

SUPPORTING AUTISTIC PEOPLE IN HILLINGDON UPDATE

Committee name	Health and Social Care Select Committee
Officer reporting	Graham Puckering – Adult Social Care and Health, LBH
Papers with report	Appendix 1 – Case Studies
Ward	All

RECOMMENDATIONS

That the Health and Social Care Select Committee:

- 1. notes the content of the report; and**
- 2. comments and questions officers and partners on any aspect of the report.**

HEADLINES

This report is provided to the Committee at its request. It is intended to provide an update on progress in supporting Hillingdon's autistic residents as well as outlining future developments.

This report is structured as follows:

- A. Strategic Context
- B. Developments and Achievements 2022 – 2024
- C. Next Steps: Priorities from 2025/26

Terminology: Autistic People or People with Autism?

Following consultation with the National Autistic Society, Autism Education Trust, and the local Autism Expert Reference Group (ERG), the term that is used in Hillingdon is '*Autistic People*'.

Definition of Autism

Autism is a neuro-divergence that causes differences in how people communicate and interact with the world. It is important to note that being autistic is not a disease or an illness and the concept of a cure is not relevant. Many autistic people share certain characteristics, but they are affected by them in different ways. Autistic people may experience:

- Social interaction and communication differences.
- Sensory differences; sensitivities or under-sensitivities, for example, with sound, touch, taste, smell, or light.
- Differences with coping with change or unfamiliar situations.

Autistic people may also have other conditions, such as a learning disability or Attention Deficit Hyperactivity Disorder (ADHD). In addition, autistic people are more likely to have coexisting mental and physical disorders, and other developmental disorders.

Partners Supporting Autistic People

The diagram below illustrates what is meant by references to '*partners supporting autistic people*' in this report.



SUPPORTING INFORMATION

A. Strategic Context

National and Local Context

National

1. The key legislative drivers in respect of support for autistic people are summarised below.
2. **Autism Act 2009:** This created a statutory duty on NHS organisations and local authorities to provide appropriate services to assess autism in adults and to support autistic adults post-diagnosis.
3. **Children and Families Act, 2014:** This introduced Education, Health, and Care Plans (EHCPs) and extended support for children and young people with special educational needs and disabilities (SEND) to the age of 25. It converted established best practice in service quality and service delivery into a set of legal requirements, such as:
 - a person-centred, joined-up approach to identifying and meeting the needs of children, young people, and their families.
 - increased engagement and participation of young people and families so that they have greater choice and control, are listened to and their concerns are resolved swiftly.
 - a published Local Offer of support, services, and provision, how to access it and how to raise concerns or seek redress.
 - the use of effective practice, data and wider intelligence and independent assessment to drive improvement.
 - clearly defined and understood roles and responsibilities.
 - increased integration of services and joint commissioning across local authorities and the NHS.

More About Education, Health and Care Plans (EHCPs)

An EHCP is for children and young people aged up to 25 who need more support than is available through special educational needs (SEN) support. EHCPs identify educational, health and social needs and set out the additional support to meet those needs.

4. **Care Act, 2014:** The Committee is reminded that this is the law that sets out how adult social care in England should be provided. It requires local authorities to make sure that people who live in their areas who meet national eligibility criteria:
 - receive services that prevent their care needs from becoming more serious or delay the impact of their needs.
 - can get the information and advice they need to make good decisions about care and support.
 - have a range of high quality, appropriate services to choose from, and
 - have more control over how their care and support is organised.
5. **Equality Act, 2010:** The Act defines a disabled person as someone with a “*physical or mental impairment*” that has a “*substantial and long-term adverse effect*” on their ability to carry out normal day-to-day activities and autism qualifies under this definition. The Act prohibits unfair treatment based on disability—including autism—in employment, education, and access to public services. Organisations are legally required to make *reasonable adjustments* for autistic individuals
6. A national strategic driver for supporting autistic people is the development of the national autism strategy that the Autism Act, 2009 required the Government to publish. The first national strategy called *Fulfilling and rewarding lives: the strategy for adults with autism* was published in March 2010. This was followed by ‘*Think Autism*’: an update to the government adult autism strategy in April 2014. In July 2021 the Department of Health and Social Care (DHSC) published *The national strategy for autistic children, young people, and adults: 2021 to 2026*. The scope of the new strategy was extended to include support for autistic people of all ages, but the statutory guidance issued under the 2009 Act has not been updated.

Local

7. Key local strategic influences are explored below.
8. **The Hillingdon Local Area SEND and Alternative Provision Strategy for Children and Young People 0-25 years, 2023 – 2028:** This was agreed in December 2023 and can be accessed via this link [Hillingdon Local Area SEND and Alternative Provision Strategy 2023-28 - Hillingdon Council](#). This is important because a high proportion of children and young people with Education Health and Care Plans (EHCPs) have autism identified as their primary need.
9. The work of the Council and partners in supporting autistic people is illustrated with case studies that can be found in **Appendix 1** to this report.

Population Profile of Autistic People in Hillingdon

10. The Committee is advised that there is no available data that accurately records the total number of autistic people at a national, regional, or local scale. However, national studies referred to in the Hillingdon Joint Autism Needs Assessment conducted in 2022 suggest that there are approximately 700,000 autistic people in the UK¹. Headlines from national studies suggest that:
 - Between 1 and 3% of children and young people are autistic. For Hillingdon this

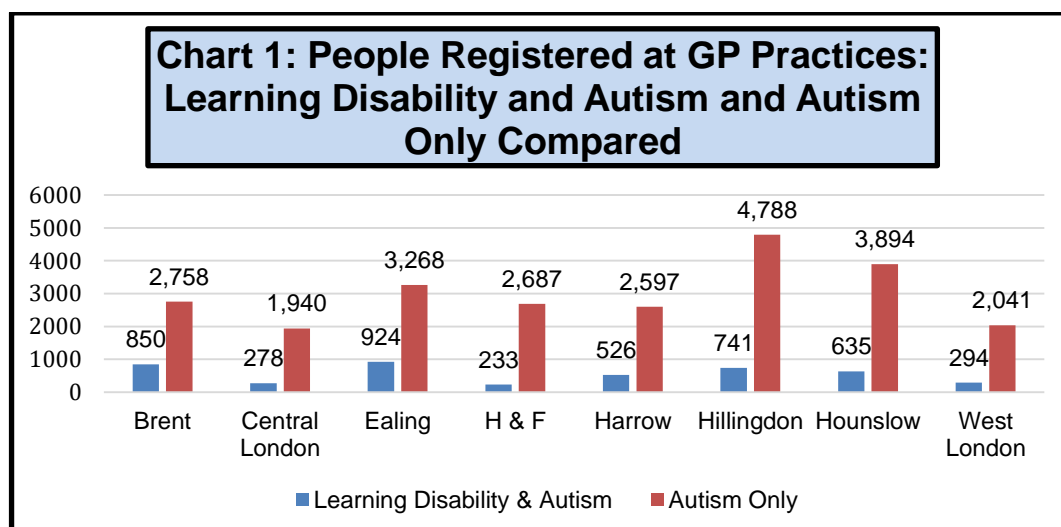
¹ [Autism - Hillingdon Council](#)

would mean between 822 and 2,467 people². Estimates suggest that between 150,000 and 500,000 people aged 20 to 49 years-old in England may be autistic but undiagnosed. Estimates also suggest that nationally between 250,000 and 600,000 autistic people over the age of 50 may be undiagnosed – more than 9 in 10 of all autistic people³.

- There is a higher prevalence of autism in males than females.
- There is a higher prevalence among Black, Asian and minority ethnic (BAME) communities.
- There is currently a lower prevalence amongst people aged 65 and over, which is projected to change over time.

11. There are six main sources of information about the numbers of autistic people in Hillingdon and these are:

- *Numbers of autistic people on GP registers:* The data in chart 1 below shows that Hillingdon-based GPs have been successful in identifying both people with a combined diagnosis of learning disability and autism as well as autism only. It shows that Hillingdon has the highest number of people registered with practices who have an autism only diagnosis in Northwest London.
- *Primary need of children and young people with Education, Health, and Care Plans (EHCPs):* The 2025 Spring School Census showed that approximately 37% of children and young people with EHCPs had autism identified as primary need. This compares to an average of 38.7% in Greater London.



Source: NHS NWL Aug 2025

- *Primary needs of children and young people with Special Educational Needs (SEN):* The 2025 Spring School Census showed that 26.6% of SEN pupils in Hillingdon had autism identified as a primary need compared to an average of 25.1% in Greater London.
- *Estimates based on national studies:* Table 1 below provides the most up to date projections for autistic adults in Hillingdon to 2040. The 2025 total is lower than the number of autistic people on Hillingdon GP registers, which supports a contention that national estimates under-estimate the actual prevalence within the population.

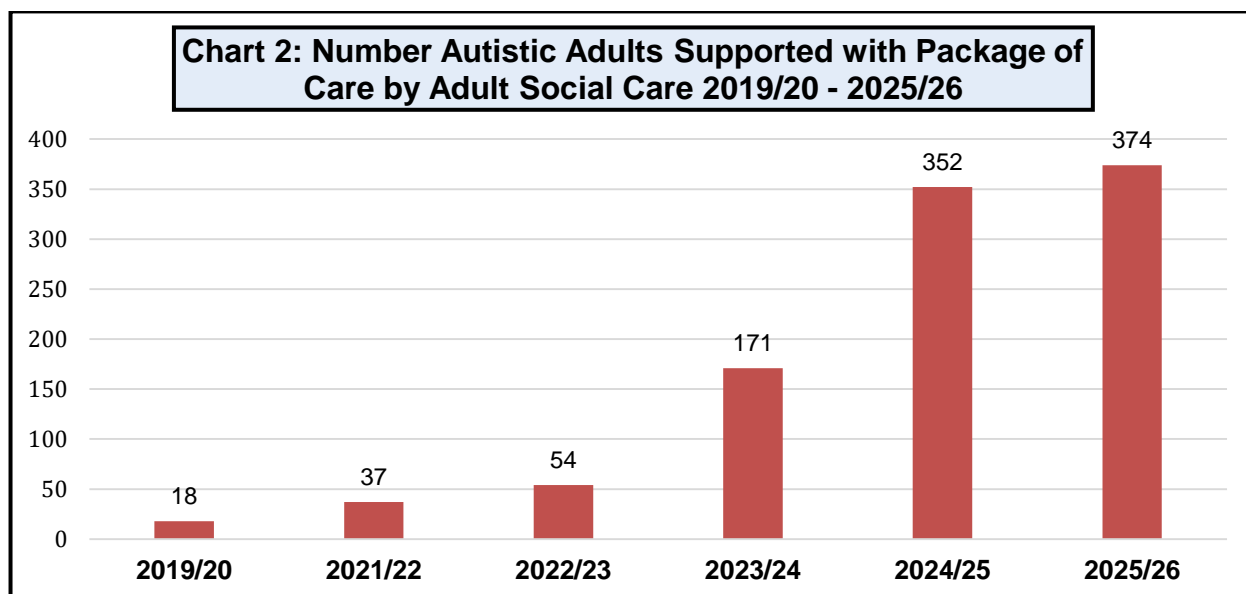
² [Population - UTLA | Hillingdon | Report Builder for ArcGIS](#)

³ [Number of autistic people in England may be twice as high as previously thought | UCL News - UCL – University College London](#)

Table 1: Projected Numbers of Autistic Adults 2025 - 2040			
Age Group	2025	2030	2040
18 - 64	2,107	2,170	2,266
65 +	411	454	532
TOTAL	2,518	2,624	2,798

Source: Projecting Adult Needs & Service Information (PANSI); Projecting Older People Population Information (POPPI) (Aug 25)

- *Numbers of people on the waiting list for an autism assessment:* As of the 28th July 2025 there were 220 children and young people awaiting an initial assessment and 1,468 who have had an initial assessment and are awaiting diagnosis. Of the 220 children and young people awaiting an initial assessment, 150 will be assessed before 31 March 2026 through an independent sector provider, *Oxford Autism*. There were 321 adults awaiting an autism assessment at the end of June 2025. *Oxford Autism* is also assisting with reducing the waiting list for adults, but this is countered by a continual rise in the number of referrals, i.e. approx. 13 per month.
- *Numbers supported with a package of care by Adult Social Care with autism (without an associated learning disability) as their primary support reason:* Chart 2 below shows how the numbers of autistic people supported by Adult Social Care with a package of care has increased between August 2019/20 and August 2025/26.



Source: Protocol Aug 2025

12. A more detailed analysis of the demographics of Hillingdon's autistic population can be found in the 2022 Joint Autism Needs Assessment and this can be accessed on the Council's website via this link [Autism - Hillingdon Council](#).

Diagnosis and Assessment

13. **Children and young people:** There is one diagnostic centre in Hillingdon for children and young people, and this is the Child Development Centre on the main Hillingdon Hospital site, which is provided by the Central and Northwest London NHS Foundation Trust (CNWL). The average expected waiting time for a diagnosis is currently between

18 months and 2 years for a diagnosis; however, most children are seen within 18 weeks for an initial assessment.

14. **Autistic adults:** Autistic adults who have a learning disability would have an autism assessment undertaken by CNWL's Specialist Learning Disability and Autism Health Team. Autistic adults who do not have a co-occurring disability would need to approach their GP for referral to a specialist assessor. CNWL has been working with an independent sector organisation called *Autism Oxford* for the last year to assist in managing the waiting list. The average expected waiting time for assessment and diagnosis is, as with children and young people, between 18 months and 2 years.

Benefits of Autism Diagnosis Explained

Parents of Autistic Children: A diagnosis can help them to:

- understand their child's needs and how they can help their child.
- get advice about support for their child at school.
- get support for parents and carers of autistic people, such as financial benefits.
- understand that their child is not just being "*naughty*" or "*difficult*".

Autistic Adults: A diagnosis can help them to:

- understand why they might find some things harder than other people.
- explain to others why you see and feel the world in a different way.
- get support at college, university, or work.
- get some financial benefits.

Issues and Challenges for Autistic People

15. Feedback that Hillingdon Autistic Care and Support (HACS) and the Centre for Attention Deficit Hyperactivity Disorder and Autism (CAAS) have received from the people who use their services is:

Autistic People

Social Inclusion: Autistic people may find it difficult to communicate in a way that others understand. This leaves people feeling isolated and alone. People express a genuine desire to make friends with others who understand autism and/or are on the autism spectrum themselves. A desire to make contact with people who share common interests and to build genuine friendships with people who can act as a support network. People feel they need support to do this.

Access to services: People report feelings of frustration and anxiety related to feeling confused/getting into troublesome situations but not knowing why or what rules they have broken. In many cases these feelings are linked to a lack of awareness and understanding about autism by staff working in community services. This often makes generic services inaccessible. Many services are also inaccessible because the physical environment is too noisy, lights are too bright etc.

Training, Employment and Education: People report a desire to gain qualifications and skills and ultimately to get a job. People also report a number of difficulties such as not performing well in interviews due to issues with communication. Once in a job people often face discrimination and bullying due to their difficulties around social communication. People report a need for better understanding of autism by employers and job centre staff. They also report a need for more opportunities to engage in voluntary work, supported employment and access to job coaches.

Family Carers

Social Inclusion: Parents worry about their adult children being isolated and alone with no friends, social interactions or relationships. People expressed anxiety about the lack of understanding from society and the vulnerability of their adult children caused by their lack of ability to communicate with others in the 'acceptable' way. Family carers want appropriate advocates to be available for their adult children.

Access to Services: Family carers report a lack of understanding about autism from community services. This leaves their adult children unable to access the same services as other people their own age resulting in isolation and an inability to get their health, further education or social needs met. This means that their adult children rely heavily on them to interpret and advocate. Family carers want their adult children to have access to services that provide them with guidance, advice and support that enables them to access generic community services to get their needs met.

Training, employment, and education: People report that many employers are unwilling to make reasonable adjustments. This leaves adults on the spectrum under enormous pressure to 'fit in' at work. Often the stress becomes too much and people on the spectrum lose their jobs. This frequently results in their adult children becoming increasingly depressed and anxious.

B. Developments and Achievements

16. Key developments and achievements over the last three years are summarised below.
17. **Establishing the All-age Autism Partnership Board:** In 2021 the Autism Partnership Board for adults was established to ensure a multi-agency approach to addressing the needs of autistic adults with autistic people. In 2024 it was further developed into an all age board that allowed a greater focus on autistic children outside of the SEND Board.
18. **Developing the Expert Reference Group (ERG):** A peer support group of autistic adults was established in 2022 to coproduce support and related services for autistic people, and to be reference point for consultation on service developments that could impact on the lives of autistic people. The ERG is supported by CAAS and has representation on the All-age Autism Partnership Board mentioned above.

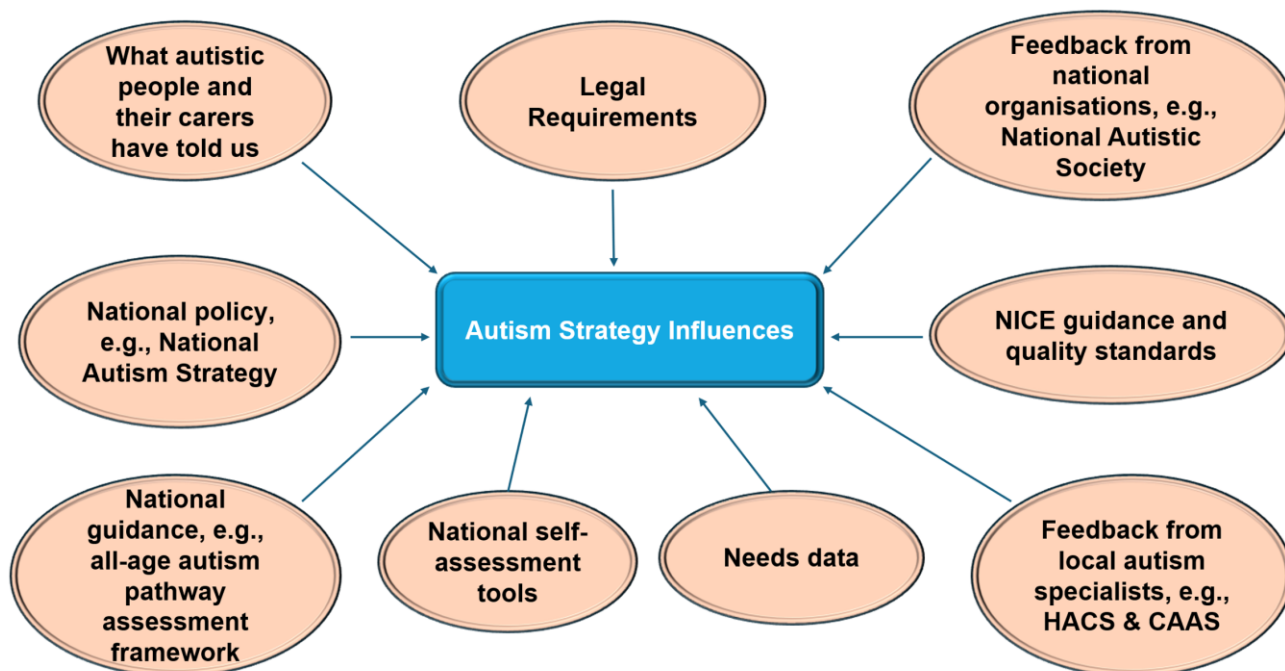
19. **Completing the Joint Autism Needs Assessment:** This concerned the needs of autistic people without a co-occurring diagnosis of learning disability. The self-assessment can be found using the link in paragraph 11. The development of an all-age autism strategy was one of the recommendations from the assessment.
20. **Centre for Attention Deficit Hyperactivity Disorder and Autism Support (CAAS) Transition Pilot:** The pilot supporting pupils with ADHD/ASD moving from primary to secondary mainstream schools has been extended into a second year (until April 2026), expanding from 4 to 6 schools. Long-term impact will be tracked but initial feedback shows benefits of the pilot in CYP with Autism successfully transitioning to new schools.
21. **Waiting well support:** Services delivered by HACS and Arts for Life funded by the ICB have been established to support children and young people whilst awaiting an autism diagnosis.
22. A new Care and Support Directory is live on the Local Offer for Children and Young People with SEND, that provides signposting for families awaiting assessments. Publicity has been shared with health services and GPs.
23. **Young People with Autism represented in Hillingdon SEND Youth Forum called 'Aim High':** Young people with SEND, including ASD, are being actively engaged in shaping SEND services, e.g., an Aim High Sub-group has been established at Meadow High Special School to ensure representation during school hours.
24. **Getting Ready for Work events:** These are held locally, and this is aimed at young people with SEND (including autism), their parents, and carers, schools, and other professionals. These events showcase supported employment and supported internship programmes available in the local area. Details are shared with all 1,500 young people in year 9 who have an EHCP. Presentations are given by young autistic people and their families and are intended to inspire other young autistic people.
25. **Supported Employment Forum:** The forum was established in 2022 to develop employment opportunities for autistic people. Partners of this forum include Jobcentre Plus, employment providers, specialist colleges, and voluntary sector organisations who support autistic people.
26. Over the past three years this forum has grown and is regularly attended by up to 40 residents. Forum meetings are face-to-face. Both small and large local businesses are represented, including Heathrow Airport. Since 2023/24 Cubelynx, a local financial modelling company, has been an active member and they have a commitment to employing at least 50% of their workforce who are autistic. The Cubelynx model will be shared with other businesses to showcase the benefits of offering employment opportunities to autistic people.
27. **Supported internships and Project SEARCH:** In the past three years, 48 young people with SEN including autism have achieved paid employment because of participating in Project SEARCH and supported internships. These paid jobs have been in the areas of administration, retail, hospitality, health, libraries and education. In addition, a variety of new supported internship programmes have been launched in recent years, these being at Hillingdon Hospitals, HS2, Heathrow Airport, and the Sheraton Skyline hotel. This brings the number of supported internship programmes in Hillingdon to 7 and from September

2025 they will be offering at least 60 places per year to young people with SEN including autistic young people.

28. **Implementation of new Social Work Autism Team:** This team was created in 2024 and comprises of two full-time advanced practitioner social workers and was established to reflect the increase in the number of people with an autism only diagnosis being referred to Adult Social Care.
29. **Training for health and care professionals:** Since 1st July 2022 all health and adult social providers registered with the Care Quality Commission have been required to ensure that their staff undergo training in learning disability and autism awareness. This is known as Oliver McGowan Mandatory Training. Autism awareness training is now mandatory for all Council staff dealing directly with residents. New statutory guidance on the delivery of mandatory training was published in June 2025 and is subject to national consultation.
30. **Establishing the Dynamic Support Register (DSR):** This is intended to identify people with a learning disability, autism or both who display (or are at risk of developing) behaviour that challenges or mental health conditions and who were most likely to be at risk of a hospital admission. Everyone on the register is entitled to a care and treatment plan, which is then reviewed. The DSR for children is maintained by the ICB and that for adults by the Council Learning Disability and Autism Team.

C. Next Steps: Priorities from 2025/26

31. Completion of the draft five-year all-age autism strategy is a key priority for 2025/26. The key influences on the development of the strategy are shown in the diagram below. The Committee is asked to note that work is in progress to coproduce the all-age strategy with autistic people, their families and organisations that support them. A multi-agency task and finish group has been established to lead the development of the strategy, and the work of this group will be overseen by the All-age Autism Partnership Board referred to earlier. The target date for completion of the strategy and its supporting delivery plan is December 2025.



Key: HACS – Hillingdon Autistic Care and Support; CAAS – Centre for Attention Deficit Hyperactivity Disorder and Autism Support

32. Key aspects of the new strategy that reflect feedback from autistic people are expected to include:

- Information, awareness and understanding of autism.
- Education and preparation for adulthood.
- Health and education support
- Housing
- Employment

33. Although subject to wider consultation, it is proposed that there is a focus on a small number of priorities that the Council and NHS and voluntary and community sector organisations have the power and control to deliver.

34. Other 2025/26 priorities as summarised below:

- **Better data coordination:** Explore how to improve coordination of data across Hillingdon's health and care system to establish a better understanding of the profile of autistic people in the borough
- **Developing integrated assessments:** A new proposal has been developed to promote integrated assessments for ASD, ADHD. This includes single referral hubs, earlier family intervention, and enhanced digital tools. The proposal is being considered at ICB management level.
- **Develop a SEND version of 'Walking in our shoes' training:** This is training provided by Autistic Young People and people with ADHD to professionals to raise awareness and empathy about Autism and other neurodiverse conditions.

PERFORMANCE DATA

35. **NICE Quality Statement 551: People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started**

within 3 months of their referral – Red: It is likely to be some time before it will be possible to achieve this target and waiting times are expected to increase temporarily as backlogs are cleared and new referrals are received. There will be a particular focus on the more complex cases where Oxford Autism were unable to undertake an assessment due to, for example, the level of risk with face-to-face appointments.

RESIDENT BENEFIT

36. This report describes actions taken by the Council and partners to maximise the independence of Hillingdon's autistic residents as well as outlining priorities from 2025/26.

FINANCIAL IMPLICATIONS

37. There are no direct financial implications arising from this report.

LEGAL IMPLICATIONS

38. There are no direct legal implications arising from this report.

BACKGROUND PAPERS

[Clinical guideline 128](#): *Autism spectrum disorder in under 19s: recognition, referral, and diagnosis* (NICE Sept 2011; updated Dec 2017)

[Clinical guideline 170](#): *Autism spectrum disorder in under 19s: support and management* (NICE Aug 2013; updated June 2021)

[Clinical guideline 142](#): *Autism spectrum disorder in adults: diagnosis and management* (NICE June 2012; updated June 2021)

[Quality standard 51](#): *Autism* (NICE Jan 2014)

Appendix 1 – Case Studies

Case Study A

Presenting Issues

Mr A is in his 40's with autism, a mild learning disability and other mental health issues. He had lived in 24 hours staffed supported living in his own self-contained flat for several years. While very reclusive and experiencing paranoia, Mr A had managed to live independently and enjoy the benefits of his own tenancy with the assistance of a support worker and his mother. However, over time due to non-engagement with mental health medication and rigid, fixed patterns of thinking around past grievances, the following social difficulties arose:

- Anger towards his mother, staff in the supported living placement and other tenants who were noisy.
- Severe health and safety problems with hygiene in the property, including failure to use his toilet properly and the proliferation of drain flies.
- Increasing aggression towards staff members and property damage which was making the building unsafe for Mr A and other tenants.
- Eventually Mr A prevented access to his flat, meaning the health and safety of the flat could not be judged.

Interventions

- Review of Mr A's needs using the Care Act 2014 but incorporating the National Autistic Society's SPELL framework⁴ by LD & Autism Service. This identified a lack of structure in his day.
- Joint work to review Mr A in the community with the Learning Disability Psychiatric service.
- Liaison by LD & Autism Service with the housing association over material damage to the property and trying to avoid eviction action from the property.
- Use of the Mental Capacity Act to determine Mr A's ability to understand and control his actions in this situation, considering the causative nexus of his autism and mental health issues.
- Eventually after concerns escalated and lesser restrictive routes were not successful, Mr A was assessed under the Mental Health Act which revealed he was not appropriate to be assessed or treated in hospital.
- Work with legal services to require Mr P to put in place appropriate and clear boundaries or risk court action using a clear easy read letter. Mr P temporarily left the property while essential deep cleaning work was completed by a specialist cleaning firm used to working with autistic people. This took place to prevent eviction.
- Joint work with support workers, Learning Disability Psychiatric services and support in the

⁴ See link for more detail [The SPELL framework](#)

community from Learning Disability Community Nursing.

Outcomes

- In consultation with Mr A, essential decluttering and maintenance work was completed leaving a home environment for Mr A with appropriate sanitation and no risks of leaks to the downstairs property.
- A better relationship with Mr A and his support workers developed with Mr P allowing regular checks on the hygiene and safety in his property.
- Outreach support to Mr A offered to attend a local activity hub, though this was eventually declined after a few visits.
- Mr A began to allow work with his Learning Disability Psychiatrist – historically a service he deeply mistrusted.
- Mr A has been able to maintain his tenancy and continue to live in his home of several years, albeit with care management intervention.

Case Study B

Mr B is in his 50s who lives in his own flat in 24 hour staffed supported living. He has an Autism diagnosis. He has difficulty controlling his emotions and managing his day-to-day affairs, especially concerning financial matters. He had lived in his own housing association flat in a supported accommodation scheme but had been repeatedly verbally and sometimes physically aggressive to staff and other tenants with care and support needs.

Presenting Issues

- Mr B had several complaints made against him by other tenants following incidents of aggression.
- This escalated and several incidents occurred in which staff members and other tenants were assaulted and the Police were called – the Police took no action due to Mr B's mental health condition.
- Mr B was unwilling to acknowledge any fault, and he seemed to lack insight to recognise his own part in these incidents and saw the problems as the result of other people's behaviour.
- Eviction action was started against him by his housing association.

Interventions

- A safeguarding protection plan put in place to help ensure safety of the other tenants.
- A review of Mr B's needs using the Care Act 2014 but incorporating the National Autistic Society's SPELL framework by LD & Autism Service took place. This identified a hypersensitivity to noise and difficulty emotionally regulating and with social interaction.
- Mr B identified to have mental capacity, when calm, about his care and accommodation.

- Use of social stories to communicate with Mr B about next steps in finding a new place to live.
- Advice from previous social worker on steps to calm Mr B implemented.
- Referral for Positive Behaviour Support for joint work.
- Carer's assessment offered to Mr B's father.

About the Positive Behaviour Support

This Council provides Positive Behaviour Support to people with behaviours that challenge, which helps with understanding the reason(s) for the behaviour and enables their needs to be better managed to enhance their quality of life and reduce the likelihood that the behaviour will recur.

Behaviours that challenge can include tantrums, hitting or kicking other people, throwing things or self-harming. Behaviour is challenging if it is harmful to the person and others around them and if it stops them achieving things in their daily life, such as making friends or going out into the community.

Outcomes

- Eviction action against Mr B by his housing association landlord was delayed.
- Mr B views and choices on housing, care and support identified with the assistance of the Positive Behaviour Support worker.
- Alternative care and accommodation options are beginning to be identified via Brokerage service, including those with autism specialism and quieter environments in line with Mr B's sensory profile.