

Haringey Children and Young People and Adults and Health  
Joint Scrutiny Panel  
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# Review of priorities for a Haringey whole of life autism strategy

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# What is autism?

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Autism is a life-long condition for which there is no 'cure'. Autism is a **spectrum condition**. This means there are a wide range of traits associated with autism and different levels of need. All autistic people share certain similarities but being autistic will affect them in different ways.

Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support.

Autism causes difficulties with social communication and interactions, as well as a 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.

## Prevalence of autism

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

Approximately 40% of autistic people have co-occurring learning or intellectual disabilities

80% of autistic people, at some point in their lives, have mental health problems such as anxiety and depression, and the majority rate their anxiety as the number one problem in their lives. Autistic people without a learning disability are 9 times more likely to take their own life than the general population.

There are under reported BME and equalities issues for autistic people, including a high prevalence of autism amongst trans people and some cultures not recognising autism and having no word for it. Autism is apparently more prevalent in males than females, but this is likely to be due to under-reporting of girls and women and their better ability to mask features and behaviours.

# Policy Context

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**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.

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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.”*

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**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 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

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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.

## Context for the development of an Autism Strategy in Haringey

### Drivers for the All Age Autism Strategy

1. Co-production has highlighted need for change
2. Transforming care programme has shown need for better early intervention and prevention
3. State of the Borough profile – annually refreshed – identifies needs of disabled people at borough level
4. Autism Needs Assessment carried out in 2017 – set out key challenges for Haringey
5. SEND Joint Strategic Needs Assessment being completed in March 2020 – with growing prevalence of autism in the borough
6. Annual Self-Evaluation Statement produced under the Autism Act covering all domains highlight need for improvement particularly for adults
7. Focused work on Transitions suggests areas for further development across the life course to support young people
8. Work across North Central London (NCL = Barnet, Camden, Enfield, Haringey and Islington) to understand prevalence, need, resources and approaches has identified areas of best practice and to take forward at NCL level as an adult diagnostic service
9. Young People at Risk Strategy highlighted the impact of SEN on increasing young people's vulnerability to becoming involved in serious youth violence
10. Reviews of both Exclusions and Alternative Provision will lead to different approaches for children both pre and post a diagnosis of autism
11. Needs identified by carers (link to carers strategy in development)

# Autism strategy development in Haringey

## Priorities

1. Improving diagnostic services for autistic children, young people and adults
2. Improving complex care services for autistic children, young people and adults
3. Improving crisis planning for autistic children, young people and adults
4. Improving care and support in the community 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

The aim of the group is to deliver a whole of life Haringey Autism Strategy by Autumn 2020.

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

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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 comfortably

## What are the challenges?

- Improving diagnostic services presents resource challenges; in terms of cost of timely diagnostic service, and increased demand for other services

## What are we doing about it?

- The new NCL adult neuro diagnostic will operate from autumn 2020. It will bring diagnosis and some pre and post diagnostic support in-borough, run by BEH
- Children's clinical providers have started to work together on joint clinics across CAMHS/ autism diagnostic services. A review of the current children's diagnostic pathway is underway
- Review and emphasis based on feedback from users on importance of pre & post diagnostic support
- Careful planning to ensure young people transitioning will not be disadvantaged by a children and adult diagnostic service, and agreement locally to ensure a whole of life pathway will underpin this.



# Priority 2 – Increasing complex care services for autistic children, young people and adults in the community

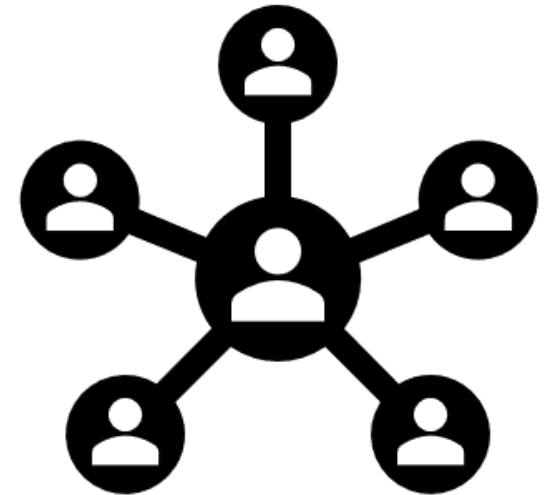
As part of the **transforming care agenda**, we are trying to support autistic people with mental health needs in the local community and reduce the need for hospital stays or placements away from home.

## What are the challenges?

- Supporting families as young people transition to adulthood autism pathway
- Having providers that can support people with very complex needs
- High levels of resources required
- Mental health services often are unwilling or able to support autistic people

## What are we doing about it?

- Working with BEH to improve support for autistic people with mental health needs
- Discharging people from hospital and avoiding admission as per Transforming Care
- Developing Positive Behaviour Support (PBS) local provider market
- Developing autism supported housing programme e.g. Linden Road, SEN 'halls' in borough
- Developing new PBS LD and Autism day service at Waltheof Gardens to support carers
- Rolling out PBS training in schools and services in the local area and providing a network for PBS supervisors from April 2020
- TCAPS is continuing to be rolled out, following successful pilot





# Priority 3 – Enhancing crisis planning for autistic children, young people and adults

We know that autistic people are over-represented in mental health services, they are amongst the most groups most likely to take their own lives. Transforming Care shows that without crisis planning that people can unnecessarily spend a long time in psychiatric hospitals.

## What are the challenges?

- Many autistic people (non LD) that we become aware of when they get into crisis do not receive social care and may be unknown to services/ no EHCP
- Mental health services can exclude or not be set up to help autistic people from access support at the right time
- There is limited budget for providing support for people with autism non LD as this money is elsewhere in the system
- There needs to be better partnership working between teams and agencies

## What are we doing about it?

- Crisis management teams e.g. AIT in HLDP – need to review crisis pathway in C&YP, and Adults MH
- The autism hub aims to provide low level mental health support, health and wellbeing support and peer support which can prevent crisis in some instances
- We hold 'at risk' registers for C&YP and LD Adults at risk of admission (but work to do on Adult MH Autism list)
- We arrange community (education) treatment reviews (CETR) in the community to prevent admission with family and professionals and independent panel of experts
- Developing Hazlemere respite service for young people and families at risk of placement breakdown and/ or admission



# Priority 4 – Developing stronger care and support in the community for autistic children, young people and adults

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Alongside needs for improved access to specialist MH or social services, autistic people and their families can benefit from a range of targeted community services.

## What are the challenges?

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

## What are we doing about it?

- Community services like Markfield, Kith and Kids,
- The LD and autism day service will provide care for people with LD and autism in the community as well as providing respite for parents and carers
- 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



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

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The autism strategy group has highlighted the limited understanding and awareness 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 understanding and awareness
- Equalities/ disadvantaged groups most affected by poor access
- May require additional resources to change culture and practice

## What are we doing about it?

- Digital accessibility is vital – e.g. Haricare, but more needed in range of media: documents such as Preparing for Adulthood Pathway guide very popular
- Driving the health check scheme to support GP's to identify all patients aged 14 + with learning disabilities, to maintain a register and offer an annual health check, including a health action plan.
- The autism hub aims to provide 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. But with 50% of CYP diagnosed attending, concern about those who do not engage.



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

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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
- Lack of SEMH long term education provision in-borough
- Creating a smooth pathway during the transition phase between 16 and 25
- Partnership working between children and adult services across Haringey
- Lack of supported employment opportunities/ targeted employment support



## 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 number of supported employment initiatives
- The autism hub will provide employment and training support for people with autism aged 16+. The hub will also employ people with autism, providing more opportunities in Haringey
- The borough partnership is prioritising adult supported employment initiatives in adults and health, this is in scoping stage currently, and intention is for this to develop at pace and grow significantly

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

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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 including the autism hub, 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
- Thinking about safeguarding in the community and making it everyone's business – need for a campaign?



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

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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 DPO which will be umbrella organisation to promote users involvement more meaningfully in Haringey commissioning – link to autism hub



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

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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 are likely to affect e.g. trans gender

## What are the challenges?

- Some people with autism, especially adults, are **undiagnosed** and are therefore not identifiable as having autism
- Statutory services (including Council and NHS services) often do not **keep records** of which people using their services have autism
- 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 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
- Through the autism hub we will be able to improve data collection around people with autism in Haringey



Questions?

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