

JSNA 2017 Autistic spectrum disorders (All Age)

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1. Introduction

1.1. What is Autism?

Autism is a lifelong developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them. This JSNA chapter examines the needs of people of all ages who are affected by autism. When referring to 'people' within this document this is intended to include children, young people and adults.

The characteristics of autism vary from one person to another, but in order for a diagnosis to be made, a person will usually be assessed as having had persistent difficulties with social communication and social interaction and restricted and repetitive patterns of behaviours, activities or interests since early childhood, to the extent that these have an impact on everyday functioning.

Autism is sometimes referred to as autistic spectrum disorder (ASD) or autistic spectrum condition (ASC). The word 'spectrum' is used to describe autism because it defines a range of conditions including Asperger's syndrome and Pathological Demand Avoidance, which are described later in this chapter.

All people with autism share certain difficulties but being autistic will affect them in different ways. Some people with autism also have learning disabilities, mental health issues or other co-existing conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and dyspraxia. Therefore, people need different levels of support. Around half of people with autism also have an IQ of 70 or below (one of the key criteria for learning disabilities)¹. A meta-analysis of the prevalence of learning disabilities among children and young people with autism showed results ranging from 15% to 84% (median of 52.5%)². Autism is linked to poor mental and emotional health; anxiety disorders are very common amongst people with autism. According to the National Autistic Society, roughly 40% have symptoms of at least one anxiety disorder at any time, compared with up to 15% in the general population.

¹ National Institute for Health and Care Excellence (NICE) (2011). *Autism spectrum disorder in under 19s: recognition, referral and diagnosis*.

² Department of Health (2010). *The Estimated Prevalence of Autism among Adults with Learning Disabilities in England*.

1.2. What is Asperger's Syndrome?

Although Asperger's syndrome has recently been removed from the Diagnostic and Statistical Manual, 5th edition (DMS-5) as a distinct category, it is still a commonly used term. Asperger's syndrome is a lifelong developmental disability that affects how people perceive the world and interact with others. People with Asperger's syndrome are of average or above average intelligence. They do not usually have the learning disabilities that many people with autism have, but they may have specific learning difficulties. They have fewer problems with speech but may still have difficulties with understanding and processing language. As with any ASD, people with Asperger's Syndrome may also have specific learning difficulties such as dyslexia and dyspraxia.

1.3. What is Pathological Demand Avoidance?

Pathological Demand Avoidance (PDA) is now considered to be part of the autistic spectrum. People with PDA share difficulties with others on the autistic spectrum in social aspects of interaction, communication, and imagination. However, the central difficulty for people with PDA is the way they are driven to avoid demands and expectations due to their anxiety-based need to be in control.

1.4. How autism can impact on a person and their family

People with autism often face barriers when attempting to access ordinary services such as housing, employment, leisure, education and health. People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with. Accessing health services can be a particularly stressful experience for people on the autistic spectrum due to fear of the unexpected, sensory difficulties and communication issues.

People with autism are especially vulnerable to abuse. Only 16% of autistic adults in the UK are in full-time paid employment, and only 32% are in some kind of paid work³. As a consequence, many people with ASD are financially deprived and live at home with their families.

People with autism can be particularly vulnerable to social isolation. One in four adults with autism describe themselves as having no friends⁴. Compared to the general population in England, a higher proportion of adults with autism reported that they often feel lonely (41% v 11%)⁵.

³ The National Autistic Society (2016). *The autism employment gap: Too Much Information in the workplace*

⁴ The National Autistic Society (2012). *The way we are: autism in 2012*.

⁵ The Mental Health Foundation (2010). *The Lonely Society*.

Many people on the autistic spectrum experience sensory issues and may be over or under-sensitive to things like sights, sounds, smells, tastes and textures. These issues can affect a person's ability to tolerate health appointments, workplaces and public spaces. It can also have an impact on their experience of and relationship to food. An autistic person may only be able to eat a limited range of foods. Conversely, they may over-eat.

It is therefore important to increase awareness and understanding of autism amongst providers of universal services, employers and professionals working in the education, health, social care and criminal justice systems. This will enable them to make reasonable adjustments to their services and workplaces.

Without early diagnosis, intervention and support, adults with autism are at a higher risk of developing other needs such as eating disorders, obsessive compulsive disorders, phobias, self-harming, sexually inappropriate behaviour, risky and offending behaviour and substance misuse. According to research at least one in three adults with autism experience severe mental health difficulties due to a lack of support⁶. Common mental health difficulties experienced include depression, anxiety and obsessive compulsive disorder.

Getting a timely assessment and diagnosis may be helpful because it can:

- Help people with autism (and their families, partners, employers, colleagues, teachers and friends) to understand why they may experience certain difficulties and what they can do about them
- Allow people to access services and support appropriately

1.5. Interventions

Many people with autism do not want or need formal services but will need those around them, including employers and providers of universal services, to make reasonable adjustments and be accommodating to their needs.

There is no 'cure' for autism. However, there are a range of strategies, interventions and approaches which some people with autism may find to be helpful. Few of these have been evaluated on a long term basis. Some interventions are designed to address the core features of autism e.g. difficulties with social communication and interaction, and restricted, repetitive patterns of behaviour, interests, or activities. Other interventions are designed to address issues such as anxiety, aggression or self-injurious behaviour. A number of nationally recognised frameworks and tools have been developed which can be useful in understanding and responding to the needs of children, young people and adults with autism.

⁶ The National Autistic Society (2008). *I Exist: the message from adults with autism in England*

The needs of the individual will determine which intervention is appropriate and whether interventions would be more effectively delivered as a group-based or individually tailored programme. Most people with autism prefer a structured and predictable programme focused on their interests.

NICE guidance for the diagnosis and management of ASD in adults (updated 2016)⁷ promotes the use of a number of psychosocial interventions for the core symptoms of autism which typically include the use of modelling, behaviour rehearsal, feedback, discussion, decision making, explicit rules and suggested strategies for dealing with socially difficult situations. Other psychosocial interventions can focus on:

- Leisure activities for people who are socially isolated or have restricted social contact
- Life skills
- Anger management
- Decision making, problem solving and personal safety skills for people at risk of victimisation and abuse
- Individual supported employment programmes for people having difficulty maintaining or obtaining employment

For adults with autism and coexisting mental health needs, pharmacological and / or psychosocial interventions informed by existing NICE guidance for the specific disorder can be effective. Cognitive and behavioural interventions for adults with autism and coexisting common mental health needs can be helpful when the method of delivery is adapted to meet the needs of the person with autism. Recent research projects have reported positive changes from cognitive behavioural therapy for people with autism including reduced anxiety, depression and improved solutions for solving social problems.

Interventions and approaches exist which can be helpful for people with autism with coexisting learning disabilities who need support with communication, sensory integration and managing change. Examples include social stories, communication passports, visual supports, functional communication timetables, intensive interaction, sensory diets and family education and consultation.

People with autism and learning disabilities can sometimes present with behaviour that is challenging to manage. The causes of behaviour can be multifactorial, and can involve physical health conditions, mental health problems, communication,

⁷ National Institute for Health and Care Excellence (NICE): Autism spectrum disorder in adults: diagnosis and management 2012, updated August 2016

<https://www.nice.org.uk/guidance/cg142?unlid=5627139520166155426>

sensory integration and environmental factors. An assessment should take all these factors and triggers into account, and consider the risk of harm to the person and others, before an intervention strategy focusing on outcomes linked to quality of life is agreed.

NICE guidance for adults⁷ recommends the development of capable environments in which support strategies are linked with reduced occurrence of challenging behaviour. Some of the characteristics of capable environments include positive social interactions, support for communication, predictability and consistency, opportunities for choice and independence and acceptable physical environments.

People with autism and challenging behaviour should not be 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.

For children and young people, NICE guidance provides details of interventions that can help some of the core features of autism, symptoms, behaviours and challenges commonly associated with autism, and support that should be offered to families and carers⁸.

2. National Policy

Fulfilling and Rewarding Lives: the strategy for adults with autism in England (2010)⁹ set out the Government's overarching vision that:

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

The strategy sets out the key interventions that are needed to achieve this vision:

- Increasing awareness and understanding of autism among frontline professionals
- Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment
- Improving access for adults with autism to the specialist and mainstream services and support they need to live independently within the community
- Improving the transition process for young people approaching adulthood
- Helping adults with autism into work.

⁸ National Institute for Health and Care Excellence (NICE) (2013). *Autism spectrum disorder in under 19s: support and management*

⁹ Department of Health (2010). *Fulfilling and Rewarding Lives;; the strategy for adults with autism in England*

'Think Autism': an update to the government adult autism strategy (2014)¹⁰ reinforced the vision and built on the priorities in the original strategy, whilst bringing renewed emphasis on building autism aware communities that are more accessible to the needs of people with autism. 'Think Autism' sets 15 priority challenges for action to ensure people with autism:

- Are treated as an equal part of their communities
- Have access to the right support at the right time during their lifetime, including timely diagnosis and support for their families
- Have opportunities to learn, work and develop their skills and independence

Statutory guidance was published in 2015 to ensure the implementation of the adult autism strategy. This JSNA chapter considers how to apply the guidance to our local population.

2.1. Key national policies and legislation

Mental Capacity Act (2005) Code of Practice (2007)¹¹

Putting People First: a shared vision and commitment to the transformation of Adult Social Care (2007)¹²

The Autism Act (2009)¹³

Fulfilling and Rewarding Lives (2010)⁸

Transforming Care: A national response to Winterbourne View hospital (2012)¹⁴

'Think Autism': an update to the government adult autism strategy (2014)⁹

Children and Families Act (2014)¹⁵

Care Act (2014)¹⁶

Building the Right Support (2015)¹⁷

Future in Mind (2015)¹⁸

¹⁰ Department of Health (2014). *'Think Autism': an update to the government adult autism strategy*

¹¹ Department for Constitutional Affairs (2007). *Mental Capacity Act (2005) Code of Practice*

¹² HM Government (2007). *Putting People First: a shared vision and commitment to the transformation of Adult Social Care*

¹³ HM Government (2009). *The Autism Act*

¹⁴ Department of Health (2012). *Transforming Care: A national response to Winterbourne View hospital*

¹⁵ HM Government (2014). *Children and Families Act*

¹⁶ HM Government (2014). *Care Act*

¹⁷ HM Government (2015). *Building the Right Support*

¹⁸ NHS England (2015). *Future in Mind*

3. Level of need

Data about the number of people with autism is available from several different sources. The most robust data source for assessing the prevalence of ASD among children and young people is the Ealing School Census, which includes children and young people of school age in high, primary and special schools, children's centres and the pupil referral unit. However, among the adult population there is no system for recording ASD which gives full coverage of the population. The Department of Health have committed to working with NHS England and with the Royal College of General Practitioners (RCGP) to look at the feasibility of introducing a Read Code for Autism¹⁹. Until use of this recording system becomes common place among GPs, our information is based mostly on service usage across different organisations.

We know how many people with a) ASD and b) ASD plus a Learning Disability have received a service from London Borough of Ealing. For those who have serious and enduring mental health needs as well as ASD we know how many have had an assessment/treatment from an integrated mental health team. We also know how many people receive treatment for mental health needs and have both a Learning Disability and ASD. What we don't know is how many people are living with ASD but not accessing any services or treatments for their condition.

The following sub-sections present some of these data sources:

- Estimated national and local prevalence of ASD based on a national prevalence study
- Prevalence of ASD in school age children and young people as recorded by the Ealing School Census
- Recorded prevalence of ASD in people with Learning Disabilities (LD) who are known to London Borough of Ealing
- Number of adults with ASD and LD who also have treatment for mental health conditions and/or challenging behaviour
- Projections of the number of adults with ASD
- Number of people receiving an ASD assessment and/or treatment
- Recorded prevalence of ASD in people with serious mental health needs, treated in secondary mental health services

3.1. Estimated prevalence

The most recent prevalence study of autism in the UK was commissioned by the Department of Health and published by the NHS Information Centre (now NHS

¹⁹ <http://www.rcgp.org.uk/clinical-and-research/clinical-news/is-your-practice-computer-coding-autism-friendly.aspx>

Digital)²⁰. The study authors reported that the “best estimate of the overall prevalence of autism in England is 1.1%. In other words, just over one in 100 adults in the population have autism.” The 95% confidence interval (which expresses the level of uncertainty associated with the estimated value) is 0.3-1.9%. Applying this estimate to the estimated population of Ealing²¹ would indicate that there are approximately 3,780 (95% confidence interval 1,030 – 6,530) people with ASD in the borough.

Studies suggest that the prevalence of ASD maybe be higher among children and young people. For example, the Centers for Disease Control and Prevention in the USA estimate a prevalence of ASD among children and young people of 1.46% (95% confidence interval 0.82 – 2.46%)²².

People of all nationalities and cultural, religious and social backgrounds can have autism, although it appears to affect more men than women. Recent studies have reported an increased prevalence, leading to an increased demand for diagnostic and support services. The reason for this increase is not fully understood.

3.2. Prevalence of ASD recorded in the Ealing School Census

The Ealing Spring School Census 2017 gives a snapshot of the pupil population (on 19th January 2017) and includes all pupils in Ealing primary, secondary and special schools, children’s centres and the pupil referral unit. Details about special educational needs (SEN) are collected in the School Census. It should be noted that information about SEN reflects the view of the school, and does not necessarily reflect a clinical diagnosis.

According to the Spring School Census 2017, there were 738²³ children and young people resident in Ealing who were recorded as having ASD in state schools in Ealing (including children’s centres, primary/secondary schools and special schools). This represents 1.5% of all children and young people in Ealing state schools who live in the borough (738 out of 49,197 pupils in total).

Of these 738 children and young people, 504 had ASD listed as their primary need whilst a further 234 had ASD classified as a secondary need²⁴. Based on the School Census, over the last five years the number of children and young people in Ealing schools recorded as having ASD has increased by 57% (Figure 1). Possible reasons

²⁰ The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Leeds: NHS Information Centre for Health and Social Care

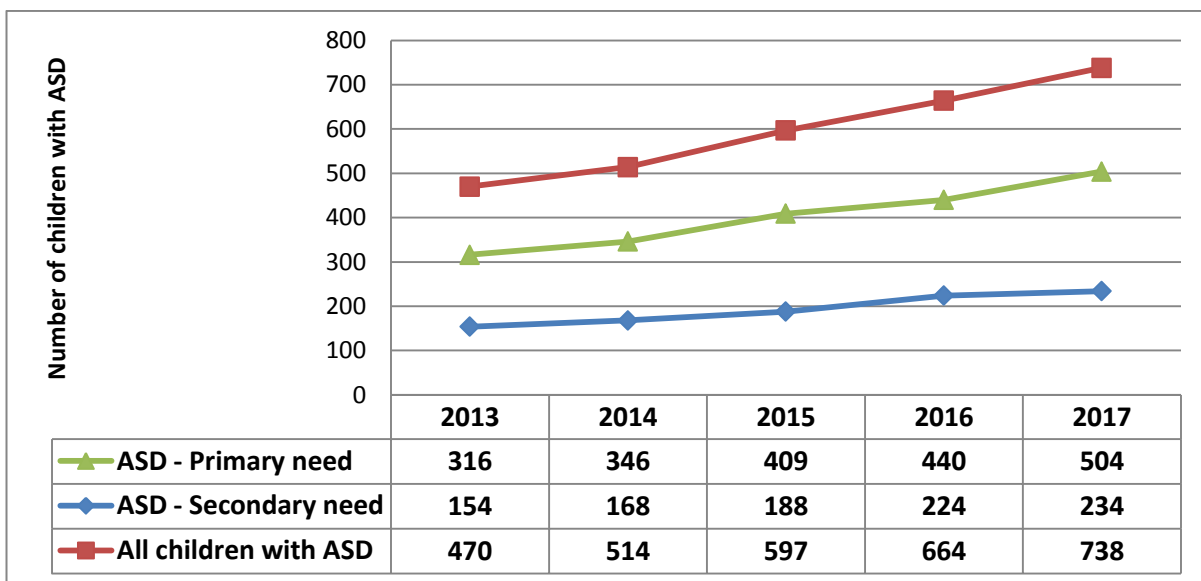
²¹ 2015 Greater London Authority Population Projection – SHLAA based

²² <https://www.cdc.gov/ncbddd/autism/data.html> (accessed on 09/02/2017)

²³ An additional 57 children who were non-Ealing residents were recorded in the Ealing Spring School Census as having an ASD; making a total of 795 with an ASD in Ealing state schools.

for this rise could include families with children and young people with ASD being attracted to Ealing to attend the specialist schools (specialist provision has increased in recent years). It may be that as awareness of ASD rises among schools and parents, the number of children and young people put forward for a diagnosis has increased. Finally, it may be that recording of ASD by schools has improved over the time period.

Figure 1: Number of children and young people attending Ealing state schools who are recorded as having ASD (Ealing residents only), 2013-2017

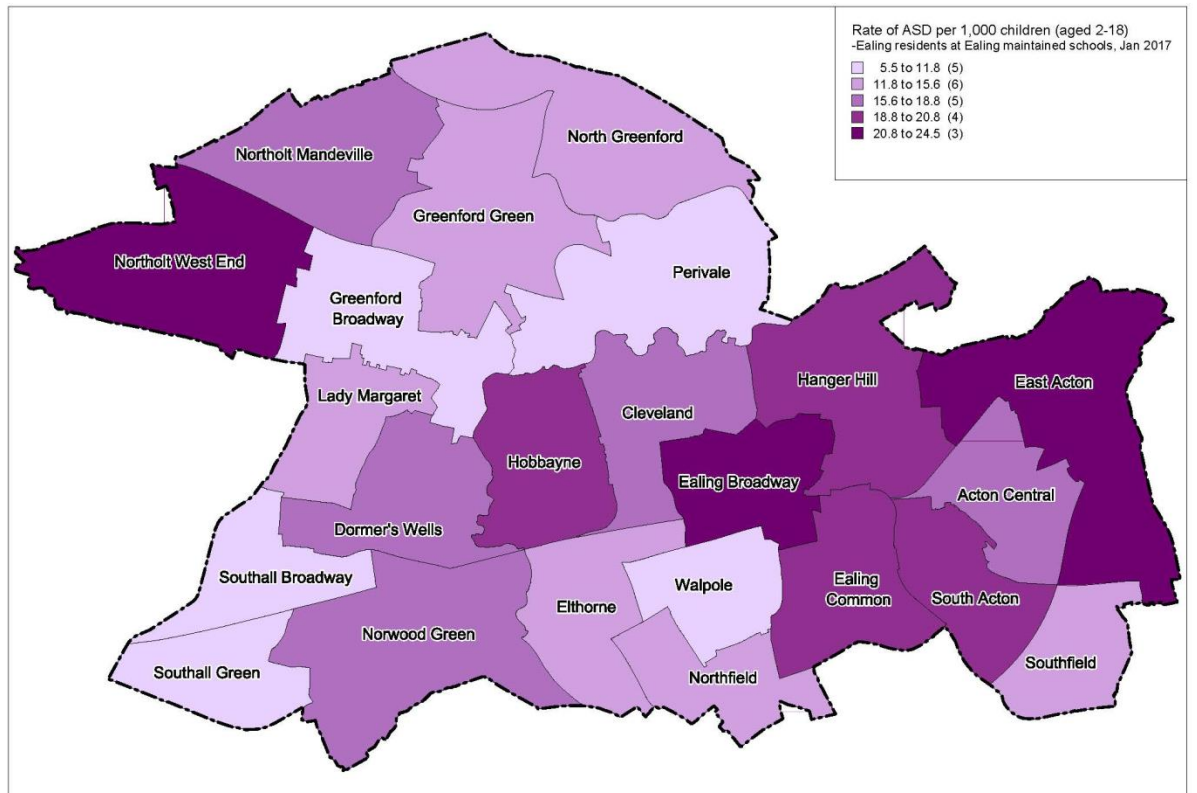


Source: Ealing Spring School Census 2017

Note: Primary and secondary need refers to clinical need i.e. whether ASD is the child’s primary diagnosis or secondary to another, more serious, condition (as reported by the school).

The rate of children and young people with ASD per 1,000 children and young people aged up to 18 is shown in Map 1.

Map 1: Rate of resident children and young people attending Ealing state schools who are recorded as having ASD (Ealing residents only), 2017



Ealing Public Health Team

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Source: Ealing Spring School Census 2017

Of the 738 resident children and young people with ASD identified in the Ealing Spring School Census 2017, 624 were male and 114 were female. As a proportion of all male and female children and young people recorded in the School Census as residents, this corresponds to 2.5% of male and 0.5% of female children and young people having ASD.

Of 738 children and young people with ASD, 478 (65%) were pre-school or primary school age (2-10 years) and 260 (35%) were of secondary school age (11-18 years).

The ethnicity of children and young people diagnosed with ASD can be compared to the ethnicity of all children and young people resident in Ealing. For all except one ethnic group, the proportion of ASD diagnoses is similar to or less than the total proportion across all children and young people. The exception is the Black/Black British ethnic group, who account for nearly 1 in 6 (15.6%) school children and young people recorded in the School Census but 1 in 4 (24.1%) children and young people with ASD (Table 1).

Table 1: Ethnicity of children and young people attending Ealing state schools who are diagnosed with ASD (Ealing residents only), 2017

Ethnic group	Number of children and young people diagnosed with ASD	% of total with ASD	Number of children and young people resident in Ealing	% of total resident in Ealing
Asian/Asian British	185	25.1%	14578	29.6%
Black/Black British	178	24.1%	7674	15.6%
Mixed	60	8.1%	4160	8.5%
White	206	27.9%	14978	30.4%
Other	103	14.0%	7332	14.9%
Unclassified	6	0.8%	475	1.0%

Source: Ealing Spring School Census 2017

At January 2017, there were an additional 146 children and young people (up to 25 years old) with an ASD diagnosis as a primary need in mainstream out borough, private or independent schools or with other arrangements²⁵ (either in Ealing or outside the borough)²⁶. Adding these 146 people to the School Census total of 738 gives a total of 884 children and young people with ASD.

3.3. Prevalence of ASD among people with a learning disability

Recent research by the Learning Disabilities Observatory indicates that around 20-30% of people with Learning Disabilities (LD) have an ASD².

At October 2016, the top registered specific condition for adults with LD in receipt of services commissioned by London Borough of Ealing was autism, followed by other physical illness, epilepsy, physical impairment and sensory impairment²⁷.

There were 149 people with LD identified as having autism (including eight clients with Asperger's Syndrome) who were eligible for support from London Borough of Ealing. Of these, 105 were male and 41 were female. When the snapshot was taken, 47 clients were using services outside of the borough (mainly in residential care).

The majority of people (58%) with LD who also have an ASD are aged 18-34 years (Figure 2).

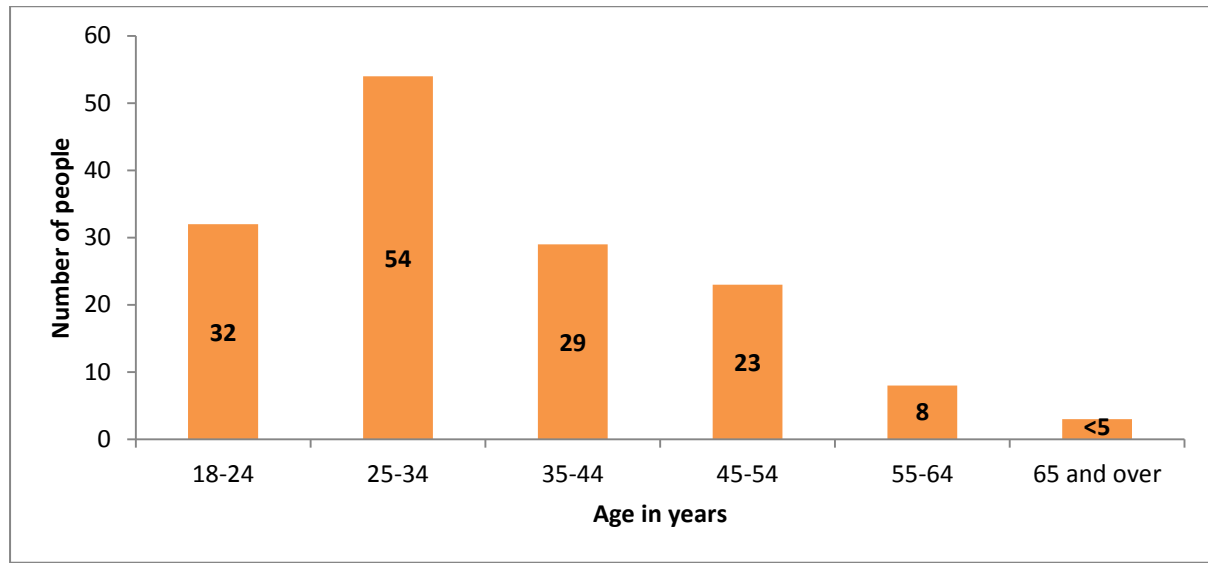
The ethnicity profile of people with LD who also have an ASD is similar to that of all people with LD in Ealing; around half are White, a quarter Asian/Asian British and a sixth Black/Black British (Figure 3).

²⁵ School types of 146 ASD pupils include: Independent Special schools (46), mainstream schools (40), further education (29), Maintained special schools (17), awaiting provision (6), arranged by parents (4), Non maintained special schools (2), Independent school (1), pupil referral unit (1).

²⁶ Source: SEN Database of Pupils, London Borough of Ealing, January 2017.

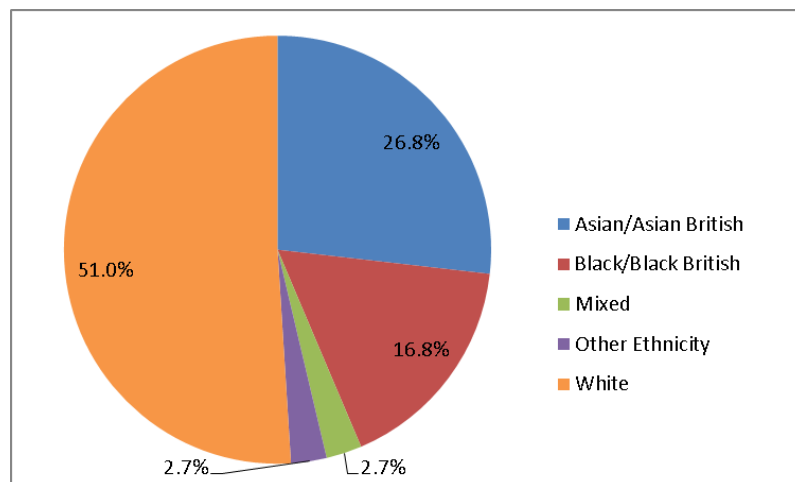
²⁷ Source: London Borough of Ealing Adults Performance & Management Team, 2016

Figure 2: Number of adults known to London Borough of Ealing with LD who also have an ASD, by age group, October 2016



Source: London Borough of Ealing: Adults Performance & Management Team, 2016

Figure 3: Number of adults known to London Borough of Ealing with LD who also have an ASD, by ethnicity, October 2016



Source: London Borough of Ealing: Adults Performance & Management Team, 2016

3.4. Prevalence of mental health and/or challenging behaviour in local population of adults with ASD and a learning disability

The needs of people with learning disabilities who have autism can be particularly complex, with many having a co-existing mental illness and/or challenging behaviour and often needing psychiatric or psychological interventions. This cohort is more likely to be at risk of admission to inpatient mental health services. At November 2016, 78% of adults with learning disabilities placed in assessment and treatment (commissioned by NHS Ealing CCG) also had a diagnosis of autism.

A recent audit was undertaken to ascertain the composition of the psychiatric caseload for the Ealing Community Team for People with Learning Disabilities (CTPLD), to determine the numbers, demographics, nature of and diagnostic profiles of the existing caseload and new referrals to the psychiatric service. This service supports people who are registered with a GP in Ealing. The audit highlighted a significant increase in the proportion of patients with ASD being referred to psychiatry since 2013; the number of recent referrals account for 41% of the caseload, compared to 26% of the pre-existing caseload. There has also been an increase in the percentage of referrals of patients with autism with complex, multiple needs including mental ill health, severe learning disability and challenging behaviour.

There were 74 patients with LD and autism on the psychiatric caseload at March 2016²⁸. Of these 74 people the audit identified that:

- 81% had challenging behaviour
- 39% had a mental health condition
- 52% had a severe learning disability

Similarly, a higher proportion of the local LD caseload of the psychological therapies team had a diagnosis of autism as compared to estimated prevalence data (63 (44%) of the 143 patients with learning disabilities receiving treatment from this team had autism). Of those with LD receiving intensive support from Case Coordinators, 82% had autism and severe challenging behaviour which can include a combination of self- injurious behaviour, aggression towards others and destruction to property.

²⁸ Ealing Community Team for People with Learning Disabilities

3.5. Projections of the number of adults with ASD

Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information (POPPI) are databases designed for analysing population data and projecting numbers into the future. With a focus on people aged 18-64 (PANSI) and people aged 65 and over (POPPI), figures from the Census 2011 are applied to Office for National Statistics population projections to give estimated numbers. Projections of the number of adults with autistic spectrum disorders are available from 2016 to 2030 (Table 2).

Table 2: Projected number of adults with an ASD by age (18+), projected to 2030

Age group	2016	2020	2025	2030
18-24	306	301	305	339
25-34	690	704	708	689
35-44	590	620	645	660
45-54	465	484	515	550
55-64	328	363	406	428
65-74	214	237	257	294
75+	167	183	221	254
Total 18+	2,758	2,891	3,057	3,213
Total 18+ (%)	1.05%	1.09%	1.12%	1.16%

Source: PANSI & POPPI, 2014; GLA 2015 population projections

The projections in Table 2 indicate a small, gradual increase in the number of adults with an ASD in Ealing. However, we have already seen that the number of children and young people in Ealing schools with an ASD has increased by 54% since 2012 (Table 1). Given this sharp increase in the number of diagnoses among children and young people, it seems logical that the increase will follow through to the adult population as these young people become adults. Whilst it is possible that some young adults with ASD may be able to live independently, this increase is likely to have implications for the demand on services from this group.

3.6. Number of adults receiving an ASD assessment and/or treatment

West London Mental Health Trust (WLMHT) provides assessments and treatment to children and young people with an ASD, whether or not they also have mental health needs. Adults who have an ASD and who are being treated by mental health

services will have needs associated with their autism addressed and reasonable adjustments made to support their access to treatments.

In the period 2015-16, 44 people were given an assessment by WLMHT and 126 received treatment for their mental health condition. The majority of those who received an assessment and/or treatment were male. The majority were also aged below 18 years old (Table 3).

Table 3: Number of people receiving an ASD assessment and/or treatment from West London Mental Health Trust, by gender and age group, 2015-16

	Assessment		Treatment	
	Number	%	Number	%
Gender				
Male	34	77%	100	79%
Female	10	23%	26	21%
Age				
Under 18	25	57%	67	53%
18+	19	43%	59	47%
Total	44	100%	126	100%

Source: WLMHT, 2016

Note: Percentages relate to the total number of assessments or treatments e.g. of all people receiving treatment $100/126 = 79\%$ were male.

The WLMHT services that treated the highest numbers of people were the Ealing Recovery Team (44 adults), Ealing CAMHS Neurodevelopment Service (38 children and young people) and Ealing CAMHS Children with LD Tier 2 (29 children and young people).

4. Assessment and Diagnosis

4.1. Children and young people

Diagnosis is undertaken by the Child Development Team in the Ealing Service for Children with Additional Needs (ESCAN) or West London Mental Health NHS Trust (WLMHT). The age of the child will determine which organisation undertakes the diagnosis.

Some children and young people may also have an Education Health and Care Plan (EHC) under the Children and Families Act 2014. EHC plans are organised by the Special Educational Needs (SEN) team at ESCAN.

ESCAN provides SEN, specialist child health, support and social care services to children, young people and their parents, on the basis of need. ESCAN is an integrated service comprising staff from the London Borough of Ealing and London North West Healthcare NHS Trust (LNWHT).

4.2. Adults

4.2.1 Adults with ASD who have co-existing learning disabilities

The Community Team for People with Learning Disabilities offer a screening and assessment service for people with learning disabilities seeking an autism diagnosis. The Autism Diagnostic Interview is conducted by a qualified clinician. Sometimes a cognitive or adaptive assessment may also be used to gain collateral information to inform diagnosis. The average waiting time between referral and assessment for people with LD seeking an autism diagnosis during 2015 – 16 was 16 weeks. Whilst the service was not compliant with the NICE guidance waiting times in 2016, it is anticipated that this target will be met from April 2017 due to recruitment to vacant posts.

4.2.2 Adults with ASD who do not have learning disabilities

For those who may have autism but who do not have a learning disability, a formal pathway for diagnosis has not been established. Initial screening is carried out at the West London Mental Health Trust, following a referral from a mental health professional, GP or other contact considering the person may have autism. The person is then referred to a specialist assessment centre for diagnosis.

At the time of writing (2017) this is provided by an out of area Mental Health NHS Trust on an individual basis. If the person receives a diagnosis of autistic spectrum disorder they can be referred to the mental health services if they also have mental

health needs, or to specific voluntary sector services locally (see below). Occasionally they may receive treatment from the specialist services where they were diagnosed if appropriate for their needs.

It is unclear if the current arrangements are compliant with the NICE guidelines as information relating to waiting times and post diagnostic interventions and signposting to the local authority for a needs assessment was not readily available. There are plans to review whether it is more appropriate to commission both diagnosis and treatment closer to home in future.

4.2.3 Social Care Needs Assessments

Social care needs assessments can be offered to adults with autism (and young people with autism approaching transition to adulthood) with care and support needs and to carers with support needs.

Social workers within the disabilities team have received training in how to prepare for and undertake social care needs assessments with adults with autism to establish whether the individual's particular difficulties make them eligible for support. They work in partnership across health and care sectors to help people with autism stay independent, safe and well for as long as possible by delivering services aimed at preventing, reducing and delaying the need for more formal care and support. They can signpost people to other services and opportunities if they aren't eligible for social care support, for example information and advice, housing related support and social clubs.

Social care needs assessments for people with autism who have co-existing learning disabilities are undertaken by social workers in the Community Team for People with Learning Disabilities (CTPLD).

5. Service Mapping for Children and Young People

This section summarises the services available to children and young people. A more detailed summary can be found in appendix A.

5.1. Schools and Colleges

Local schools are used wherever possible but some children and young people have needs that require specialist provision that can only be met by attending out of borough schools.

- There are six state funded special schools in Ealing. Of these, one is specifically for children and young people aged 4-16 years with complex ASD and five can cater for children and young people with ASD.
- Three state funded mainstream primary schools have support units which cater for children and young people with a range of learning difficulties and/or behavioural difficulties including severe learning difficulty with ASD, developmental delay and communication difficulty.
- One state funded high school has additional resourced provision (ARP) to meet ASD needs and a further two relevant ARPs are currently in development.
- There are two independent sector ASD specific schools located in Ealing
- There are eight independent sector ASD specific schools located outside Ealing that are attended by Ealing children and young people
- There are three independent sector day schools that cater for the needs of children and young people with ASD that are attended by Ealing children and young people
- There are six independent sector ASD specific boarding schools used by Ealing children and young people
- There are two ASD specific colleges attended by Ealing young people

5.2. Support for Ealing schools

- Autism support is provided by Ealing's state funded ASD specific school to mainstream primary and secondary schools. This includes advice and training for staff working with individual pupils and training for staff groups.
- ESCAN speech and language service, occupational therapy service and Educational Psychology service all work with state funded schools to support individual children and young people and groups of staff

5.3. Early Years

- Early Bird (pre-school children) and Early Bird Plus (5-8 year olds) are autism-specific programmes for parents/carers, which give weekly post-diagnosis support and advice over a 3-month period. Education practitioners enable children to take part in these sessions.
- There are specialists in three children's centres. One children's centre has a specialist service for children aged 2 to 4 years with identified social communication difficulties.

5.4. Health

- Diagnostic and treatment services are provided by two local NHS trusts on an age specific basis.

5.5. Care and Support

- The early intervention in autism project supports children and young people to remain in local school and at home
- Therapeutic short breaks works at a more intensive level to prevent breakdown when families are at crisis point.
- Contact a Family provides autism specific support programmes to parents.

5.6. General services for children and young people with SEN and/or disabilities and their parents or carers

- The Ealing I SAID service (Impartial Advice, Information and Support on Disability and special educational needs) provides free and confidential advice, information and support to parents, carers, children and young people aged up to 25.
- There are two websites providing information and advice: Ealing Help and the London Borough of Ealing Local Offer
- Community support is provided by a number of voluntary organisations and domiciliary care providers
- Residential short breaks and community based short breaks are provided by schools and voluntary organisations

5.7. Transition into adulthood

Transition into adulthood can be a difficult time for many young people with autism. A Preparing for Adulthood Steering Group has been established to oversee the local implementation of the Special Educational Needs and Disability (SEND) reforms for young people including people with autism. Education, Health and Care (EHC) planning processes cover the support that is needed up to age 25. The planning process during transition for people with a co-existing learning disability is led by a transition social work team and SEND co-ordinators. There is significant joint working across children's and adults' services (health, education and social care) with input from the psychologists who provide in-reach support into schools. A transition protocol is currently being developed to support transition from child to adult psychiatric services.

There isn't a formal transition pathway for young people with autism approaching adulthood who aren't eligible for social care or an EHC Plan.

6. Service mapping for Adults

This section summarises the services available to adults. A more detailed summary can be found in appendix A.

6.1. Services provided by the voluntary sector

The voluntary sector is commissioned by NHS Ealing CCG and London Borough of Ealing to provide a range of services to adults with autism and their family carers. These include:

- ASSIST (Asperger's Support Signposting Information Services Team)
- Travel buddy project
- Ealing Specialist Advice Service Support planning and brokerage
- The Carer's Centre
- Treat Me Right

Ealing, Hammersmith and West London College offer a two year transitional programme called The Gatehouse which has been set up to enable students with a diagnosis of Asperger's Syndrome or High Functioning Autism, to prepare and acquire the skills and qualifications needed to access mainstream provision. The college also delivers supported learning courses from two campuses aimed at students with LD including young people with autism. Most courses have an employment focus and provide opportunities for work experience and internships.

Job Centre Plus employ Work Coaches who offer assistance and advice to jobseekers with autism and other disabilities including support with work preparation, recruitment, interview coaching and confidence building.

More detailed information about these services is provided in appendix A.

6.2. For adults with ASD who have a learning disability

The Community Team for People with Learning Disabilities (CTPLD) is a joint health and social care multi-disciplinary team. They work to support adults with autism who have learning disabilities, to live safe and fulfilling lives in the community. The team consists of social workers, senior practitioners, psychologists, physiotherapists, nurses, music, art and speech and language therapists, and a psychiatrist. Ealing CCG has identified funding to create a specialist LD Occupational Therapist post. The emergency duty team provide a service out of hours for social care support but the health component of this service is only available on Monday to Friday from 9am-5pm. Clinical interventions for adults with ASD are included in appendix A.

Care and support for people with autism who have learning disabilities and their families is delivered by a range of providers from the voluntary, statutory and independent sector. The London Borough of Ealing currently commissions the private and voluntary sector to provide accommodation based and community services in Ealing, as well as providing a number of services directly. The main services available include supported living, residential care, day opportunities, respite and short breaks, outreach, homecare, transport and advocacy. There is a need to ensure that all providers offering services to people with autism employ staff with the right skills and expertise needed to support people with autism. The local supported living services offer accommodation for people with autism and LD through a range of tenures – shared lives, shared ownership, private rented, and social housing. There is a London wide shortage of affordable housing stock, and it is especially difficult to identify affordable accommodation that is suitable for people with autism and challenging needs who require spacious and/or self-contained accommodation. Consequently, residential care and supported living for this cohort sometimes has to be provided out of borough.

People living with their families have access to support, which aims to promote the health and wellbeing of both the person with autism and their family, as well as enabling family carers to have a break from their caring role. These services include day-opportunities, outreach, support at home and short-breaks. There are 12 resource centres in Ealing offering a base for day opportunity programmes. One of these is a specialist service for adults with autism. There are two residential short breaks services in the borough; one caters for people with challenging behaviour, the other for people with profound and multiple learning disabilities. The respite service for people with challenging behaviour is currently unable to meet the increasing demand arising from young people with learning disabilities and autism transitioning into adulthood.

In addition to directly commissioning services, the London Borough of Ealing works in partnership with the voluntary sector and the wider community to promote access to mainstream services, facilities and activities such as leisure, sports, arts and culture and transport.

6.3. For adults with autism who have a mental health condition

West London Mental Health Trust provides a range of inpatient and community mental health services, all of which can be accessed by people who have a diagnosis of autism and a mental health condition. If the needs arising from their autism are particularly complex, a referral to a specialist autism service may be recommended. There is scope to improve access to reasonably adjusted mental health services by providing autism training to clinical and non-clinical staff working in the Trust, and staff working in the voluntary sector.

The West London Mental Health Trust has a Single Point of Access (SPA) for all services, open 24 hours a day, 7 days a week, 365 days a year. The following services are available via the SPA:

- Improving Access to Psychological Therapies (IAPT)
- Primary Care Mental Health Team
- Recovery Team, including Recovery College and Recovery Hub
- Crisis Assessment and Treatment Team

In addition to the statutory mental health services described above, people with a diagnosis of autism and a mental health need can access Supported Accommodation and Housing Related Support, and Residential Care and Supported Living if they are eligible for social care. These services play an important role in supporting people to build up abilities and confidence, and are part of a pathway to living independently as well as helping to support prevention.

Voluntary and community sector services in Ealing are part of the bigger picture in helping people to live their lives as they wish. They provide a range of support such as help to learn new skills, employment support, peer support and practical support to manage benefits claims and housing applications. Examples are Community Activities Project Ealing (CAPE); Mind Pathways, and Solace. As these are not specialist autism services, the provision of autism awareness training would be beneficial.

7. The views and experiences of people with autism and their families

7.1. The experiences and views of people with autism

Public Health England invites local authorities to lead on the submission of an annual Autism Self-Assessment which focuses largely on the provision of services and support available locally for adults with autism. Integral to the process is capturing the views of self-advocates, and the opportunity for people with autism to share their stories. In seeking the views of people with autism, the 2016 self-assessment highlighted the following areas as working well.

- People using a specialist signposting, advice and support service for people with Asperger's have commented on the importance of being understood, and being treated as a person. Support to prepare for and stay in employment was highly valued, as was the opportunity to meet and talk to other people with autism. The women's group was cited as been helpful in raising confidence and self-esteem. People who use the service have said they appreciate the social activities organised because they have given them the opportunity to meet new people with autism and make friends, thereby helping them to feel

less isolated. Their ability to hold meetings in different venues (e.g. home visits, a library, coffee shop, park or the autism centre) is one of the features valued by the people they support. People said they benefited from the flexibility and choice in how they receive support e.g. Skype, text, email, twitter, face to face appointments, workshops or social activities. One person with Asperger's from Ealing said the service "keeps me stable, gives me something to look forward to and gives me a routine and a goal"

- Young people with autism gave feedback about the outcomes they have achieved through completing a supported internship programme. The project offers structured work experience and training opportunities to young people with learning disabilities. The structure and consistency of the support from the job coaches in the workplace was highly valued, enabling them to develop the confidence and skills needed to secure paid work

The main issue raised by adults with autism was the barrier to getting a timely diagnosis. Some people reported difficulties in finding out where to go to seek a diagnosis in the first instance and then having to wait for a long time between referral and assessment.

An Autism Focus Group, facilitated by National Autistic Society and Mencap, has recently been established to provide a forum for young people with autism to share their views and experiences and inform future priorities for the Autism Board. The main areas that young people said were important to them include:

- Being able to access mainstream services alongside members of the community who respect and understand their needs
- Having an education and getting a job
- Feeling safe in the community
- Getting the right support to live independently

Some people were unsure about where to get information and advice. They recommended that information should be available in a variety of formats including face to face and should include topics such as entitlements and benefits.

People consulted felt that many employers and universal service providers lacked awareness of the needs of people with autism and the reasonable adjustments that can be made to improve access to the community and support to get and keep a job. Specific examples included leisure activities such as the gym, transport and Jobcentre Plus. The young people thought the best way to develop autism aware communities is for people to see, hear and learn from people with autism, and therefore recommended that any autism awareness training is co-delivered by people with autism.

7.2. Experiences and views of families

During March 2016, a series of engagement events were held with family carers on the “Building the Right Support” service model. The families consulted included those who had an adult relative with ASD, a learning disability and challenging behaviour.

In 2016 the Ealing Parent and Carer Forum prepared a google survey which was sent out to parents of children and young people with autism to get feedback on their experiences in accessing services.

Whilst there were some common themes which were highlighted by families as being important to children, young people and adults with ASD alike, some areas were age specific.

7.2.1 Important to people with ASD of all ages

- Care and treatment from mainstream health professionals who understand the needs of children, young people and adults with autism, particularly those who experience sensory issues and find it difficult to tolerate health appointments and waiting rooms. Examples of successful reasonable adjustments which families gave were appointments being available in the home or at a day centre, being able to see the same health professional, short waiting times, quieter appointment times and establishing a routine. For hospital treatment, minimising the number of appointments leading to an operation to cover planning, consent and medical checks was helpful for one family.
- The dentist at the Grand Union village was described on a number of occasions as excellent in supporting people with autism. Patients were allowed to take their time, weren't kept waiting, and didn't have to sit in the dentist chair while having their treatment.
- Blood tests were highlighted as being a great source of anxiety for people with autism and their families. One carer described the regular blood tests their relative requires. They have established a routine which makes this possible i.e. having the same person take the blood, with a specific needle, on a specific day/time. If the routine changes, the person finds it difficult and challenging behaviour is more likely to occur.
- Parents said they valued opportunities to meet with other families who have relatives with autism and share advice, information, support and their experiences.

7.2.2 Important for children and young people with ASD

- Access to a timely diagnosis. The waiting times between referral to assessment when parents sought an autism diagnosis for their child varied considerably and often exceeded the recommended waiting times in the NICE guidelines. In some cases, parents reported that they had waited over 2 years.
- Signposting to local services, information and support for recently diagnosed children and young people. Some parents found it difficult to navigate the system as information about local services was not readily available
- Some parents highlighted the lack of specialist post 16 education for young pupils with autism who don't have a moderate or severe LD as being a local gap.

7.2.3 Important for adults with ASD

- An understanding by professionals that a parent's aspirations for their son or daughter with autism are the same as those for their other children. This means the same opportunities to live independently, to learn and work, and to have a network of important relationships
- Allocation of a Case Coordinator or Social Worker to act as a central and consistent point of contact and advice.
- Access to responsive, flexible respite from a service families know and trust, with support provided by staff who like and respect your relative was felt to be essential.
- Access to flexible and frequent psychological therapy sessions when needed. Some families reported that their relative benefited from more frequent sessions initially followed by less frequent follow up appointments. Parents told us that in their experience, this level of flexibility was not available with Ealing IAPT.

8. Gaps

There are areas we have identified where we need to explore solutions and focus on improvement. Work has already started on these areas but we need to do more.

- NICE guidance recommends proceeding with an autism diagnostic assessment for children and young people aged under 19 years within 3 months of the referral to the autism team. There is a diagnostic pathway in place for children and young people but this target is not consistently being met. Although the absence of a formal diagnosis doesn't prevent access to therapy, the timeliness of diagnosis is an area highlighted by families and professionals for further development.

- There is a need to ensure that providers delivering support and education to children and young people with autism are adequately trained. This includes staff working in schools, SEND Coordinators and community based services such as domiciliary care.
- Access to information and signposting for recently diagnosed children and young people is a gap highlighted by parents
- Transition into adulthood is a stressful time for many people with autism. Support for young people with high functioning autism is limited as they approach adulthood. This cohort are unlikely to have an EHP or be eligible for social care, but may face barriers to education and employment and be at risk of social isolation, offending, substance misuse and developing mental health needs.
- The lack of specialist post-16 education facilities for young people with autism who don't have a moderate or severe LD was highlighted as a gap by families
- The diagnostic pathway in Ealing for adults with autism who do not have a learning disability has not been formalised or published, and the commissioning and governance arrangements need to be strengthened. Whilst initial screening is undertaken locally, if further assessment is appropriate, the person is referred to a specialist autism service (usually in South East or North London) for the delivery of diagnostic assessment, and specialist interventions/therapies if needed. Information on the waiting times between referral and assessment was not readily available and there was no evidence of people being signposted to the local authority for a needs assessment following diagnosis. The development of a local or regional service would allow better oversight and scrutiny and ensure that the process clearly triggers automatic signposting to adult social care services for a needs assessment and where appropriate to local mental health services, and services to support with social skills, leisure and employment. It would also respond to the difficulties some people with autism face travelling by ensuring people received services closer to home.
- The average waiting time between referral and assessment for people with LD seeking an autism diagnosis during 2015-16 was 16 weeks. Although this diagnostic pathway was not compliant with the 12 week waiting time in the NICE guidance, the CTPLD anticipate this target will be met in 2017/18 as there are additional clinicians within the team who are qualified to undertake assessments
- Adults who have autism but do not have a learning disability or a mental health need are at risk of falling between services and not having their needs met, as many would not be eligible for social care support. This is a particular risk for people who are not diagnosed until adulthood and for whom there is no published care pathway. For individuals who do not meet the adult social care eligibility criteria, post diagnostic support both immediately and in the long term is limited to services provided by the voluntary sector.

- Public Health England invites local authorities to lead on the submission of an annual Autism Self- Assessment which focuses largely on the provision of services and support available locally for adults with autism. Ealing's submission for 2015-16 highlighted that autism awareness training is not an integral part of ongoing workforce development for staff working in the criminal justice system, advocacy services, drug and alcohol services, housing, primary and secondary healthcare and the voluntary sector.
- Access to specialist occupational therapy assessments for adults with learning disabilities and autism is currently not available. The CCG have re-directed funding to create a specialist occupational therapist post to provide functional skills assessments and sensory integration profiling.
- Whilst the local adult mental health services do not exclude people with autism, there is no evidence to illustrate that reasonable adjustments are routinely made and if the potential variations in cognitive style, communication, narrative and value system that might come with autism are routinely taken into account by all clinicians. There is scope to improve access to services at all stages of the local mental health care pathway by offering general autism awareness training and specialist training for clinicians in selected roles working in the Trust.
- There is a shortage of affordable housing that is suitable and safe for adults with autism and challenging needs, particularly the cohort who struggle to share space with others due to the frequency and intensity of the challenging behaviour they exhibit and the risks they present to themselves and others. This often results in vulnerable people being placed out of borough away from their families and social networks. Failure to provide a suitable environment where risks can be safely managed often leads to placement breakdown and ultimately to admissions to assessment and treatment
- The local specialist 3-bed residential respite service for adults with learning disabilities and autism who have challenging behaviour and live at home with their families doesn't have the capacity to meet the increasing demand. This service is currently unable to provide overnight respite for some young people who have turned 18 within the last year and will struggle to offer the level of service needed to the seven young people with autism and challenging behaviour who will turn 18 in 2017.
- Access to support from clinicians working in the CTPLD is only available from Monday - Friday from 9am - 5pm. The North West London Transforming Care Partnership is currently exploring models which could offer a 7-day service across the region for adults in crisis.
- There is a need to ensure that all providers delivering support to children, young people and adults with autism and challenging behaviour have the right skills and expertise to work collaboratively with local clinicians to implement services which are compliant with the recently published NICE guidelines.

8.1. Lack of data to understand the prevalence of ASD

A national GP register of patients with ASD does not currently exist. Hence, it is not clear how many people with ASD live in Ealing. The best estimate available comes from applying the modelled prevalence²⁰ of people with ASD to the population of Ealing, which indicates that approximately 3,780 (95% confidence interval 1,030 – 6,530) people with ASD live in the borough.

London Borough of Ealing hold data on children and young people whilst they are engaged with the education system. However, there are gaps in data held about the adult population. London Borough of Ealing are aware of adults with an ASD if they either have a learning disability or a recognised mental health condition; these individuals are known to adult social services or adult mental health services. One possible way to better understand the size of the adult population with ASD would be to develop a register among GPs within the borough.

9. Recommendations

9.1. Data improvement

Data held by London Borough of Ealing about people living with ASD in Ealing is incomplete. To help understand the recorded prevalence of ASD within Ealing, local GPs should systematically record diagnoses using READ codes suggested by the Royal College of General Practitioners¹⁹. Ealing CCG should champion this and promote recording of ASD diagnoses among local GPs.

9.2. Children and young people

- Re-design the autism pathway and, if necessary, further increase capacity within LD/CAMH psychiatry in Ealing to support the completion of timely ASD assessments for children and young people
- Roll out a programme of foundation and enhanced Positive Behaviour Support training to family carers, clinicians, and staff working with children and young people with autism in a range of care and education settings
- Create two specialist SEND co-ordinator posts to produce EHC plans with young people with autism who have complex needs using money from the London Borough of Ealing transformation fund
- Bid for Department for Education funding to support the creation of a multi-disciplinary team to provide skilled support and early intervention to young people with autism age 14 – 25 who are at risk of exclusion, social isolation and offending.
- Work with the Preparing for Adulthood Power Group to improve the information in the Local Offer and Care Place websites

- London Borough of Ealing to undertake a strategic review of SEND provision in 2017-18. This should include a review of experiences and outcomes for pupils with autism (aged 16+) attending mainstream schools and other educational settings, and identify the future progression pathways and the best ways to support mainstream schools/colleges to meet needs and any provision requirements
- London Borough of Ealing to work with key local education providers on good autism practice and the use of a national autism competency framework to set out training standards and to support continuing professional development in education settings

9.3. For people with autism without a learning disability

The Ealing Autism Board will develop an Autism Strategy for Ealing. This will examine how to meet the needs detailed here, and further explore solutions where development areas have been identified. The Strategy will address the needs of young people (aged 14+) and adults through planned actions over a five-year period, and will be produced with people who understand autism, including those with lived experience and families, friends and carers.

Recommendations for inclusion in the strategy include:

- Development of a multi-agency autism training plan for staff working in the criminal justice system, advocacy services, drug and alcohol services, housing, transport, primary and secondary healthcare and the voluntary sector.
- Work with the Community Education Provider Network to roll out autism training for primary care staff, and to work with Health Education North West London to ensure that training is rolled out to all NHS staff.
- Voluntary sector partners and young people with autism to quality check mainstream services and make recommendations to organisations about reasonable adjustments to improve accessibility for people with autism.
- Undertake an audit of patients on the autism diagnostic pathway against the NICE quality standards to identify gaps and areas for improvement.
- Explore the development of a local or regional NICE compliant autism pathway
- Work with the voluntary sector and Jobcentre Plus to establish a project to support people with autism into employment
- Work with IAPT to explore reasonable adjustments to improve the outcomes for patients with autism including consistently offering an increased number of therapy sessions at a time when people need them
- Continue to fund the voluntary sector to provide a pre and post diagnostic information, support and signposting service for adults with autism who are not eligible for social care funding

9.4. Adults with autism who have a learning disability

- Progress work with local support provider and housing association to develop specifications for the capital works and the support service to expand the respite service for people with challenging behaviour living at home with family carers.
- Recruit a specialist Occupational Therapist to provide assessments and interventions for adults with LD, autism and challenging behaviour
- Develop a proposal for a crisis intervention pathway for people with LD across North West London
- Develop self-contained accommodation and crisis support service in Ealing for people with autism and challenging behaviour by March 2018
- CTPLD to establish a virtual multi-disciplinary challenging behaviour team to develop a local multi-agency Quality Assurance Framework to identify training and development needs, tools and approaches for local providers to improve support for adults with learning disabilities and autism who have challenging behaviour.
- Roll out a programme of foundation and enhanced Positive Behaviour Support training to family carers, clinicians, social workers and support staff working with adults with autism in a range of care settings

Appendix A – Service mapping for children, young people and adults

This appendix gives more detail about the services available for children, young people and adults with ASD.

1. Services for Children and Young People

The information below describes the services that are available for children and young people.

1.1. Schools and Colleges

State funded schools

- Belvue Special School - for pupils with moderate to severe learning difficulties aged 11-18 yrs. This is not ASD specific but does have children and young people with ASD.
- Castlebar Special School - for children aged 3-11 years with moderate or mildly severe learning difficulties. This is not ASD specific but does have children with ASD.
- Springhallow Special School - for children and young people aged 4 to 16 years who have complex autistic spectrum disorders.
- Manderville Special School - for pupils with severe learning difficulties and who may have additional physical, medical and/or sensory disabilities or autism. This is not ASD specific but does have children and young people with ASD.
- St Anns Special School - for young people with severe learning difficulties or profound and multiple learning difficulties. This is not ASD specific but does have children and young people with ASD.
- John Chilton Special School - for pupils ranging from 2 – 18 years who have physical and/or medical disabilities.
- Drayton Green Primary School - has a support base unit which caters for a small group of statemented children with a range of learning difficulties and/or behavioural difficulties.
- Allenby Primary School – has a support base unit which caters for children who have a severe learning difficulty with autistic spectrum disorder, developmental delay or communication delay

- Costons Primary School – has a support base unit which caters for a small group of statemented children with a range of learning difficulties and/or behavioural difficulties
- William Perkins High School – has additional resourced provision (ARP) to meet ASD needs
- Other secondary ARPs are planned for Elthorne Park High School and Greenford High School

Independent sector ASD specific schools located in Ealing:

- Sybil Elgar School (National Autistic Society)
- North West London School – (TCES)

Independent sector ASD specific schools located out of Ealing:

- Hillingdon Manor
- Rainbow School (Beyond Autism)
- Snowflake School
- Treehouse School (Ambitious about Autism)
- Kestral School (Acorn group)
- Priory Lodge School (Priory group)
- Moat House
- Helen Alison School (National Autistic Society)

Independent sector day schools that cater for the needs of children and young people with ASD

- North West London, TCES
- Pield Heath
- Insights

Independent sector ASD specific boarding schools (used by Ealing children and young people)

- Kisimul School
- Priors Court
- The Loddon School
- Farleigh FE College
- Grateley House School
- Sybil Elgar (in Ealing)

ASD specific colleges or services within colleges

- West Thames – Ambitious about Autism (day provision)
- West Heath (residential)

Note that local schools are used wherever possible but that some children and young people have needs that require specialist provision that can only be met by out of borough schools.

1.2 Support for Ealing schools

- Autism support is provided by Springhallow School to mainstream primary and secondary schools and includes advice and training for staff working with individual pupils, training programme for whole staff groups and bespoke accredited training courses and school specific training.
- Pupils with ASD may attend any of the borough's mainstream schools and colleges and those outside of Ealing. Staff in Ealing schools have access to training to help them to meet needs including the ASD outreach service (detailed in the previous bullet point); ESCAN speech and language service and occupational therapy service; specialist teaching alliances and independent sector training; online resources.
- ESCAN speech and language and occupational therapy services work with the Borough's special schools to provide therapy to children and young people, training to teaching assistants and input in to communication and behaviour improvement with Multi-Disciplinary Team members
- ESCAN'S Educational Psychology Service works with ASD pupils providing assessment and advice, training for staff teams and individual staff working

with ASD children and young people, both targeted and specialist interventions are provided

1.3. Early Years

- Early Bird (pre-school children) and Early Bird Plus (5-8 year-olds) - these are autism-specific programmes for parents/carers, giving them weekly post-diagnosis support and advice across a 3 month period. Education practitioners working with the children can take part too.
- Specialist SEN facilities in Greenfields, South Acton and Windmill Children Centres.
- South Acton Children's Centre has a specialist service for children aged 2 to 4 years with identified social communication difficulties and provides a highly structured approach to intervention, with regular integration into the mainstream service at the Centre.

1.4. Health

- Diagnostic and treatment services – LNWH (Child Development Team and therapies) and WLMHT
- The LD/CAMHS service within WLMHT works with children and young people with ASD at diagnostic and post diagnostic stages.
- See also the next section

1.5 Care and Support

- Early intervention in autism project – EIP jointly funded (Local Authority and CCG) project to maintain children and young people in local school and at home
- Intensive therapeutic short breaks – to prevent breakdown when families are at crisis point
- Autism support group in Contact a Family and other parenting support -parent workshops and parent focused interventions

1.6 General Services for children and young people with SEN and/or disabilities and their parents or carers

- ISAID – independent and impartial information and advice services for children and young people with SEN and/or disabilities
- Ealing Help – independent information and advice website run by MENCAP for parents of children and young people with additional needs
- Community support - domiciliary care, PESTS and Contact a Family
- Residential short breaks and community based short breaks including Log Cabin (after school and holiday club), MENCAP (after school and holiday club) and summer holiday short breaks programme

2. Local Services for Adults with ASD

2.1 Voluntary Sector

The voluntary sector is commissioned by NHS Ealing CCG and London Borough of Ealing to provide a range of services to the local autistic population and their family carers. These include:

- **ASSIST (Asperger’s Support Signposting Information Services Team)** is a pre and post diagnostic information and advice service for adults living in Ealing, who do not receive social services from the London Borough of Ealing. The project is run by the National Autistic Society and offers 1:1 appointments which aim to provide practical help to people with some of the difficulties they may be experiencing such as filling out forms, liaising with employers and university lecturers, looking for work, attending hospital appointments and exploring their diagnosis and developing strategies. Appointments can also be made with family members or other professionals. The service also runs weekly social groups, a monthly outings group and a Women’s group. ASSIST has also become a Community Partner with the British Museum; this allows entrance to the museum before the general public come in which enables those with additional sensory sensitivities to visit.
- **Travel buddy project** to support the use of public transport
- **Ealing Specialist Advice Service** provides advice and information to young people and adults with additional needs, including autism. The advisors can provide information on housing, benefits, disability rights, assistive technology, transport, education, health and social care, and personal budgets. The service also provides information about employment, Access to Work and reasonable adjustments to the workplace
- **Support planning and brokerage** service for people using direct payments

- **The Carer's Centre** is a resource and support centre for all unpaid carers, of any age. The service facilitates peer support groups, drop-in sessions and forums for carers as well as providing access to free counselling and independent advice and help with benefits claims
- **Treat Me Right** which provide autism awareness training, advice and guidance to mainstream health professionals to enable them to make reasonable adjustments to improve access to local health services for patients with autism

In addition to directly commissioning services, the London Borough of Ealing works in partnership with the voluntary sector and the wider community to promote access to mainstream services, facilities and activities e.g. leisure, sports, arts and culture and transport.

2.2 Employment and education

Ealing, Hammersmith and West London College offer a two year transitional programme called The Gatehouse which has been set up to enable students with a diagnosis of Asperger's Syndrome or High Functioning Autism, to prepare and acquire the skills and qualifications needed to access mainstream provision. The college also delivers supported learning courses from two campuses aimed at students with LD including young people with autism. Most courses have an employment focus and provide opportunities for work experience and internships. Project SEARCH Supported Internships are open to all applicants with moderate learning disabilities (MLD) who are aged between 18 and 24 and are interested in gaining paid employment (not necessarily at the host business or organisation) at the end of the programme. They are designed to develop transferable skills, knowledge and attitudes in readiness for paid employment. Through training and direct work experience young people will develop employability skills, self-confidence, job-specific skills and Maths, English and ICT skills whilst working alongside employees in a real employment setting.

Job Centre Plus employ Work Coaches who offer assistance and advice to jobseekers with autism and other disabilities including support with work preparation, recruitment, interview coaching and confidence building.

2.3 The Community Team for People with Learning Disabilities (CTPLD)

CTPLD is a joint health and social care multi-disciplinary team. They work to support adults with autism who have learning disabilities, to live safe and fulfilling lives in the community. The team consists of social workers, senior practitioners, psychologists, physiotherapists, nurses, and music, art and speech and language therapists, and a psychiatrist and physiotherapist. Ealing CCG has agreed to fund an Occupational Therapist post as this is currently a gap. The emergency duty team provide a service

out of hours for social care support but the health component of this service is only available on Monday to Friday from 9am – 5pm

Clinical interventions include:

- Support for communication from a Speech and Language Therapist
- Consultation around psychiatric issues or co-existing mental disorders
- Positive Behaviour Support planning and other interventions linked to quality of life for people with challenging needs or emotional issues
- Sensory profiling and sensory diets for learning about sensory integration difficulties
- Social Stories to support people to prepare for change
- Music or Art Therapy to support with communication, anger management, relaxation
- Family centred support, including psychoeducation on autistic patterns
- Training and consultation for support staff to develop capable environments associated with reduced occurrence of challenging behaviour