



Merton Autism Profile December 2018

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Merton Autism Profile 2018

Introduction

Autism is the name for a range of similar conditions, including Asperger syndrome, that affect a person's social interaction, communication, interests and behaviour. It affects how a person makes sense of the world around them and lasts throughout a person's life.

Autism is a spectrum of different needs and characteristics, which means all people with autism are on a different point of the spectrum and affected in different ways. Some people with autism will have good language and communication skills and will be able to live independently, whilst others may have very limited language skills and will require specialist support throughout their lives.

Aim of profile

This profile looks at the available data on autism in the London Borough of Merton and summarises what is happening locally to improve the lives of people with autism. It links to the London Borough of Merton and Merton NHS CCG's Autism Strategy and Action Plan for 2018-2023, which can be found at <https://www.merton.gov.uk/strategies>.

The Merton Autism Strategy sets out local ambitions for Merton to be an autism-friendly borough in which people with autism are able to live fulfilling and rewarding lives within a society that accepts and understand them and reach their full potential at all stages of their lives. The strategy for the next five years which takes a whole life course approach, encompassing children, young people and adults with autism and taking into consideration the needs of families and carers

Summary of key facts

- Based on population estimates, there were 541 children and young people (CYP) aged 0-25 with autism in Merton in 2017; however, local data indicate actual numbers might be higher.
- In 2017, there were 407 CYP who had an Education Health and Care Plan (EHCP) with autism recorded as their primary need.
- 85% of Merton CYP with autism recorded as their primary need on an EHCP were male.
- Around half of Merton CYP with autism recorded as their primary need on an EHCP were recorded as being from a white ethnic group, black or black British represented the second largest group at 19%
- Between 2013 and 2017 the number of CYP with autism recorded as their primary need rose by roughly 60% from 255 to 407 individuals.
- In 2017, approximately 40% of Merton CYP with an EHCP and autism attended a mainstream school.
- Based on population estimates, there were 1,202 Merton adults (aged 16+) with autism in 2017.
- In 2017, 178 adults (aged 16+) with a diagnosis of autism were receiving adult social care and support.
- There are gaps in the data available on people with autism and further work is needed to accurately evaluate the needs of the autistic population in Merton.

Policy Context

The Autism Act 2009 was created in response to evidence that many people with autism are excluded, both socially and economically. This act required the Government to create a national Autism Strategy: Fulfilling and Rewarding Lives, the strategy for adults with autism in England, which was published in 2010.

An updated strategy, 'Think Autism' was published in 2014 reflecting progress made and changes in the organisation of public services. Statutory guidance from the Department of Health was then produced in 2015 to assist local authorities and NHS agencies turn the strategy into action.

Local Picture

Prevalence

We do not have data on the number of Merton residents with autism, either diagnosed or undiagnosed. Instead, we have to use prevalence data based on national estimates and then applied to our local population.

The most recent prevalence estimates for adults in England come from the combined Adult Psychiatric Morbidity Surveys (APMS) 2007 and 2014. This research suggested around 0.8% of adults (1.5% of men and 0.2% of women) have autism (6). Since autism is a life-long condition, APMS estimates may be applied to all populations.

Based on APMS, in 2017 there were an estimated:

- 541 children and young people aged 0 to 25 with autism in Merton
- 1202 adults (aged 16+) with autism resident in Merton.

As the population grows, the number is projected to rise, increasing by 14% to reach approximately 1,570 adults in 2030. This implies there will be an associated increase in need for care and support for adults with autism in Merton over time.

Gender and Ethnicity

Similar to the national picture, there is a difference in prevalence between males and females in Merton; in 2017 85% of CYP recorded with autism as a primary need in Merton were male. It has been suggested that this difference may in part represent under-diagnosis in females.

In 2017, among Merton's CYP with an EHCP and a primary need of autism ethnicity was recorded for 84% and of these CYP:

- Approximately 50% were in a white ethnic group.
- CYP of Black or Black British origin represented the second largest group, making up 19%.
- 14% were Asian or Asian British
- Just over 10% was of mixed ethnicity
- 3% were of other ethnic origins

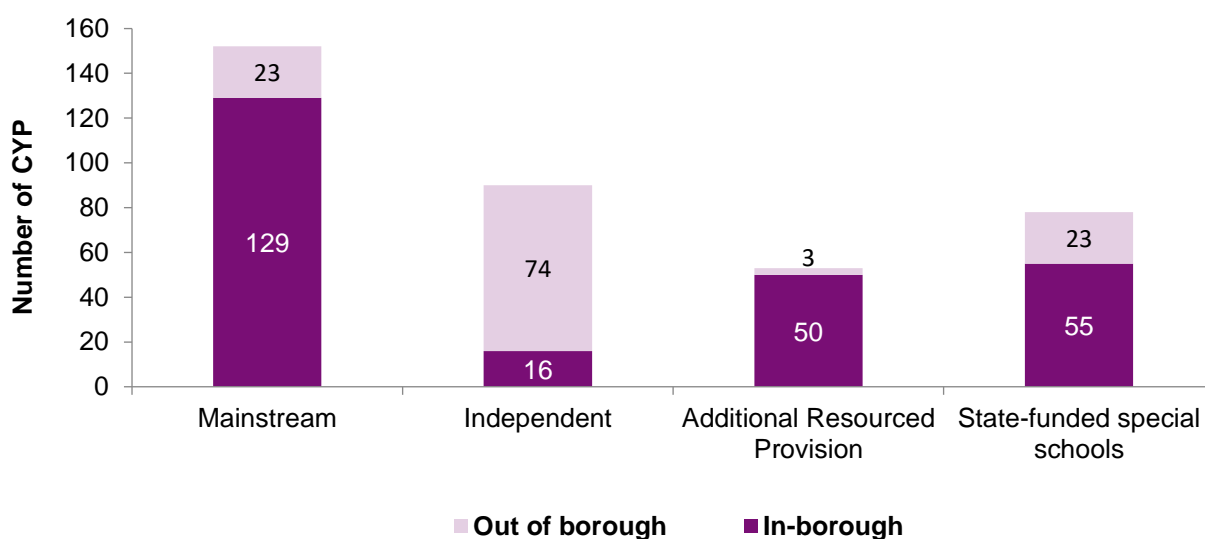
This is comparable to school ethnicity in Merton indicating that ethnic groups are represented equally in terms of autism diagnoses.

Education

Between 2013 and 2017, the number of CYP with an EHCP and autism as their primary need rose by roughly 60%. Of the estimated 541 CYP in Merton with autism in January 2017, 407 had an EHCP with autism recorded as the primary need. This leaves approximately 134 CYP who do not have an EHCP or do not have autism recorded as a primary need.

Of those with autism recorded as a primary need, 40% attend a mainstream school. Roughly equal proportions attend state-maintained special schools and independent schools, with the lowest proportion attending additional resourced provision (ARP) bases (see chart 1). ARP's are schools which have additional specialist provision for children with autism.

Chart 1: Number of CYP with ASD placed in- and out-of borough , by educational establishment, Merton 2017



Health

Data on the assessment and diagnosis of people with autism by health services is not published routinely. Data for adults is not currently available. Data for children aged 0-4 years who are assessed by Community Paediatrics services is not currently available.

The data presented here on CYP aged 5-17 years reflects the work undertaken by the Mental Health Trust as part of the Waiting Time initiative to clear a backlog of children waiting for diagnostic assessments across South West London. This includes children with autism, Attention deficit hyperactivity disorder (ADHD), comorbid neurodevelopmental conditions, and other conditions.

In 2017/2018 there were 1,906 referrals to Child and Adolescent Mental Health Service (CAMHS) single point of access. Of these, 149 (7.82%) listed ASD as the presenting problem, and 95 (4.98%) listed ASD/ADHD as the presenting problem. It is estimated that there is a 90% conversion rate from autism assessment to diagnosis.

CYP 5-17 years: Top 10 Presenting Problems YTD	Referrals 17/18	% 17/18
Behavioural	329	17.26%
Anxiety	227	11.91%
Emotional Wellbeing	202	10.60%
ADHD Assessment	162	8.50%
Low mood	162	8.50%
ASD Assessment	149	7.82%
ADHD / ASD Assessment	95	4.98%
ADHD	62	3.25%
Suicidal Ideation	56	2.94%
Self Harm	53	2.78%
Other	409	21.46%
Total	1906	100.00%

Source: Merton SPA Q4 report. St London and St Georges mental health NHS Trust

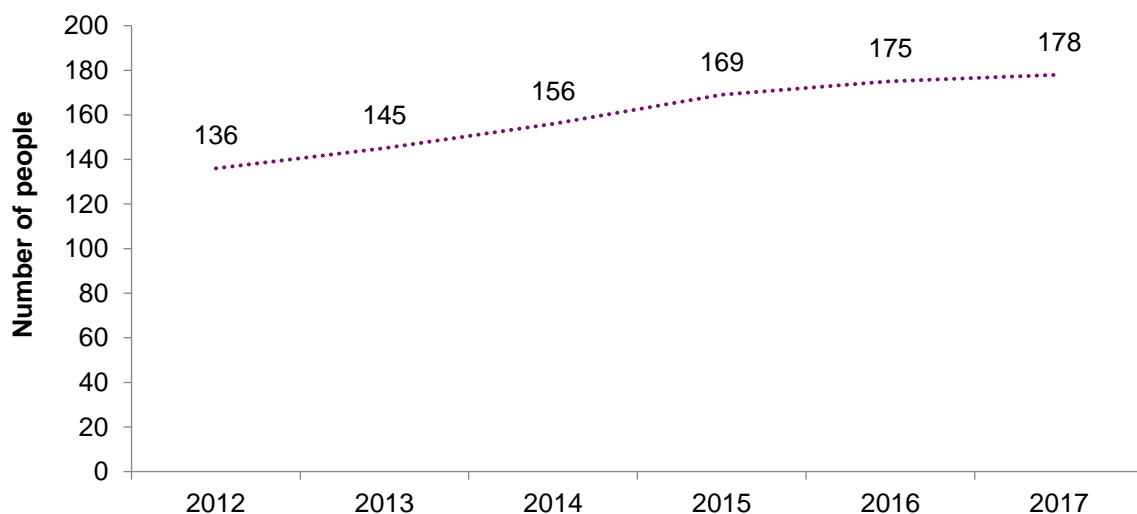
It is recognised that there are gaps in the data available and in order to fully evaluate Merton's health services for people with autism it is recommended to collect and independently validate routine data on:

- Numbers referred for ASD assessment (CYP and adults)
- Waiting times for ASD assessment (CYP and adults)
- Conversion rate from referral to ASD diagnosis
- Co-morbidities recorded in those with a diagnosis of autism
- Presentations to A&E departments with issues related to autism

Adult Social Care

In 2017, 178 adults (aged 16+) in Merton with a diagnosis of autism were receiving adult social care and support. The number of adults with autism receiving adult social care has gradually increased year on year since 2012, as chart 2 depicts.

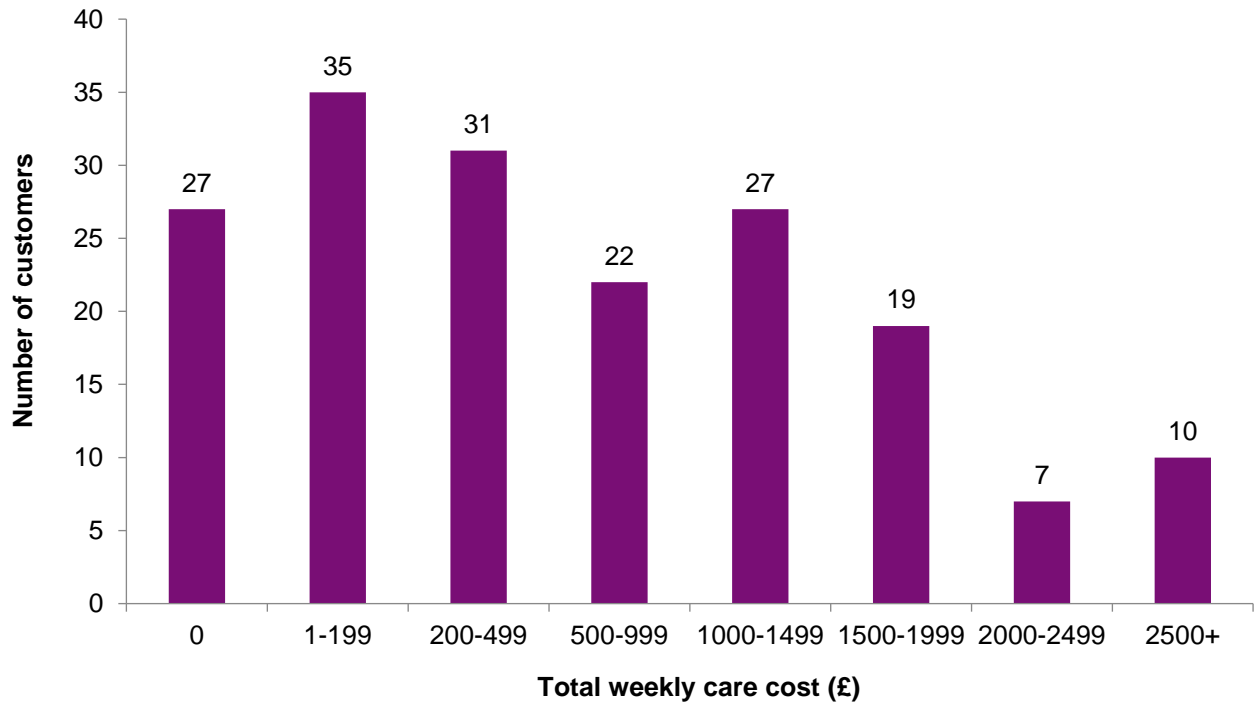
Chart 2: Number of adults with autism receiving adult social care



The number of care agreements in place ranged from one to nine per person, demonstrating varied levels of need among the group. Approximately 75% of service users were receiving at least one professional service, which may be support from social workers or health professionals. 30% were being supported in residential care, and around one quarter were receiving home care.

The majority of social care customers with autism receive relatively low cost care, but there are small numbers receiving high cost, more intensive support (see chart 3 below).

Chart 3: current adult social care customers with autism, by total weekly care cost (£), Jan 2017

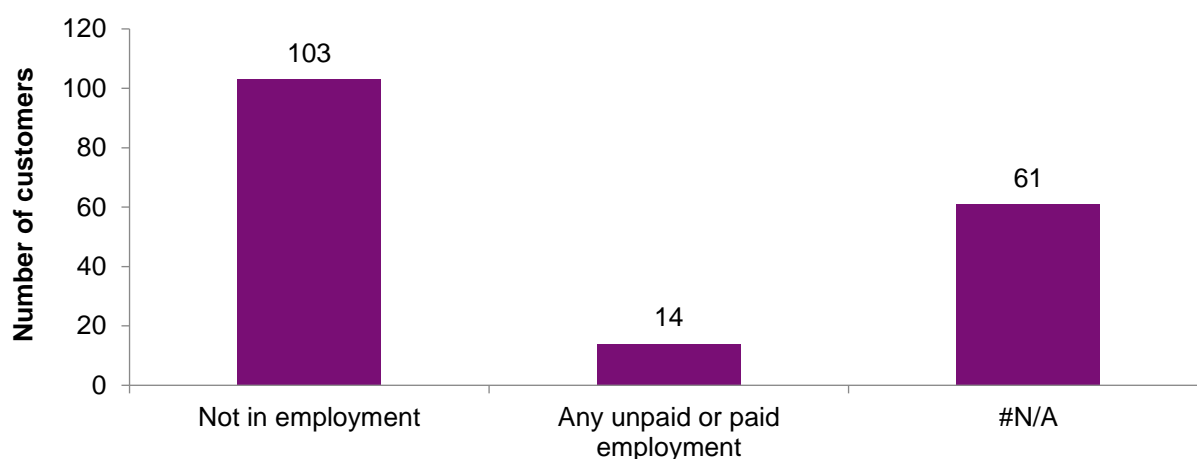


Employment

The National Autistic Society (NAS) estimates only 16% of autistic adults in the UK are in full-time paid employment, and only 32% are in some kind of paid work.

In Merton, the vast majority of adults with autism who are receiving social care support are not in employment (see chart 4). We do not know the overall rate of employment amongst people with autism in Merton.

Chart 4: current adult social care customers with autism, by employment status, Jan 2017



Merton Voice

As part of stakeholder engagement work in 2018, a survey was carried out to identify the issues that Merton residents feel should be addressed as a priority in order to improve the lives of people with autism in Merton. Focus groups were also undertaken with adults and young people with autism, parents and carers and professionals working with people with autism. In total 146 people were engaged in the process.

Key findings from the survey are listed below;

- the need for better multi-agency collaboration;
- the need to involve people with autism and families and carers better;
- the need for clearer support pathways and information;
- the need to increase staff awareness;
- the need to create appropriate environments that enable people with autism to participate socially;
- the need to strengthen training and employment opportunities and support;
- the need to recognise the needs of people with autism from Black and minority ethnic groups and the needs of girls and women with autism.

A full report detailing the feedback received during the Autism Strategy public engagement period can be accessed at:

<https://www2.merton.gov.uk/Autism%20Strategy%20Engagement%20report.pdf>

What works – Guidance and evidence

NICE guidelines

The NICE autism pathway brings together all National Institute for Health and Clinical Evidence (NICE) evidence, guidance, quality statements, and other information relating to health and care support for children, young people and adults with autism. It recommends the following:

- service organisation and delivery of care should be led by a multi-agency strategy group;

- care, assessment and support should be delivered by specialised children and young people and adult autism teams, which consist of professionals from a range of disciplines;
- partnership working for delivering high-quality and comprehensive local services and support.

NICE quality statements are concise, prioritised statements designed to drive measurable improvements. The NICE autism quality standard (QS51), comprises eight quality statements relevant to the care of CYP and adults with autism. The quality statements are not mandatory (required by law), but are designed to form the basis of local audit criteria to support continuous quality improvement, and should be measured using locally collected data. Table 1 details the quality statements.

<i>Table 1: NICE autism quality statements for CYP and adult autism services [QS51]</i>
Quality 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.
Quality statement 2: People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.
Quality statement 3: People with autism 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.
Quality statement 4: People with autism are offered a named keyworker to coordinate the care and support detailed in their personalised plan.
Quality statement 5: People with autism 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.
Quality statement 6: People with autism are not prescribed medication to address the core features of autism.
Quality statement 7: People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.
Quality statement 8: People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

Our local services

A comprehensive overview of services for people with autism in Merton is set out on pages 17-25 of Merton's Autism Strategy 2018-2023. This outlines services provided by health, education, social care and the voluntary sector for people with autism:

<https://www2.merton.gov.uk/health-social-care/publichealth/strategies.htm>

What are we doing?

Merton Local Authority and Merton NHS CCG and partners have developed and agreed a new Autism strategy for Merton for the next 5 years. The strategy encompasses children, young people and adults with autism and takes into consideration the needs of families and carers. Key actions to be delivered over the duration of the strategy include;

- Deliver a new programme of training for CYP workforce. This will include targeted training for Early Years workforce on recognising the signs of autism, including recognition in girls, to enable early intervention.
- Redesign local referral, assessment and support services to meet the needs of children and young people (and their parents or carers) who may need a diagnosis of autism.
- Promote autism champions in all education settings to raise awareness amongst staff, enable early identification of autism and ensure that staff provide appropriate support.
- Work with the voluntary sector to explore opportunities/resources available to improve opportunities for people with autism to participate socially. This could include increasing access to mainstream services, peer support and advocacy services, volunteering programmes, social prescribing etc.
- As part of the development of the CYP 0-19 assessment, diagnosis and support pathway, we will work with partners to identify resources to increase the availability of parenting programmes on offer in the borough-particularly for those with children over 8 years old.
- Develop an all-services, electronic information hub to provide a single place for information about local services and resources relevant to autism, including the local SEN offer.
- A Merton Autism Steering Group has been established to provide oversight and leadership for the delivery of the Merton Autism Action Plan.

Useful links

Merton Autism strategy 2018-2023: <https://www2.merton.gov.uk/health-social-care/publichealth/strategies.htm>

Merton Autism Strategy action plan 2018-2023 <https://www2.merton.gov.uk/health-social-care/publichealth/strategies.htm>

Merton Autism Strategy engagement report <https://www2.merton.gov.uk/health-social-care/publichealth/strategies.htm>

Merton SEND local offer [Local Offer | Merton All Services](#)

NICE guidelines autism [Autism | Guidance and guidelines | NICE](#)

'Think Autism': an update to the government adult autism strategy ['Think Autism': an update to the government adult autism strategy - GOV.UK](#)

National Autistic Society homepage [The National Autistic Society | - NAS](#)

Glossary

Additional Resourced Provision (ARP)	School which has been given extra funding to support children who have additional learning needs, including speech, language and communication difficulties.
Autism Spectrum Disorder (ASD); also known as Autism Spectrum Condition (ASC)	ASD is a developmental condition affecting how people interact, communicate and behave, as well as how people make sense of the world.
Attention Deficit Hyperactivity Disorder (ADHD)	A behavioural disorder that includes symptoms such as inattentiveness, hyperactivity and impulsiveness.
Child and Adolescent Mental Health Services (CAMHS)	CAMHS are the NHS services that assesses and treat young people with emotional, behavioural or mental health difficulties.
Education, Health and Care Plan (EHCP)	An education, health and care plan (EHCP) is for children and young people aged up to 25 who need additional special educational provision to meet their special educational needs than is from SEN support.
National Institute of Health and Care Excellence (NICE)	The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care.
Special Educational Need (SEN)	A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for them.