

We have heard from autistic people that a fundamental part of conceptualising autism is understanding key concepts underpinned by lived experience perspectives and expertise. This is the foundation of culture change described below. These key concepts are outlined in our Appendix, and include:

- Neurodiversity and neurodivergence
- Social model of disability
- Double empathy problem
- Monotropism

- Interests and hyperfocus
- SPELL Structure, Positive (approaches and expectations); Empathy; Low arousal; Links
- REAL Reliable, Empathic, Anticipatory and Logical

- Masking
- Autistic burnout
- Meltdowns and shutdowns
- Sensory difference
- Alexithymia and anxiety

- Co-occuring conditions and diagnostic overshadowing
- Masking



We recommend the National Autistic Society's language document for further guidance on how to talk and write about Autism - <u>How to talk and write about</u>

There are national challenges with autism data collection. Some of the reasons for this could be:

- Not all autistic people are known to services.
- Not all autistic people have a diagnosis and there are significant wait times for diagnostic assessments.
- Autism is not recorded consistently across services.
- There is not a national register so actual numbers are unknown.

The National Autistic Society suggests that more in than 1 in 100 people are autistic and there are at least 700,000 autistic adults and children in the UK.

These numbers are not the same as the number of people with an autism diagnosis. They are based on research about the true figure, which is likely to be higher. More research is needed to know for sure. People of all ages, genders and ethnicities can be autistic. But people from marginalised groups can face more barriers to accessing a diagnosis and support.

What we do know is autistic people face a number of barriers and inequalities across health and social care, education, employment and mental health support.

Key statistics



80% of autistic adults report difficulty visiting a GP.⁷



Only 14% of autistic adults said there were enough mental health services in their area to meet their needs.¹³



Autistic people are over three times more likely to say they frequently leave a healthcare appointment feeling as though they did not receive any help at all.8



Only **26%** of autistic pupils say they feel happy at school.¹⁴



Autistic people die around six years earlier than the general population, and autistic people who also have a learning disability die up to 15 years earlier.⁹



7 in 10 parents of autistic children say their child's school place doesn't meet their needs.¹⁵



There are 1,410 autistic people in psychiatric hospitals in England.¹⁰



There were 14,000 appeals to the SEND tribunal in the 2022/23 academic year. This was an increase of 24% on the previous year.¹⁶



The number of autistic people without a learning disability detained in mental health hospitals has increased by 122% since 2015.



98% of SEND tribunal cases were resolved in favour of parents, demonstrating that the issue is not the legitimacy of requests for support, but barriers to implementation.¹⁷



As of September 2024, 204,876 people were waiting for an autism assessment in England. This is a 25% increase in just one year.¹²



12

Only 3 in 10 autistic adults are in work, compared to 52.6% of disabled people - the lowest for any disability.

UK-wide national key statistics from National Autistic Society, January 2025

What we know about autism in Camden

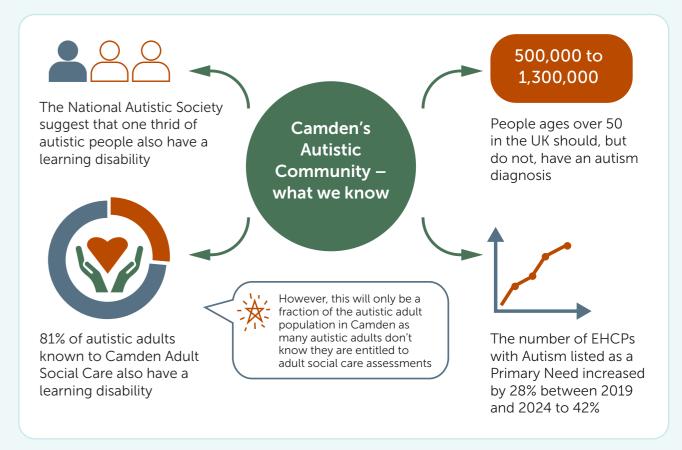
Camden's autistic community

If autistic people are likely to make up 2% of the population (based on the latest 'official' estimate of Camden's resident population of 279,500 at mid-2020), there could be approximately 5,590 autistic residents in Camden.

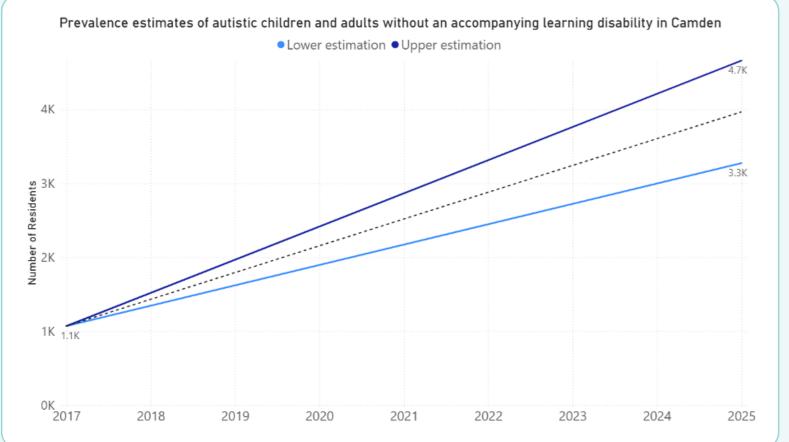
13

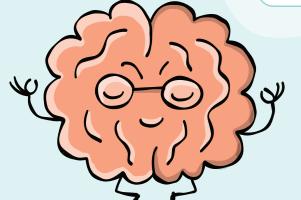
Population projections have suggested that the number of autistic adults in Camden is likely to increase year on year. Data from the Special Educational Needs and Disability (SEND) Joint Strategic Needs Assessment (JSNA) has found that between 2019 and 2024, the number of Education Health and Care Plans (FHCPs) with autism listed as a Primary Need has increased by 28%, making autism the Primary Need on 42% of EHCPS. Within older adults, research of UK General Practice (GP) records has estimated that between half a million and 1.3 million people aged over 50 should, but do not, have an autism diagnosis. We therefore know that in Camden there are older autistic residents without a diagnosis who need autism-informed support.

The National Autistic Society suggests that one third of autistic people also have a learning disability. However, due to the challenges in getting accurate data there are varying estimates around this.



Autistic adults who do not have an accompanying learning disability have shared that autistic children, young people and adults are not accurately represented in the data and that there is a disparity in access to autism-informed multidisciplinary, integrated care and support depending on whether an autistic person has an accompanying learning disability or not.





Over the years, there have been different terms and phrases used to describe autism. We will use **identity-first language** in this strategy – we have chosen the term "autistic people", rather than people with autism as that is currently how many people describe themselves. We acknowledge that people have different preferences when describing themselves and their autism. National Autistic Society's weblink about how to talk and write about autism.

What we know about autism in Camden



Co-production process – the story so far

Camden's autistic community has been at the heart of Camden's work on autism.

The feedback from autistic residents has informed the themes and content of this strategy. Camden's work on autism started with a commitment to prioritise autismand trauma-informed co-production with autistic adults and parents and carers of autistic children. This was a response to the historical lack of involvement of autistic individuals and their families in shaping the services that are supporting them.



We know that it is essential that we hear from those who draw on services, those who deliver services, community groups and residents who may experience barriers in accessing services so that we can ensure we have a plan in place that works best for our residents. Our approach has been to all work together and commit to meaningfully co-producing Camden's autism strategy and implementation plan through ongoing partnerships and collaboration. We have learnt how important meaningful co-production, creating safe spaces to build equal partnerships and a focus on wellbeing, autism-informed and trauma-informed practice are to achieving the cultural shift we are working towards.





There have been several advisory and co-production spaces led by lived-experience perspectives which have shaped the key messages in this Autism Strategy.

Membership included autistic adults, parents and carers. These participants have suggested how we can all work together across the duration of this strategy implementation to improve autistic people's, their families', friends' and carers' experiences of services. The themes that emerged from these co-production spaces can be found on pages 18 and 19. These groups worked with the Autism Partnership Board, which was co-chaired by an autistic resident.

Autistic children and young people have also inputted into the strategy – autistic children at Primrose Hill School, both in the Autism Resource Provision and mainstream school, shared what they liked in their community and what they wanted to see more of. Other sessions have taken place with groups of children and young people.

What we know about autism in Camden

The autistic community has generously shared experiences and insights with us.

Their expertise has already created some clear and tangible actions – for example, co-production with autistic residents led to the Autism Hub receiving a grant to address structural inequalities, and the Autism Education Trust training that was offered to the workforce has now been extended to parents and carers. Co-production led to some dedicated work on anti-racism with the Race Equality Foundation and the Autism Hub – which included regular forums to raise awareness. Residents have shaped service and training offers on an ongoing basis.

The messages from co-production are weaved into the themes for this strategy – with resident quotes for each theme, and resident experience built into these themes. Autistic residents have been involved at each stage - strategy themes and emerging work have been shared with residents through the Autism Partnership Board, and through a consultation process.

In creating this strategy we have also received guidance from key autistic-led, and autism-specialist organisations –the National Autistic Taskforce, the Camden and Islington Autism Hub and the National Autistic Society.

Residents have worked together to create films, photography, poetry and song to share their experiences. Thank you to all those who have been generous with sharing their ideas, thoughts and experience to shape this strategy. We have included live drawings from our previous Autism Partnership Board which highlight some of the key themes and feedback from autistic residents, and partners:





The Think Local Act Personal Making It Real themes:

Wellbeing & Independence: Living the life I want, keeping safe and well

Information & Advice: Having the information I need, when I need it

Active & Supportive
Communities: Keeping
family, friends and
connections

Flexible & Integrated Care and Support: My support, my own way

When Things Need to Change: Staying in control

Workforce: The people who support me

The co-production themes resonate with key elements outlined in the We Make Camden ambitions, the Think Local Act Personal Making It Real themes and the National Autistic Taskforce's report: An independent guide to quality care for autistic people.

Key topics discussed in coproduction

- A whole life approach starting well, living well and ageing well – life-long autism-informed support
- Advocacy and information about rights
- Autistic-led and Neurodivergentled perspectives and collaborative research
- research matters researching what matters
 to autistic people and
 developing an evidence-base
 to influence service delivery
- Camden Disability Action Leader's Change Model and implementation of the Social Model of Disability

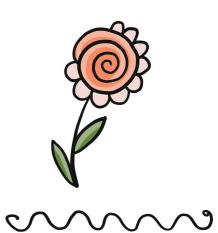
- Care and support for autistic children, young people and adults, their families, friends and carers
- Communication
- Community connection and leisure activities
- Co-occurring conditions
- Criminal justice
- Cultural shift lived
 experience perspectives and
 autistic researchers, scholars
 and academic's evidenced
 based work shaping the way
 we understand, describe and
 celebrate autism as well as
 how services are shaped to
 support autistic people, their
 families, friends and carers

- Data data matters
- Diagnosis and pre- and post-diagnostic support
- Drug and alcohol support
- Early help
- Education start well, education settings that understand autism and opportunities for life-long learning
- Emotional wellbeing and mental health
- Employment
- Gender equality
- Housing, homelessness, and accommodation

- Information and advice
- Intersectionality identity matters
- Language language and terminology matters
- LGBTQ+ equality
- Peer support
- Physical health
- Race equality
- Reasonable adjustments
- Relationships, friendships, and intimate lives

- Safety and keeping safe
- Sensory needs
- Social activities around different interests for groups and individuals
- Social care
- Training and reflective spaces
- Transitions and preparing for adulthood
- Trauma-informed practice
- Welfare and benefit support

- Workforce development
- And much more...



An independent guide to quality care for autistic people – National Autistic Taskforce

- 1. Respect and promote autonomy
- 2. Support communication effectively throughout the lifespan
- 3. Provide care which is autistic person-centred
- 4. Tackle environmental and other stressors
- 5. Remove barriers to access
- 6. Fight stigma and discrimination
- 7. Recognise behaviour as distress
- 8. Ensure better transitions
- Ensure ongoing, practical, autismspecific staff training
- 10.Accept difference and support positive autistic identity







The principles for our Autism Strategy

Creating a culture change

Our ethos in the Camden Autism Strategy is about creating a culture change. We are committed to all staff in Camden working towards changing the way they understand, view and respond to the autistic community.

Through the strategy implementation, we will actively seek to develop and reflect on our approach – we will learn from the good practice in the National Autistic Taskforce, Think Local Act Personal Making It Real, British Association of Social Workers Capabilities Statement for Social Work with Autistic Adults and other guides and frameworks that we come across as we learn more. Frameworks will help to guide our journey to creating a culture shift and will help us to measure impact.



Below we outline what we mean by a culture change in Camden around autism. For this, we have taken inspiration from the National Autistic Taskforce's Independent Guide for Quality Care for Autistic People, and adapted this for a Camden context, based on feedback from Camden's autistic residents.

Proactively seek to better understand autism, and celebrate autistic identities through

- Ongoing, practical, autism-specific staff training.
- Accepting difference and supporting positive autistic identity.
- Fighting stigma and discrimination.
- Recognition of some behaviour as distress.

Taking steps to make services and spaces autism-informed, person-centred, predictable, clearly communicated and visible through

- Communicating effectively throughout the lifespan.
- Seeking to offer a variety of ways to communicate and keeping information up to date.
- Ensuring better transitions.

Continuously reviewing and addressing potential barriers to Autism inclusion through

- Considering and removing potential barriers to access.
- Tackling environmental and other stressors.

The above culture change principles underpin each of the strategy's 7 themes, which have been taken from Think Local Act Personal Making it Real.

Theme 1

Information and advice - Having the information I need, when I need it



What do we know and what have residents told us?

"It takes time to get where you need to be, the 'system' doesn't always help you get there"

"If I was not persistent, I would not get help"



For autistic adults, parents and carers in Camden, we've heard that asking for help across the system can feel like being a burden.

Autistic people and their families, friends and carers need clear and accessible information and advice about what support is available for them, and how to ask for it.

Autistic adults need to be aware of their legal rights including the right to a Care Act assessment, to advocacy, and to reasonable adjustments.

The themes of our Autism strategy

During this strategy term (5 years) we will focus on:

Starting Well

- Making it easier for families and autistic young people to find useful information.
- Supporting all children and young people to understand autism and promoting equity and neurodivergent-positive attitudes.
- Providing clear and transparent information about what is on offer for autistic children (including those without a formal diagnosis) and their families, and where eligibility varies, setting out the criteria.
- Creating and promoting social opportunities and networks in addition to health and social care services for autistic families.

Living and Ageing Well

- Adults being supported to maintain networks and support from childhood to adulthood, and having clear and accessible information on what additional support is available at different life stages.
- Making it easier for all autistic adults, parents and carers in Camden to ask for help, and ensuring transparency about what is on offer and what support is available, including their rights and entitlements.
- Making information available for all the areas adults say are important for them, for example early help, maintaining good mental health, getting a job and support with their finances or housing.
- Supporting autistic adults to find support to meet their needs and wishes; making them aware of their rights to a Care Act assessment and reasonable adjustments.

Theme 2

Health, Wellbeing and independence – Living the life I want, staying safe and well

What do we know and what have residents told us?

"housing situation impacts on mental wellbeing, and housing situation also has an impact on if they can access the right mental health at the right time"

"We need to prioritise autistic people's wellbeing"



Whilst autism is not a mental health condition, we know that autistic people are at greater risk of developing mental health needs and autistic people have told us about the challenges they face accessing mental health services.

The principles for our Autism Strategy

The Mental Health Foundation estimates that, nationally, 7 out of 10 autistic people also have a mental health condition. Camden's National Autistic Society survey of the autistic community and their parents and carers, found that 71% of children and young people have reported needs related to their mental health and 80% of adults have identified a need related to their mental health.

Autistic people also experience a higher prevalence of some physical health issues, including long term health conditions, and certain elements of maintaining physical health and wellbeing can be challenging for autistic residents. We know that navigating health systems and engaging with health professionals can be difficult for autistic residents if their reasonable adjustments and needs are not recognised and accommodated.

Barriers such as these to accessing healthcare often lead to poorer health outcomes for autistic residents. We are committed to working with our health partners, especially the NHS, to address these inequalities in physical and mental health.

We have heard from the autistic community the importance of being able to live independent lives. Whether this is autistic children and young people being able to access inclusive community environments and opportunities that help them to build their skills, confidence and networks, or autistic adults being able to access housing and accommodation which meets their sensory and individual needs – this is a key priority. Autistic residents have consistently told us that we need to improve access to good quality, affordable housing and safe and inclusive communities in the Borough. For parents and carers of autistic children, we have heard the importance of being informed about what is available to support their child's wellbeing and independence.



The themes of our Autism strategy

During this strategy term (5 years) we will focus on:

Starting Well

- Working with our NHS partners to make it clearer which health services are available for autistic children and young people, reduce waiting times, and provide information to help in the absence of a diagnosis.
- Improving age-appropriate information and advice about maintaining good mental and physical health for autistic children and young people.
- Taking an equity approach to children's services, recognising that autistic children and young people without a learning disability experience additional barriers to accessing universal services.
- Working to ensure that autistic children and young people find it easier to access and engage with Camden services and events.
- Improving our support to schools to meet the needs of autistic pupils.
- Supporting autistic pupils to thrive through reviewing and improving the outreach and advisory support available to schools and developing a Meeting Predictable Needs Toolkit to provide practical information and advice in mainstream settings.

Living and Ageing Well

- Working together to tackle inequalities in access to health, social care and wider community services.
- Making health, social care and wider community service offers autisminformed, consistent and reliable.
- Addressing the causes of poor physical and mental health and the barriers people face accessing earlier help.
- Working together to promote wellbeing and independence across health and social care services.
- Ensuring our housing offers are accessible to autistic adults and our housing support services are tailored to their individual needs, including sensory needs.
- Proactively informing autistic adults about how to access care and support tailored to their age and life stage.
- Ensuring all support providers are autism-friendly, consistent, reliable, and skilled
- Ensuring all Adult Social Care accommodation is accessible and meets people's needs. Ensuring statutory and in-house accommodation services and providers are autism-informed, consistent and reliable.



The themes of our Autism strategy

Theme 3

Active and Supportive communities – Keeping families, friends and connections



What do we know and what have residents told us?

"support everyday life challenges, loneliness, peer support and transitions"

"build in support for parents and carers"



The National Autistic Society highlights that autistic people are more likely to experience loneliness than the general population.

In the National Autistic Society survey of Camden's autistic community in autumn 2024, 63% of autistic adults surveyed reported feeling lonely. Active and supportive communities across the life course can help to support autistic residents and reduce loneliness. Whether this is inclusive education and activities for young people to enable social inclusion and fun, good quality and paid work for autistic adults, or autism-informed care and support, our vision is for no autistic residents in Camden to be socially isolated or unable to connect to the Camden community. Autistic children told us they would like more activities – whether this is at the cinema, climbing, trampolining, art or the zoo – they'd love to see more of this. Autistic adults have highlighted the wellbeing benefits of pursuing their interests, and the need for tailored support to access and explore these.

The themes of our Autism strategy

During this strategy term (5 years) we will focus on:

Starting Well

- Making spaces, activities and services inclusive for autistic children and young people.
- Developing our support offer for families, friends and carers of autistic children and young people.
- Identifying and creating opportunities for autistic young people to volunteer, work and share common interests.

Living and Ageing Well

- Ensuring autistic adults can access peer support, inclusive activities and social networks.
- Supporting autistic adults to access and engage in work, training, education and volunteering of their choice.
- Ensuring Camden's social care, housing, criminal justice and health services are autism-informed
- Enabling autistic adults and their families, friends and carers to access autism-friendly support providers and wider services.
- Meeting the needs of older autistic people in Camden's housing, criminal justice, social care and health services recognising that many will not have a diagnosis.

Theme 4

Flexible and integrated care & support – My support, my own way

What do we know and what have residents told us?

"assessments are a barrier"

"there is a lack of support for autistic children without a learning disability" "Ping ponged between services all saying 'no' because I do not have a learning disability".



We want to make Camden an autism-friendly Borough for everyone, with or without a diagnosis. Too many autistic residents struggle to get an autism diagnosis.

In England, National Autistic Society data from March 2024 shows that 86% of those waiting for an assessment have been waiting for longer than the 13 weeks recommended by the National Institute for Health and Care Excellence (NICE). A diagnosis is not needed in order to access social care support, but autistic residents have told us about the journey from diagnosis to social care assessment and the challenges they have often faced. We have heard from autistic residents that they feel many offers of support are not available to them with or without a formal diagnosis.

Of 149 surveyed for Camden's National Autistic Society survey, 19% had a care act assessment or social work assessment. Navigating getting an autism diagnosis is a key part of an autistic resident's journey - support to access and undergo a diagnostic assessment for autism is a key priority for Camden's autistic community, at each stage of the life course.

The themes of our Autism strategy

During this strategy term (5 years) we will focus on:

Starting Well

- Develop a clear offer of support to meet a range of needs common to autistic children and young people, including for those waiting for assessment, self-identifying and post-diagnosis."
- Working together with partners across education, health, social care and universal services to provide coordinated support and take into consideration a child's wider interests and personal goals when planning support.
- Developing accessible universal services with good knowledge of wider offers available beyond their own, which are able to direct people to more specialist support where this is needed.
- Upskilling staff across children's services to identify the needs of autistic children and young people to ensure their plans reflect the support they need.

Living and Ageing Well

- Providing integrated care and support for autistic adults that enables them to live and age as they want to, and recognises their individual strengths and needs.
- Ensuring services are accessible and have good knowledge of wider offers available beyond their own, and are able to direct people to more specialist support where this is needed.
- Promoting collaborative working between autistic adults, social care, health, housing and other community services to implement autismand trauma-informed Team Around Me approaches.

The themes of our Autism strategy

Theme 5

Transitions: When things need to change – staying in control

What do we know and what have residents told us?

"nobody understands how important it is to have predictability and reliability" "make the first contact with a service autism informed – I can see things very black and white, and I can turn off a service from one bad experience"



Moving between different stages of life, for example changing schools, moving home, starting a new job, and navigating relationships, is especially hard if you find change difficult as many autistic residents do.

Autistic residents have told us that services are difficult to navigate, and support throughout transitions is inconsistent. Our vision is that residents are supported to live a good life locally through each stage of the life course – with proactive, early and streamlined support to avoid crisis.

Transitions to adult mental health services by autistic young people with mental health needs but without an accompanying learning disability can be very challenging. Parents of autistic young people describe it as a "cliff edge" and a very worrying time. We have also heard that support for life skills, and developing independence is key. Research suggests that "[o]ver three quarters of autistic adults (77%) reach crisis point while waiting for care." The Autism Alliance launches Breaking Point — Autism Alliance UK

The themes of our Autism strategy

During this strategy term (5 years) we will focus on:

Starting Well

- Learning from the experiences of autistic children, young people and their families to build services' understanding of the stages in an autistic child's life where additional support may be needed, and identifying resources to support navigating these times.
- Analysing our crisis interventions to understand what is working or not and identify good practice, gaps and co-creating preventative solutions.
- Supporting autistic young people to develop independence and life skills and creating safe spaces to practice these.

Living and Ageing Well

- Developing a clear preparation for adulthood pathway from children's to adults' services for autistic young people. This will include clear and transparent information and advice and, as far as possible, advance planning and preparation for changes.
- Improving access to autism-informed statutory and non-statutory advocacy, particularly during periods of change and transition.
- Ensuring autistic people will have consistent and reliabile support that is streamlined between different services (for example, mental health and social care teams).
- When autistic adults experience challenge, transition, or crisis, promoting collaborative working between autistic adults, social care, health, housing and other community services to implement autism- and trauma-informed Team Around Me approaches.
- Foregrounding the rights, wishes and best interests of autistic people throughout adulthood and older age, especially during big changes, such as needing to move to a new home or requiring autism-informed care and support to maintain their independence.

Theme 6 Workforce

What do we know and what have residents told us?

"when people do listen, it can make me feel good and happy that I was listened to" "all contact with services should be autism informed and trauma informed"



In a National Autistic Society survey of Camden's autistic community, 46% of respondents reported that staff's lack of understanding of autism is a barrier to getting help.

Awareness and understanding of autism, and autism- and trauma-informed practice is key for all professionals working in Camden. Through high quality training, we will work to ensure that all Camden staff across the partnership can implement autism-informed and trauma-informed practice.

During this strategy term (5 years) we will focus on:

Start Well, Live Well and Age Well

All Camden staff, including leaders, non-specialist staff and frontline practitioners have understanding of:

- Autism-informed practice
- Trauma-informed practice
- Reasonable adjustments

Intersectionality, inclusion, equity and diversity.
We will ensure there are spaces for staff to explore how to apply these approaches in their work, share good practice, and promote ongoing learning.

We will also ensure that there is good support for neurodivergent staff, and partner with local organisations to encourage adoption of this support in their services.



Theme 7

Access, inclusion and equity across diverse identities

What do we know and what have residents told us?

"Ageism
is really
important to
consider"

"I had to go private to get a clinical psychologist who has African heritage like me"

"There's lots of discrimination against Black and Asian minority – a lot struggle to get their voices heard"



Every autistic person's experience will be different. In Camden, we acknowledge and value the diversity of the autistic community. We want to work with partners and take an intersectional, whole system approach to culture change, actively tackling inequality and promoting neuro-affirmative understandings of autism.

The themes of our Autism strategy

Data tells us that autistic people's experiences vary greatly. For example, 2023 data highlights that boys are more likely than girls to be identified through autism diagnostic assessments or Education Health and Care Plans (EHCP) by the age of 5, whereas girls are more likely than boys to be identified after they are 13.

There are also differences in prevalence of EHCPs when looking at ethnicity – the prevalence of EHCPs was significantly higher among pupils of Black/Black British ethnicity than for pupils of White, Chinese or 'any other' ethnicities.

As outlined above, among Camden residents between the ages of 0 and 25, autism is the most often identified Primary Need on EHCPs at 42%. 6% of Camden children with an EHCP or accessing Special Educational Needs and Disability support are from Black or Black British backgrounds. There is currently not data that allows us to look further at autism and EHCPs by ethnicity.

In addition to this, of 136 surveyed for the National Autistic Society survey, 7% reported they were non-binary.

Nationally, autistic adults are over-represented in criminal justice and homelessness populations,





The themes of our Autism strategy

During this strategy term (5 years) we will focus on:

Start Well, Live Well and Age Well:

- Our vision is to reduce the inequalities experienced by autistic people of all ages.
- We will improve our data and recording to better understand if autistic residents from all backgrounds are having their needs met and work to adjust services accordingly.
- Across the Council and our partners, we will tackle the structural inequalities, ableism and discrimination faced by autistic people, their families, friends, carers, and networks.

Where to get support

There is a range of support available for autistic residents in Camden.

Camden's Local Offer has a full range of information about support for children and young people SEND Local Offer - Camden Council.

Camden Care Choices has a range of information about support for autistic adults - <u>Help for Autistic</u> <u>Adults - Adult Social Care | Home</u>.

There are also user-led organisations in Camden who provide support for autistic people, and who have been instrumental in the development of this strategy:

Camden Disability Action (CDA) is a peer-led organisation run by and for Disabled people. We work from lived experience, using the Social Model of Disability to challenge barriers and shift culture. Our work is grounded in a leadership and coaching model and the Social Model of Disability. Together, they challenge assumptions and put lived experience at the centre, showing what access and barriers really look like, which are often overlooked in mainstream thinking.

The Autism Hub is a user led charity, by and for autistic adults who do not have a co-occurring learning disability. There is little provision in place for this group of autistic adults, who have often fallen through the gaps in services only to be told they do not meet the criteria for support and are ultimately left without the support they need. The Autism Hub offers advocacy, peer support, workshops, activities, as well as expert advice, information, autism adjusted counselling and signposting to autistic adults, their families, carers and other professionals. The Autism Hub empowers autistic adults, challenges inequality and improves community connection and wellbeing for autistic adults.

Closing remarks





Cllr Marcus Boyland Cllr Anna Wright

Closing remarks from Cllr Marcus Boyland, Cabinet Member for Best Start in Life and Cllr Anna Wright, Cabinet Member for Health, Wellbeing and Adult Social Care

In Camden, we are committed to being a place where everyone has the opportunity to succeed and no one is left behind.

Autistic residents, and their parents and carers, face a number of barriers and inequalities including in education, employment, housing and health and wellbeing. Yet every autistic person is different and will have different experiences. We have developed this strategy with a clear understanding that autism is a spectrum and that every person's journey is unique. This is a strategy for everyone – for those with or without a formal autism diagnosis, for those with or without an accompanying learning disability. As part of our

commitment to being an accessible and friendly Camden, we want to ensure that we are a neurodiversity friendly borough and that autistic residents have access to all that Camden has to offer.

We will take forward the commitments in this strategy through an implementation plan which sets out the actions that Council services, and others across the partnership, must undertake. The strategy and its implementation will be monitored through governance focused on transparency, accountability and open engagement to ensure that residents are always at the heart of what we do.





Appendix

Key concepts

We have heard from autistic people that a fundamental part of conceptualising autism is about understanding key areas being discussed by autistic researchers, scholars, academics and autism organisations to raise autism awareness.

This appendix contains some key concepts to increase your knowledge of autism.

Some of these concepts are listed below and have weblinks to where more information can be accessed (including some weblinks to video explanations):

Neurodiversity and neurodivergence

Autistica explain that "neurodiversity describes the idea that people experience and interact with the world around them in many different ways. Whilst we all see the world differently, research suggests that 1 in 7 of the population is neurodivergent. This includes people who are autistic, and those with dyslexia, dyspraxia, dyscalculia, and Tourette's syndrome. Many neurodivergent people have more than one diagnosis" (Autistica).

The neurodiversity movement

The National Autistic Society says that "the 'neurodiversity movement' is a social justice movement that seeks civil rights, equality, respect and inclusion for all neurodivergent people... The main aim of the movement is to end the discrimination neurodivergent people face in society. This includes fighting against

the 'pathologisation' of neurodivergence, including autism, which means changing views in medical science and society more widely so that people understand neurodivergence as a difference, not a 'deficit' or 'disorder'" (National Autistic Society's webpage on theneurodiversity-movement).

Double empathy problem

The double empathy problem was coined by Dr Damian Milton and suggests that autistic and non-autistic people struggle to empathise with each other due to different experiences of the world and communication styles (National Autistic Society's webpage about the double empathy problem by Dr Damian Milton).

To learn more, here is a weblink to <u>National</u>

<u>Autism Trainer Programme Double Empathy</u>

<u>Problem Video</u> which gives a full explanation.

This video also features in the National Autism

Trainer Programme (NAPT). To learn more about NAPT, here is a webpage to <u>National</u> <u>Autism Trainer Programme project leads on importance and key outcomes video</u>

Social model of disability:

The Social Model of Disability was developed by Disabled people and describes people as being disabled by barriers in society, not by our impairment or difference. If modern life was set up in a way that was accessible for Disabled people, then we would not be excluded or restricted.

The social model of disability helps us recognise barriers that make life harder for Disabled people. These barriers are identified as being the physical environment, people's attitudes, the way people communicate, how institutions and organisations are run, and how society discriminates against those of us who

Appendix

are perceived as 'different'. Removing these barriers creates equality and offers Disabled people more independence, choice, and control. (Social Model of Disability: Language Disability Rights UK)

Monotropism

Monotropism is a theory which was first developed by Dinah Murray and Wenn Lawson Monotropism is an individual's tendency to focus their attention on a small or singular number of interests at any time.

The National Autism Trainer Programme video explains that "the theory of monotropism describes the way which autistic people's neurology processes sensory information, engages with something in order to give it our full focused attention, works to move our attention from one thing to another and validates autistic experience in a non-pathological way".

To learn more, here is a weblink to National Autism Trainer Programme Introduction to Monotropism video which gives a full explanation. This video also features in the National Autism Trainer Programme (NAPT).

Interests and hyperfocus

Pete Wharmby is an autistic author, advocate and ex-English teacher. Here he discusses interests and how they should be embraced: "the vast majority of autistic people will have 'special interests' - topics they are capable of exploring in huge detail for long periods of time. Often misunderstood as 'hobbies' or 'pastimes', they are in fact much more than that. The complete absorption into a topic or activity (or "hyperfixations") can be both lifeaffirming and life-allowing: they give depth and meaning to our lives but also enable us to enjoy our lives, by acting as a kind of mood regulator, keeping our stress levels down and helping us get through the events of the day" (National **Autistic Society webpage).**

SPELL stands for: Structure; Positive (approaches and expectations); Empathy; Low arousal; Links:

SPELL is the National Autistic Society's framework for understanding and responding to the needs of autistic children and adults. It focuses on five principles that have been identified as vital elements of good practice when working with autistic people, and emphasises ways to change the environment

and our approaches to meet the specific needs of each person. The SPELL framework recognises the individual and unique needs of each child and adult and emphasises that planning and intervention be organised on this basis. The SPELL framework can be used with all autistic people, regardless of age or level of support needs (The SPELL framework).

REAL stands for: Reliable, Empathic, Anticipatory and Logical

REAL is an autism-informed approach.
"Enacting the REAL principle amounts to doing what you say you are going to do reliably, empathising with the world view of the individual, anticipating potential difficulties and addressing them before they arise, and communicating clearly and logically to avoid ambiguity." (University through the eyes of autistic students and staff Martin, N. & Milton, D. (Editor), Sept 2020, Neurodiversity Reader.)

Masking

"To 'mask' or to 'camouflage' means to hide or disguise parts of oneself in order to better fit in with those around you. It is an unconscious strategy all humans develop whilst growing up in order to connect with those around us.

Appendix

However, for us autistic folk the strategy is often much more ingrained and harmful to our wellbeing and health. Because our social norms are different to others around us, we often experience greater pressure to hide our true selves and to fit into that non-autistic culture. More often than not, we have to spend our entire lives hiding our traits and trying to fit in" (Dr Hannah Belcher on the National Autistic Society website).

Autistic burnout

Autistic people often talk about autistic burnout as a source of distress, but it's only just starting to be recognised in wider conversations.

At the National Autistic Society website, Dr Dora Raymaker, Research Assistant Professor discusses research exploring autistic people's experiences of autistic burnout. "Autistic burnout is a state of physical and mental fatigue, heightened stress, and diminished capacity to manage life skills, sensory input, and/or social interactions, which comes from years of being severely overtaxed by the strain of trying to live up to demands that are out of sync with our needs."

(National Autistic Society's webpage on understanding autistic burnout).

Meltdowns and shutdowns

Autistica describe meltdowns and shutdowns as "reactions to extreme distress. Meltdowns involve a range of behaviours which may include self-injury, crying, shouting, rocking and other outward signs of distress. Shutdowns are similar to a 'freeze' response, where someone may struggle to communicate or move. Meltdowns and shutdowns can happen from stressors such as sensory overload, social overwhelm, uncertainty and unexpected changes" (Autistica Public Transport Report).

Sensory differences

The National Autistic Society explain that "processing everyday sensory information can be difficult for autistic people. Any of their senses may be over- or under-sensitive, or both, at different times. These sensory differences can affect how they feel and act, and can have a profound effect on a person's life" (National Autistic Society).

To learn more, here is a weblink to the <u>National</u> Autistic Society guide for all audiences about sensory differences, <u>NDTi's</u> supporting autistic people flourishing at home and beyond: considering and meeting the sensory needs of autistic people in housing and <u>Miguel Jiron's</u> Sensory Overload video.

Alexithymia

Autistica explain that "around a half of autistic people have difficulties understanding and describing their own emotions. This is known as Alexithymia. Alexithymia can make anxiety feel worse for autistic people" (Alexithymia | Autistica).

To learn more, here is a weblink to <u>Autistica's</u> video anxiety in autism explained. This video talks about stimming and alexithymia too.

Anxiety

Anyone can experience anxiety. It is common to feel anxious when in a stressful or challenging situation. However, some autistic people may feel anxious in their day-to-day lives due to navigating social and sensory environments that might be difficult or challenging. Research suggests autistic people are more prone to experiencing anxiety and estimates that up to half of all autistic people experience high levels of anxiety on a regular basis

Appendix

Co-occurring conditions

The National Autistic Society explain that "autism is often diagnosed alongside other conditions. It's important to support people with more than one condition in a way that meets all their needs, while understanding that the needs that arise from being autistic are distinct" (National Autistic Society).

To learn more about different co-occurring conditions, here is a weblink to the **National Autistic Society where this is discussed in more detail.**

Diagnostic overshadowing

The Local Government Association suggest "Diagnostic overshadowing occurs when clinicians or caregivers attribute a person's symptoms or behaviours to their autism and / or learning disability diagnosis without considering other potential causes, such as medical conditions, mental health issues, or other neurodevelopmental conditions" (Local Government Association).

To learn more, here is a webpage to <u>Local</u> <u>Government Association's report on diagnostic overshadowing</u>.

Stimming

The National Autistic Society describe stimming as: "Stimming or self-stimulating behaviour includes arm or hand-flapping, finger-flicking, rocking, jumping, spinning or twirling, headbanging and complex body movements. It includes the repetitive use of an object, such as flicking a rubber band or twirling a piece of string, or repetitive activities involving the senses (such as repeatedly feeling a particular texture). Many non-autistic people stim. Although stimming varies from person to person, the reasons behind it may be the same: for enjoyment an attempt to gain sensory input, e.g. rocking may be a way to stimulate the balance (vestibular) system; hand-flapping may provide visual stimulation an attempt to reduce sensory input, e.g. focusing on one particular sound may reduce the impact of a loud, distressing environment; this may particularly be seen in social situations to deal with stress and anxiety and to block out uncertainty" (National Autistic Society's webpage about stimming).

To learn more, here is a webpage to the **National Autistic Society's information about stimming**.

Identity and intersectionality

In a video from the National Autistic Society Embrace Autism Series, the National Autistic Society talks about intersectionality being anything "that is a part of your identity and that is a part of who you are, that might impact how you navigate the world and also, how the world might perceive you. Intersectionality is the acknowledgment that everyone has their own unique experience of discrimination and oppression, and we should consider everything and anything that can marginalise people - gender, race, class, sexual orientation, physical ability etc. To help you with this, we've got resource documents on the National Autistic Society's Embrace Autism web page that you can access and be sign posted to various organisations that cover a range of intersectionalities" (National Autistic Society)

To learn more, here is a weblink to the <u>National</u> <u>Autistic Society's identity and intersectionality video: Embrace Autism Series</u>.



Camden All-Age Autism Strategy 2025 – 2030

