

SUPPLEMENTARY AGENDA

HEALTH AND WELLBEING BOARD

**Wednesday, 22nd September, 2021, 2.00 pm - 40 Cumberland Road,
London, N22 7SG**

Members: Please see list attached under item 2.

Quorum: 3 voting members, including one local authority elected member and one of the Clinical Commissioning Group Chair or the Healthwatch Chair (or substitutes).

10. AUTISM STRATEGY (PAGES 1 - 26)

To consider the Autism Strategy.

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Tuesday, 21 September 2021

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Report for: Health and Wellbeing Board – 22 September 2021

Title: Haringey All Age Autism Strategy 2021-2031

Report

Authorised by: Charlotte Pomery, AD Commissioning, London Borough of Haringey

Lead Officer: Georgie Jones-Conaghan, Lead Commissioner Learning Disabilities and Autism, London Borough of Haringey and North Central London Clinical Commissioning Group
Kathryn Collin, Head of Children’s Commissioning, North Central London Clinical Commissioning Group

1. Describe the issue under consideration

1.1 Autism is a lifelong neurodevelopmental disability which affects how people communicate and interact with the world. Through co-production, this Strategy has sought to reframe autism in Haringey and to set out changes which it is believed will benefit autistic and other neurodivergent people whether or not they choose to have a diagnosis. This is an inclusive strategy to improve outcomes for all autistic children, young people and adults with or without a diagnosis and their families and supporters and it is for this reason that the Strategy is coming to the Health and Wellbeing Board for approval.

2. Recommendations

Members of the Health and Wellbeing Board are asked:

- 2.1 To approve the draft All Age Autism Strategy 2021-2031 attached as Appendix 1 to the report.
- 2.2 To agree to updates on progress against the Strategy to come back to the Health and Wellbeing Board at regular intervals.

3. Background Information

3.1 The Haringey All Age Autism Strategy has been co-produced through a multi-disciplinary strategy group involving autistic residents and parent carers of autistic children, young people and adults. There has been considerable codesign and engagement with a broad range of stakeholders over the past two years to develop a shared understanding across partners and with residents of where we are now and where we need to get to. The group has led the development of an inclusive and person-centred approach which is reflected in the draft Strategy before the Board.

- 3.2 The vision set out in the Strategy is that Autistic children, young people and adults have equal opportunities for a happy and healthy life in Haringey. To achieve this vision, the Strategy requires all borough partners to commit to embedding a neurodiverse understanding of autism within their organisations. This Strategy therefore signals a move away from a deficit model that needs to 'fix' autistic people to fit within a neurotypical world. It puts an emphasis on all local organisations and systems moving to autism acceptance and accessibility for all residents and their families. It is believed that in this way it will be possible to have the meaningful support for and positive attitudes towards autistic people locally, meaning that autistic people will in turn feel empowered to be themselves, lessening their chances of developing poor mental health and avoiding a lifetime of stigma and masking.
- 3.3 The Haringey All Age Autism Strategy is committed to the following outcomes for autistic children, young people and adults:
- I can get a diagnosis in a timely way with an offer of some pre or post diagnostic support locally
 - I can get the right support at the right time
 - I feel accepted by an autism friendly community
 - I can access education and help if I need it in my local community and do not have to travel far away to have my needs met
 - I have opportunities to lead a fulfilling life
 - I have good access to physical and mental health services and expect good outcomes if I need these services
 - I feel encouraged to speak up and be me
 - I feel safe from bullying, hate crime and harassment
 - My family, my friends, my teachers and others I trust know how to help me best when I need extra support. They create spaces for me or with me that help me learn and thrive.
 - My friends and family have access to support, information and advice as part of their journey alongside me
- 3.4 In addition, there are significant cross-cutting themes which will underpin the improvements mapped out above. They are:
- Workforce Development and Training – for which needs are high across the system.
 - Support and intervention – this have historically been reactive rather than proactive with children, young people and adults often heading into crisis before help is available, the Strategy aims to turn this around: identify need earlier and respond swiftly and flexibly.
 - Transition Pathways and handover points – there are a number of points of handover which need to be smoothed and support e.g. from Children's to adults, psychiatric hospital to the community, education to employment, health to social care.
- 3.5 This is a high level 10-year strategy (2021-2031) which is underpinned by three schedules of improvement plans each focused on tackling three of the nine priorities at a time in three year blocks. There is considerable work set out in each schedule, the first of which will tackle the 3 priority areas selected by the

Autism Strategy Group, where some of the detail has already been co-produced through working with autistic residents and other stakeholders. The three areas represent significant programmes of work, which will require extensive multi-agency working:

3.5.1 Improving diagnostic services for autistic children, young people and adults

- 3.5.1.1 Improved children's diagnostic pathway which is clear and accessible, close to home with reduced waiting times
- 3.5.1.2 Adult Neuro-diverse diagnostic services in-borough, close to home
- 3.5.1.3 Greater collaboration across CAMHS and Autism diagnostic providers for Children and Young People. Joint multi-disciplinary clinics and creation of neurodevelopment pathways to diagnose co-morbid conditions such as ADHD
- 3.5.1.4 Defined Pre and post diagnostic support offer for all ages
- 3.5.1.5 Support Pathways linked to #ActuallyHaringey hub

3.5.2 Improving complex care and crisis care services for autistic children, young people and adults

- 3.5.2.1 Improved access to a wide range of complex and crisis care services based on a preventative, rather than reactive, approach.
- 3.5.2.2 Reduced Inpatient admissions
- 3.5.2.3 Increased numbers of autistic people able to live in and access education in borough, without the need for high cost out of area residential care

3.5.3 Improving care and support for autistic children, young people and adults

- 3.5.3.1 Young people and families at point of transition feel aware, informed and supported.

4. Contribution to strategic outcomes

- 4.1 The All Age Autism Strategy represents a significant contribution to improve health, wellbeing and broader outcomes for local autistic residents of all ages in the borough. The Strategy will lead to a body of work which will continue to be co-produced by autistic residents, parent carers and partners covering a wide range of areas. There are opportunities through this approach to reduce inequalities, to improve health and wellbeing outcomes and to build a new approach to autism in Haringey.

5. Statutory Officer Comments (Legal)

- 5.1 The Strategy is a health and social care partnership document and aligns with the Board's function of encouraging health and social care services to work in an integrated manner to advance the health and wellbeing of people in its area.
- 5.2 The Statutory Guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (March 2015) which local authorities and NHS bodies are obliged to have regard to provides that "Health and

Wellbeing Boards have a crucial role to play in overseeing implementation of the Adult Autism Strategy. As a local health and wellbeing system leader, bringing together partners from NHS England, CCGs, HealthWatch and Local Authorities, the Health and Wellbeing Board is central to ensuring the needs of people with autism are addressed locally.”

6. Use of Appendices

6.1 Draft All Age Autism Strategy

7. Background Papers

None

Haringey All Age Autism Strategy 2021-2031

Foreword

1. Introduction: What is autism?

There are several names used to describe the autism spectrum, including Autistic Spectrum Disorder, Autism Spectrum Condition, and others which have been used to describe a part of the spectrum, such as Asperger Syndrome or Classic Autism. In this strategy we use the term 'autism' to refer to the whole autism spectrum and the strategy recognises that autism is one of a wider range of neurodiverse conditions.

“Autism is a lifelong neurodevelopmental disability which affects how people communicate and interact with the world. One in approximately 100 people are on the autism spectrum and there are around 700,000 autistic adults and children in the UK. Autism is a spectrum condition and affects people in different ways. Like all people, autistic people have their own strengths and weaknesses.” (<https://www.autism.org.uk/advice-and-guidance/what-is-autism>)

Different features of autism vary from individual to individual, as well as over the lifespan. How an autistic person appears in a particular environment may not be representative of how they appear in other environments.

Autism causes difficulties with social communication and interactions such as being overly literal or struggling to understand conversation shortcuts or additional context such as reading facial expressions. Autistic people can have potentially restricted and repetitive range of behaviours, activities or interests. Autistic people are more likely to have environmental sensitivity. This means they may be hypersensitive or under sensitive to pain, temperature or other aspects of their surroundings. This will vary in type and intensity from person to person.

The social model of autism is increasingly moving away from seeing autism as a 'disorder' and adopting a 'neurodiverse' understanding that sees autism as being different but not deficient. This is the direction we are adopting in this Strategy which reframes autism in Haringey.

Our aim is that changes promoted by this strategy will benefit autistic and other neurodivergent people whether or not they choose to have a diagnosis, or indeed regardless of whether they view or experience autism positively or not. This is an inclusive strategy for all autistic children, young people and adults with or without a diagnosis and their families and supporters, that aims to make life a bit better for all.

2. Background: Drivers for the Haringey All-Age Autism Strategy

Around 1 in 100 children have a diagnosis of autism nationally. Prevalence of autism in children has been rising over the past decade, both nationally and in Haringey.

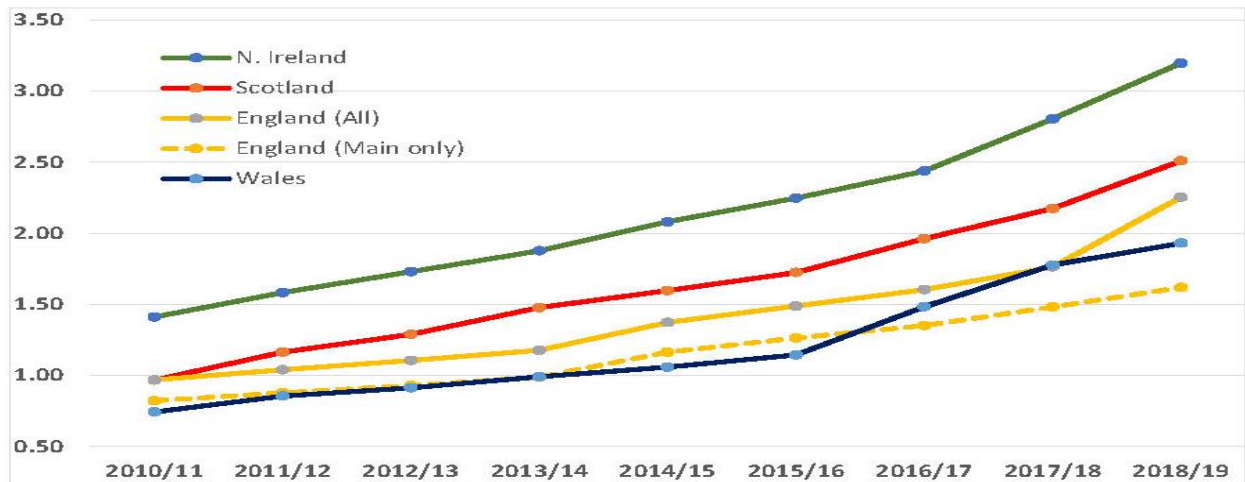


Figure 1. The prevalence rates of pupils with ASD in each country of the UK in the school years 2010/11 to 2018/2019 [Colour figure can be viewed at wileyonlinelibrary.com]

Referrals for autism diagnosis have risen. Professionals across North Central London report an approximate 59% rise in school age Autism Spectrum Disorder need between 2015 and 2019.

We have also seen a corresponding increase in demand for community therapy and other Special Educational Needs and Disabilities (SEND) services. Education Health and Care Plans (EHCP) numbers have risen in Haringey, driven in part by the rise in diagnosed autism. However, levels of funding have broadly remained stable which has led to significant capacity issues particularly in terms of diagnosis waiting times.

Haringey has at times had high rates of young people with autism in Tier 4 mental health inpatient beds and often the inpatient units are not able to best meet their needs. For the first time nationally the LD and Autism Transformation Programme (formerly Transforming Care) reports there are more autistic adults in psychiatric hospitals than people with a learning disability. It is likely that this trend will continue as learning disability partnerships have a better grip on keeping people with complex needs in the community, than mental health services who tend to support autistic people without a learning disability.

There is increasing demand for high cost, out of borough residential placements for children with autism, with or without a learning disability. Earlier intervention to prevent escalation of need is key. We have identified that a borough-wide system response to identifying children with autism who need extra support and signposting them to services, increasing use of personal budgets, and access to local accommodation if the family becomes unable to cope would help lessen this demand locally.

The SEND Joint Strategic Needs Assessment highlights the growing prevalence of autism in the borough. We are seeing more young people coming through children's social care with autism but without a learning disability, which is causing pathway and transition issues for all teams involved, including delayed transitions and unclear pathways into adult social care.

Haringey's 2019 Annual Self-Evaluation Statement produced under the Autism Act covering all domains highlights a real need for improvement, particularly for adults.

Work across North Central London (Barnet, Camden, Enfield, Haringey and Islington) identified best practice developments for adults and children's diagnostic pathways.

Children's diagnostic pathways are fragmented with very long waits, further impacted by Covid-19. As at Quarter 3 2020/21, the average wait from referral to completed assessment was 79 weeks for 5-12 year olds. Haringey adult diagnostic pathway uses diagnostic services in South London, with no local pre or post diagnostic support. Waiting lists are also long.

Young People at Risk Strategy highlighted the impact of SEN on increasing young people's vulnerability to becoming involved in serious youth violence. Autistic people are overrepresented in the prison population, Feltham Young Offenders Institution and Prison identified 4.5% of their inmates as autistic in 2016, which is over four times more than the number diagnosed in the general population.

Reviews of Exclusions and Alternative Provision will lead to different approaches for children both pre and post a diagnosis of autism.

The Learning Disability and Autism Transformation Programme 3 year delivery plan and the 2021 NHS England Autism Strategy identifies many of the same gaps across NCL and England, and will be supporting and driving change in diagnosis, complex and crisis care as well as workforce development specifically for autism non-learning disabled residents.

From September 2021 the LeDER programme which reviews all deaths of people with a learning disability will be extended to include autistic people without a learning disability as there is the same concern about the inequality of health outcomes.

Policy context driving an autism strategy in Haringey

The Autism Act (2009) is the only disability-specific law in England. It recognised that autism demanded specific and specialist approaches, and that many autistic people were falling through the net of traditional statutory support systems.

The first national autism strategy – **Fulfilling and Rewarding Lives** – was produced in 2010. This was updated in 2014 and published as **Think Autism**.

“All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.”

The Children and Families Act 2014 introduced improvements to adoption and the Family Courts system and critically a sweeping set of reforms for children with special educational needs and or a disability: the SEND Reforms.

The SEND Code of Practice is statutory guidance for organisations that work with and support children and young people with SEND.

The Care Act 2014 places specific duties to provide information, advice and guidance, invest in diverse and quality markets, preventative services and integration. It also identifies thresholds care and support needs. Many autistic adults do not receive support but are eligible.

The NHS Long Term Plan 2019 has identified autism and learning disability across all ages as a clinical priority in their ten-year plan to improve health services in England.

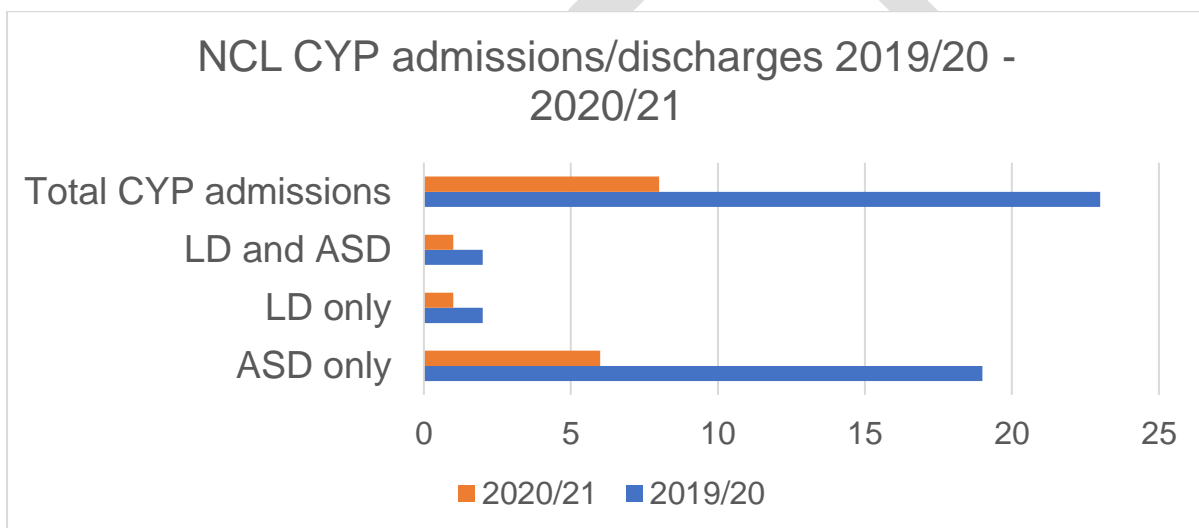
Building the Right Support – resulting from Winterbourne View gives commissioners a clear framework to develop more community services for people with learning disabilities and/or autism

who display behaviour that challenges, including those with a mental health condition, and close some inpatient facilities.

3. Local Autism Needs Analysis

There are at least 700,000 autistic people living in the UK, which is approximately 1% of the population.

Approximately 40% of autistic people have co-existing learning disabilities, without about 60% of the population who are autistic having no learning disability. Whilst there is often a lot of health and social care need from autistic people with a learning disability and their families, in Haringey there exists a clearer offer and pathways of support at all ages for this cohort. This remains under constant development and review through our approach to learning disabilities more broadly. However, we recognise there is a gap in our response for autistic people without a learning disability with outcomes often poor for this group, which is the case across England.



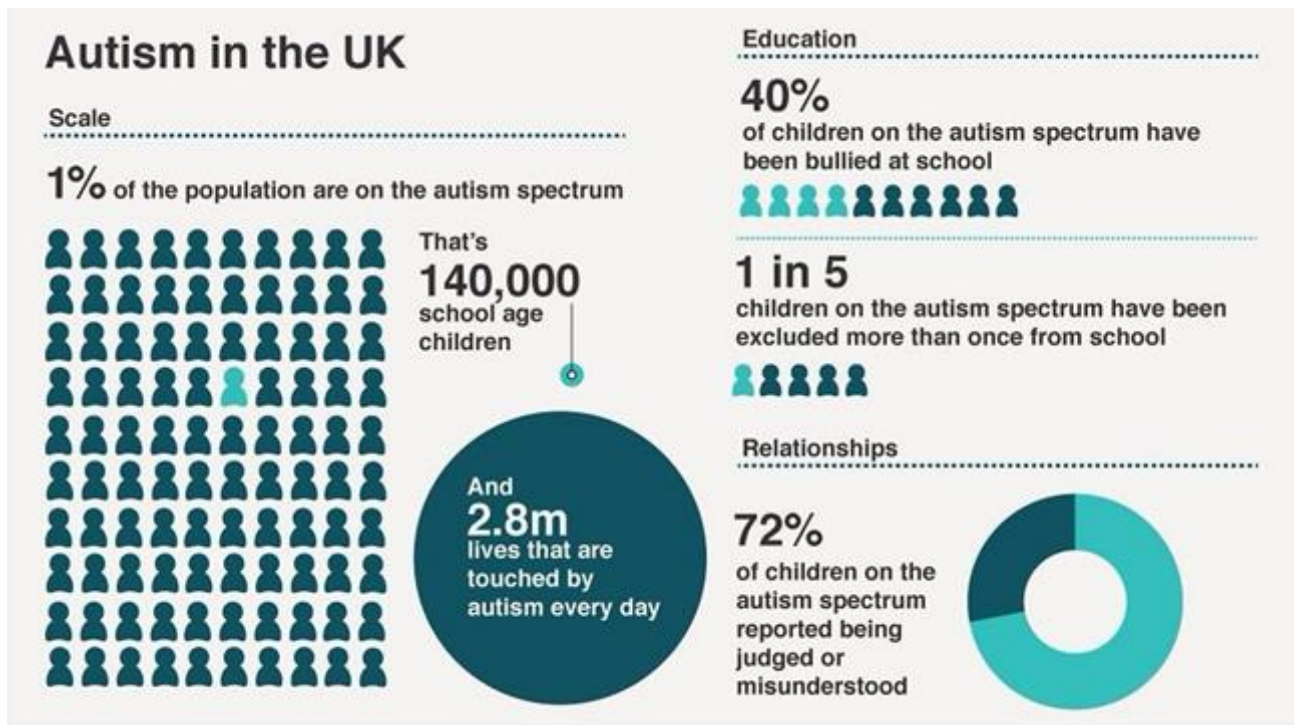
Graph 1: Showing North Central London Children and Young People Admissions to Tier 4 Psychiatric beds- Continued high % of young autistic people being admitted (80% autism only).

80% of autistic people, at some point in their lives, experience mental health problems such as anxiety or depression, and the majority rate their anxiety as the number one problem in their lives. Autistic people without a learning disability are nine times more likely to take their own life than the general population and autistic children are 28 times more likely to think about or attempt suicide¹ than non autistic children.

We are not very good at collecting data about autistic people but we do know that there are under-reported equalities issues for autistic people which lead to disproportionate impacts for black, Asian and minority ethnic communities. There is also a high prevalence of autism amongst trans people. Women and girls are under diagnosed and therefore underreported, with some people not realising women can be autistic. This is likely to be due to ‘masking’ of autistic traits and diagnostic tools that are developed to detect autistic traits in males. There are some cultures where autism is not really diagnosed or understood, which can hinder acceptance and understanding.

¹ [Suicide - Autism | Autistica | Autistica](#)

We need good equalities data so we can make evidence-based improvements for autistic children, young people and adults.



Diagnosis

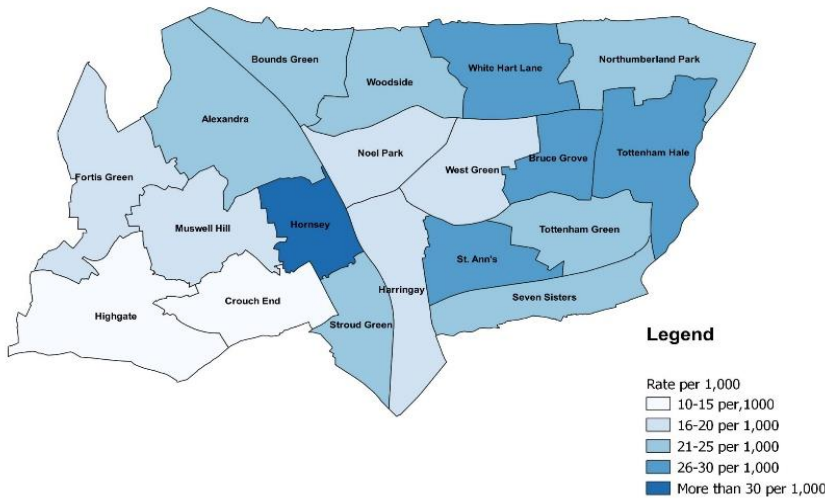
Children’s diagnostic pathways are fragmented across three age groups with very long waits for each age cohort, further impacted by Covid-19. The average waiting time for diagnosis is 35 weeks (range 6-83 weeks). For 5-11s it is 80 weeks average wait (range 52-100) and for over 12s the wait is 17 months.

Adult waiting times are approximately 18 months and in addition, residents have to travel to the South London and Maudsley for their assessment.

We have also seen that the pandemic has exacerbated already long waiting times. For 5-11 year olds, the wait grew by 33 weeks between December 2019 and December 2020.

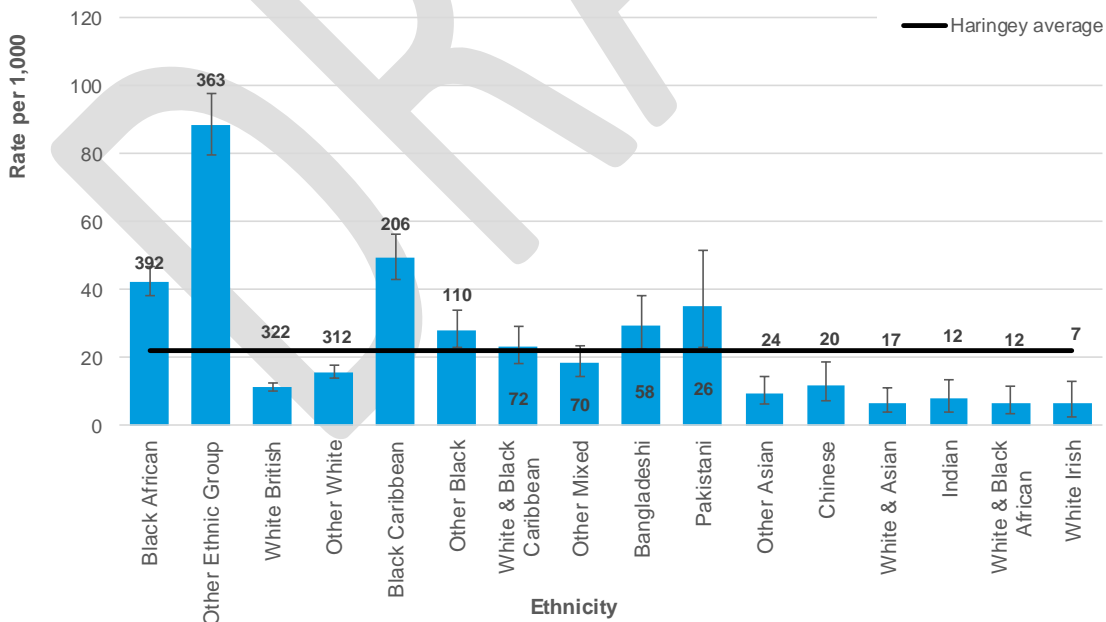
Autistic children and young people and future demand for services

Education Health and Care Plans



Map 1: Number of Children with education health and care (EHC) plans by Haringey Wards

The number of children with an EHC plan per 1,000 children aged 0-25 in Haringey is highest in Hornsey (34 per 1,000 children). The number of children with an EHC plan per 1,000 children is also high in White Hart Lane, Tottenham Hale and Bruce Grove (26-30 per 1,000). The most common primary need in all wards in Haringey was Autistic Spectrum Disorder.

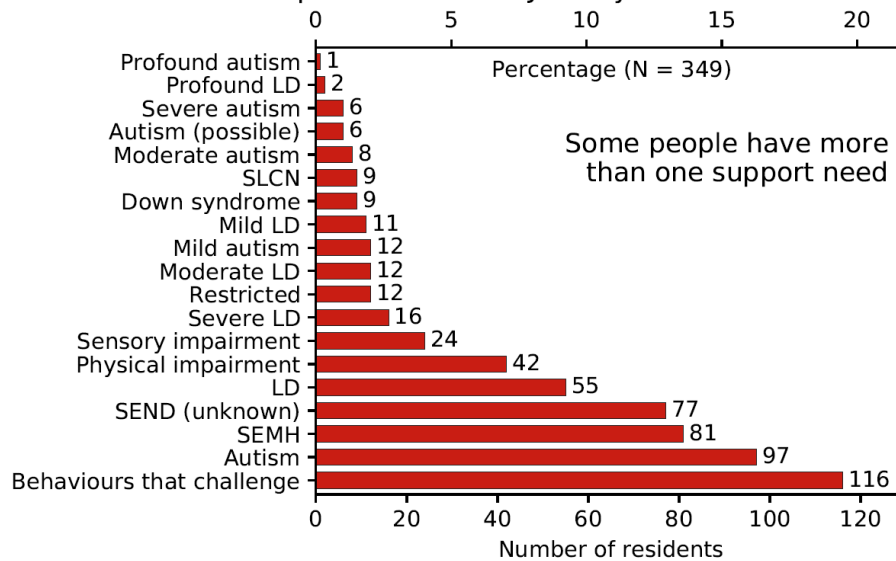


Graph 2: Breakdown of ethnicity for Children and young people in Haringey with an Education Health and Care Plan.

Graph 2 shows the number of EHC Plans per 1,000 children aged 0-25 among Black African, Black Caribbean, Other Black and Other Ethnic Group residents is significantly higher than the Haringey average.

Children and Young People known to Haringey Children’s Social Care

13-18 year olds known to social care and receiving costed services
Snapshot taken 31st January 2021

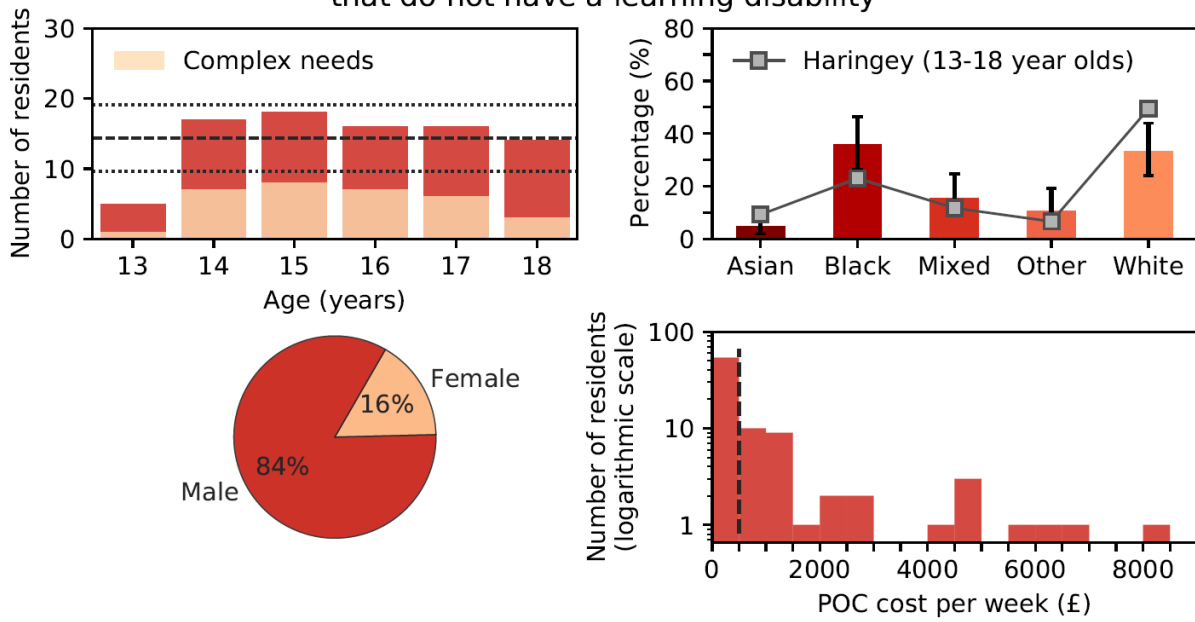


Graph 3: Current 13-18 year olds known to Haringey’s Disabled Children’s team, by primary need.

Graph 3 uses data from children’s social care in Haringey to stratify need of existing young people known to their services. It shows there is a high prevalence of autism, either as a stand-alone care need or as a co-morbidity with another condition or disability. The care categories taken from Mosaic the client database Haringey social care uses, highlights the need for better data collection (priority 9). Many of the terms are now out of date or disproven, however we included the graph as it still signifies the size of the autistic cohort in children’s services.

Out of the 593 young people aged 13-18 that are currently receiving packages of care (POC), at least 349 (59%) have some form of disability, impairment, or an additional support need. Of this group 128 (42%) are autistic. Of these 86 (30%) are autistic but do not have a learning disability; and 42 (15%) are autistic and do have a learning disability. Despite the fact the largest section of the children’s care population are autistic when they transition to adulthood there is no clear autism pathway if their autism is their primary need and they do not have a learning disability.

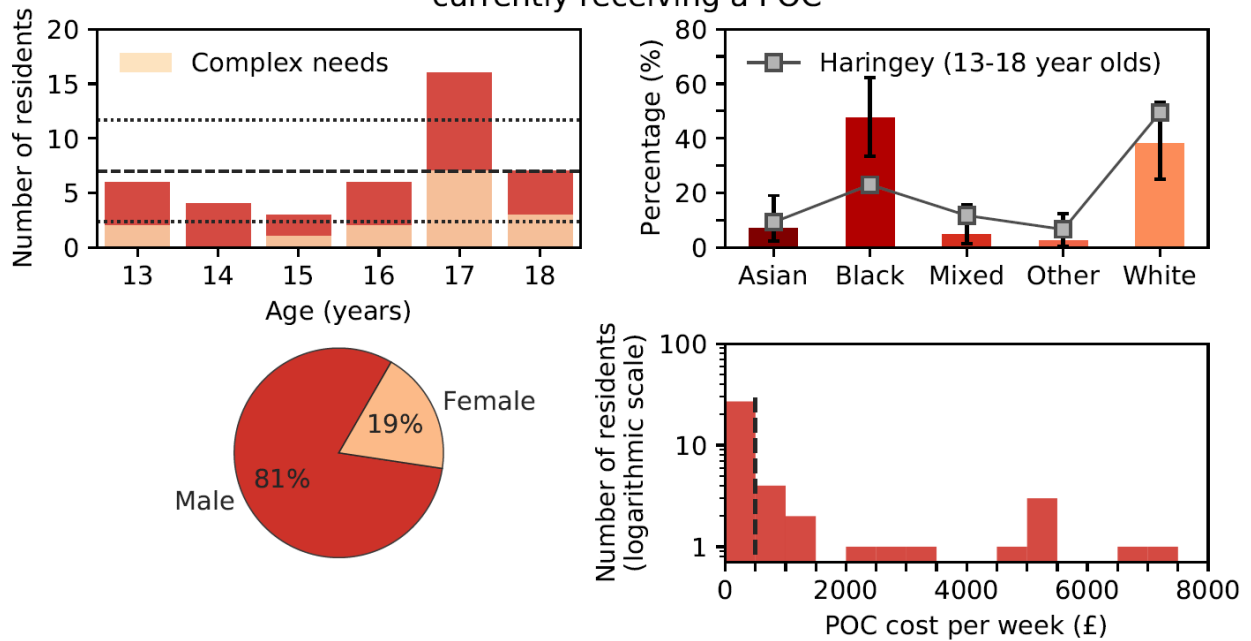
Overview of autistic young people currently receiving a POC that do not have a learning disability



Graph 4: Overview of Haringey’s autistic young people known to Children’s social care that do not have a learning disability.

Graph 4 supports national findings that Asian and other minority ethnic and female autistic clients are underrepresented in Haringey. We need to understand why Black young people appears to be overrepresented which goes against national findings and may mean that Haringey is better at diagnosing autism in some communities than others. We need to use the diversity information we have to ensure that diagnosis, SEN support and a neurodiverse understanding of autism is embedded in our communities.

Overview of autistic young people with a learning disability currently receiving a POC



Graph 5: Overview of Haringey’s autistic and learning disabled young people known to Children’s social care.

Graph 5 shows the needs of young people aged 13-18 currently in Children’s social care for those with a learning disability and autistic. Similarly to Graph 4 the number of females are underrepresented as is the case nationally, but again Black Young People appear overrepresented and White Young People underrepresented compared to all Children and Young People known to social services, which requires greater analysis.

Graph 4 and 5 containing the costs of care packages show a considerable number of care packages cost more than £2k per week. We know spending on out of area residential colleges with split funding by health, social care and SEN has increased from approx. £1.2m in 2018/19 to £5.4m in 20/21. These young people usually have a diagnosis of autism and ‘behaviours that challenge’ – either with or without a learning disability. This evidences that Haringey’s integrated care system are spending our collective resources on autism support but we know we need to do more to improve outcomes through our collective spend in this area.

4. Vision and outcomes

Our vision is that

Autistic children, young people and adults have equal opportunities for a happy and healthy life in Haringey.

To achieve this vision, the Haringey all-age autism strategy requires all borough partners to commit to embedding a neurodiverse understanding of autism within their organisations. This strategy signals a move away from a deficit model that needs to ‘fix’ autistic people to fit within a neurotypical world. It puts an emphasis on our local organisations and systems to move the dial from autism awareness to autism acceptance and accessibility for our residents and their families. We will start to have the right support and attitude for autistic people locally and autistic people will in turn feel empowered to be themselves, lessening their chances of developing poor mental health and avoiding a lifetime of stigma and masking. We see this shift as an essential part of the wider equality and diversity environment that makes Haringey so rich in social capital.

The Haringey All-Age Autism Strategy is committed to the following outcomes for autistic children, young people and adults:

- ✓ I can get a diagnosis in a timely way with an offer of some pre or post diagnostic support locally
- ✓ I can get the right support at the right time
- ✓ I feel accepted by an autism friendly community
- ✓ I can access education and help if I need it in my local community and do not have to travel far away to have my needs met
- ✓ I have opportunities to lead a fulfilling life
- ✓ I have good access to physical and mental health services and expect good outcomes if I need these services
- ✓ I feel encouraged to speak up and be me
- ✓ I feel safe from bullying, hate crime and harassment

- ✓ My family, my friends, my teachers and others I trust know how to help me best when I need extra support. They create spaces for me or with me that help me learn and thrive.
- ✓ My friends and family have access to support, information and advice as part of their journey alongside me

5. Approach and scope of the strategy

The Haringey all-age autism strategy seeks to develop an inclusive and person-centred approach to supporting autistic children, young people and adults, and their families, in Haringey. In order to achieve this we are working as a multi-disciplinary strategic group involving autistic residents and parent carers of autistic children, young people and adults. There has been considerable codesign and engagement with a broad range of stakeholders over the past two years to develop a shared understanding across partners and with our residents of where we are now and where we need to get to.

In order to deliver real improvements, we have heard first-hand that we need an ambitious approach that crosses age and organisational lines. We have therefore set out an approach which borrows from public health, that looks at all the determinants of someone’s life in conjunction with how their autism is experienced and accepted in the community, to try and ensure the strategy works towards levelling the playing field.



The all-age strategy is for autistic children, young people and adults in Haringey. Young people sit within both the Start Well and Live Well boards to ensure a joined-up approach that covers the ‘transition years’ from both perspectives to stop young people falling through the gaps and ensure a smoother transition into adulthood. Issues and gains relating to older autistic people will be shared

with the Ageing Well Board. The strategy includes autistic people with or without a learning disability or additional support needs including mental illness, other neurodiversity such as ADHD, dyscalculia or behaviours that are described as challenging. This strategy also includes those who may not have a diagnosis of autism and those who may or may not identify as autistic – as our aspiration is for people regardless of differences to have equal access to support when or if they need it and not be defined by this diagnosis.

The strategy is written in an autism positive or ‘neuro-diverse’ way, however we acknowledge this viewpoint is not shared by some autistic individuals and/ or their families for a number of reasons. But we hope over time improvements such as those outlined in this document will help create a more accepting community.

Below identifies the nine areas that the strategy aims to improve in Haringey. We recognise that not all priorities can be rolled forward at the same time, and that we need to programme these over the life of the Strategy, through an iterative Improvement Action Plan, as set out in Table 1 below.

Priority areas for improvement

1. Improving diagnostic services for autistic children, young people and adults
2. Improving mental health, complex and crisis care services for autistic children, young people and adults
3. Improving care and support for autistic children, young people and adults
4. Improving community links for autistic children, young people and adults
5. Improving accessibility for autistic children, young people and adults
6. Improving education, employment and training in the community for autistic children, young people and adults
7. Improving community safety for autistic children, young people and adults
8. Empowering autistic children, young people and adults
9. Improving data collection for autistic children, young people and adults

Cross Cutting Themes

There are significant cross-cutting themes which underpin the improvements mapped out above. They are:

- Workforce Development and Training – for which needs are high across the system.
- Support and intervention – this have historically been reactive rather than proactive with children, young people and adults often heading into crisis before help is available. The aim of our strategic work is turn this around: identify need earlier and respond swiftly and flexibly.
- Transition Pathways and handover points – there are a number of points of handover which need to be smoothed and support e.g. from Children’s to adults, psychiatric hospital to the community, education to employment, health to social care.

6. Priority areas for the strategy

An overarching, high level 10 year strategy (2021-2031) underpinned by three schedules of improvement plans each focussed on tackling three priorities at a time in three year blocks. Table 1 below shows an approximate delivery plan for each of the improvement areas, however there will be work ongoing in each of the nine areas during the life of the ten-year strategy as BAU within the relevant teams and services.

Autism improvement area	2021	2022	2023	2024	2025	2026	2027	2028	2029	2030	
1. Improving diagnostic services											
2. Improving mental health, complex and crisis care services											
3. Improving care and support											
4. Improving community links											
5. Improving accessibility											
6. Improving education, employment and training											
7. Improving community safety											
8. Empowerment and neurodiversity											
9. Improving data collection											

Table 1: High level Gantt chart showing approximate time frame for improvements against each area.

6.1 Priority 1 – Improving diagnostic services for autistic children, young people and adults

Diagnosis may facilitate access to benefits, specialist services, or adapted mainstream services. Especially for those diagnosed in later life, it can be a relief and provide an explanation for challenges and difficulties they have faced, as well as providing a framework for understanding triggers which can help inform adjustments to make every day living more comfortable.

What are the challenges?

- Diagnosis in Haringey for children and young people is fragmented and the waiting times are too long.
- Adults are currently referred to the South London and Maudsley for diagnosis, with long waiting times and out of area support that is disconnected from any local offer.

What are we doing about it?

- The new North Central London adult neurodiverse diagnostic service is being commissioned and will operate in late 2021. It will bring diagnosis and some pre and post diagnostic support in-borough, run by Barnet Enfield and Haringey Mental Health Trust (BEH). The new Haringey Autism Hub #ActuallyHaringey will provide pre, post and no diagnosis peer support.
- Children’s clinical providers have started to work together with commissioners to scope delivery of joint clinics across CAMHS/ autism diagnostic services and greater partnership working will help improve fragmentation.
- Some non-recurrent funding from NHS England has been awarded to Haringey to help clear some of the backlog in children’s autism diagnosis.

- NCL CCG's strategic Community Services Review includes the autism diagnostic pathway. Commissioners and Providers are meeting regularly across the five North London Boroughs to share learning and best practice. Improvement plans have been developed and new models are being considered e.g. exploring using digital platforms for diagnosis for some residents.
- We know that post-diagnostic support is particularly important for our residents and there are gaps in our local offer, especially for young people. NCL has been awarded funding from NHS England to train a significant number of professionals in the evidence-based social intervention programme PEERS programme from UCLA in America². This training will be delivered virtually in Autumn 2021.
- Careful planning to ensure young people transitioning will not be disadvantaged by a separate children and adult diagnostic service, and agreement locally to ensure a whole of life pathway will ensure a joined up approach between pathways for people aged 16-20.
- North Central London CCG Learning Disability and Autism Transformation Programme Delivery Plan for 2021-24 provides consistent plans for improving autism diagnosis across North Central London

6.2 Priority 2 – Improving mental health, complex and crisis care services for autistic children, young people and adults in the community

As part of the **transforming care agenda and reflecting the NHS Longer Term Plan**, we are trying to support autistic people with their mental health needs in the local community. We aim to reduce the need for hospital stays or placements away from home. We know that autistic people are over-represented in mental health services but don't always receive the same access or outcomes from health services that the neurotypical population may expect. There is a gap in complex care and delivering 'transforming care' for autistic people with complex needs who do not have a learning disability. There is a significant lack of access to adult mental health services for our autistic residents currently which the system is in agreement needs urgent action.

What are the challenges?

- Support for children, young people and adults is often reactive and not proactive enough to prevent admissions or crisis – sometimes due to lack of services, sometimes if they do not have a learning disability they are not known to social care
- Lack of a clear complex care transition and social care pathway for autistic people without a learning disability.
- Need for a developed Positive Behaviour Support (PBS) market in children's services, and suitable housing for all ages

² [PEERS | Semel Institute for Neuroscience and Human Behavior \(ucla.edu\)](https://semel.ucla.edu/peers/)

- Complex care in the community is very costly and commissioners are not always funding the right thing due to a lack of options e.g. out of area residential colleges instead of SEN and PBS support in their community.
- Generic mental health services are not accessible for autistic adults; and very little specialist autism health care is commissioned for autistic adults without a learning disability in Haringey.
- 'Building the Right Support' is happening much more in adult learning disability but learning and model of care is less developed in Children and young people's services and adult mental health – requires transformation of commissioned services.

What are we doing about it?

Children and Young People

- Key workers in the community are supporting a small number of autistic Haringey young people in Haringey alongside CAMHS to support them to live well in the community and to prevent escalation in a young person's risk or need.
- Following the success of the community key worker project, a new key worker service will launch later in 2021 to support children and young people with the highest mental health risks on discharge from inpatient mental health units. This service aims to support a young person safely in the community and aims to prevent re-admissions to hospital.
- Embedding a CAMHS Practitioner in the Haringey Disabled Children's Team to support our children with the most complex needs in the community. Through intensive support, we hope we can keep more Haringey young people living and accessing their education locally, avoiding the need for out of borough, residential school placements.
- Increased use of personal health budgets to engage young people in meaningful activity and to foster their hobbies and interests e.g. language lesson, art, sport which holistically supports their health and wellbeing. For our most complex young people, this aims to prevent admission to hospital.
- New South London and Maudsley Crisis team for CAMHS working across London to provide advice and support for the most complex clients at risk of admission

Adults

- Developing options for a virtual autism multi-disciplinary team to support autistic people with complex needs. Their aims will be to improve local partnership working between teams or agencies for a joined-up and more holistic offer of mental health or complex care support for autistic adults without a learning disability to mirror the support in the HLDP.
- Working with mental health services to improve support and access for autistic people at all ages with mental health needs – complex as needs resourcing and workforce development plans, which we are developing. Duty under Equalities Act to not discriminate due to disability so is essential and a MUST DO!

- The autism hub #ActuallyHaringey aims to provide low level mental health support, health and wellbeing support and peer support which can prevent crisis in some instances. They are commissioning group art and creative therapeutic support for their users using one-off funding from NHS England.
- Developing Positive Behaviour Support (PBS) local provider market, quite strong in adults but continuing to develop in children's services e.g. Rolling out PBS training in schools and services in the local area and providing a network for PBS supervisors
- Developing autism supported housing programme for young people and adults e.g. Linden Road, 57 White Hart Lane. Received joint capital funding from NHS England and Haringey Council to progress these plans which will prevent people needing to be placed out of area.
- Commissioned a new PBS LD and Autism day service at Waltheof Gardens in Tottenham, run by Centre 404 – Haringey Opportunities Project (HOP)
- North Central London CCG Learning Disability and Autism Transformation Programme Delivery Plan for 2021-24 provides complimentary plans for improving complex and crisis care services across North Central London with a particular focus on autistic residents without a learning disability due to the health inequalities

6.3 Priority 3 – Developing stronger care and support in the community for autistic children, young people and adults

For autistic children, young people and adults who have eligible care and/or support needs there are social care teams and care providers in Haringey who are able to meet people's individual needs in a person-centred way. However, pathways between teams are not always working as well as they should be, especially if the autistic person does not have a learning disability.

What are the challenges?

- Partnership working between teams including access to a skilled social worker if the child or young person is autistic with a mental health comorbidity but without a learning disability
- Transitions between children and adult social care teams especially if the young person is autistic without a learning disability
- Transformation of social care and community health teams for autistic people without a learning disability to mirror the improvements in learning disability community services and commissioning from Transforming Care and Building the Right Support.

What are we doing about it?

- Developing adult autism pathways from transitions e.g. options of enhanced mental health services for autistic people having undergone appropriate training, and/ or exploring a standalone adult autism virtual team

- Bidding for funding and /or piloting dedicated autism professional roles in social care e.g. social worker linked to CAMHS for CYP without a disability, 24 months funding for a senior practitioner for adult autism social work
- Alongside needs for improved access to specialist MH or social services, autistic people and their families can benefit from a range of commissioned community services e.g. new PBS day services, housing, community support available and more being developed.

6.4 Priority 4 – Improving Community Links for autistic children, young people and adults

We want Haringey to be an autism friendly borough, where autistic people can lead happy healthy lives and if they need help, they know where to go and can access it early, stopping longer term or bigger issues to arise.

What are the challenges?

- Knowing what is out there and identifying any gaps or missing links to offer strengths based support in the community
- Developing the community and the local autism market, with limited resources, to address the gaps
- Making Haringey an autism friendly borough

What are we doing about it?

- Identified housing as a need especially for families with autistic children –this requires better planning and housing needs assessments
- Working collaboratively with Community services and the voluntary sector like Markfield and Kith and Kids.
- The autism hub will provide a place for the community to come together in a safe and accessible environment for people with autism and their support networks
- Autism Hub will provide autism awareness training in borough to help make Haringey more autism friendly

6.5 Priority 5 – Improving accessibility for autistic children, young people and adults

Autistic people and their families/ advocates have identified limited understanding and acceptance of autism in mainstream services including health, education and social care; reducing their ability to meet the needs of autistic residents, and many autistic residents and their families don't know where to go for help.

What are the challenges?

- Improving accessibility in services requires partnership working with a variety of different groups to improve autism understanding and acceptance
- Equalities/ disadvantaged groups within Haringey are most affected by poor access
- May require additional resources to change culture and practice and requires large scale cultural shift

What are we doing about it?

- Digital accessibility is vital – but more needed in range of media: documents such as Preparing for Adulthood Pathway guide are very popular, #ActuallyHaringey launched as virtual service and will operate an in-person service at the new hub in Tottenham.
- Primary Care, HLDP and Commissioners are driving up performance in the annual health check scheme to support GPs to identify all patients aged 14 + with learning disabilities and/ or autism, to maintain a register and offer an annual health check, which helps patients access health services
- The autism hub #ActuallyHaringey provides signposting, training and support in the community to improve access to services and awareness of autism.
- Parent post diagnosis workshops and courses including Signet create vital peer support groups that help families navigate services. New post-diagnostic social skills intervention in late 2021, early 2022 will support connecting young people.
- Whittington Health NHS Trust has led some very exciting projects with young people and adults with autism and or a learning disability to help ensure families have the resources they need and to make clinical spaces autism friendly. We need to learn from this and disseminate across the Borough
<https://www.whittington.nhs.uk/default.asp?c=38579>

6.6 Priority 6 – Improving education, employment and training in the community for autistic children, young people and adults

Many children and young people face challenges with the education settings they are in and this may increase the challenges they face in finding employment or training post 16. Many people with autism are under-represented in employment and this can impact their independence, health and wellbeing.

What are the challenges?

- Higher risk of exclusions for children and young people with undiagnosed SEND
- Inadequate SEMH long term education provision in-borough
- Creating a smooth pathway during the transition phase between 16 and 25
- Lack of supported employment opportunities/ targeted employment support
- Lack of support and acceptance of autism to help maintain employment, when attained.

What are we doing about it?

- Work underway in Transitions and SEND to improve the offer and pathway during transitions
- Alternative Provision Review is addressing the gap in SEMH long term education provision and enabling new approach to exclusions
- SEN commission Project Search and a number of supported employment initiatives – but much more to do be done for adults
- The autism hub #ActuallyHaringey provides employment and training support for people with autism aged 16+. The hub employs autistic people and is planning to develop volunteer programmes to help develop capacity and skills
- The Live Well borough partnership is prioritising adult supported employment initiatives across adults and health, this is in scoping stage currently, and intention is for this to develop at pace and grow significantly

6.7 Priority 7 – Developing stronger community safety for autistic children, young people and adults

Evidence suggests that people with autism are over-represented in criminal justice systems both as victims and perpetrators of crimes. For those without a diagnosis there is no provision for specialist support in criminal justice systems. Autistic people can be very vulnerable in the community

What are the challenges?

- There are partnership challenges working with justice services and making this a priority
- Lack of awareness across agencies about the impact of autism on behaviours and responses
- Rates of hate crime increasing nationally, regionally and locally
- Links between children with special educational needs and serious youth violence are becoming increasingly well understood – but there remain gaps in support

What are we doing about it?

- Support in schools available – but to what extent is this getting people ready for adulthood?
- Links with community safety need to be better established – there is crossover with PREVENT and hate crime/ mate crime agendas where autistic people are over-represented in case work
- Community services do spend a lot of time supporting their users around these topics, however their reach is, currently, relatively small

- Implementing the Young People at Risk Strategy with clear focus on supporting those most vulnerable to risk
- Development of vulnerable adult protocol in Haringey
- Thinking about safeguarding in the community and making it everyone's business – need for a campaign?

6.8 Priority 8 – Empowering autistic children, young people and adults

The 2017 Haringey Strategic Needs Assessment has highlighted that there is not enough representation of people with autism in the designing and commissioning of services.

What are the challenges?

- Identification of autistic people, resourcing/ advocacy, 'deficit' understanding of autism vs Neurodiverse

What are we doing about it?

- The autism strategy group has included autistic residents and parent carers to improve representation and ownership – and challenge old norms of 'disorder' e.g. neurodiverse
- The specification for the autism hub is being designed alongside a series of community engagement sessions with autistic residents and community groups
- The autism hub will work closely with be coproduced with autistic residents, community groups and partners – we are looking for autistic users and staff to steer the service via committee
- Main function of the hub will be about facilitating peer support, so autistic people can support each other and find solutions to issues themselves or in a community
- Development of Disability People's Organisation which will be umbrella organisation to promote users' involvement more meaningfully in Haringey commissioning – link to autism hub

6.9 Priority 9 – Improving data collection for autistic children, young people and adults

The 2017 Haringey Strategic Needs Assessment on adults and children with autism highlighted that there are a number of significant gaps in the data which make it difficult to present a comprehensive picture of the autistic population in Haringey and their needs. This makes it harder to commission services for autistic residents in Haringey. Also it means we are not aware of a range of equalities issues that we may need to work more closely on e.g. trans populations are more likely to be autistic than the general population.

What are the challenges?

- Some people with autism, especially adults, are undiagnosed and are therefore not identifiable as autistic
- Statutory services (including Council and NHS services) often do not keep records of which people using their services are autistic
- There have been issues in accessing data held in different parts of the system and data available is not always up to date or complete
- Improving data collection will take time and resources in order to get an understanding of the issues facing autistic residents in Haringey

What are we doing about it?

- Through the delivery of the autism strategy we will try and embed better autism data collection in services e.g. adult diagnostic service
- Through the community engagement for the autism hub we have been able to improve our understanding and awareness of the issues facing the local autistic community

7. Resources

Resourcing the Autism Strategy will be one of the most challenging strands for borough partners to work through over the years. Whilst all borough partners understand and buy-in to the improvements that are required for our autistic residents, organisationally few are currently set up to meet autistic children, young people, adults, and their families' needs. Whilst autistic residents may use their services, significant mapping will be required to understand the cost-benefit of where and what resources should be allocated for autistic people and their families.

We know that autistic users of services can be costly to an organisation, particularly in health and social care where they may disproportionately present in crisis due to a lack of early help on the part of existing services. These are poor outcomes for autistic people and poor value for money for the organisations. Unfortunately, ten years of austerity to public services mean there is no new funding and resources will need to be moved around which can be time consuming and complex e.g. restructuring and/or reviewing the skill mix of teams that are not currently providing the right level of expertise for autistic people.

In May 2021 we expect the overdue NHS autism strategy to be published. Early indications suggest Local Authorities will be able to bid for funding attached to this strategy to enable change locally. Haringey's planned approach mirrors much of the NHS long term plan mandates. As we still have a way to travel, we plan to be ambitious with our bids for national funding.

Another opportunity that Haringey has started to explore but could make greater use of is technology. Brain in Hand is a well-known app which helps people with a range of needs develop individualised coping strategies in order that they can feel confident living their lives in the community. Similarly, digital platforms are likely to play a role in managing autism waiting times for some residents in the near future.

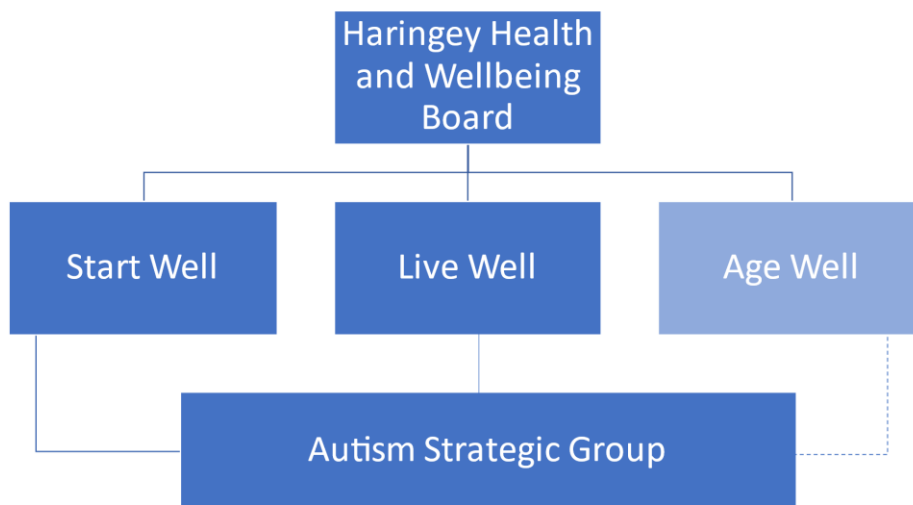
Our key priorities in this area are:

- Organisations to map their resources for autistic residents against current and future demand in order to improve services
- Resources may need disentangling to be redirected where they will have better outcomes for people
- Haringey to continue to take advantage of funding initiatives over the next few years
- Opportunities for use of technology to be fully exploited in Haringey 2021+

8. Governance

The governance for Haringey’s All-age Autism Strategy is illustrated below. The review and refresh of the autism strategy will come to the Health and Wellbeing Board annually. The general oversight of the programme will be provided by the Start Well and Live Well Boards. Issues relating to older autistic people will come to Age Well. The Autism Strategic Group will sit under these boards and provide steering and support to the work. There will be a number of task and finish groups that will emerge to work on specific elements of the strategy and will report into the Autism Strategic Group to present their findings and recommendations.

Governance of Haringey’s Autism Strategy



Appendix A

Stakeholders and engagement that contributed to Haringey's All-Age Autism Strategy

Haringey Autistic residents

Parent Carers of Autistic Children, Young People and Adults

Haringey Joint Commissioning

Markfield

ALAG

The Grove School – Autism specialist school in Haringey

Haringey Language and Autism Team

Haringey Adult Social Care - Mental Health

Haringey Adult Social Care - Learning Disability

Educational Psychology

BEH Adult Mental Health Community Services

BEH CAMHS

Haringey Autism and Language Team

Tavistock LD and ASD service

Specialist Speech and Language Whittington Hospital - Children's ASD Diagnostic Service

Open Door SEND Psychology

Consultant Psychiatry HLDP BEH

SEN Haringey Council

Children's Social Care and Safeguarding

NCL CCG commissioning (adult and children's across NCL)

Primary Care

#ActuallyHaringey Autism Hub

Royal College of Psychiatrists – diagnosis best practice event for practitioners

Haringey Adult Learning Partnership

Learning disability and autism transformation programme, NCL CCG