



Autism Joint Needs Assessment

2022

Author:	Gary Collier – Health and Social Care Integration Manager, Hillingdon Council
Date:	March 2023
Reviewed:	Kelly O'Neill – Interim Director of Public Health, Hillingdon Council
Date:	March 2023

AUTISM JOINT NEEDS ASSESSMENT, 2022

Table of Contents

	Item	Page
1.	Introduction: Purpose of Assessment	3
2.	Understanding Autism	3
3.	Local Picture: Autistic People in Hillingdon	12
4.	Supporting Autistic People: Current Service Provision in Hillingdon	21
5.	Analysis and Gaps	26
6.	Recommendations	27

AUTISM JOINT NEEDS ASSESSMENT, 2022

1. Introduction: Purpose of Assessment

This assessment is intended to:

- Summarise available data about autistic people in Hillingdon and their health and wellbeing needs.
- Summarise how their needs are currently being met.
- Make recommendations based on an analysis of available data about the needs of autistic people.

2. Understanding Autism

What is Autism?

Autism Spectrum Disorder (ASD) 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. ASD is a spectrum condition, meaning that whilst all autistic people share certain characteristics, they are affected by them in different ways¹.

ASD is characterised by two main features:

- Persistent challenges in social interaction and communication, and
- The presence of rigid and repetitive behaviours, resistance to change or restricted interests².

Co-occurrence

ASD does not often present itself as a single presenting condition and almost half (44%) of people with ASD have a co-occurring learning disability³, defined⁴ as a significant reduced ability to understand new or complex information, to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development and being a lifelong condition. An additional group of people with ASD perform in the borderline learning disabilities adaptive functioning range⁵ – while a quarter of people with ASD are non-verbal.

¹ Autism.org.uk. (2018). Autism - NAS. [online] Available at: <https://www.autism.org.uk/about/what-is/asd.aspx#> .

² National Institute for Health and Care Excellence (2016) *Autism spectrum disorder in adults: diagnosis and management* (NICE Clinical Guideline 142). Available at: <https://www.nice.org.uk/guidance/cg142/chapter/Introduction> .

³ Baxter AJ, Brugha TS, Erskine HE, Scheurer RW, Vos T, Scott JG. The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*, 2015; 45(3): 601–13.

⁴ Department of Health (2001) *Valuing People A New Strategy for Learning Disability for the 21st Century*.

⁵ Salvador-Carulla L, Garcia-Gutierrez JC, Ruiz Gutierrez-Colosia M, Artigas-Pallares J, Garcia Ibanez J, Gonzalez Perez J *et al*. Borderline intellectual functioning: Consensus and good practice guidelines. *Revista de Psiquiatría y Salud Mental*, 2013; 6(3): 109–20.

For as many as 83% of cases⁶ ASD also commonly co-occurs with other neurodevelopmental, psychiatric, neurologic, chromosomal and genetic diagnoses. ASD also commonly co-occurs with other neurodevelopmental, psychiatric, neurologic, chromosomal and genetic diagnoses in up to 83% of cases⁷. It is, however, important to note that many autistic people have average or high intelligence without a co-occurring learning disability.

Causes of Autism

Evidence identifies that there are many factors that increase the likelihood that a person has ASD, including environmental and genetic factors. Some of the factors that are associated with an increased prevalence of autism include⁸:

- A sibling with autism
- Birth defects associated with central nervous system malformation and/or dysfunction.
- Gestational age <35 weeks
- Parental schizophrenia-like psychosis or affective disorder
- Maternal use of sodium valproate in pregnancy
- A learning disability
- Attention deficit hyperactivity disorder.
- Neonatal encephalopathy or epileptic encephalopathy, including infantile spasms.
- Chromosomal disorders such as Down's syndrome
- Genetic disorders, such as Fragile X
- Muscular dystrophy
- Neurofibromatosis
- Tuberous sclerosis

There is no evidence of a causal association between ASD and measles, mumps and rubella vaccine; previous historical studies suggesting a causal link were found to be filled with methodological flaws^{9, 10} and academically discredited. Neither is there any evidence that the use of thiomersal preservative and aluminium adjuvants contained in inactivated vaccines has a link to ASD.

Autism Prevalence in General Population

The prevalence of Autism in the General Population

There is no available data that accurately records the total number of people with autism on a national, regional or local scale. It is estimated that there are approximately 700,000 people with ASD in the UK, the data is based on two epidemiological studies on the prevalence of ASD in the UK applied to figures from the 2011 census¹¹. The British Medical Association

⁶ Levy SE, Giarelli E, Lee LC, Schieve LA, Kirby RS, Cuniff C et al. Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of Developmental & Behavioral Pediatrics*, 2010; 31(4): 267–75.

⁷ Levy SE, Giarelli E, Lee LC, Schieve LA, Kirby RS, Cuniff C et al. Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of Developmental & Behavioral Pediatrics*, 2010; 31(4): 267–75.

⁸ National Institute for Health and Care Excellence (2016) *Autism spectrum disorder in adults: diagnosis and management* (NICE Clinical Guideline 142). Available at: <https://www.nice.org.uk/guidance/cg142/chapter/Introduction>.

⁹ Wakefield's affair: 12 years of uncertainty whereas no link between autism and MMR vaccine has been proved. *Maisonneuve H, Floret D. Presse Med.* 2012 Sep; French.

¹⁰ (2) *Lancet* retracts Wakefield's MMR paper

Dyer C. *BMJ* 2010;340:c696. 2 February 2010.

¹¹ Autism.org.uk. (2022). Autism - NAS. [online] Available at: <https://www.autism.org.uk/about/what-is/asd.aspx>.

estimates that 1 in 100 children and young people are autistic.¹² Analysis between 2018 and 2020 based on data collected from a million school pupils identified a general prevalence of 1.76%.¹³

Autism Prevalence in BAME Communities

Data about prevalence of autism among people from Black, Asian and minority ethnic communities (BAME) is even more limited than that for the general population. The Jama Pediatrics' (March 2021) study (see footnote 12) suggested a significantly higher prevalence; 2.11%, amongst Black pupils.

Autism Prevalence by Gender

The National Autistic Society (NAS) website references studies undertaken since 1943 that record a higher prevalence of autism in males compared with females. This national gender trend is reflected in the gender breakdown of the people supported by NAS in 2015, where the ratio was 3:1 male to female for their adult services and 5:1 in the Society's schools. In the Jama Pediatrics' study, the male to female ratio was 4:1.

There are a range of theories regarding why there are more males than females diagnosed with autism, however, there has been insufficient research that draws any conclusion¹⁴. One theory argues that there is no inherent difference between autism diagnosis between men and women and that the difference can be explained by how society treats and socialises males and females. Another is the '*Female autism phenotype*' theory that looks at the autistic characteristics that are usually unique to women. These include:

- Being able to hide certain behaviours during social interaction.
- Having a small number of very intense friendships.
- Experiencing fewer repetitive behaviours, or having repetitive behaviours associated with nervousness, such as humming.
- Having more advanced social skills than men with autism.
- Having a more socially acceptable interest or obsession, for example literature or gardening.

This theory supports the hypothesis that there may be a comparable number of women with autism as there are men. Another theory suggests that there may be a range of biological and environmental factors that mean men and boys have a higher prevalence of autism. Biological factors would include sex chromosomal gene dosage and sex hormone levels.¹⁵

¹² BMA.org.uk (2022) Available at: [Autism spectrum disorder \(bma.org.uk\)](https://www.bma.org.uk/autism-spectrum-disorder)

¹³ Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England Andres Roman-Urrestarazu, MD, PhD; Robin van Kessel, PhD; Carrie Allison, PhD; Fiona E. Matthews, PhD; Carol Brayne, MD; Simon Baron-Cohen, PhD (Jama Pediatrics March 2021). Available at: https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fjamanetwork.com%2Fjournals%2Fjamapediatrics%2Ffullarticle%2F2777821%3FguestAccessKey%3Db485a18e-0e11-40b4-b644-2688dcb4ec4%26utm_source%3DFor_The_Media%26utm_medium%3Dreferral%26utm_campaign%3Dftm_links%26utm_content%3Dftl%26utm_term%3D032921&data=05%7C01%7Cgcollier%40hillingdon.gov.uk%7C08b47aceb21f40f03a2908da5b6d37d1%7Caaacb679c38148fbb320f9d581ee948f%7C0%7C0%7C637922821910850037%7CUnknown%7CTWFpbGZsb3d8eyJWljojMC4wLjAwMDAiLCJQIjoiV2luMzliLCJBTiI6IkhWwWlCjXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=I0MDd7jaHn8XshnJbTY8OXxPL06h37IXpEpnRht6Vj4%3D&reserved=0

¹⁴ NAS website [Autistic women and girls \(autism.org.uk\)](https://www.autism.org.uk)

¹⁵ Sex differences in autism spectrum disorders (2015), Donna M Werling & Daniel H Geschwind. Available at: [Sex differences in autism spectrum disorders - PMC \(nih.gov\)](https://pubmed.ncbi.nlm.nih.gov/26884441/)

Examples of environmental factors would include parental age, maternal physical and mental health pre-birth and economic wellbeing.¹⁶

Older People and Autism

The Oxford Brookes University and Institute of Public Care's Projecting Older People Population Information (POPPI) system estimates that the total number of autistic people aged 65 and over in 2020 in England was 98, 046 and this is expected to increase to 119,596 by 2030 and 137,027 by 2040.

Quality of Life and Economic Impact

Lack of recognition of autism can lead to the health and wellbeing needs of autistic people being overlooked. They may develop mental and physical health needs as a consequence and be unable to access the appropriate treatment, are less likely to be able to live independently, find paid employment, and experience a fulfilling life. Autistic people without a co-occurring learning disability may feel that they have a '*hidden*' condition which is not easily recognised or understood by professionals or the public.

The economic impact associated with ASD is substantial and includes direct medical and direct non-medical costs as well as costs associated with economic inactivity¹⁷. Studies estimate that the lifetime cost of caring for an individual with ASD and learning disabilities is circa £1.5million in the United Kingdom (UK) which is lower, £0.92 million for people with ASD who do not have a learning disability¹⁸. In addition, if unrecognised, ASD can contribute to poor educational attainment and difficulty with employment, leading to negative economic implications.

Autism can affect the quality of life of autistic people as well as their families. Some autistic people can lead independent lives but for many living independently can be challenging. ASD interferes with the quality of their lives and those of their parents. Many experience increased anxiety and depression. Family members often have to decrease hours worked due to their child's diagnosis¹⁹.

The families of many autistic children worry about their education and time spent at school. Only 52% of parents feel that their child is making good educational progress, and 63% of autistic children are not in the kind of school their parents think would best support them²⁰. Autistic children often find school to be a difficult environment: a quarter of autistic children are not happy at school, and one in five do not feel safe²¹.

¹⁶ Environmental factors influencing the risk of autism (2017), Padideh Karimi, Elahe Kamili, Seyyed Mohammad Mousayi & Mojgan Karahmadi. Available at: [Environmental factors influencing the risk of autism - PMC \(nih.gov\)](#)

¹⁷ Amendah D, Grosse SD, Peacock G, Mandell DS. The economic costs of autism: A review. In Amaral D, Geschwind D, Dawson G (eds.). Autism spectrum disorders. Oxford: Oxford University Press, 2011: 1347–60.

¹⁸ Buescher AV, Cidav Z, Knapp M, Mandell DS. Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA Pediatrics, 2014; 168(8): 721–8.

¹⁹ Azeem MW, Dogar IA, Shah S, Cheema MA, Asmat A, Akbar M et al. Anxiety and depression among parents of children with intellectual disability in Pakistan. Journal of the Canadian Academy of Child and Adolescent Psychiatry, 2013; 22(4): 290–5.

²⁰ Reid, B. (2011). Great Expectations. London: The National Autistic Society

²¹ Reid, B. (2011). Great Expectations. London: The National Autistic Society

Autistic adults do not have access to the support and services required to live independently or enter employment. Over 44% of autistic adults live at home with their parents, and only 32% of adults with autism are in some form of paid work²².

Autistic People from BAME Communities

In 2014 research by NAS identified five barriers to people from BAME communities obtaining an ASD diagnosis that consequently was a barrier to accessing appropriate support²³. The barriers were:

1. *Challenges getting a diagnosis:* Some participants considered that low levels of understanding of autism in their communities may have delayed people seeking a diagnosis. It was also identified that teachers can fail to spot characteristics of autism due to incorrect assumptions about a child's behaviour or language skills.
2. *Barriers to accessing support services:* Feedback from parents suggested that there were challenges in understanding autism and knowing what services are available due to information often only being available in English, and the use of medicalised terms by professionals.
3. *Communication problems with professionals:* Some families said that they did not feel confident dealing with professionals and some reported that people from BAME communities may have limited confidence and trust of professionals and statutory authorities.
4. *Awareness and understanding of autism within communities:* Feedback suggested that although communities can be an important source of support, they can also have judgemental attitudes. It was reported that disability can be stigmatised in some communities and blamed on parents. Some parents reported a lack of support from faith groups and places of worship.
5. *Denial and isolation:* Some families said they initially refused to acknowledge that their child had autism. Some also felt that their child's difficulties should remain private and not be discussed outside the home. Along with feelings of blame and shame, many said that these issues could lead to parents, carers and siblings missing out on support and becoming socially isolated.

Autistic Women and Girls

The lower reported prevalence and limited awareness that autism can manifest itself differently in women and girls compared with men and boys means that they can face difficulties in obtaining a diagnosis. NAS feedback suggests that some diagnosed women and girls face difficulties accessing services.

Autistic Older People

A key issue for autistic older people is that if they are not diagnosed earlier in life autism symptoms can mirror other age-related conditions can be missed. For example, conditions

²² The National Autistic Society (2016). The autism employment gap: Too Much Information in the workplace.

²³ Diverse perspectives: The challenges for families affected by autism from Black, Asian and Minority Ethnic communities (NAS 2014). Available at: <https://www.autism.org.uk/about/bame-autism.aspx>.

that impact how the brain functions, such as dementia may mask certain autism traits. Being less mobile and having a reduced social circle can also impact an older person's social communication skills, which again could mask underlying autism.

Older people can also be more susceptible to certain mental health problems, particularly loneliness and depression. This can have a knock on effect on their self-esteem and behaviour, and cause people to avoid social situations.

Some of the most common autism traits in older adults include:

- Being sensitive to noise. For example, autistic older people may find being in a loud restaurant, or around a barking dog uncomfortable.
- Finding bright lights, and certain smells and tastes overwhelming.
- Having an intense interest in something to the point where the older person thinks about it and talks about it a lot of the time.
- Liking things done in a very particular way. The older person might not feel happy unless something is perfect.
- Getting anxious at times but being unsure why.
- Finding eye contact is difficult, or sometimes staring too much.
- Being diagnosed with a mental disorder such as depression or bipolar.
- In a social situation, you often say the wrong thing, or blurt something out without thinking²⁴.

A study by Goldsmiths, University of London (2016) found that an apparent increase in the intensity of some ASD traits as people aged, e.g., difficulties with socialisation, communication and imagination.²⁵

Autistic People and Risk of Suicide

Research by the University of Cambridge and University of Nottingham reinforces the findings of earlier research that suggests that autistic people are at a higher risk of suicide than people who are not autistic.²⁶ Figures show that as many as 66% of autistic adults have thought about suicide during their lifetime and up to 35% had planned or attempted suicide.²⁷ Autistic people are also more at risk of dying by suicide than non-autistic people, with the

²⁴ [https://www.elder.org/ Understanding autism in older adults | Elder](https://www.elder.org/Understanding-autism-in-older-adults-Elder)

²⁵ *Demographic and cognitive profile of individuals seeking a diagnosis of Autism Spectrum Disorder in adulthood* – Journal of Autism and Developmental Disorders (August 2016). Available from: <https://www.gold.ac.uk/news/autism-and-ageing>

²⁶ *Autism and autistic traits in those who died by suicide in England*. Cassidy, S et al. *British Journal of Psychology*; 15 Feb 2022; DOI: 10.1192/bjp.2022.21

²⁷ *Brief Report: Social Support, Depression and Suicidal Ideation in Adults with Autism Spectrum Disorder* Hedley, Darren; Uljarević, Mirko; Wilmot, Mathilda; Richdale, Amanda; Dissanayake, Cheryl *Journal of Autism and Developmental Disorders*, Volume 47 (11) – Aug 31, 2017

highest risk seen in autistic people without a co-occurring learning disability, and also autistic women.²⁸

Comparable with the general population, experiencing mental ill-health, social isolation and unemployment can increase the risk of suicide amongst autistic people. However, being autistic in itself is thought to contribute to this risk over and above these other factors.²⁹

Key Drivers: International, National and Local

International

In 2008, the United Nation General Assembly (GA) adopted resolution A/RES/62/139 designating 2nd April each year as World Autism Awareness Day increasing international awareness about ASDs. In 2012 the (GA) adopted resolution 67/82: "*Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities*". The U.N. outlined that the full employment by people with ASD will contribute towards advances in social and economic development of societies and communities. The GA voices its concern "*that persons with autism spectrum disorders [...] continue to face barriers in their participation as equal members of society*" and calls this "discrimination" and "a violation of the inherent dignity and worth of the human person". It recommended that:

- Member states enhance access to appropriate support services
- Equal opportunities for inclusion and participation is enhanced
- Training and awareness raising is provided
- Innovative and integrated approaches for effective and sustainable intervention programmes are developed
- Inclusive education programmes for infants, children and adults with ASD are developed.
- Data, information and statistical information is improved.

National

This section identifies the key national drivers influencing or directing how the health and wellbeing of autistic people should be supported.

National Autism Strategy: The first national autism strategy called *Fulfilling and rewarding lives: the strategy for adults with autism* was published by the Department of Health in March 2010 in compliance with a requirement under the Autism Act, 2009. Statutory guidance on the implementation of the strategy was published in 2011. The national strategy was updated in April 2014 with '*Think Autism: an update to the government adult autism strategy*'. An updated version of the statutory guidance was then published in March 2015.

In July 2021 the Department of Health and Social Care 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. However, no changes have been

²⁸ [A 20-year study of suicide death in a statewide autism population](#) Kirby, Anne V.; Bakian, Amanda V.; Zhang, Yue; Bilder, Deborah A.; Keeshin, Brooks R.; ... [+] Autism Research, Volume 12 (4) – Jan 21, 2019

²⁹ [Risk markers for suicidality in autistic adults](#) Cassidy, Sarah; Bradley, Louise; Shaw, Rebecca; Baron-Cohen, Simon Molecular Autism, Volume 9 – Jul 31, 2018

made to the statutory guidance issued under the Autism Act, which relates to the updated strategy issued in 2014.

NHS Long Term Plan: Published by NHS England in 2018 sets out the ambition for the NHS and identifies ASD as a priority, committing to the following actions:

1. Tackle the causes of morbidity and preventable deaths in autistic people, by:

- Piloting the introduction of a specific health check for people with autism, and if successful, extend it more widely.
- Ensuring that 75% of people with learning disabilities aged over 14 will receive an annual health check every year.
- Reduce the usage of psychotropic drugs

2. Improve the whole NHS understanding of the needs of people with autism, and work together to improve their health and wellbeing, by:

- NHS staff receiving information and training on supporting people with autism.
- Sustainability and Transformation Partnerships (STPs) and integrated care systems ICSs being expected to make sure all local healthcare providers are making reasonable adjustments to support people with autism.
- National improvement standards being implemented and applied to all services funded by the NHS. These standards will promote greater consistency, addressing themes such as rights, the workforce, specialist care and working more effectively with people and their families.
- 2023/24, a '*digital flag*' in the patient record will ensure staff know a patient has autism.
- Working with the Department for Education and local authorities' awareness of, and support for, children and young people with autism or both will be enhanced.
- NHS England working with partners to bring hearing, sight and dental checks to children and young people with autism or both in special residential schools.

3. Children and young people with suspected autism wait too long before being provided with a diagnostic assessment. Reduce waiting times for specialist services, by:

- Testing and implementing the most effective ways to reduce waiting times for specialist services.
- Children and young people with autism with the most complex needs will have a designated keyworker. Key worker support will first be provided to children and young people who are inpatients or at risk of being admitted to hospital.

4. By March 2023/24, inpatient provision will have reduced to less than half of 2015 level, through:

- Local providers being able to take control of budgets to reduce avoidable admissions, enable shorter lengths of stay and end out of area placements.
- Where possible, people with a learning disability, autism or both will be enabled to have a personal health budget (PHBs).
- Increase investment in intensive, crisis and forensic community support so that people receive more personalised care in the community and closer to home.

5. Focus on improving the quality of inpatient care across the NHS and independent sector.

By 2023/24, all care commissioned by the NHS will need to meet the Learning Disability Improvement Standard, by:

- Working with the CQC to implement recommendations on restricting the use of seclusion, long-term segregation and restraint for all patients in inpatient settings, particularly for children and young people
- All areas of the country implementing and being monitored against a '12-point discharge plan' to ensure discharges are timely and effective.
- Reviewing and looking to strengthen the existing Care, Education and Treatment Review (CETR) and Care and Treatment Review (CTR) policies, in partnership with people with a learning disability, autism or both, families and clinicians to assess their effectiveness in preventing and supporting discharge planning.

NICE Quality Standard: The National Institute for Health and Care Excellence (NICE) has a statutory function to improve outcomes for people using NHS and other public health and social care services by producing evidence-based guidance and by developing quality standards and performance metrics for those providing and commissioning these services. An autism quality standard (qs51) published in January 2014 contains eight quality standards are shown below.

- **Statement 1:** 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.
- **Statement 2:** People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.
- **Statement 3:** Autistic people have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.
- **Statement 4:** Autistic people are offered a named key worker to coordinate the care and support detailed in their personalised plan.
- **Statement 5:** Autistic people have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.
- **Statement 6:** Autistic people are not prescribed medication to address the core features of autism.
- **Statement 7:** Autistic people who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.
- **Statement 8:** Autistic people with behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

The Autism and Education in England Report (2017), an All-Party Parliamentary Group, made 22 recommendations for Government, Local Authorities, and the Education System that includes the call for a national children and young people autism in education strategy. It focuses on:

- Workforce development around SEND and autism for teachers.
- Ensuring that there is a special curriculum for people with autism who need it.

- Setting out reasonable adjustments for schools.
- Reduce bullying and harassment through greater awareness raising.
- Setting out clearer guidance around diagnostics, including potential pathways between diagnosis and education health and care plans.
- Better alignment between schools and mental health services.
- National review of SEND funding.
- Development of local hub models to share information.

Core capabilities framework for supporting autistic people: In October 2019 Health Education England published the framework for health and care staff that had been developed led by Skills for Health, working in collaboration with Skills for Care, the National Autistic Society and Opening Minds. There are five domains within the framework and these are:

- Domain A. Understanding autism
- Domain B. Personalised support
- Domain C. Physical and mental health
- Domain D. Risk, legislation and safeguarding
- Domain E. Leadership and management, education and research

Local

Joint Health and Wellbeing Strategy: Hillingdon's joint 2022 – 2025 strategy, the development of which is a statutory requirement contains two priorities relevant to autistic people. The priorities and relevant actions are shown below

Priority 2: Tackling unfair and avoidable inequalities in health and in access to and experiences of services.



Action: We will help to improve the life chances of people with learning disabilities and/or autism through increased integration between health and social care.

Priority 5: Improving mental health, learning disability and autism services through prevention and self-management.



Action: We will implement the requirements of the National Autism Strategy published in July 2021.

Action: We will increase support for people newly diagnosed with ASD.

3. Local Picture: Autistic People in Hillingdon

Autistic Children and Young People

The table below shows the total number of children and young people in Hillingdon in education during the 2021/22 academic year.

Total number of children and young people in education 2022	
	Number of CYP on roll
Type of Setting	Jan 2022
Mainstream schools*	50,780
State funded special schools	694
Non-maintained or Independent schools	1
Specialist resource provision (SRPs) within mainstream schools	-
Other (ie educated otherwise than at school by parents/alternative provision)	10
Special free schools	637
Early years settings	3,915
TOTAL	56,037
*This includes pupils in referral unit, state funded primary & secondary excluding special free schools and SRPs.	

Source: Spring 2022 census

The table below provides a comparison of the number of people with Education, Health and Care Plans (EHCPs) between September 2019 and May 2022. This shows that in May 2022 there were 3,088 CYP in education with EHCPs.

Number of Children and Young People with EHCPs in Hillingdon				
Type of Setting	Number of CYP with EHCPs at:			
	Sep-19	Sep-20	Mar-21	May-22
Early Years Setting	1	0	1	57
Further education settings	311	422	421	366
Independent school	36	49	49	
Independent special schools	74	86	95	235
Mainstream schools	774	915	991	1,316
Non-maintained schools	69	78	85	
Other (i.e., educated otherwise than at school by parents/alternative provision)	321	303	273	185
Special schools	649	672	711	823
Special free schools	104	102	102	
Specialist resourced provision (SRPs)	102	118	127	106
TOTAL	2,441	2,745	2,855	3,088

Source: 2018 - 2021 BSL SEN database, May 22 EHM database

The table below provides a breakdown of the primary needs of CYP in education with EHCPs. This shows that autism is the highest primary need by a wide margin.

Primary Needs of Children and Young People with EHCPs in Hillingdon				
Primary Need	Number of CYP with EHCPs at:			
	Sep-19	Sep-20	Mar-21	May-22
ASD	1,026	1,197	1,227	1,409
Speech, Language & Communication Needs (SLCN)	444	513	541	576

Social Emotional and Mental Health Needs (SEMH)	97	122	134	245
Moderate Learning Difficulties (MLD)	214	212	223	227
Physical Disability (PD)	120	129	124	156
Severe Learning Difficulties (SLD)	167	164	155	121
Specific Learning Difficulties (SpLD)	38	48	48	81
Other i.e.: (Medical/ mental health)	74	95	93	77
Hearing Impairment (HI)	55	60	69	68
Profound and Multiple Learning Difficulties (PMLD)	57	59	60	68
Visual Impairment (VI)	28	29	28	39
Multi-Sensory Impairment (MSI)	6	7	6	12
SEN support but no specialist assessment of type need				6
Cognition and Learning	3	8	11	1
BESD	102	98	99	
<i>Unclassified</i>	10	4	37	2
TOTAL	2,431	2,741	2,855	3,088

Source: 2018 - 2021 BSL SEN database, May 22 EHM database

The table below presents an overview of specialist educational provision in Hillingdon. Capacity increased at Grangewood, Moorcroft & Northwood schools from May 2022.

An overview of the specialist provision for children and young people with EHCPs currently available within Hillingdon and its capacity					
School	Planned Place Number 2022/23	Number of CYP with EHCPs			
		Sep-19	Sep-20	Mar-21	May-22
Cherry Lane SRP	10	8	9	9	7
Coteford Infants SRP	10	6	5	7	8
Coteford Juniors SRP	13	8	11	10	9
Deanesfield Primary SRP	8	2	3	4	1
Glebe Primary SRP	10	9	13	12	11
Grangewood	131	72	64	67	94
Harlington School SRP	7	4	5	5	5
Hayes Park Primary SRP	13	11	13	14	12
Hedgewood	190	149	136	157	155
Lake Farm Park SRP	12	8	8	9	8
Meadow High	250	232	245	248	237
Moorcroft	148	76	88	86	94
Northwood SRP	10	5	4	5	3
Oak Wood SRP	12	11	13	14	11
Pentland Field	150	102	101	102	98
Pinkwell Primary SRP	10	4	6	8	12
St Martin's Primary SRP	15	7	9	7	7
The Willows School Academy Trust	60	29	25	32	31

Vyners SRP	16	14	11	11	8
The Pride Academy	83	37	39	43	41

Source: 2018 - 2021 BSL SEN database, May 2022 EHM database

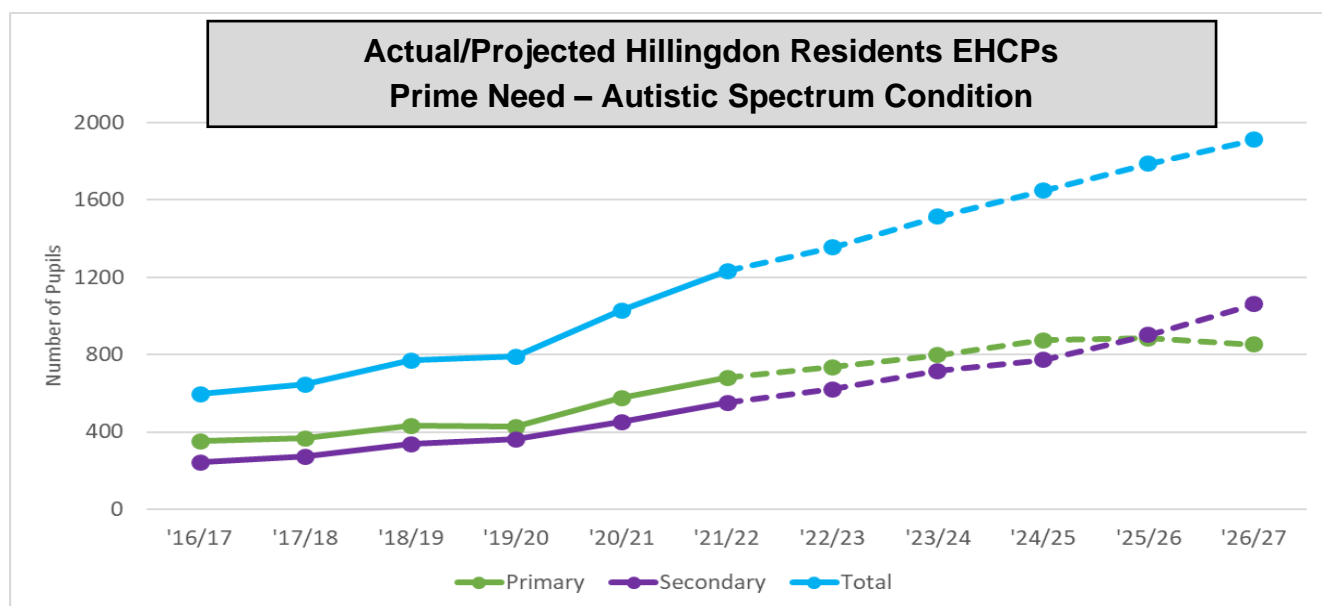
Autistic Children and Young People: Forecast Demand

Analysis of current pupil population data and forecasts for 2016 – 2027, together with primary SEND categorisation and placement data for the same period has been done, in order to assess where current and future pressure for provision lies in the system.

It should be noted that figures, analysis and associated assumptions are not definitive as there are a number of other factors informing provision demand and capacity, including the fact that needs categorisation is not mutually exclusive and that many young people will have needs that span needs types. The information provided is therefore indicative and is being used to guide the shaping of provision alongside other sources of intelligence from families and professionals in the SEND field.

Having considered the available data, the following areas of need have been identified for specific attention given the forecast percentage increases and volumes within in the context of provision planning.

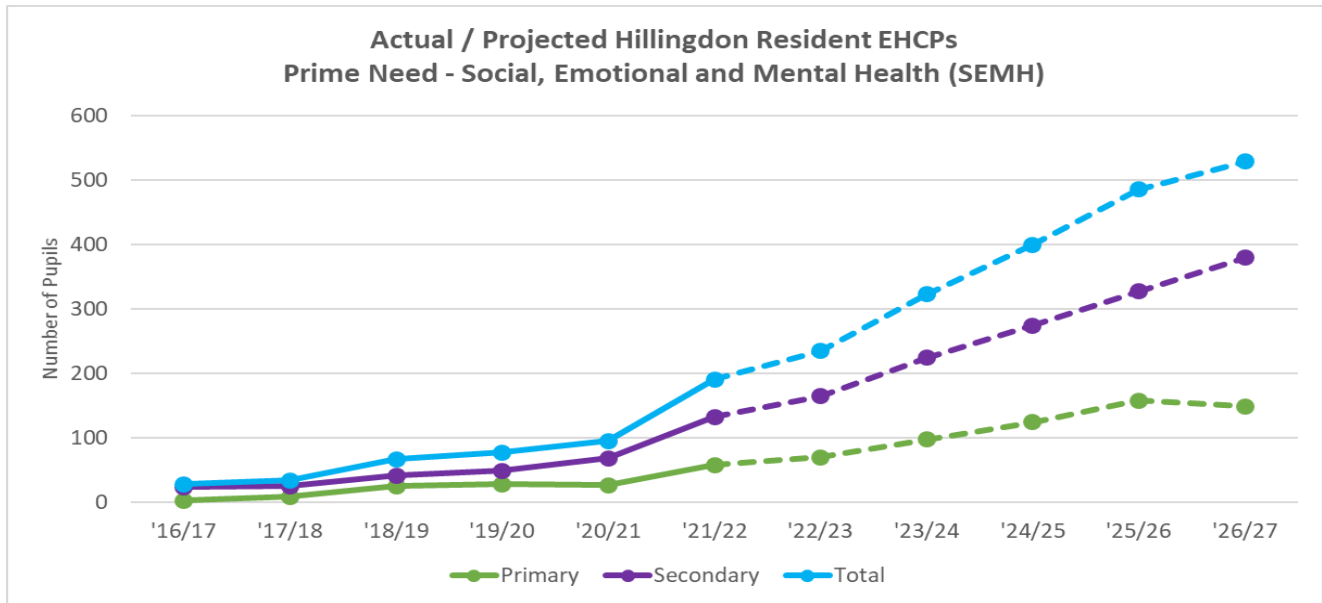
Autistic Spectrum Disorder (ASD)



Source: SEND Internal Projections, 20/09/2022

Data indicates that there is increasing ASD need and the associated demand for provision. This is consistent with the experiences of both settings and families. It should also be noted that there is a correlations between this area of need and the associated social, emotional and mental health need category.

Social, Emotional and Mental Health (SEMH)

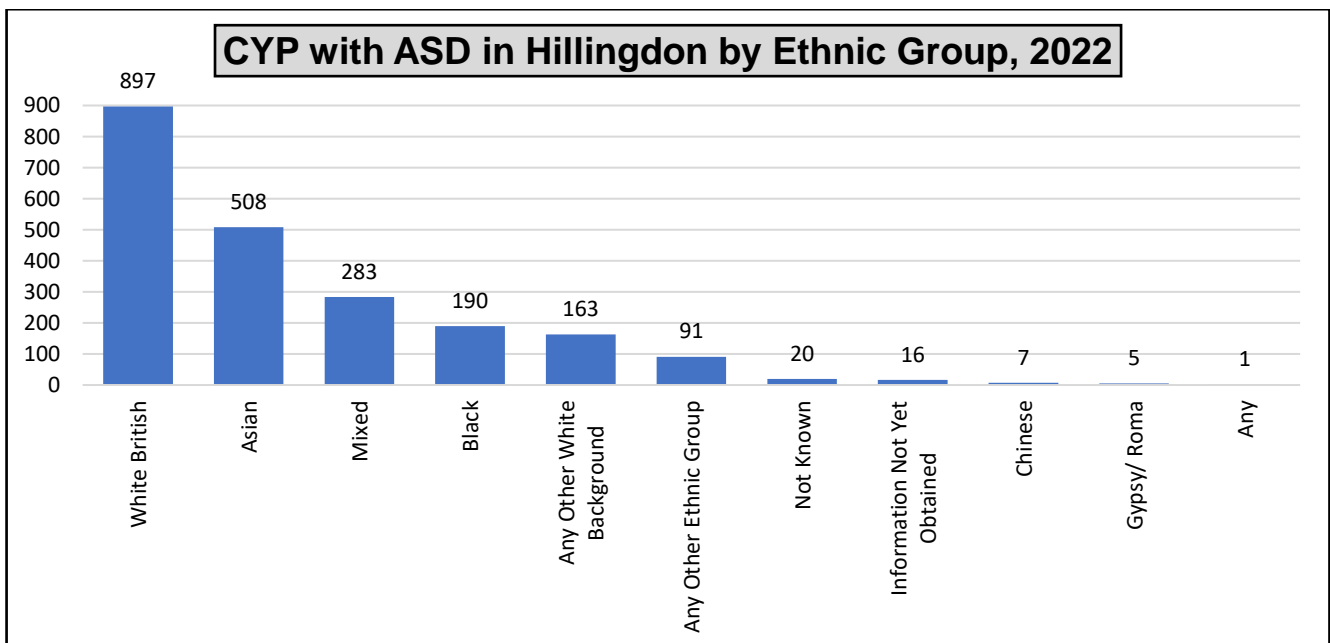


Source: SEND Internal Projections, 20/09/2022

The significant forecasted increase in demand in this area is consistent with previous assessments and warrants specific attention in terms of provision planning and development. It is projected that there will be a 68% increase in this area between 2022 and 2024, with further increases over the rest of the forecast period.

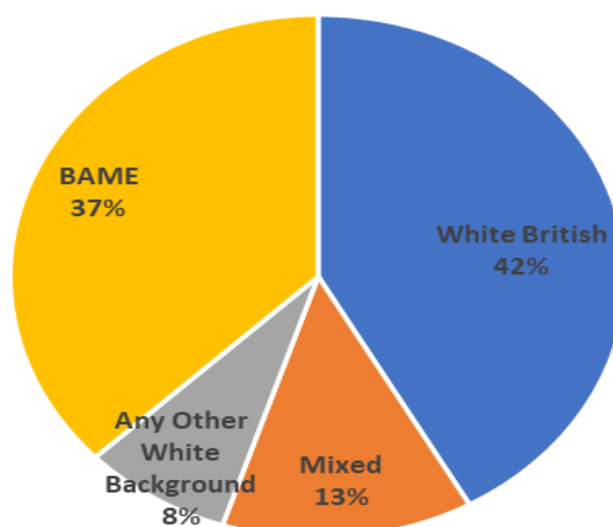
Autistic Children and Young People by Ethnicity

As illustrated in the charts below, the 2022 school census shows that the White British ethnic group has the most pupils with ASD in Hillingdon (897, 41.1%), whilst BAME groups make up 36.5% (Asian 508, Black 190, any other ethnic group 91, Chinese 7).



Source: School Spring Census, 2022

Ethnic Breakdown: Percentage of Hillingdon pupils with Autism, 2022



Source: School Spring Census, 2022

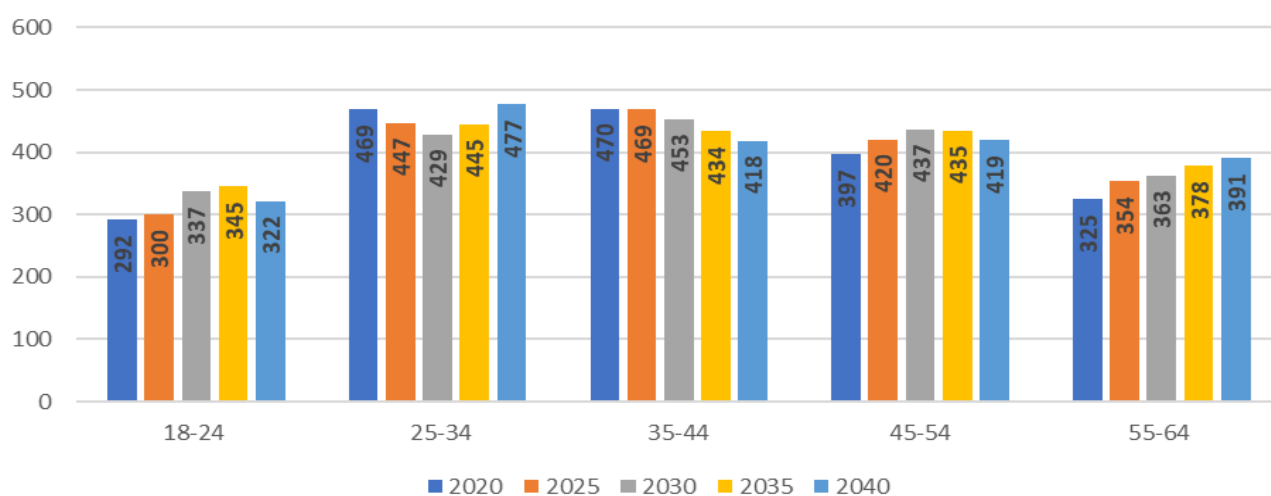
Children and Young People Public Health England Prevalence Data

PHE's Learning Disabilities profile for 2020 showed that at 28 per 100,000 people aged under 18 Hillingdon had the fourth highest proportion of autistic children who were known to services of the London boroughs. Hillingdon's position was significantly higher than both the London average of 20.4 and that for England of 18³⁰.

Adults

Population projections for adults aged 18 to 64 with ASD in Hillingdon using the estimated prevalence rates are shown in the chart below.

Autistic Residents in Hillingdon Aged 18 – 64 Projected to 2040

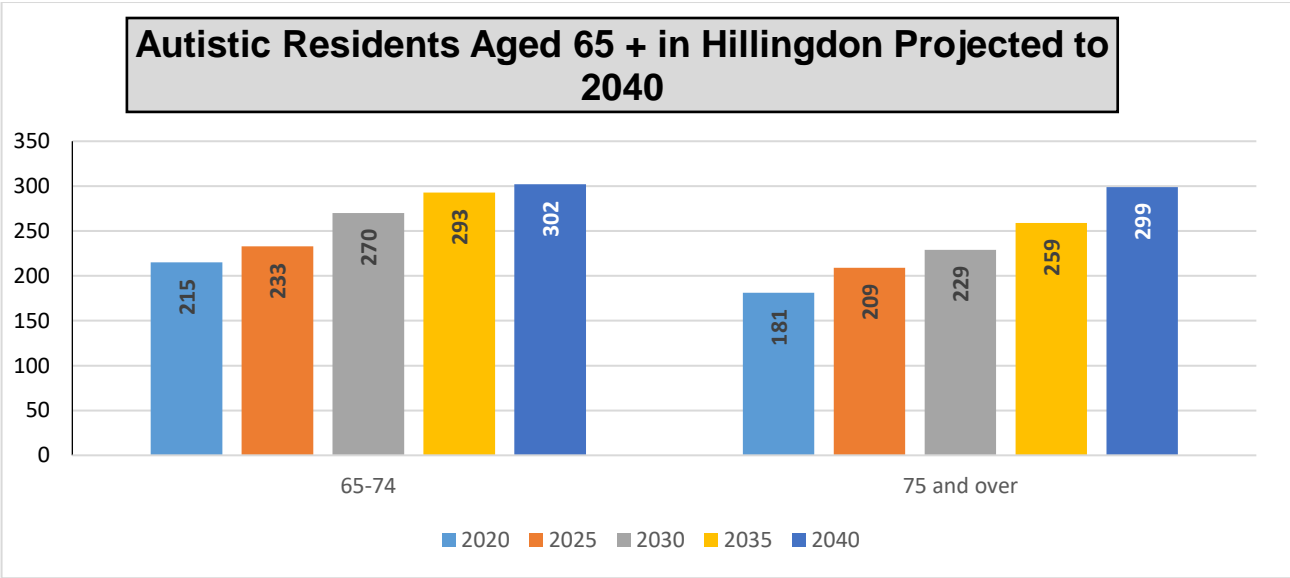


Source: PANSI.org.uk. (2021). Autism Spectrum Disorders: People aged 18-64 predicted to have Autism Spectrum Disorders, by age and gender, projected to 2040.

³⁰ [Learning Disability Profiles - OHID \(pne.org.uk\)](https://pne.org.uk/learning-disability-profiles/)

The chart above shows autism rates for ages 25-34 and 55-64 will continue to increase whilst the 35-44 year old group will decrease over the time period up to 2040. Overall, there are predicted to be 1,953 adults between 18-64 with ASD in Hillingdon in 2020, increasing to 1,991 people by 2025, and 2,026 people by 2040. The ASD projections in the chart above are based on *Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007*, which was published by the Health and Social Care Information Centre in September 2009.

There is a lower number of older people identified with ASD, but this is set to increase possibly because of more recent awareness and improvements in diagnosis. Population projections for adults over the age of 65 with ASD in Hillingdon using the estimated prevalence rates are shown in the chart below. As previously stated, an issue for older people is that symptoms of autism are often mistaken for other conditions more closely associated with old age.

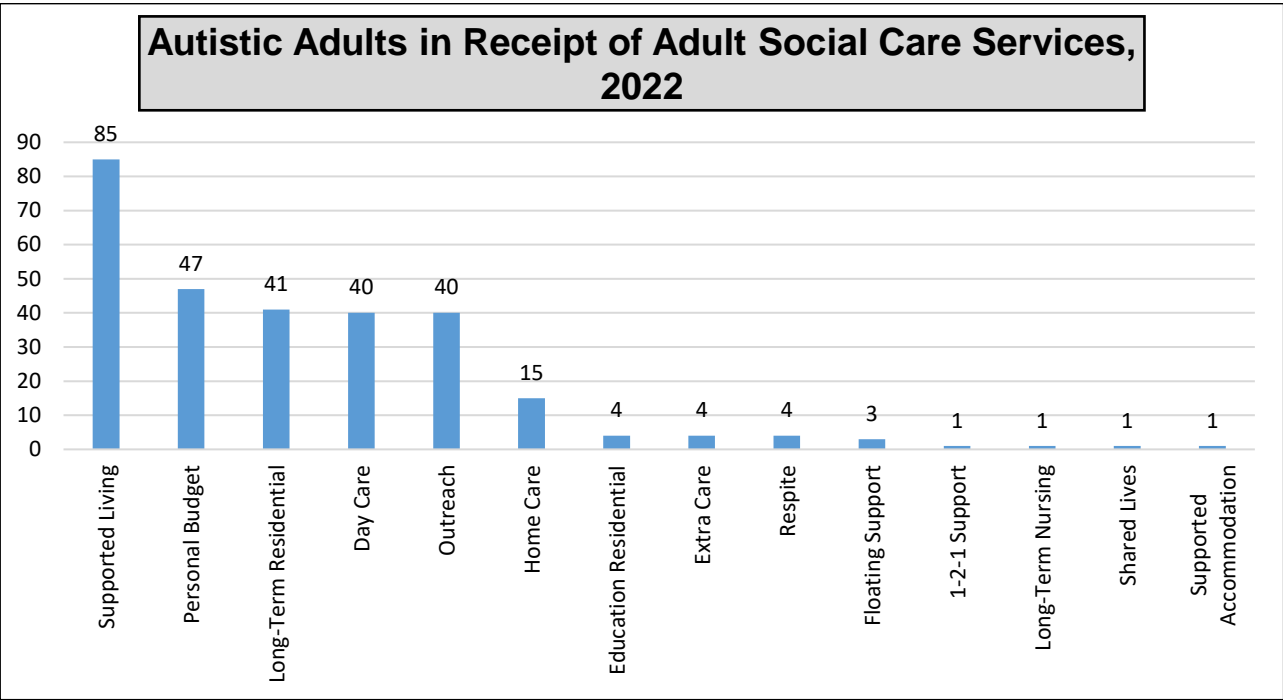


Source: POPPI.org.uk (2021). People aged 65 and over predicted to have autistic spectrum disorders.

The chart above shows 75+ age group has lower predictions than the 65-74 age group and is set to increase to have 299 people with ASD in Hillingdon by 2040.

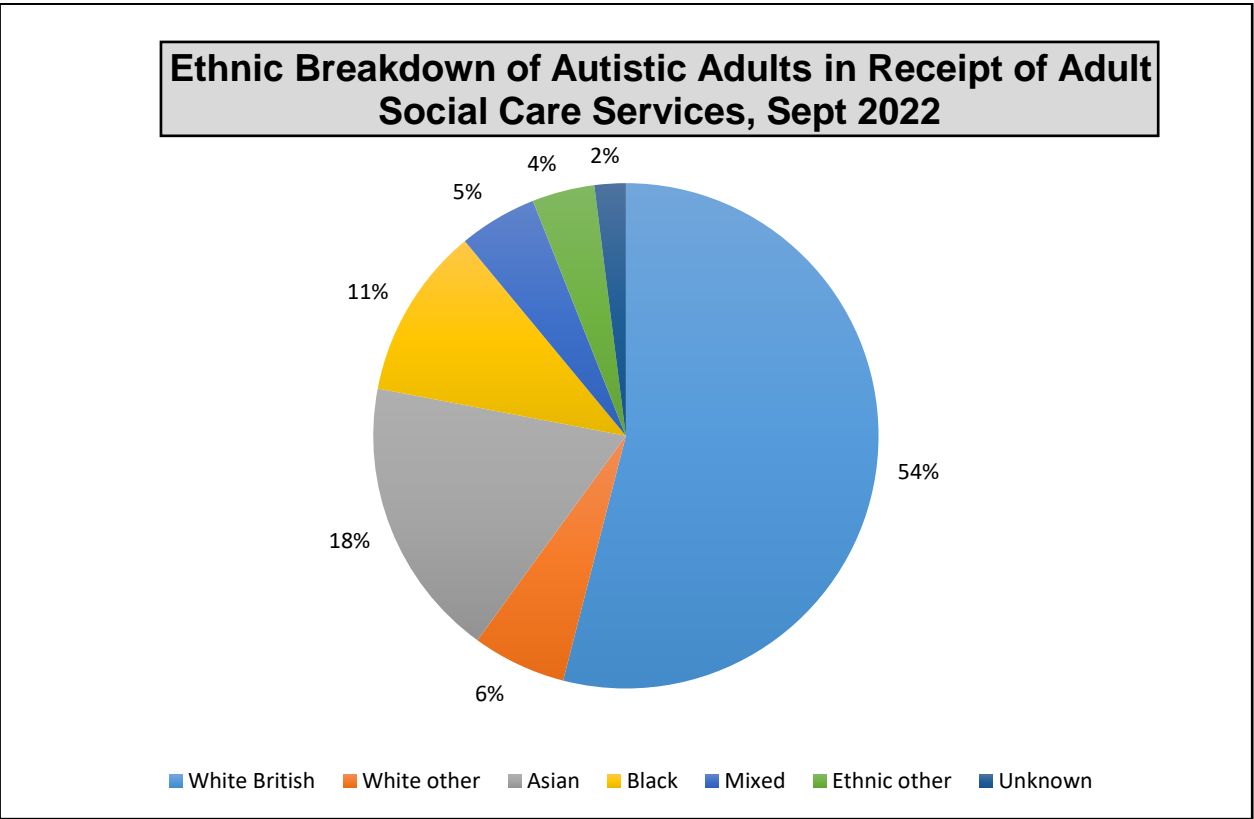
Autistic Adults Supported by Adult Social Care

As of 30th September 2022, there were 287 autistic adults who were receiving support from the Council in meeting their assessed social care needs following an assessment under the Care Act, 2014.



Source: Adult Social Care IAS system, Sept 2022

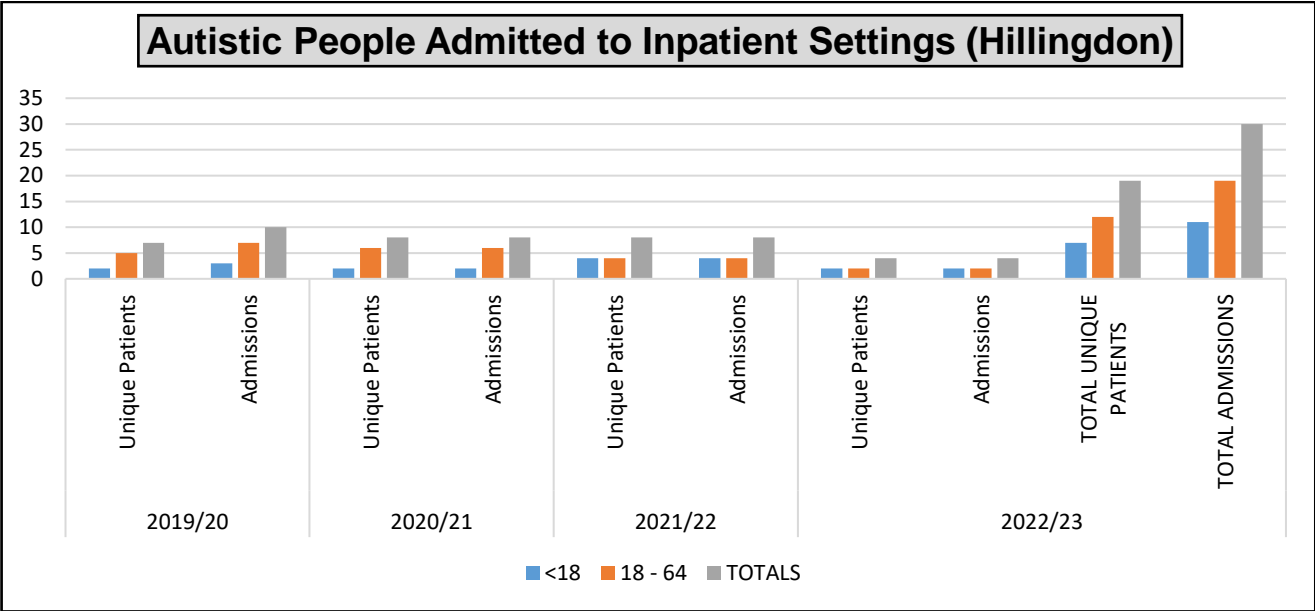
The chart below shows that in September 2022 54% (155) of autistic adults in receipt of Adult Social Care services identified as being White British, 18% (52) identified as being Asian, 11% (33) as Black, 6% (17) as White other, 5% (15) as mixed race, 4% (13) as another ethnic group and 2% (2) who did not disclose.



Source: Adult Social Care IAS system, Sept 2022

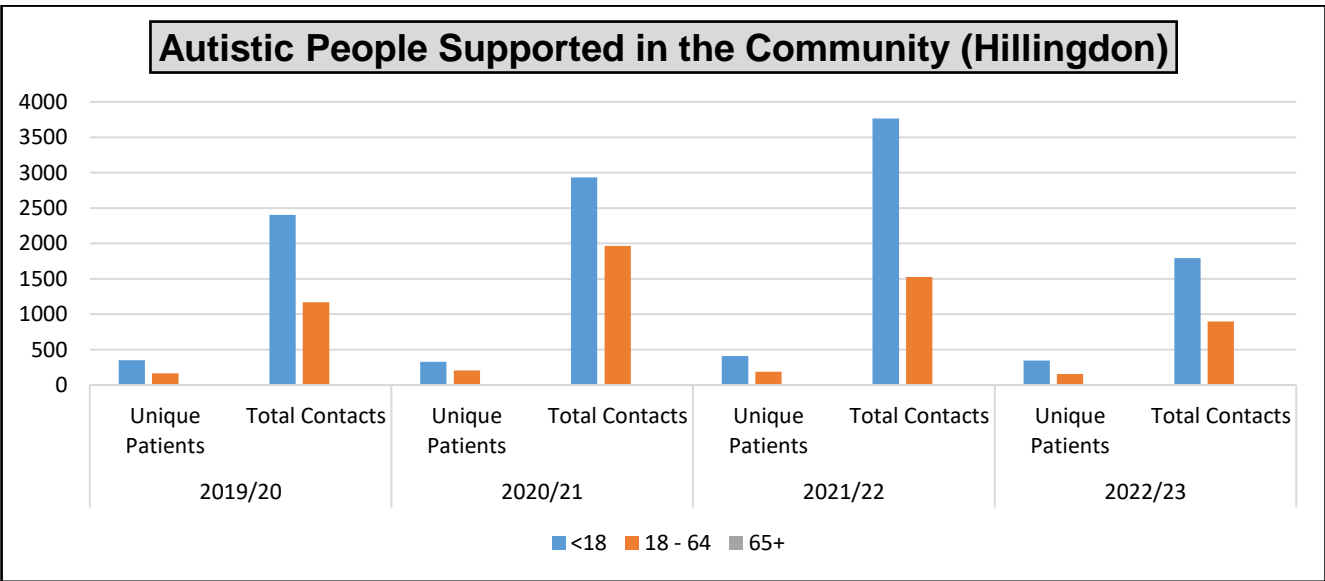
Autistic People Supported by CNWL

The chart below shows that between 2019/20 and 2022/23 (up to September 2022) there have been a total of 19 different autistic people admitted to inpatient settings and a total of 30 admissions. 63% (12) of the unique patients were people aged between 18 and 64, who also accounted for 63% (19) of admissions. Numbers have broadly remained the same during this period.



Source: CNWL Dec 2022

The chart below shows that between 2019/20 and 2022/23 (up to September 2022) there have been a total of 1,016 autistic people supported in the community and nearly 70% (710) were of people aged under 18. During the review period there were 16,464 separate contacts and 66% of these were for people aged under 18, for whom each year has seen an increase in the number of contacts. Of the people supported during the review period only two were people aged 65 and above, who accounted for a total of 12 contacts. This suggests that autism in older people is not being recognised or is hidden by other conditions.



Source: CNWL Dec 2022

Feedback from Autistic People

Consultation by North West London Clinical Commissioning Group in 2021 with experts by experience identified the following key areas where improvements were required to support autistic people:

- Meaningful co-production with autistic people as equal partners in training and service design.
- Reducing waiting times for diagnosis with support whilst people wait.
- Adaptations to the autism assessment process (including use of language) so that it is a more positive experience.
- Provision of person-centred post diagnostic support – a combination of face to face and remote.
- Developing autism aware communities.
- Using autism flags to identify autistic patients so that reasonable adjustments can be made.
- Developing autism expertise in mental health services.
- Improved access to GPs.
- Access to practical and peer-led support.
- Adapting the current Talking Therapies (also known as Improving Access to Talking Therapies or IAPT) model to meet the needs of many autistic people.
- Shifting to service provision based on needs so that autism does not become a diagnosis of exclusion.

HACS undertook consultation about post-diagnostic support in 2022 and this identified six key areas of concern that are listed below in order of priority to consultees:

- Development of a peer support programme
- Social relationship building opportunities
- Employment support
- Clinical support
- Benefit support
- Independence and life skills

4. Supporting Autistic People: Current Service Provision in Hillingdon

Specialist Support

There are two specialist third sector organisations in Hillingdon that provide support to autistic people of all ages. These are Hillingdon Autistic Care and Support (HACS) and Centre for Attention Deficit Hyperactivity Disorder and Autism Support (CAAS).

About HACS: HACS is a registered charity that was founded in 1997 by a group of parents and carers in Hillingdon with an autistic family member and is now supporting over 1,100 autistic people and their families. Their services include family support, children and young people's services, training and events, skills and employment support and support for adults

About CAAS: CAAS is a registered charity that provides services for parents and carers, young people aged 11 to 25 and adults aged 25 and above.

Diagnosis and Assessment of Needs

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. As of the 13th February 2023 there were 968 children and young people awaiting an autism assessment with an average expected waiting time of 18 months for a diagnosis. All children are seen within 18 weeks for an initial assessment.

Autistic adults who have a learning disability would have an autism assessment undertaken by CNWL's Specialist Learning Disability and Autism Team. Autistic adults who do not have a co-occurring disability would need to approach their GP for referral to a specialist assessor. As of the 1st February 2023 there were 115 adults awaiting an autism assessment with an average expected waiting time of 18 months for a diagnosis.

Care Act Assessment

Anyone can request an assessment of need under the Care Act, 2014. A Care Act assessment would be undertaken by the Council to identify whether the person being assessed met the National Eligibility Criteria for Adult Social Care, for which confirmation of an autism diagnosis would be an important factor. Anyone with assessed social care needs would then undergo a financial assessment that helps determine how the cost of meeting this need would be met, i.e., by the Council, jointly by the Council and the person being assessed or entirely by the person being assessed.

Mental Health Act Assessment

Assessments under the Mental Health Act, 1983, are undertaken by Approved Mental Health Professionals (AMHPs) employed either by the Council or the community mental health provider, CNWL. AMHPs have a professional background in social work, occupational therapy, nursing or clinical psychology and have been approved by the Council to carry out duties under the Mental Health Act. They are responsible for coordinating a Mental Health Act assessment.

Supported Further and Higher Education

Both HACS and the CAAS provide support to autistic young people without a co-occurring learning disability to access further education.

There is also independent living and life skills provision for autistic adults at the Options West London Community College based in Hayes. Places there are purchased by the Council in accordance with Education, Health and Care Plans. Timetables include sessions such as cookery, social skills, vocational skills and personal hygiene. The College seeks to equip students with a skill set to lead as independent a life as possible. Students also have the option of selecting academic study into their timetable and are able to undertake qualifications such as GCSEs and ASDAN.

There is no other provision in Hillingdon to support autistic people who do not have a co-occurring learning disability aged 20 and above.

Supported Employment

Hillingdon Autistic Care & Support (HACS) run an employability programme supporting autistic people from age 16 into employment. The HACS Skills and Employment Service intends to equip autistic people with a variety of skills including social interaction development through their participation in supported work placements, enhanced wellbeing through increased confidence and increased general employability skills.

Employment support is also available through the Central and North West London Foundation Trust (CNWL) for autistic people with a co-occurring learning disability and/or severe and enduring mental health needs. There is no specific service available to support autistic people who do not have a co-occurring learning disability and no other diagnosed mental health needs.

Supported Employment Forum has been established by the Council to promote employment opportunities, information sharing, and looking at ways for organisations to improve their approach in supporting autistic people into employment. Representation includes colleges, training providers, internship providers, DWP, employability providers, Parent Carer Forum, Careers Hub and the voluntary sector.

Three year funding to 2026 has been secured from the Department of Work and Pensions as part of the Internships Work Initiative that is intended to support people with learning disabilities and autistic people into employment.

Advocacy

As autistic people have difficulties in communication and in articulating their needs, access to advocacy services is essential. Hillingdon Autistic Care and Support Service (HACS) provides advocacy at education, health and social care meetings through its Family Support Service. The Council also has a contract with POhWER to provide advocacy where there are discussions about how it is discharging its responsibilities under the 2014 Care Act.

Housing

Based on national studies, it is thought that at least 40% of autistic people without a co-occurring learning disability are living with their parents. When linked with the findings that 60% of parents, carers or siblings do not consider the autistic people without a co-occurring

learning disability they are caring for could live independently, this indicates a need for supported housing.

Supported Accommodation

The Council has developed a range of supported living schemes over the last ten years, including extra care for older residents. The level of support within these schemes ranges from 24-hour on-site care and support to onsite support during office hours.

There is also support available in the wider community through a floating support service.

Brokerage and Personal Budgets Support

The Council has an in-house brokerage team to support people eligible for assistance with meeting their assessed social care. Support to enable eligible service users to self-manage their personal budgets, including through the route of Direct Payments, is also available.

Social Integration

It is recognised that the issues of social isolation and loneliness faced by some autistic people may have become more challenging during the Covid-19 pandemic. There are a range of services provided by the third sector to enable autistic people, including people without a co-occurring learning disability, to establish and maintain relationships with a range of people. Examples of these services are shown here.

Examples of Third Sector Services Supporting Social Integration *Autistic Children and Young People*

HACS provide social activities for children and young people them to enjoy whilst developing skills and making new friends. Our Short Breaks offer includes:

- Youth clubs for 10 – 25 years
- Saturday Clubs for 7 – 25 years
- Holiday Play schemes for 7 – 25 years
- Flexible individual support packages for complex needs

They also offer a variety of personal development programmes to help young people understand their diagnosis, build their confidence, and help them become more independent:

- Think Safe Be Safe – a social safety curriculum
- Duke of Edinburgh Award
- Girls Group –Occupational Therapy programme for 14 years +
- SocialWise – Social communication programme for 10-16 years

Attention Hillingdon supports the development of attention and listening skills and promotes the development of social communication skills and is currently running in nurseries, playgroups and children's centres within the borough. The intervention supports the development of attention and listening skills and promotes the development of social communication skills.

Friends of EarlyBird is a monthly support group run by parents for other parents. It runs on the third Friday of the month at Colham Manor Children's Centre, Violet Avenue, Hillingdon, UB8 3PT. For further information call 01895 250211. Children are welcome to come along and access the play facilities including a sensory room.

Supporting Autism is a support group for parents whose child is either waiting for or has a diagnosis of autism. The group is run by a parent and experienced staff at Oak Farm Children's Centre.

Examples of Third Sector Services Supporting Social Integration

Autistic Adults

There is a range of services provided for adults by the Centre for Attention Deficit Hyperactivity Disorder and Autism Support and these include:

- **CAAS North West London Project** – This provides information, advice and support to autistic young people and adults with the aim of improving quality of life and developing autism aware communities. They offer:
 - One to one individual support
 - Monthly planning for adulthood workshops
 - Monthly partner, parent & supporters online drop-in support group
 - Monthly Autism Connect sessions for professionals
 - Understanding Autism training for professionals
- **Therapeutic and Social Group** - This group is for adults with a diagnosis, or suspected diagnosis of autism and meets on the third Tuesday of the month from 7.00pm till 9.00pm. A therapeutic discussion group will take place at our Centre which will allow a space where individuals can discuss any issues in their lives, their worries and anxieties in a safe, non-judgmental environment.
- **Younger Therapeutic and Social Group** - This group is for younger adults with a diagnosis, or suspected diagnosis, of autism aged 18-25 years old. The group meets on the last Monday of the month in the evening.
- **Women's Forum** - This group is an open forum for women who have a diagnosis of autism, or who think they may be on the autism spectrum. The group is held on the first Tuesday of each month from 7.00pm till 9.00pm.
- **Creative writing for adults on the autism spectrum** - Creative writing runs every 4-6 weeks and is a safe space to explore writing in a non-judgmental and supportive setting.
- **Book Group for Adults on the autism spectrum** – The book group runs every 4-6 weeks. In the Book group, we discuss a book chosen by one of the group. The resulting conversations are wide-ranging and stimulating.
- **Adult ADHD Group** - This group is for adults with a diagnosis, or suspected diagnosis of ADHD. The group meets twice a month for a daytime and evening session.
- **Adult ADHD Strategy Group** - This 10-week group will run twice per year and focuses on funding and discussing ways to:
 - Better manage the difficulties associated with Adult ADHD/ADD.
 - Use and harness the strengths associated with Adult ADHD/ADD.

The HACS Autism Hub provides personalised support, accessible advice and social activities for adults living in Hillingdon, to support adults to understand their needs and look after their well-being. They offer:

- One to one coaching sessions
- Peer learning programme to learn more about autism and related areas
- Monthly drop-in sessions for advice and practical issues
- Regular social activities

Access to psychological therapies, in particular Cognitive Behaviour Therapy, has been shown to be effective. The Talking Therapies Service is delivered by CNWL and people can self-refer into the service.

Family/Carer Support

The Hillingdon Carers Partnership (HCP) offers support and advice to carers as well as access to short break opportunities.

For parents of autistic children and young people the HACS' Family Support Service also offers:

- Drop-in Autism Surgeries
- Parent Coffee Mornings
- Information helpline
- One-to-one appointments

5. Analysis and Gaps

Research projects identified earlier in this document suggest an overall prevalence of autism in the general population of 1.76%. The 2021 census showed that in March 2021 Hillingdon had a population of approximately 305,900 people. If the prevalence rate was applied to the general population number this would suggest that there are 5,384 autistic people in Hillingdon.

Forecasted data indicates an increasing population of autistic people. The resource implications of supporting the health and wellbeing of the increasing numbers of autistic children and young people as they progress to adulthood will need to be recognised and the increased demand on services planned for by Hillingdon's statutory agencies.

Research projects suggest an autism prevalence amongst BAME communities of 2.11%. The 2021 census shows that in March 2021 51.8% of Hillingdon's population identified themselves as being from BAME communities.³¹ Applying the prevalence rate would suggest that there could be 3,343 autistic people from BAME communities in Hillingdon.

Data concerning people with protected characteristics, i.e., women and girls, people from BAME communities and older people, is lacking in Hillingdon as in many places, and this makes it difficult to draw any conclusions about the extent to which there are autistic people who are not receiving support and the potential for crisis situations to develop in the future that will be more resource intensive for statutory agencies.

Responsibilities for identifying and addressing needs sits with many different organisations who all collect data to address their specific requirements. What is lacking is the coordination of this data so that it is possible to obtain of place-based understanding of need and how it is being met.

Feedback from autistic people has identified gaps in both pre and post diagnostic support. It has also identified how these gaps can be addressed.

³¹ [How life has changed in Hillingdon: Census 2021 \(ons.gov.uk\)](https://ons.gov.uk)

6. Recommendations

The key recommendations from this assessment are:

1. Health and care partners develop an all-age autism strategy to establish an agreed vision for supporting the health and wellbeing of autistic people in Hillingdon and identifying how it will be delivered over an agreed timescale.
2. Data in this assessment should be kept under review and updated.
3. Partners should 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. Data recording should specifically highlight ethnicity, sex and age of people being referred for and accessing services, including referrals for diagnoses.
4. To develop a greater understanding of the extent to which the needs of autistic people are being met by current service provision and how service provision can be developed to effectively address future demand within a challenging financial environment.
5. That partners are progressive in engaging with autistic residents and their carers, and that they are actively involved in designing services that best support them.