City and Hackney
Autism Needs Assessment

September 2019

Authors: Anni Dong, Lucy Wilson, Karim Mitha, Nicole Klynman

Executive Summary

Autism is neither a learning disability nor a mental health problem. It is a lifelong neurodevelopmental condition which affects how an individual perceives the world around them and how they communicate with others. It is a spectrum condition and characterised by difficulties in social interaction, communication, and imagination. It is not an illness or a disease. It cannot be "cured" and is often considered a "hidden disability". A person with autism may have some but not all of the features of the condition and presentation can vary from individual to individual. Diagnosis of autism is clinical; there are no biochemical or radiological tests available. Diagnosis is made based on certain characteristics which have been present since early childhood. Due to the spectrum nature of the condition, it is inevitable that there will be a subgroup of people with autistic traits who do not have a formal diagnosis of autism and who remain undiagnosed throughout their lifetime. Approximately half of autistic people have a learning disability but many will have a normal or above-average intellectual ability.

It is estimated that there are approximately 700 000 people with autism in the UK, which is approximately 1.1% of the UK population. Estimates of autistic people within Hackney and the City vary depending on the methodology used and age profile of the population examined; it is estimated that approximately 1.6% of children aged 5-9 in state schools in Hackney and the City are autistic, equating to approximately 119 students in that age band. Additionally, it is estimated that 0.8% of the 18+ population in Hackney and the City are autistic, equating to approximately 1900 individuals, however this is likely to be an underestimate. It is worth noting that only 569 individuals 18+ are identified as autistic from GP registers within Hackney and the City, suggesting approximately only 31% of the estimated numbers of autistic adults are being identified on GP registers. It is worth noting, however, that these figures are likely an underestimate as there is limited data on the number of autistic individuals that are homeless, living in temporary accommodation, in prisons, and in minority populations. Data on the prevalence of autism in children comes from estimates of those who attend state-schools, and so does not reflect young people who are educated in other settings. Data from adult social care show approximately 3900 individual cases were attributed to an autistic person between September 2014 and March 2019.

Autism is a relatively new diagnosis; the term 'autism' only came into common clinical use in the 1960s and whilst most diagnosis now occurs in childhood many adults remain undiagnosed. This is seen in the analysis of GP register data, where the greatest proportion of autistic patients identified in Hackney and the City are in the 5-11 age band. Older adults identified with autism are more likely to have been identified later in life, ie: during adulthood. A key challenge for many older adults with autism is that they will have had significant support from their families, but as families age, this becomes less possible and they are a group particularly at risk of loneliness and social isolation. Indeed, data from adult social care show that the majority of people making contact and who are likely to be autistic) are over the age of 65, however 2/3rds of adult social care clients who are autistic are under the age of 40. As with diagnosis of autism nationally, there is an approximately 3:1 ration of males:females diagnosed with autism – this may reflect differences in presentation and diagnosing of autism between males and females.

Under the Equality Act, a person has a disability if they have a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. Autism qualifies as a mental and/or physical impairment. A person does not have to have a formal diagnosis to be considered disabled. Many autistic people do not identify as having a disability but understand that being autistic entitles them to protections under disability legislation.

There are additional social issues experienced by autistic people including experience of care, stigma/discrimination, under/unemployment, lack of support/reasonable adjustments in educational and employment settings, housing, and being victims of crime. Additionally, autistic people may experience other health and wellbeing conditions than the general population, such as epilepsy, mental health conditions, neurodevelopmental disorders, and functional problems and disorders such as sleep disturbances and vision/hearing impairment. Depending on the individual and their level of need, an autistic person may also require support to access services. Some people may require personal support to help them navigate complicated processes and environments, which can be provided by carers (either professional staff or unpaid carers such as family members), particularly given the disadvantages autistic people may experience in care settings due to clinicians not having training or experience in responding to the needs of autistic individuals. That said, given autism involves difficulties in social communication, this may make it difficult for autistic people to form and sustain relationships and thus they may have smaller networks for social and caring support.

The Care Act places a duty on local authorities to *provide preventative support for people in their communities*. As part of this duty they are required to consider the needs of autistic people living in their area who *do not* meet the eligibility threshold for social care While there are a number of programmes and services available to autistic people living within Hackney and the City, there are also areas for further development, such as targeting supported services for BAME communities and older people and more robust reporting and data collection.

There is therefore a need to address the experiences of autistic people within a person-centred approach, incorporating a social model of disability, improving training/awareness, developing better diagnosis and care pathways, providing effective support and service planning and delivery, working with communities and carers, redeveloping housing and employment pathways, and building on existing national and local policies and strategies.

This needs assessment will highlight areas of need relating to health and wellbeing for autistic children and adults who are resident in the London Borough of Hackney and the City of London. It will suggest recommendations for meeting the needs of this population and aims to guide the development of services in the boroughs of Hackney and the City of London.

Contents

1 Introduction

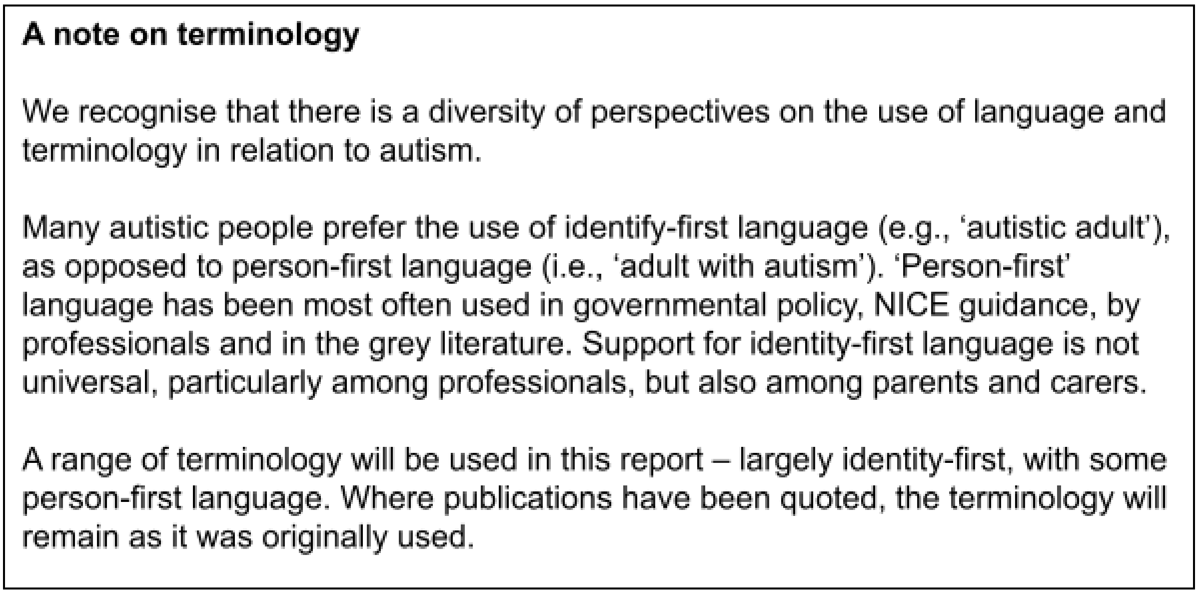
This report describes the findings of a population health and wellbeing needs assessment of autistic adults and children in Hackney and the City.

1.1 Defining autism

Autism is a lifelong neurodevelopmental condition. It affects how an individual perceives the world around them and how they communicate with others [1]. It is a spectrum condition: a person with autism may have some but not all of the features of the condition, presentation varies from one individual to another. The term 'spectrum' therefore denotes the wide variability in manifestations of the condition and therefore the vast range of different needs that people with autism may have. On a population level this can make identification and service planning challenging.

The Autism Act was passed in 2009. The Act required Government to produce a strategy for meeting the needs of adults with autism. The first national strategy, *Fulfilling and Rewarding Lives*, was published in March 2010. [2]

Box 1: A note on terminology



A note on terminology

We recognise that there is a diversity of perspectives on the use of language and terminology in relation to autism.

Many autistic people prefer the use of identify-first language (e.g., 'autistic adult'), as opposed to person-first language (i.e., 'adult with autism'). 'Person-first' language has been most often used in governmental policy, NICE guidance, by professionals and in the grey literature. Support for identity-first language is not universal, particularly among professionals, but also among parents and carers.

A range of terminology will be used in this report – largely identity-first, with some person-first language. Where publications have been quoted, the terminology will remain as it was originally used.

There have historically been several defined behaviour profiles in autism[1]. Nearly half of autistic people have a learning disability[2], but many will have a normal or above-average intellectual ability (often described as 'high-functioning'). Autism is often described as a 'hidden impairment': autistic people with normal - or above normal - intellectual ability may not have an obvious physical disability and their

---

[1] Behaviour profiles defined in autism include: *atypical autism, classic autism, Kanner autism, pervasive developmental disorder (PDD), high-functioning autism (HFA), Asperger syndrome* and *pathological demand avoidance (PDA)*.

[2] A learning disability is defined as having a significant impairment of intellectual functioning, significant impairment of adaptive/social functioning; with an age of onset before adulthood [105]. This is different to 'learning difficulty', which is often used in educational settings and refers to individuals who have specific problems with learning.

verbal and language skills may appear normal, but their ability to perform everyday tasks may still be impaired. A person with Asperger's syndrome would fit this profile: generally there is no delay in development of cognition and language - but there may be difficulties with social communication and/or motor developmental delay.

The diagnosis of autism is clinical; there are no biochemical or radiological tests available. Diagnosis is made often with the aid of diagnostic tools such as questionnaires in adults and by multidisciplinary assessment in children.

The DSM-5 diagnostic manual groups the profiles under the same umbrella term of 'autistic spectrum disorder'. [3] For the purposes of this needs assessment, the term 'autism' will be used to refer to all diagnoses on the autism spectrum.

Diagnosis requires presence of the following features:

1. *Persistent difficulties with social communication and social interaction*
2. *Restricted and repetitive patterns of behaviours, activities or interests (this includes sensory behaviour*[3]*)*

Diagnosis is made based on the above features if they have been present since early childhood and if they are to the extent that they 'limit and impair everyday functioning'. [3]

Under the Equality Act, a person has a disability if they have a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. [4] Autism qualifies as a mental and/or physical impairment. A person does not have to have a formal diagnosis to be considered disabled. Many autistic people do not identify as having a disability but understand that being autistic entitles them to protections under disability legislation (discussed later in section 4.1.6).

1.2 Purpose of this needs assessment

In June 2009 the National Audit Office published a report on the services available to autistic adults in England. [5] The authors commented on the limited data available (in terms of service uptake) when trying to compare outcomes between people with and without autism accessing services. The key areas for improvement identified were the need for (i) better strategic planning and (ii) raising of awareness of the nature of autism and the needs of autistic people.

The Autism Act remains the only disability-specific law in England. *Fulfilling and Rewarding Lives,* the first autism strategy, was built on and updated in 2014 with *Think Autism* [6].These will be discussed in more detail in section 3.1.1.

---

[3] Many autistic children and adults experience sensory issues; this can present as an oversensitivity or lack of sensitivity to auditory, visual, olfactory or tactile stimuli. In certain environments exposure and oversensitivity to multiple stimuli can be overwhelming. This experience may be termed 'sensory overload'. The person may demonstrate stereotypic behaviours, 'stimming', which can be a coping mechanism to help them manage this.

A population health needs assessment was undertaken to review the health and wellbeing issues facing autistic children and adults in the City and Hackney. The specific objectives of this needs assessment are set out below, along with the relevant chapter(s) of this report that address them.

Table 1: Objectives of this needs assessment

Needs assessment objectives:	Covered in chapter:
Discuss the main concepts in relation to autism and define the objective of the needs assessment	1. Introduction
Outline the main data sources and limitations	2. Methods and limitations
Discuss the influences on health and the wider social determinants of health affecting this population	3. Health and wellbeing impacts
Outlining extant policies, strategies, and best practice recommendations for addressing and meeting the needs of this population	4. Evidence and best practice
Describe the prevalence of autism in Hackney and the City	5. Local data and inequalities
Describe current health and related services and support available locally for people with autism	6. Local services
Make recommendations for commissioning and service provision, based on the evidence presented	7. Recommendations
Giving an overview of the literature regarding specific needs in this population	8. References

1.3 Scope

This needs assessment will highlight areas of need relating to health and wellbeing for autistic children and adults who are resident in the London Borough of Hackney and the City of London. It will suggest recommendations for meeting the needs of this population and aims to guide the development of services in the boroughs of Hackney and the City of London.

2 Methods and limitations

2.1 Introduction

This chapter aims to give a brief overview of the methods used to capture and describe the health and wellbeing needs of autistic children and adults in the City and Hackney. The chapter is structured around the key chapter headings used in this report. Some of the methodological and data limitations which may affect the results and conclusions are highlighted.

1.1

1.2 Literature review and data sources

Key governmental policies relating to the health and wellbeing of children and adults with autism were searched for using the Gov.uk website and the national archives relating to governmental documents.

Major policies and reports produced by national organisations were identified either through hand-searching the references of previously identified reports, or through a search of the grey literature via Google Scholar in relation to autism and the wider determinants of health as suggested by the Dahlgren and Whitehead model. [7]

Following local discussion, current strategies produced by the Hackney and City Public Health team were also reviewed: for example, the Adult learning disabilities and Disabled children and young people Joint Strategic Needs Assessment (JSNA) chapters.

Relevant National Institute for Health and Care Excellence (NICE) guidance regarding best practice was identified through searching the NHS Evidence website. Further local data have been provided by the Clinical Effectiveness Group, Adult Social Care and Hackney Learning Trust. Where relevant data have not been available from these sources, a search of the grey literature for further information via Google has been performed.

Information regarding current local service provision was collected by contacting relevant contacts - within the Council, diagnostic services and Hackney Learning Trust -obtained through colleagues in Public Health. If the information required was outside the scope of one contact’s service or knowledge, the contact would signpost to other contacts. Key services and organisations were identified through collaboration with the Autism social worker, Adult Social Care, Autism Alliance Board, Local Offer lead and other colleagues within Hackney Council, the City of London and community groups.

1.3 Limitations

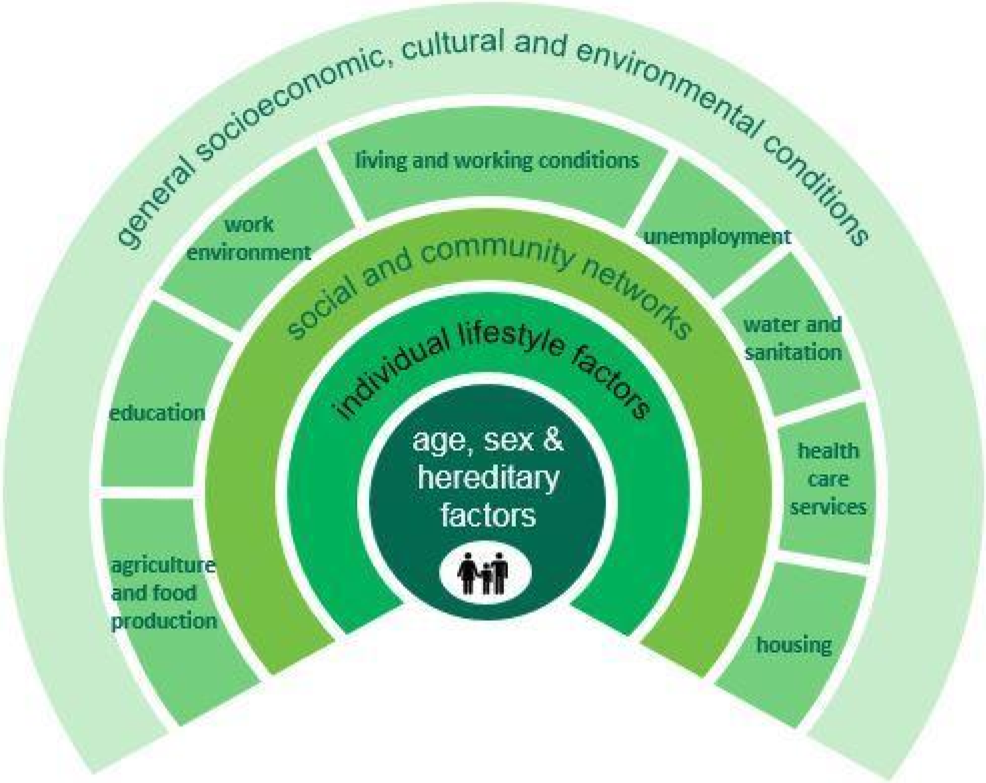
The rapid evidence review has attempted to be as comprehensive as possible in describing the health and wellbeing impacts of autism and what the best practice evidence suggests for meeting the needs of this population. In addition, efforts have been made to describe the full range of health, care and related services available to children and adults with autism in Hackney and the City within the time and resources available. However, it is possible that some relevant research or policy papers have not been identified and, therefore, their recommendations not reflected in the results. It is also likely that some services or programmes have been omitted, particularly those delivered by the voluntary sector.

2 Health and wellbeing impacts

Autism is a spectrum condition, which means the presentation of the condition varies significantly between autistic individuals.

In a clinical setting there are a range of physical and mental health conditions that are more prevalent in autistic people (discussed later in this section). The health and wellbeing of populations is affected not only by individual genetic and lifestyle factors, but on a larger scale, the environments in which the population lives and works – for example, education, housing conditions and others – often termed the 'wider determinants of health' – represented in the Dahlgren-Whitehead model, shown in Figure 1. The literature suggests that having autism may adversely affect some of the wider determinants of health. Having autism is thought to affect multiple aspects of an individual's life, from how they are educated, find employment, access local services (including housing) or form relationships and community networks. Autistic people have been shown to have a significantly lower life expectancy than people who do not have autism. [8]

Figure 1: The Wider Determinants of Health



Source: Dahlgren and Whitehead, 1991 [7]

Due to the spectrum nature of the condition, it is inevitable that there will be a subgroup of people with autistic traits who do not have a formal diagnosis of autism, and who remain undiagnosed throughout their lifetime. It is unlikely that they have been captured as part of the population of interest in this needs assessment. This subgroup may have experienced adverse health and wellbeing outcomes by not having access to services.

2.1 Life expectancy

The effect of autism on life expectancy has not been studied on a large scale in the UK population. [9]

In a large-scale case-control study in Sweden, researchers found that life expectancy was 16 years lower for people who had a diagnosis of autism compared to those without. [8] Autistic people were significantly more likely to die earlier from all causes of death studied apart from infection. The most significant causes of death were epilepsy and suicide. The prevalence of epilepsy among autistic people is at least 20 times higher than that of the general population. [10] Other clinical conditions which have been shown to occur more frequently in autistic people will be explored in Section 3.2.

The Swedish study above showed that there was eight times the odds of dying by suicide by those with autism than their matched controls. The risk was greater in people with 'high-functioning' autism compared to 'low-functioning' autism. This is supported by results from a UK study which demonstrated a significantly higher rate of suicidal ideation among people with Asperger's syndrome (66%) than in a general population sample (17%). [11] The rate of suicidal ideation was higher than the rate of self-reported depression, suggesting that the interplay between the two may be different in this population and therefore require different preventative strategies. [11]

It is likely that there are several inter-relational factors that contribute to the lower life expectancy. [8] Modifiable lifestyle risk factors for disease have been noted to be more prevalent in people with autism. Difficulties in accessing healthcare services – which may be related to differences in how autistic people experience illness and disease, staff attitudes and communication, and clinical environments which may be hostile and inhospitable to an autistic person - may also contribute. [12] These factors will be explored further in Section 3.3.

2.2 Prevalence of co-existing conditions

There are a number of clinical conditions that occur at disproportionately higher rates in autistic people in comparison to people in the general population. The National Institute of Clinical Excellence (NICE) refer to these in their guidelines (CG12: Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum) as 'co-existing conditions'. [13] Why these disorders are observed more frequently is not well understood. In addition, the quality of the available evidence on this subject is low, with prevalence estimates on the same condition varying widely between studies and lack of replication of findings across studies. The variation in prevalence estimates may reflect differences in how co-existing conditions were identified in each study and differences in the populations studied. [13] It was not possible judge how comparable the studies were with each other and how applicable to the UK population they could be. Despite this, NICE recommends assessing for the disorders they consider as co-existing conditions to facilitate prompt identification and intervention by clinicians. [13] The list is not exhaustive; the conditions were selected on the basis that they were more prevalent in autistic people, had a high impact on present quality of life, and had the potential to impact on the future development of the child or young person.

Box 2: NICE guidelines for assessment of coexisting conditions

Consider whether the child or young person may have any of the following as a coexisting condition, and if suspected carry out appropriate assessments and referrals:
Mental and behaviour problems and disorders:

- ADHD
- anxiety disorders and phobias
- mood disorders
- oppositional defiant behaviour
- tics or Tourette syndrome
- OCD
- self-injurious behaviour.

Neurodevelopmental problems and disorders:

- global delay or intellectual disability
- motor coordination problems or DCD
- academic learning problems, for example in literacy or numeracy
- speech and language disorder.
- Medical or genetic problems and disorders:
- epilepsy and epileptic encephalopathy
- chromosome disorders
- genetic abnormalities, including fragile X
- tuberous sclerosis
- muscular dystrophy
- neurofibromatosis.

Functional problems and disorders:

- feeding problems, including restricted diets
- urinary incontinence or enuresis
- constipation, altered bowel habit, faecal incontinence or encopresis
- sleep disturbances
- vision or hearing impairment.

Source: NICE [13]

This list of co-existing conditions has been developed by NICE in order to help clinicians identify their presence and intervene early. While this list is helpful, some of the conditions are very rare and not well understood - it important to highlight some of the more commonly occurring co-existing conditions to be aware of and those on which a meaningful impact could be made. These are: learning disability, attention deficit hyperactivity disorder (ADHD), epilepsy, obsessive compulsive disorder (OCD) and anxiety and depression; epilepsy, anxiety and depression being particularly important in light of epilepsy and suicide being the major causes of death in autistic people. These have been summarised in Table 2.

Note the addition of obesity to the table. Though not selected as a co-existing condition by NICE, obesity is more prevalent in children and adolescents with autism compared to the general population [14] [15]. Obesity is an important issue in City and Hackney, hence its inclusion in this report. There is a high prevalence of child obesity in the local population. Child obesity is a strong predictor of adult obesity. For more information on this please see the Obesity JSNA chapter.

Table 2: Co-existing conditions associated with autism

Clinical condition	
Learning disability	A learning disability is a lifelong condition which affects learning across all areas. Not all autistic people have a learning disability. Prevalence estimates based on the work of Baird et al (2006) indicate that 55% of autistic people also have an IQ below 70 (an indicator of learning disability). [16] Autism is more common among people with a learning disability. Rates of autism in people with learning disability range from 20-36% among children with severe learning disability and 5-14% in children with a mild learning disability. [17]
Attention deficit hyperactivity disorder (ADHD)	ADHD is a neurodevelopmental disorder with onset in early childhood, characterised by symptoms of inattention, impulsiveness and/or hyperactivity. [18] Self-reported rates of ADHD among autistic adults are higher than that of the general population. [19] Prevalence estimates for clinically significant levels of ADHD symptoms in autistic people vary widely between studies, from 16% to 75%. [20]
Epilepsy	Epilepsy is a neurological disorder marked by seizures. It confers on the individual a risk of sudden death independent of other co-morbidities. An estimated 20-40% of autistic people have epilepsy, compared to 1% of the general population. The rate of epilepsy is higher among autistic people and a concurrent learning disability. [10] As previously noted, epilepsy is one of the major causes of earlier mortality in the autistic population.
Obsessive compulsive disorder (OCD)	OCD is characterised by presence of obsessive thoughts and/or compulsive behaviours. A core feature of autism is a repetitive and restrictive behaviour pattern and it has been postulated that the conditions may be related. A Danish study found that autistic people were up to twice as likely to have a later diagnosis of OCD. [21]
Anxiety and depression	There is a higher prevalence of both anxiety and depression in autistic people compared to the general population. A systematic review by Hollocks et al showed that the lifetime prevalence of anxiety and depression among autistic adults was 42% and 37% respectively. [22] A review of studies looking at diagnosed anxiety disorders in autistic children found prevalence estimates ranging from 42% to 55%. [23]
Obesity	Obesity is more prevalent in children and adolescents with autism compared to the general population [14] [15]. In a US study, older age, lower parent education levels, presence of

	sleep disorder and anxiety and/or depression were predictors for unhealthy weight in the population studied [15]. Similar results have been obtained in adults [24].

2.3 Access to services

There are several factors which affect an individual's access to services - these are explored in detail in the *Use of Local Services* chapter of the JSNA. [25] [26]

Depending on the individual and their level of need, an autistic person may require support to access services. Some people may require personal support to help them navigate complicated processes and environments, which can be provided by carers (either professional staff or unpaid carers such as family members).

'Reasonable adjustments' are a key stipulation under the Equality Act and are designed to support people with a range of needs (including those with autism) to access services. Reasonable adjustments are explained in more detail in the *Evidence and Best Practice* section of this report. [27] [4]

For autistic adults there can be specific barriers that affect access to services. The Westminster Autism Commission is an independent cross-party group of parliamentarians, stakeholders, autistic adults and parent-advocates set up with the aim of making society more autism-friendly. In 2016 they published a report on access to healthcare for autistic people and cited several obstacles impacting on health care access including: [28]

- Lack of training for health professionals and lack of strong accountability and leadership to ensure that health services meet the specific needs of the autistic population;
- Leading to perceived poor understanding of autism and the feeling among autistic people that their health treatment is unsatisfactory
- Sparse data collection on autism leading to autism being 'invisible' in the health system. 74% (n= 241) of autistic people and parent-advocates surveyed as part of data gathering for the report said their GP did not make any reasonable adjustments for them or their autistic child. This suggests that health professionals may not consistently identify autistic people and make accommodations for their needs
- Autistic people reported that they can struggle to identify changes in their health needs and seek appropriate help.
- Social isolation; some autistic people may need assistance to access healthcare but many are socially isolated and lack support networks

First-hand experiences of autistic people and their carers were published as part of a national Self-Assessment exercise in 2016. Common themes were highlighted as having a negative impact on patient satisfaction and experience, some of which are outlined below. [27]

Staff awareness and communication
In the context of healthcare services, autistic people may be disadvantaged by clinicians looking after them who have not had training or experience in looking after

autistic people or are unaware of the particular needs of that individual. [5] This can mean reasonable adjustments are not made to meet that person's needs. This may then affect their engagement with health professionals in the future.

Due to difficulties with language and communication, autistic people may find it difficult to report physical symptoms and communicate their needs. This can complicate the diagnostic process. Many autistic people have sensory processing difficulties that mean they require additional time to process verbal information. Adults may experience difficulty if questions asked of them are vague or non-specific. Instructions may be taken literally, for example, 'take a seat outside [in a waiting room]' may lead to the autistic person literally going outdoors to wait. [29] A child who is unable to verbally communicate their needs may have early barriers to accessing healthcare until a diagnosis is made. They may be perceived as having a 'tantrum' or behaving badly when distressed. [30] Authors of a German study on barriers to health in autism suggested autistic people may experience tactile sensitivity and refuse physical examination. [31]

The barriers are not exclusive to healthcare experiences. An autistic person presenting to services in the community could be perceived as being rude or 'odd' by lack of eye contact or demonstrating stereotypic behaviours. This may impact on the attitude of staff towards the autistic person. Lack of tolerance from others (subsequently increasing stress and anxiety in the autistic person and/or their carer) has been cited as a barrier to accessing services. [32]

Environment

Another barrier to accessing services can be the environment. For example, a waiting room at a GP surgery may have disturbing levels of light and noise which can be distressing to an autistic child or adult with sensory sensitivity. It can be difficult for a person who relies on structure and routine to understand or cope with the unpredictability of long waiting times or cancellations. [31] This can also be the case for community statutory services and employment services as well as with transport services. The unpredictable nature of public transport for example has been cited as particularly stressful – when a bus does not arrive at the stated time or is overcrowded this can create significant anxiety and potentially increase social isolation as the individual avoids this mode of travel in the future. Examples of good practice have been given where bus drivers recognised that the individual (giving the account of their experience) required time to find a seat before the bus started driving away from the stop. [32] This is an example of a reasonable adjustment. There is an interplay here with staff awareness and communication – training of staff in understanding the importance of reasonable adjustments is critical to ensuring that environments are acceptable to autistic people.

2.4 Lifestyle and behaviours

Individual behaviour plays an important role in determining how healthy or unhealthy people are. The *Lifestyle and Behaviour* chapter of the JSNA outlines how individual health behaviours are rarely a free lifestyle 'choice', but are strongly determined by the environmental, cultural and social influences a person is exposed to. Behavioural risk factors such as smoking, alcohol, physical activity, diet and substance misuse all impact upon an individual's risk of disease, disability and death. [33]

Table 3 summarises the main behavioural risk factors for health and their association, if any, with autism, with supporting evidence from the literature.

It should be noted that the majority of the evidence base is affected by recruitment bias, where the sample populations were taken from diagnostic centres[4] which means results may not be generalisable to all autistic people.

Table 3: Individual lifestyle factors and their prevalence in autistic people

Lifestyle factors	Prevalence
Smoking	Reports in the literature are inconsistent. In a UK adult population, smoking rates for autistic people were broadly similar to that of the general population [34]; in another study the rate of smoking among autistic adults was lower [35].
Alcohol	Reports in the literature are inconsistent. Alcohol abuse has been shown to be less common in autistic adults and adolescents. [24] [36] [37] In contrast, increased problematic alcohol use has been reported among autistic adults compared to matched controls. [34] In this study there was no difference in rate of alcohol uptake in the autism group but it was found that once drinking had been established, autistic people were more likely to get into a more problematic pattern of drinking. The authors hypothesised this could be a form of self-medication for anxiety or to facilitate social interactions.
Substance misuse	Varying prevalence estimates for different age groups have been reported. As above, studies have reported that adolescents with autism are less likely to have substance misuse problems. [37] A study performed in a UK adult population found a prevalence of substance misuse of 30% in those with autism which is comparable to reported figures for people with mental health conditions but more than would be expected in the general population. [38] In a population of older adults studied, substance use was uncommon [36].
Diet	Individuals with autism can have unique behaviours around food. Food selectivity encompasses food refusal, having a limited repertoire of tolerated foods and high frequency of eating the same thing. This is more commonly seen in autistic children compared to typically developing children. Food refusal and a limited repertoire can arise from aversion to specific textures, colours, smells, temperatures, rigidity with brands. This can lead to a restricted diet which may result in nutritional deficiencies [39].
Physical inactivity	Autistic children and young adults have generally lower levels of physical activity and higher levels of sedentary behaviour when compared to typically developing children. [40] Possible reasons

---

[4] Centres where either a carer or an individual have self-reported autism symptoms and may receive further investigation to determine a diagnosis

	may include disinterest in a particular sport, insistence on completing activities others may find less worthwhile, poor coordination, challenging behaviour, reduced understanding of instructions and reluctance to engage in team sports.

2.5 Social and community networks

Social relationships affect mental and physical functioning, health behaviours and the risk of mortality. Social isolation is detrimental to an individual's physical and mental health. [41]

One of the key features of autism is difficulty with social communication and understanding social relationships. There is a wide range in how this manifests in different individuals. The difficulty can range from a child being 'non-verbal' or displaying a delay in development of speech and/or limited vocabulary, to an adult with normal verbal skills but inability to make eye contact, respond to questions appropriately or recognise social cues. It could be inferred that these traits could make it difficult for autistic people to form and sustain relationships. This can lead to social isolation, loneliness and depressive symptoms. [42]

Gender appears to be a factor in the presentation of autism and differences have been observed in the social motivation (the need for social interaction and acceptance by others) displayed by boys and girls with autism. Studies have shown girls with diagnosed autism tend to have similar levels of social motivation and similar quality of friendships to girls without autism, while boys have had significantly lower social motivation and report different quality of friendships compared to boys without autism. [43] Girls may develop compensatory behaviours such as staying in close proximity to peers, whereas boys may play alone making their social challenges easier to identify. [44] This may account for under- or delayed diagnosis in this group. Delayed diagnosis could lead to reduced access to support services and poorer health outcomes. [44]

Studies on social networks in autism have largely been performed in children and adolescents. As autism is a lifelong condition it is likely that any impairments will persist into adulthood. In a UK study there was a significantly lower rate of marriage among autistic adults compared to adults without autism. [34]

2.6 Crisis behaviours

Autistic children and adults can experience periods of acute agitation, termed crises, or meltdowns. [45] These are usually temporary and represent a maladaptive response to an accumulation of stressors. Triggers can include sensory issues, changes in routine, anxiety and communication difficulties. The behaviours displayed in a crisis can be verbal (e.g. shouting and crying) or physical (e.g. aggression and self-harm). Episodes of crisis can be difficult to predict and difficult to manage by carers because autistic people may be less likely to respond to verbal intervention and may also not be able to explain what is triggering the crisis. [45]

2.7 Housing

Health and wellbeing is shaped by the places and environments in which people live their lives. These include the home, educational establishment and workplace.

The housing needs of autistic people vary significantly and this reflects the wide spectrum nature of how people present with the condition. Some specific areas that have been highlighted by policy include consideration for adults being cared for by family members and what might happen when their carers develop their own increasing health and care needs [12].

A study in the UK showed there may be a high rate of underdiagnosis of autism in homeless people, with autistic traits found in 12.9% of the study population. [46]

2.8 Education and training

An independent report on autism and education published by the All Party Parliamentary Group on Autism found that children with autism were particularly vulnerable to bullying and were at high risk of exclusion. Lack of understanding from some schools resulted in childrens' anxiety being misinterpreted as bad behaviour. Parents reported experiencing frustration in trying to find the right provision for their children. [47]

The report found that: [47]

- Less than 50% of children and young autistic people said they were happy at school
- Less than 50% of parents said that their child's school place fully met their child's needs.
- 70% of parents said that support was not put in place quickly enough for their child.
- Less than 50% of teachers said that they were confident about supporting a child on the autism spectrum.

In 2018, autism was the most common type of primary need for an Education, Health and Care plan (EHCP; discussed further in Section 3.8), recorded as a need for 28.2% of pupils. [48]

2.9 Employment and unemployment

Paid work can promote social inclusion, confidence and financial independence, all of which have positive impacts on health and wellbeing.

In a 2016 survey of autistic people performed by the National Autistic Society found: [49]

- 77% wanted to work.
- 16% were in full-time paid employment – static since 2007
- 16% were working in paid part-time employment, an increase from 9%

In this survey, employees reported feeling that their employers did not make the most of their skills while employers reported worrying about not approaching the employee's autism in the correct way.

Jobseekers with autism may find employment service (e.g. Jobcentre) environments too noisy and stimulating. Some may find the written correspondence from the Jobcentre difficult to understand. People may have difficulty communicating during job interviews without adequate support and reasonable adjustments - they may not understand the questions asked and could be perceived negatively by a prospective employer if they avoid making eye contact. [50]

2.10 Living and working conditions

Autistic people may struggle with relationships with colleagues and employers. Lack of awareness from other staff can lead to bullying. [49] These can have sustained impacts on an individual's confidence, social functioning and mental health.

2.11 Criminal justice system

An autistic person, regardless of whether victim, witness, or offender may find the experience of criminal justice proceedings distressing at multiple stages. For example, the sensory input of bright lights and noise of police sirens; processing difficulty delaying understanding of questions when being interviewed; new and alien environments (for example, a courtroom, police station or prison); and lack of awareness of staff, who may mistake lack of eye contact and communication difficulties for rudeness or defiance.

Research into Antisocial Behaviour Orders found that people with learning disabilities or autistic spectrum disorders often did not understand the terms of the Order or why it was imposed. This makes compliance with such community-based penalties highly unlikely, which in turn increases the likelihood of eventual custody. [51]

Prison can have an adverse effect on the health and wellbeing of an autistic individual. Governments, according to the World Health Organisation, have "a special duty of care for those in places of detention which should cover safety, basic needs and recognition of human rights, including the right to health." [52]

The Equality Act requires that public organisations take into account of how the experience of their services may differ in people with autism and make reasonable adjustments so that this group is not disadvantaged. [4].

Identification of people with autism (in order for reasonable adjustments to be made) is difficult if individuals with autism do not disclose the diagnosis or, indeed, are undiagnosed. [53] A study looking at autism awareness among prison staff found that a third of staff surveyed did not know what autism was. Less than half of staff surveyed were not aware of whether or not they had worked with an autistic person. [54]

There have been no published studies looking at the prevalence of autism in English prisons. A study in a secure hospital (a hospital in which offenders are detained, usually under the Mental Health Act) reported a 2.3% prevalence of Asperger's syndrome, compared to 1.1% in the general population [55] [56].

2.12 Carer health and wellbeing

An informal carer includes any person – such as a family member, friend or neighbour – who is giving regular, ongoing assistance to another person without payment for the care given.[5] Carers of children or adults with autism may face considerable challenges. [57] For example, many parents cite the frustrating process of finding the right educational setting to meet their child's needs. [47] Pressures may be emotional, financial/employment and time burden related and can consequently affect the health and wellbeing of the carer. [57]

There are higher reported rate of stress, depression and anxiety in parents of autistic children compared to parents of typically developing children. [58] Addressing the needs of carers is imperative in order to improve the quality of life of the autistic individual. Behavioural intervention strategies in autism are reportedly less effective if parental mental health needs are not met. [58]

Carers have the right to request an assessment from local social care teams to ensure they are adequately supported. [59]

2.13 Health and wellbeing impacts – key points

This chapter has explored the health and wellbeing impacts of autism on both an individual level and, through its effect on the wider determinants of health, on a population level.

Autistic children are more likely to be overweight, have restricted diets and perform less physical activity [14] [15] [39] [40]. There is a higher prevalence of modifiable lifestyle risk factors among autistic adults and a higher rate of anxiety, depression, learning disability and epilepsy. [13]

It can be challenging to obtaining the right educational support for autistic children and, in addition to the child not being able to meet their maximum potential, this can cause considerable parental stress. By its nature, autism can affect the individual's ability to form connections with others. Many autistic people wish to work but are unemployed. [49] This may be due to lack of employment support or due to unsuitable work environments or employer attitudes. This can contribute to social isolation.

Autistic people may face barriers to accessing community and healthcare services; these include reduced awareness among staff, communication barriers and lack of

---

[5] Informal carers may be in receipt of Carer's Allowance, which is money (provided by central government) to support people in their caring role. This is not the same as being paid to provide care to others as a 'care worker' in a professional capacity.

reasonable adjustments. [32] Unaddressed problems can lead to deterioration of mental and physical health.

It should be acknowledged that many autistic people see their autism as an integral part of their identity rather than a disease, disorder or problem that needs to be cured. However there is a growing body of evidence that suggests that the autistic population are at a greater risk developing health and social problems and having a reduced life expectancy than those that are not autistic. [8] It is important to highlight these inequalities so that changes can be made to redress the balance.

3 Evidence and best practice

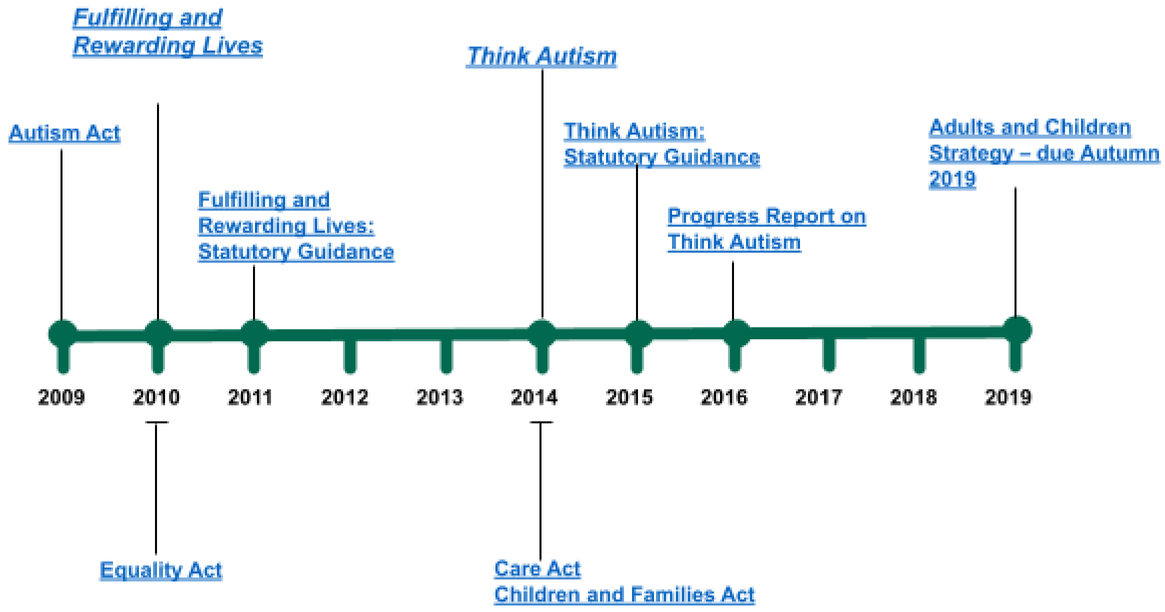
This chapter describes some of the key policies, guidance and evidence-based interventions which aim to improve the lives of autistic people. Current National Institute for Clinical Excellence (NICE) guidelines will be described in greater detail in section 4.2.1.

Figure 2 provides a visual summary of the key national policy documents published in the last decade which impact upon the lives of autistic people. During this time period there has been significant political change which has coincided with large reforms to the health and care sector.

The Autism Act, passed in 2009, required the Government to produce a strategy to meet the needs of autistic adults. The first national strategy, *Fulfilling and Rewarding Lives*, was published in 2010, followed the year after with statutory guidance for local authorities on its implementation. [60] [61] The Strategy was updated in 2014 with *Think Autism*. Think Autism placed a new focus on increasing awareness of autism, improving community involvement and innovative ideas to improve the lives of autistic people. [12] The strategy was updated in line with recent wider legislative changes; these included the introduction of the Care Act and educational reforms brought in as part of the Children and Families Act, both of which had impacts on autistic children and adults. [62] [59]

The national strategy is aimed towards meeting the needs of autistic adults. However it does place a focus on young people in regards to their transition to adulthood. . In this report, legislation that is not necessarily autism-specific but which is relevant to autistic children will be referred to. A new national autism strategy for adults and children is due to be published in Autumn 2019.

Figure 2: Infographic on the key policy drivers for autistic people (2009-2019)



3.1 Prevention

In this section, prevention refers not to preventing the onset of the condition but prevention of escalating need or requirement for support. The focus in this section is on secondary and tertiary prevention, whereby support is provided, services planned and adaptations are made to reduce the impact that being autistic might have on the individual’s health and wellbeing. This includes removing barriers to accessing healthcare, appropriate educational support and employment.

3.1.1 Supporting the needs of people who may not qualify for statutory social care support

Evidence suggests there is a high proportion of autistic people who do not meet the criteria for statutory social care support, despite having impairments that increase their vulnerability to poor health. [63]

The Care Act places a duty on local authorities to *provide preventative support for people in their communities*. As part of this duty they are required to consider the needs of autistic people living in their area who *do not* meet the eligibility threshold for social care. [59] Assessment of eligible needs should not be influenced by availability of services. [64]

The social communication difficulties and sensory issues that affect many autistic people can hinder the development of social connections, access to employment and appropriate housing. This can lead to loneliness, isolation and vulnerability towards developing mental or physical ill health leading them to require more support in future. Low level support can take the form of: mentorship, buddy systems, projects which aim to promote inclusion in social activities, or support with finding employment, for example. [12]

A review of evidence performed by the Department of Health in 2016 explored the effectiveness and cost-effectiveness for low level support for people with ‘high-functioning’ autism. [63] A service mapping exercise was performed as part of this to see what strategies were being used in England. The report acknowledged the paucity of research on efficacy of many of the strategies currently employed. There was no evidence of significant adverse effects. For some of the services provided, such as employment support and training in social skills, there was some evidence to support their continued use. Rather than concluding a lack of efficacy in low level support strategies, the report highlights a need for greater research in this area.

3.1.2 Targeting support to known inequality groups

Targeting support to particular societal groups is an important step to address health inequalities experienced by autistic people.

In a report commissioned by the National Autistic Society, families of autistic children within Black, Asian and Minority Ethnic (BAME) communities reported difficulties in obtaining a diagnosis, accessing services and integrating the child within the community. [65] Certain additional challenges were found to be more prevalent in BAME communities, some relating to the communities themselves, including: low level of knowledge of autism as a condition, services available, and parental rights. Families can experience shame and stigma and a feeling of needing to cope with the child’s autism independently.

Service providers should actively seek to engage with and be accessible to these communities. Awareness and understanding of autism in local BAME communities should be raised, where needed, and service providers’ information on autism and their services should be promoted to BAME communities (for example, through faith leaders and other community networks) and readily available in appropriate languages. Local authorities and Clinical Commissioning Groups (CCGs)[6] should consult families from BAME communities about their specific needs when commissioning autism services. [65] Ethnic diversity data should be recorded when gathering data on autism prevalence and on use of local services. [12]

Advocacy, translation and interpretation services should be provided for families from BAME communities who require support during and following an autism diagnosis. Peer support forums for parents and carers from local BAME communities should be commissioned and, where appropriate, support services tailored. [50] [65]

The updated national strategy highlighted the importance of considering services for older autistic people. [12] This is a historically neglected group in terms of service provision, as autism was only described in the 1940s. Therefore these are likely to have been the first generation of adults to be diagnosed and are now entering older age, which brings its own potential concurrent health conditions. This group is likely

---

[6] CCGs are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area.

to have had significant support from older relatives and advance planning of the care and support they are likely to need in future is vital. [12]

3.1.3 Autism Partnership Boards

One of the key recommendations in the original autism strategy, *Fulfilling and Rewarding Lives,* was that autistic people and their families should be involved in the development of local services. Every local area should have an Autism Partnership Board (APB) in place, the idea being that all relevant stakeholders, including autistic people and their families and senior commissioners of health and care services are all involved in identifying local need and planning appropriate services and support. The APBs should be comprised of individuals across public bodies - including social care, health, education, housing and criminal justice. They may work with other statutory local groups, such as Health and Wellbeing Boards. Effective APBs should define clear goals and monitor progress. [60] [61]

3.1.4 Service design and Joint Strategic Needs Assessment informed

The Autism Act, passed in 2009, required each local authority area to develop a local autism strategy. A key function of a local strategy is to enable the development and provision of health and social care services to meet the needs of autistic people (aged 14+). Local authorities should allocate responsibility to a named joint commissioner / senior manager to lead commissioning of community care services for adults with autism. [61]

Local service commissioning plans should reflect joint strategic needs assessment (JSNA) output and other prevalence data. [2]

3.1.5 Supporting independence

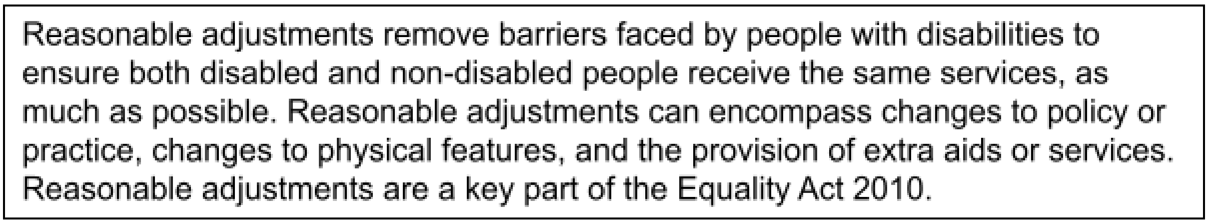
Fulfilling and Rewarding Lives placed a focus on improving access for autistic adults to the services and support they need to live independently within the community. Recommendations included:

- Use of reasonable adjustments (to physical environment, communication; See Section 4.1.6) as is a requirement of services underpinned by equality and human rights legislation – ‘disabled adults’ includes adults with autism.
- Personalisation of social care including direct payments and personal budgets. A person receiving direct payments can arrange their own services instead of receiving the services directly from the local authority with the aim of providing a person with more choice and control over the care services that they receive.

3.1.6 Reasonable adjustments

Autistic people should be able to benefit fully from mainstream public services to live independently and healthily, including access to appropriate housing to meet individual needs and education and employment services. Without reasonable adjustments many services can be inaccessible for autistic people.

Box 3: Reasonable adjustments



Reasonable adjustments remove barriers faced by people with disabilities to ensure both disabled and non-disabled people receive the same services, as much as possible. Reasonable adjustments can encompass changes to policy or practice, changes to physical features, and the provision of extra aids or services. Reasonable adjustments are a key part of the Equality Act 2010.

3.1.7 Education

The Children and Families Act 2014 introduced significant reforms to care of children and young people with special educational needs and disabilities (SEND). [62] The aim of the reforms was to better assess and support children and young people with SEND, including those with autism, and their families.

Special educational needs (SEN) support is provided in mainstream schools and this may be adequate for many children. Prior to the reforms, a child with SEND could have a statement of special educational needs, which would confer eligibility for a higher level of educational support. Learning difficulty assessments (LDA) were carried out for young people under 25 who were either in or about to enter post-16 education and who the local authority assessed as needing additional support. The Act replaced SEN statements and LDAs with coordinated Education, Health and Care Plans (EHCP). The latter were designed to be more person-centred and involve a more participative and coordinated assessment.

To be eligible for an EHCP the child needs to have a learning need that cannot be met by SEN support alone. If the child has a health need but does it does not affect their education, they do not require an EHCP – but would have a school based health plan. There is no requirement for a ‘primary need’ on an EHCP (as there was with SEN statements) as the emphasis is on meeting all the child’s needs rather than place a focus on one. A young person with an EHCP is entitled to receive support *up to the age of 25* provided they have a demonstrable ongoing educational need.

The process of requesting an EHCP and an outcome should take no longer than 20 weeks. The threshold for referral is low – the child has to have a suspected learning need.

Those with an EHCP may be entitled to a personal budget, which can be used to buy services that support their plan. The information required on an EHCP is divided into the following categories – the specific categories of need listed followed by the corresponding provision:

- Views/aspirations of the child or young person
- SEN needs
- Health needs
- Social care needs
- Outcomes
- SEN provision
- Health provision – Clinical Commissioning Group (CCG) or Local Authority (LA) funded – the organisations agree a percentage split
- Social care provision – e.g. personal budget
- Placement

If a provision is recorded in the EHCP it must be delivered. If a health provision is recorded, the CCG (or LA, depending on the service) has a statutory duty to provide this. A specific learning setting deemed and agreed to meet the child's needs is named on the EHCP and the LA then has an obligation to fund the child's place in that setting. If the setting is a registered school the EHCP funding goes to the school. Annual review of the EHCP is undertaken.

In 2015, of all children with SEN identified in the UK - with the primary need being an autism spectrum disorder - 60% had a SEN statement or EHCP. Most recent data from the Department of Education shows that the number of pupils in January 2018 with SEN increased from the previous year from 14.4% to 14.6%; the percentage of pupils with a statement or EHCP rose from 2.8% to 2.9%. 'Autism spectrum disorder' was unchanged as the most common type of primary need for a SEN statement or EHCP, for 28.2% of pupils. [48]

Local authorities, NHS bodies and NHS Foundation Trusts should recognise that young autistic people who do not have increased provision from an EHCP can still have difficulties across all four main areas of need:

- communication and interaction;
- cognition and learning;
- social, emotional and mental health difficulties;
- sensory and/or physical needs. [50]

Reasonable adjustments in education settings can benefit young autistic people. Examples of adjustments to the physical environment may include providing low-light and/or quiet areas.

Many young people with SEN will move on from the school or college setting at around age 19. Some may continue in a specialist or mainstream education setting, whilst others may continue their education outside a formal institution. Autistic young people with SEN, aged 19 or over, who do not have an EHCP (which would provide them with educational support until the age of 25), may be eligible for additional financial assistance. This may come in the form of Learner support funding, which is provided by the Department for Business, Innovation and Skills to colleges and training providers through the Education and Skills Funding Agency. This funding can contribute to reasonable adjustments (e.g. equipment) required. [12] It is means-tested and can be applied for through the learning provider, who decides on the funding amount. The money could be:

- a direct payment which does not need to be paid back
- a loan
- paid to someone else, for example a landlord

Priority may be given to those who are disabled, have a learning disability or are financially disadvantaged. The Government also provides individual support for disabled students in the form of disabled student allowances. These are non- means tested grants which are available for various types of support including hiring a note-taker, electronic equipment and software, social skills training, travel training, and 1:1 support. [12]

3.1.8 Employment support

Rates of unemployment are high among autistic adults. [49] Published in 2017, the report *Improving lives: the future of work, health and disability* sets out Government plans to transform employment prospects for disabled people and those with long term health conditions over the next 10 years. [66]

These include providing enhanced personalised support for autistic adults to find work and a focus on transition from education to employment. The Children and Families Act also placed an emphasis on supporting young people with SEND find employment. [62] Moving from the structured and supported environment of education to the unknown world of work can be particularly challenging for autistic young people. [66] Initiatives in progress include work experience programmes, supported employment and jobcentre support for schools targeting young people who have a health issue or disability that could disadvantage them in the labour market.

NICE recommend individual supported employment programmes for autistic adults without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment. [67] Supported employment will be discussed in Section 5. A programme may include help with CV writing, job applications, job matching, interview preparation, guidance on reasonable adjustments and support for the prospective employee and employer throughout the application process and after the employee starts work.

The face-to face consultation process involved in claiming social security benefits can cause anxiety for an autistic person. [12] Examples of reasonable adjustments to mitigate this include allowing the individual to bring a relative, friend or a professional who can support them to help manage any anxiety they may feel and who can provide additional information and explanations about the person’s difficulties. Frontline staff involved in making assessments for benefits should accommodate this and be trained to ensure they understand the needs of autistic people. [50]

3.1.9 Access to services

Autistic people can experience a number of potential barriers to accessing services. Both physical and mental health problems are more common among people with autism. During the life course an autistic person may develop long term conditions which require input from primary and secondary healthcare services. [8]

In a healthcare setting, an autistic person may not be able to describe their symptoms effectively, either due to their autism or perhaps as a consequence of co-existing anxiety or depression. For effective communication in this setting, the individual needs to be able to describe a certain physical or emotional state (including pain and discomfort) and be able to understand and process the information given to them. Both of these tasks can be difficult for an autistic person. They may need additional time to describe their symptoms but also may need to be asked specific questions in order to elicit symptomatology. Ambiguity should be avoided as it can cause confusion or be misinterpreted. They may require additional time to process written or verbal information, or require it in an EasyRead format. Being seen by an unfamiliar GP or other healthcare professional can be distressing for an autistic child or adult who is used to routine and familiarity. Many autistic people find it frustrating having to explain their history and the adjustments they require multiple time, to new faces. This can mean they have difficulty engaging with clinicians. The result is that important symptoms may not be elicited, and conditions may be overlooked. These barriers can lead to future avoidance of healthcare services, potentially impacting on health outcomes. [12]

The ‘Hospital passport’ was developed by the National Autistic Society (NAS). [68] It is a document designed to be completed and carried by the autistic person and presented to healthcare professionals in order for staff to be aware of their individual needs. This mitigates some of the need for the person to repeat themselves and the individual can choose to include information about how they communicate or express pain and what reasonable adjustments are needed. The document template was updated and evaluated in 2017 following consultation with autistic people and healthcare professionals. It is accessible through the following link: https://www.autism.org.uk/about/health/hospital-passport.aspx.

Since 2010, a number of guides have been published on making reasonable adjustments in health care settings. An example is the Green Light toolkit, which is a guide on auditing and improving mental health services to make them more effective in supporting autistic people and people with learning difficulties. [69]

Think Autism, published in 2014, recommended possible reasonable adjustments that could be implemented across multiple public service settings to improve access to services for autistic people. [12] These are grouped into four categories: Environmental; Processes; Communications and Planning and preparation:

- Environmental: taking account of hypersensitivities and providing quiet or lower-light areas. This could take the form of an ‘autism hour’ of low sensory stimulation, which could be during certain times of day and be implemented across a range of services – in a leisure centre or Jobcentre, for example.

- Processes: scheduling appointments (e.g. for outpatient clinics in secondary care or in primary care settings i.e. the GP surgery) at less busy times, allocating extra time to adults with autism and being flexible about communication methods, for example, less reliance on telephone-based services. This is particularly relevant in GP surgeries – difficulties making appointments over the phone, or challenges with telephone consultations have been cited as problematic for autistic people. [32] Providers of specific specialist services to people with autism should be exploring the use of assistive technologies with the people they support to help develop their confidence, sense of achievement and independence. [12]

- Communications: avoiding ambiguous questions, not pressurising adults with autism in conversation, being aware of sensitivity to touch; ensuring essential documents and forms are available in accessible formats, in particular, easy read versions and formats that take account of sensory issues in their choice of colours

- Planning and preparation: offering opportunities for adults with autism to visit settings in advance to familiarise themselves with what to expect, for example visiting a court prior to giving evidence or an optician's prior to an eye test. [12]

Carers often play an important role in advocating for the person they look after. For some autistic people, the carer is the person who knows them best. It is imperative that their views and opinions are taken into account both when the autistic person is accessing services and when local authorities are planning and developing services. [70]

The Westminster Autism Commission's report on access to healthcare made a series of recommendations including mandatory training and inspection, better data gathering – including for GP practices to keep a register of autistic people to allow reasonable adjustments to be made, running annual health checks and development of resources to help autistic people access healthcare. [28]

The Quality and Outcomes Framework (QOF) system was introduced in 2004. It is a pay-for-performance system in which GP practices are paid for achieving certain prescribed performance targets – 'indicators'. It comprises a significant part of practice income. In July 2017 NICE introduced a new Quality and Outcomes Framework (QOF) indicator, requiring that GP practices keep and maintain a register of all patients with a diagnosis of autism. [71] This should mean that patients who are autistic are easily identifiable to staff in the surgery and allow reasonable adjustments to be made to meet these patients' needs.

In its annual report on QOF in 2018, NHS England recruited and interviewed reference groups of patients, practices and commissioners to identify areas for improvement. [72] Participants suggested use of electronic flags to highlight patients in primary care that might require longer appointments. The Learning Disability and Autism group advocated prioritising access for certain patients to avoid anxiety when appointments are running late. The group also stressed the importance of providing

EasyRead information to support self-care. Echoing those surveyed in the Westminster Commission on Autism report, they also supported the expansion of the annual health check service to autistic people in order to improve quality of care and access. Providing support for people with autism was subsequently included as one of the specific actions in the NHS's Long Term Plan. [73] Commitments include the introduction of a 'digital flag' in the patient record by 2023/24 to ensure staff know that a patient has autism; providing information and training to NHS staff to support those with autism; ensuring reasonable adjustments are made so that wider NHS services can support people with autism; and piloting the introduction of a specific health check for people with autism (with wider extension if successful).

3.1.10 Housing

Fulfilling and Rewarding Lives made a series of recommendations in regards to meeting the housing needs of autistic adults.

- *The needs of adults with autism should be taken into account in local housing planning, design and allocation, in line with local priorities.*
- *Support should be available for adults with autism who want to, or have to, live independently – both on an on-going basis and during the transition period into a new home.*
- *Adults with autism and their carers should be given help to understand the options available to them, including the financial help they may be entitled to.* [60]

Local authorities are required under the Disability Discrimination Act to consider the needs of disabled adults, including those with autism, when considering housing provision. [74] This may include factoring in proximity of support services to the home or taking into account the individual sensitivities, for example sensitivity to bright lighting, and making reasonable adjustments for this. In addition local authorities should make reasonable adjustments to housing design with advertised choice based lettings. [12]

The Homelessness Reduction Act 2017 significantly reformed England's homelessness legislation by placing duties on local authorities to intervene at earlier stages to prevent homelessness in their areas. It also requires housing authorities to provide homelessness services to all those affected, not just those who have 'priority need'. [75]

3.1.11 Criminal justice system

The updated national autism strategy made reference to work within the criminal justice system to improve services for autistic people. This included meetings of a multi-agency Cross Criminal Justice System Government Group which covered topics including awareness, training and reasonable adjustments; and training tools developed with and used by the Crown Prosecution Service, the College of Policing and police forces. [12]

The National Autistic Society has produced guidance for staff working in the criminal justice system and for police officers. [76] [77]

In policing terms, an individual is deemed vulnerable if there is a reason to suspect they have may have difficulty in the communication process. Autism is included as a relevant condition that could give rise to a risk of miscommunication. Vulnerable suspects may be designated an 'appropriate adult' to support them while they are being questioned by police. Vulnerable victims, witnesses, suspects and defendants with significant communication difficulties may be designated an 'intermediary'. An intermediary assesses the communication needs and abilities of the vulnerable person and advises on how best to communicate with the individual. The duty of the intermediary is to the court, not the vulnerable person. [78] [79]

Liaison and diversion services provide early intervention to people identified as having vulnerabilities including autism - this facilitates early referral to appropriate services and possible divergence from the criminal justice system. The National Offender Management Service has developed tools to help staff identify and meet specific communication needs of offenders with autism. [12]

3.1.12 Community involvement

There were three key elements to *Think Autism*: (i) a heavier emphasis on community involvement; (ii) innovation with respect to services and (iii) improved data collection and coordination of advice and information services for autistic people. [12]

The government assigned £4.5 million to the *Think Autism* awareness and champions programme and to the Autism Innovation Fund in the 2013/2014 year. The awareness programme was developed with the aim of supporting autistic people and autism workers to fund activities, working with local partners, to increase awareness and understanding about autism in their communities. The Autism Innovation Fund was set up to fund innovative ideas for local services and projects - in particular, services that would provide lower-level support, targeting those service users that did not meet eligibility criteria for statutory support.

The progress report on *Think Autism* summarised the how the Autism Innovation Fund had been spent, illustrated with case studies of good practice, with particular emphasis to low level support in terms of early intervention and crisis prevention. [50]

3.2 Identification and early intervention

This section focuses on best practice recommendations for how to develop a quality diagnostic and post-diagnostic service for autism and on how to ensure that awareness of frontline staff is such that services are accessible and acceptable to those accessing them.

3.2.1 Provision of diagnostic pathway

The national autism strategy requires every area to develop a 'clear, consistent pathway for diagnosis, followed by the offer of a personalised needs assessment'. [60] The NICE clinical pathway on management of autistic adults was published in June 2012. [67]

Local authorities should be following NICE guidance on diagnostic pathways and using a framework for assessing care and support needs of autistic people. A diagnosis of autism should prompt a carers' assessment. [12]

Benefits of diagnosis in childhood include: timely access to educational support in school; and access to support for parents and carers. Increasing awareness of autism has led to an increasing number of people receiving a diagnosis in adulthood. Though this population will be identified too late to benefit from school educational support, benefits to having a diagnosis include potential access to social care and welfare support, employment seeking support and rights to reasonable adjustments to the workplace under the Equality Act. [4] Receiving a diagnosis can also help individuals understand why they may experience the world differently to their peers. Statutory guidance has been issued on the post-diagnosis information autistic adults are likely to need and the requirement for routine assessment and audit of quality of diagnostic pathways. [64]

3.2.2 Awareness (frontline staff training)

One of the biggest barriers to autistic children and adults accessing services cited is lack of awareness and tolerance of staff. [28] More work needs to be done to increase the awareness and understanding of autism among frontline professionals. [60] Autism should be included in equality and diversity training across all public services. [12] Services should work with partners to develop effective training to be used by local authorities and there should be provision of specialised training for certain professions including health and social care, staff in the criminal justice system and disability employment advisors - in order to improve understanding of the condition and enable staff to make reasonable adjustments to the services they provide. [6]

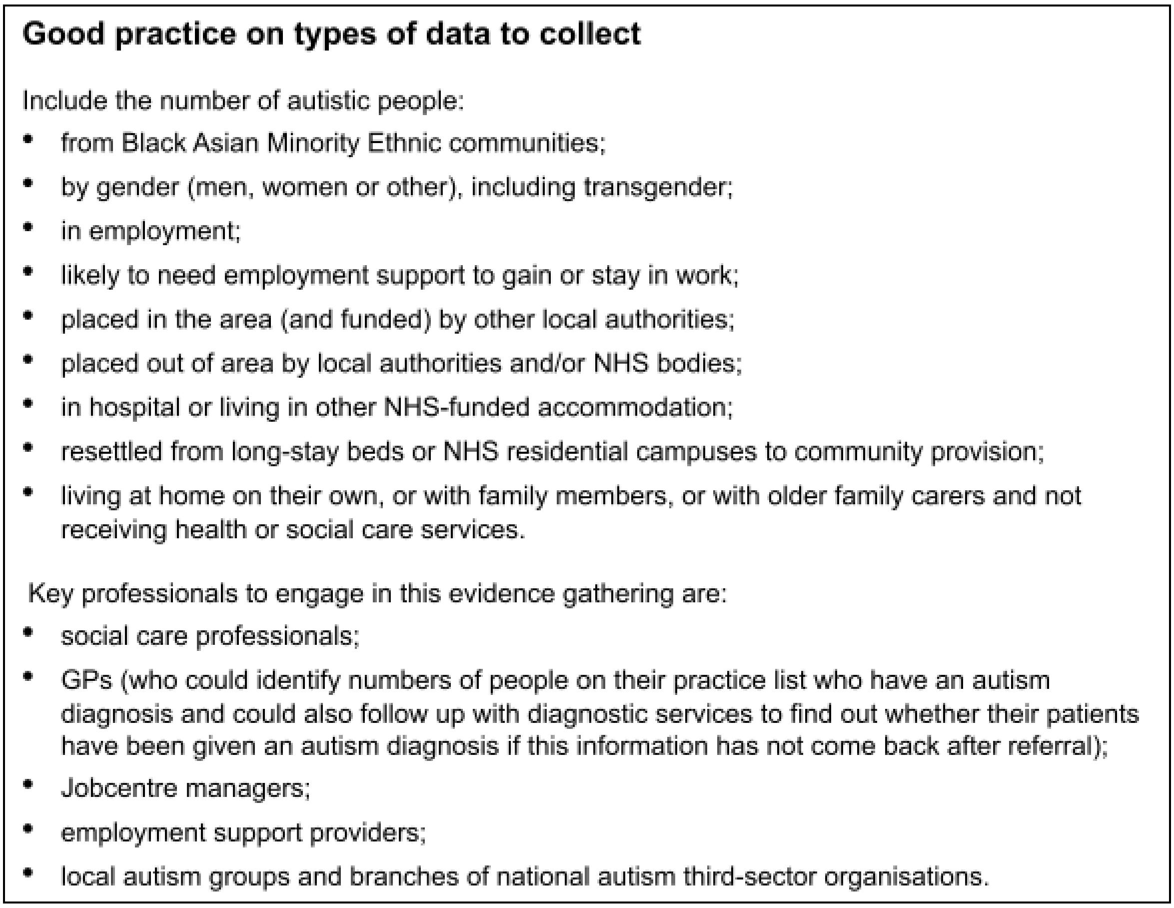
In February 2019, the Government published proposals for all health and social care staff to receive mandatory training on autism and learning disability. [80] At the time of writing this report, these proposals are out for public consultation.

3.2.3 Data collection and coordination of information

One of the challenges of planning services for autistic adults is variable data quality. [50] It is difficult to plan accurately for the needs of a population if some parts of the population are difficult to access, or if demographic data/recording of diagnosis is incomplete.

Service providers and commissioners need to understand the characteristics of the population they serve in order to best meet their needs. Therefore it is important to capture certain types of information in the dataset collected. [50] Box 4, from the national strategy progress report, outlines the important types of data to collect.

Box 4: Good practice on types of data to collect



Good practice on types of data to collect

Include the number of autistic people:

- from Black Asian Minority Ethnic communities;
- by gender (men, women or other), including transgender;
- in employment;
- likely to need employment support to gain or stay in work;
- placed in the area (and funded) by other local authorities;
- placed out of area by local authorities and/or NHS bodies;
- in hospital or living in other NHS-funded accommodation;
- resettled from long-stay beds or NHS residential campuses to community provision;
- living at home on their own, or with family members, or with older family carers and not receiving health or social care services.

Key professionals to engage in this evidence gathering are:

- social care professionals;
- GPs (who could identify numbers of people on their practice list who have an autism diagnosis and could also follow up with diagnostic services to find out whether their patients have been given an autism diagnosis if this information has not come back after referral);
- Jobcentre managers;
- employment support providers;
- local autism groups and branches of national autism third-sector organisations.

3.2.4 Local authority responsibility to identify people <18 who may require support (Care Act)

The Care Act requires local authorities to identify individuals under the age of 18 who are likely to have care and support needs after turning 18. [59] The Act's accompanying care and support statutory guidance is intended to help local authorities identify young people who are not receiving children's services but who have a high chance of requiring care and support as adults, for example, autistic young people whose needs to date have been met by their educational institution – but who may need further support after leaving that setting.

3.2.5 Prompt of carer's assessment

All adults receiving a diagnosis of autism should be offered a community care assessment, regardless of where they are on the spectrum. [59]

Under the Care Act 2014, a carer for someone with a health problem or disability is entitled to their own assessment for statutory support regardless of whether the individual whom they look after is eligible themselves. [59]

NICE guidance recommends that families, partners and carers of autistic adults should be offered an assessment of their own needs. [67] They may require personal, social and/or emotional support. Practical support in their caring role, such as arranging respite care and planning future care for the autistic person, should be offered.

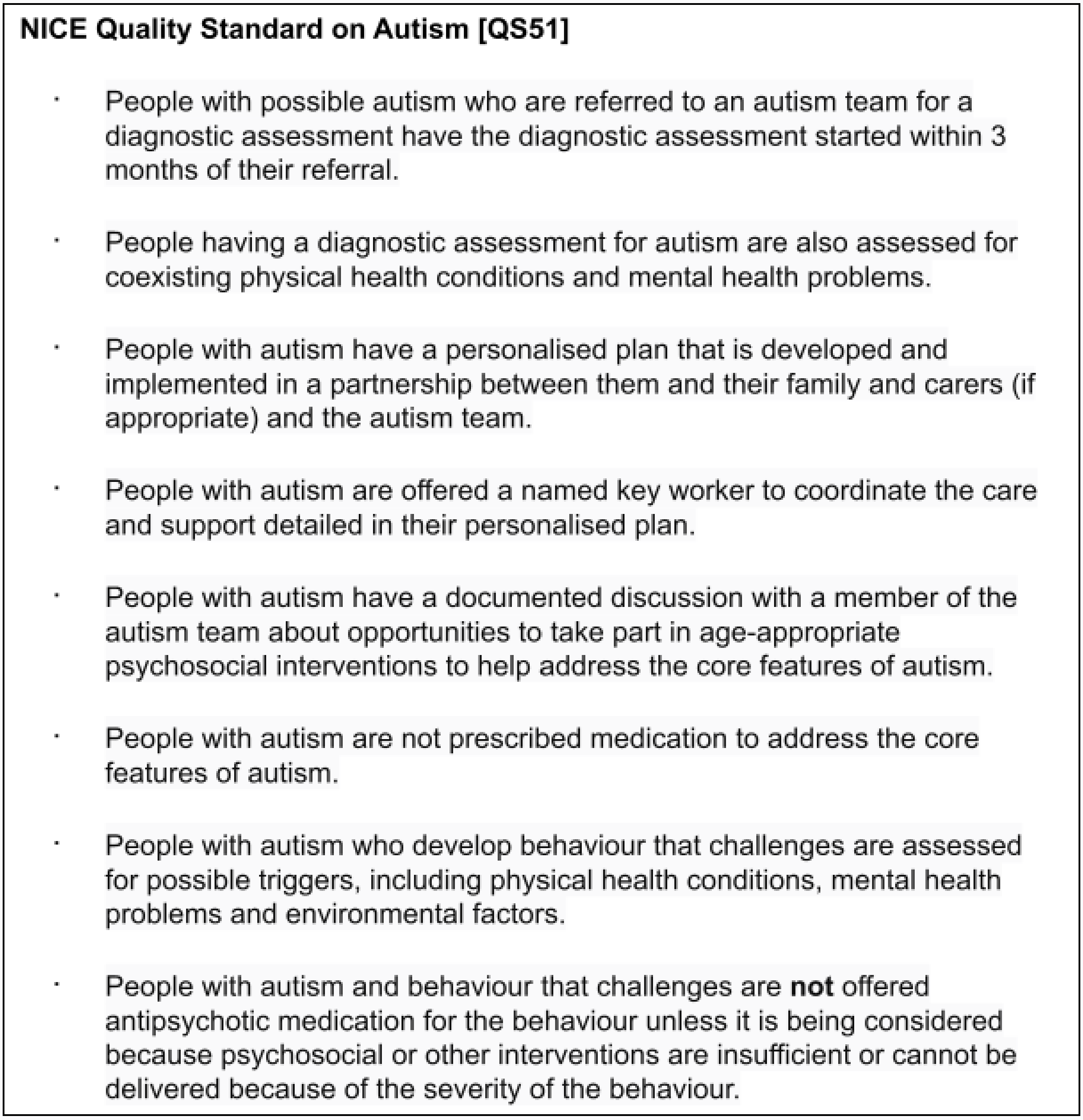
3.3 Treatment, care and support

There is no single intervention that will benefit all autistic people due to the spectrum nature of the condition. Autism is a lifelong condition and behaviours may change over time. Interventions need to be personalised and be responsive and evolve over the person’s life to adapt to changing needs.

There is no ‘cure’ for autism, but there are interventions which can be helpful in managing some of the core features of autism and some of its associated behaviours. There are also interventions which can support families and carers.

The Health and Social Care Act 2012 sets out a clear expectation that the care system, i.e. commissioners and providers of health and social care, should consider NICE quality standards in planning and delivering services, to ensure continuous improvement in quality. [81] These standards, produced in 2014, describe high-priority areas for quality improvement (Box 5) and cover health and social care services for autistic adults, young people and children. [82]

Box 5: NICE Quality Standard on Autism



NICE Quality Standard on Autism [QS51]

- 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.
- People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.
- 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.
- People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.
- 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.
- People with autism are not prescribed medication to address the core features of autism.
- People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.
- People with autism and behaviour that challenges are **not** offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

Source: NICE [82]

3.3.1 Interventions

The National Institute for Health and Care Excellence (NICE) has developed clinical guidelines for both children and adults for diagnosis of autism as well as management and support. [67] [83]

Psychosocial interventions for the core symptoms of autism

For the core features of autism in children and young people NICE recommends considering a specific social-communication intervention that includes play-based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person.

For adults with autism without a learning disability or with a mild to moderate learning disability, who have identified problems with social interaction, NICE recommends considering:

- a group-based social learning programme focused on improving social interaction
- an individually delivered social learning programme for people who find group-based activities difficult.

Psychosocial interventions focused on life skills

NICE guidelines recommend offering autistic children and young people support in developing coping strategies and accessing community services, including developing skills to access public transport, employment and leisure facilities.

For adults with autism of all ranges of intellectual ability, who need help with activities of daily living, NICE recommends considering a structured and predictable training programme based on behavioural principles.

For adults with autism without a learning disability or with a mild to moderate learning disability, who are socially isolated or have restricted social contact, consider:

1 a group-based structured leisure activity programme
2 an individually delivered structured leisure activity programme for people who find group-based activities difficult.

For adults with autism without a learning disability or with a mild to moderate learning disability, who have problems with anger and aggression, an anger management intervention, adjusted to the needs of adults with autism, should be offered.

For adults with autism without a learning disability or with a mild learning disability, who are at risk of victimisation, anti-victimisation interventions based on teaching decision-making and problem-solving skills should be considered. These interventions can include identifying and, where possible, modifying and developing decision-making skills in situations associated with abuse and developing personal safety skills.

For adults with autism without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment, an individual supported employment programme should be considered (as discussed in Section 4.1.8)

Biomedical (pharmacological, physical and dietary) interventions and the core symptoms of autism

In their guidance NICE list a number of treatments that have been studied that are ineffective in managing the core features of autism, in addition to their use being potentially risky, and so should not be used. Further detail can be found in the NICE Guidance. [84]

3.3.2 People with co-existing mental disorders

In their guidance for under-19s, NICE recommends assessing for co-existing medical and mental conditions and recommends assessing and intervening for sleep disorders in children. [84]

Autism can co-exist with mental health problems. The underlying autism may be masked by the mental health problems, e.g. anxiety and depression. As such, using various interventions like antidepressants alone may not be appropriate or effective.

For adults with autism and a coexisting mental disorder the pharmacological or psychosocial interventions informed by existing NICE guidance for the specific disorder should be used but may need to be adapted for autistic people following consultation from a specialist autism team.

For the management of anxiety in autistic adults The National Autistic Society recommends strategies such as keeping diaries, using anxiety management apps, using relaxation techniques and getting support from other autistic people. [85]

3.3.3 Challenging behaviour and crisis services

Autistic people, particularly those with co-existing learning disability, can sometimes present with behaviour perceived by others to be ‘challenging’. Challenging behaviour has been defined as:

‘Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.’ [86]

Assessment usually requires observation and a physical assessment to exclude physical causes with the development of a behavioural support plan and referral to secondary care services. The causes of behaviour that challenges for an autistic person can be multifactorial, and can involve physical health conditions, mental health problems and environmental factors (that is, relating to the person's social or physical environment, e.g. abusive or restrictive social environments.). NICE has issued guidance on prevention and interventions for challenging behaviour. An assessment should take all these factors into account, and also consider the risk of harm to the person and others, before appropriate interventions are agreed for the behaviour and any identified physical health conditions or mental health problems. [87] Psychosocial interventions are first-line if physical and mental health disorders have been excluded. Anti-psychotic medication should only be considered if there is no improvement with psychosocial interventions alone. [87]

3.3.4 Carer support

All adults receiving a diagnosis of autism should be offered a community care assessment, regardless of where they are on the spectrum, and all carers should be informed of their right to a carer's assessment. [59]

3.3.5 Transition to adult services

Despite being primarily developed to meet the needs of autistic adults, both national autism strategies to date have placed a focus on young people – specifically, their transition from children to adult services. While there may be geographical variation and disparities in services available to autistic young people, it is generally accepted that the availability of support available after leaving children's services significantly diminishes, particularly if the adult is deemed ineligible for social care or does not have a co-existing learning disability or mental health diagnosis (therefore not falling under the remit of these dedicated services).

The Children and Families Act makes provision for children and young people with SEND aged up to 25. [62] One of the criticisms of the previous system was the fact that the legislation that applied to SEND in schools was not coordinated with legislation that applied to young people with learning difficulties in further education. Children aged 16 would 'fall off a cliff edge'. The reforms brought a 0-25 year old system and as such a continuity of support beyond 18 and up to 25, should an individual require further support and training to achieve their educational goals. The problem with this is that many health services have their own cut-off ages – for example child psychology and adult psychology are separate branches and a child psychologist may not see a service user over the age of 18.

Good transition planning in schools brings together education, health and social care staff when a young person has complex needs. [12] NICE have produced clinical guidelines to aid clinicians in managing children transitioning to adulthood. [88] Local authorities should reassess young people at around age 14 years of age to determine ongoing need for support into adulthood and the provision that will be required to meet these needs. This assessment should encompass multiple domains including personal, educational, occupational, social and communication functioning as well as assess co-existing conditions such as depression or anxiety. If treatment is required into adulthood the transition process should be performed smoothly with full knowledge and understanding and involvement of the young person by the time they reach 18 years of age. [88] Effective transition planning should include career preparation up to age 16 and plans for education, employment, training, transport, housing and leisure from 16 to 25 and beyond.

The Children and Families Act made it mandatory for local authorities to prominently display what services were available in the form of a local offer, with input from service users i.e. children, young people and parents, in its development. [62] The local offer was required to include advice and support sources to help young people transitioning from school and post 16 provision into adult life. There was Department of Education funding for the National Autistic Society to publish a guide for local authorities to involve young autistic people in developing their local offers. [8]

3.3.6 Advocacy

Advocacy as defined in the statutory guidance of the Care Act is ‘supporting a person to understand information, express their needs and wishes, secure their rights, represent their interests and obtain the care and support they need’. [59] The nature of the communication problems some autistic people have means that this can sometimes be difficult. This may be needed at any time in the life-course, for example during the transition from child to adult services, or when seeking housing or employment. However complex people’s needs are, local authorities must ensure people are supported to express their views and helped to consider what options they have, which increases individuals’ control and self-determination. The Care Act, therefore, places a duty on local authorities to offer support from an independent advocate, if required, to enable people to be involved in decisions about them and their care and support. [59]

The professional advocate will provide support and encouragement to a service user to enable him/her to access services needed to live an independent life in the community. Advocates work in partnership with the service user, researching options so that the service user can make an informed choice, and then providing support in seeing the decision through.

3.4 Summary of evidence and best practice

Best practice guidance is informed by several pieces of legislation, including the Autism Act, the Children and Families Act and the Equality Act, in addition to NICE guidelines, the national strategy for autistic adults and its associated statutory guidance. [2] [62] [4] [64]

Key interventions for children are early diagnosis and access to appropriate educational provision. There should be an emphasis on local provision as upheaval can be distressing for the child and family.
Effective transition planning should start at age 14 and include career preparation up to age 16 and plans for education, employment, training, transport, housing and leisure from 16 to 25 and beyond. [88]

For adults, key interventions include access to diagnostic services, social support such as employment and education support, housing and psychosocial input/social skills training to help reduce isolation. [67] In order for service providers and commissioners to effectively meet the needs of the population a complete data set must be collected that captures the characteristics of that population, including ethnic diversity. [50]

Children and adults with autism experiencing mental health problems should have access to appropriate specialist preventative support and intervention.

Public services should offer an accessible environment for autistic people. [12] The needs of carers and family members need to be considered and appropriately addressed due to the nature of autism and the impact this can have on family and carers’ health and wellbeing. [57]

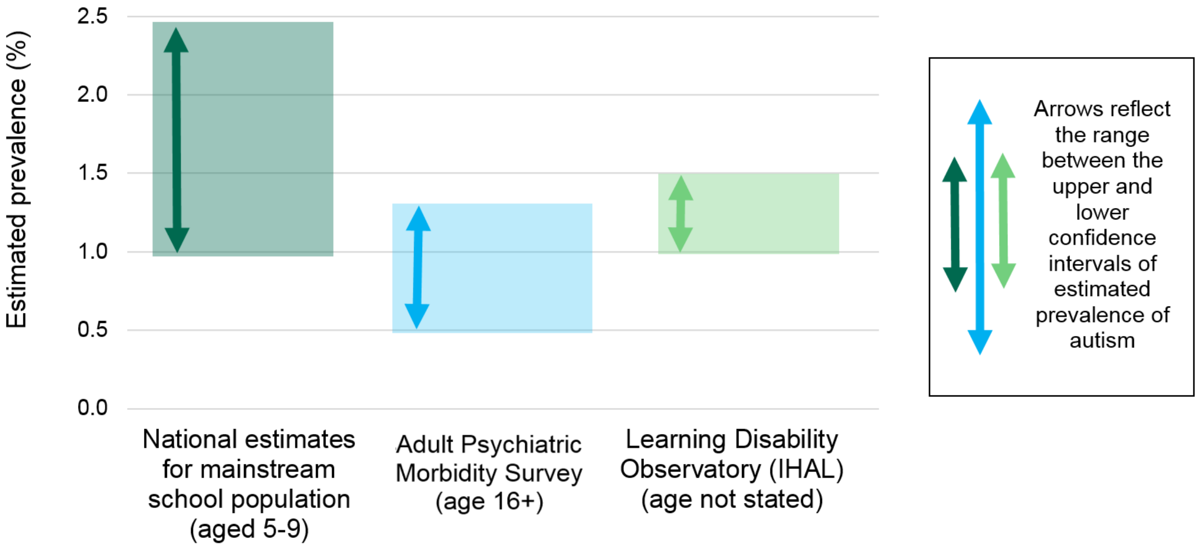
4 Local data and inequalities

4.1 National estimates applied to the local population

4.1.1 Estimating autism prevalence

In order to estimate the prevalence of autism in the general population, reliable and well-constructed research is required. Some of the factors which contribute to 'good' research include: testing a representative sample of the population (by age, gender, ethnic group, and socio-economic status), using reliable methods of detection, and using robust and validated measures. Unfortunately, when determining a "true" prevalence of autism, few of these factors are routinely present in the extant literature. Differences in methodologies and approaches have resulted in a range of estimates regarding the prevalence of autism, and these are indicated in Figure 3 below.

Figure 3: Presentation reflecting the range of prevalence estimates



Source: Adult Psychiatric Morbidity Survey (2014), Improving Health and Lives (2010), Baron-Cohen (2009) [89] [90] [91]

Childhood autism

Estimates for the prevalence of autism in children are derived from a study by Baron-Cohen and colleagues, which conducted a survey of children aged 5-9 on the SEN register in Cambridgeshire, and subsequently estimated the prevalence who may be undiagnosed. [91]

According to this study, approximately 1.6% of children aged 5-9 in state schools are estimated to be autistic (including diagnosed and undiagnosed), with a range between 1.0 and 2.5%. When this prevalence is applied to the local school census information, this would equate to 119 students aged 5-9 estimated to be autistic, with a range from 75-186.

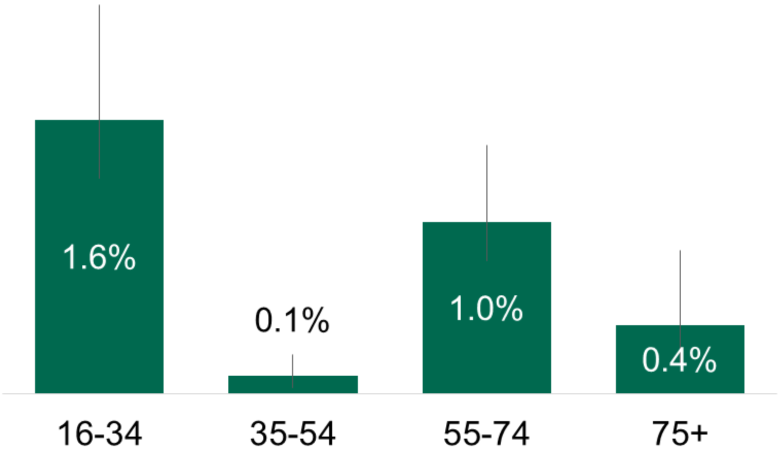
Estimates suggest the ratio of known to unknown diagnoses of autism in children age 5-9 is around 3:2 (for every three diagnosed students there are two without a diagnosis). This equates to an estimate of between 0.8 and 1.2% of 5-9 years olds known to be autistic locally (mean of 0.9%). Applying this prevalence to the local population would result in approximately 71 students (with a range of 57 to 88). [91]

Adult autism

The most commonly used population estimates for autism come from the Adult Psychiatric Morbidity Survey (AMPS), which sampled adults (age 16+) living in private households in England. The estimates used a combination of self-completed screening tools (AQ-20) and semi-structured follow-up assessment of a subset of the sample. The national survey estimates 0.8% of adults (age 16+) have autism, however the ‘true’ prevalence is likely to be between 0.5% and 1.3% of the population. Some limitations of this dataset are that the sample does not cover people who are homeless, living in temporary accommodation or living in prison and the screening tool is not robustly validated. [90] The low prevalence estimates from the survey may reflect reporting and recording biases and thus may not be entirely reflective of the true population prevalence of autism.

In Figure 4, which shows the prevalence of autism by age group, the uncertainty of the estimates is demonstrated by wide variation amongst the age groups, and in particular evidenced by the sharp drop in estimated prevalence in the 35-54 year age group (despite autism being a life-long condition).

Figure 4: Prevalence of autism in England, by age group (2007 and 2014 combined)



Source: Adult Psychiatric Morbidity Survey

Using the prevalence figures from the APMS, the estimated numbers of residents with autism in City and Hackney have been estimated in Table 4.

Table 4: Estimated number of residents with autism (2019)

	City of London		Hackney	
Age group	Estimated number	Estimated Range	Estimated number	Estimated Range
16-34	40	20 < 83	1595	776 < 3252
35-54	3	1 < 8	104	35 < 306
55-74	17	8 < 38	323	143 < 723
75+	2	1 < 10	34	8 < 149
All 16+	57	34 < 95	1844	1111 < 3055
Estimates applied to 18+ population (for comparison purposes)	56	34<93	1,798	1,083<2,978

Source: Adult Psychiatric Morbidity Survey (2014), GLA housing-led population projections (2019)

4.1.2 Potential unmet need

Children

Estimates from the literature (applied to our local population) suggest between 75 and 186 children aged 5-9 in state-maintained schools are autistic. Of these, between 57 and 88 would be known to have the condition (using the SEND system).

Locally held records on SEND are not directly comparable to estimates because detailed SEND information (that shows autism) is not routinely submitted to the CAPITA system by academy schools and there are 17 academies in Hackney. This means not all students with SEND relating to autism will be reflected in local data.

Despite this imperfect comparison, local data shows 242 students aged 5-9 are recorded with autism. Whilst this prevalence is already higher than that those estimated from the literature, given that autism is often under-diagnosed this would suggest that local prevalence is even higher than the estimated prevalence.

Adults

As discussed in the previous section, there are some significant limitations to the reliability of prevalence estimates for the autistic adult population. The estimated prevalence of autism by age along with the methods of screening, indicate these methods provide a highly conservative estimates for the prevalence of autism in adults.

The most comparable source of local data (to population estimates) comes from the recorded prevalence of autism in GP practices. However given the known recording bias seen with a condition like autism and population data from GP registers tends to over-estimate the resident population, this source also has several limitations when trying to predict level of unmet need.

Prevalence estimates using the APMS suggest that there are 1854 autistic adults within Hackney and the City in 2019, with a range of 1,117 and 3,071 people. However, the number of adults (aged 18+) recorded with autism by their GP is 569. This suggests there are between 548 and 2,502 City and Hackney residents aged 18+ who may have undiagnosed autism.

Given the relatively recent developments in professional and societal understanding of autism, it is likely there are high levels of under-diagnosis and reporting of the condition (both locally and nationally) which contributes to the level of unmet need in the population.

4.2 Local data and unmet need

There is no one source of local information on people with autism, therefore this section draws data from several areas where individuals are known to be identified with the condition.

Data from state-maintained schools is the most complete dataset for investigating autism prevalence, and is available for both Hackney and the City of London.

Autism records collected by GPs involves low numbers of patients which can be potentially identifiable at small geographical levels, so data is only presented for Hackney and the City of London combined.

4.2.1 Special educational needs and disability (SEND)

Notes on Hackney SEND data

The SEND information used in this section reflects students recorded in Hackney school census 2018. The data reflects students attending state-maintained schools[7] within the geography, and does not reflect young people who are educated in other settings (such as private schools, home schooling or some independent schools). Approximately 22% of school-aged children in Hackney attend independent and private schools - this is particularly relevant for the local Charedi (orthodox Jewish) population who represent one in five people under the age of 18 in the local area.

Hackney

In Hackney schools there are a total of 609 student records recorded with a SEND relating to autism. This number reflects 1.8% of the recorded student population. The majority of students recorded with autism also have an Education Health and Care Plan (EHCP) (80%). An EHCP is used to support students whose needs are beyond the capacity available within routine school provision (SEN support) which indicates the majority of students known to have autism are likely to have a higher level of impairment. [92]

City of London

In the City, there is one state maintained primary school in the local area. All secondary provision (4 schools) is operated privately, however the City of London Corporation manage 2 of those sites, therefore information about young people attending these schools is more readily available for reporting purposes. In total 15 pupils are known to have an SEND relating to ASD and 8 of those have an EHCP.

---

[7] Maintained school – funded by the local authority (LA)

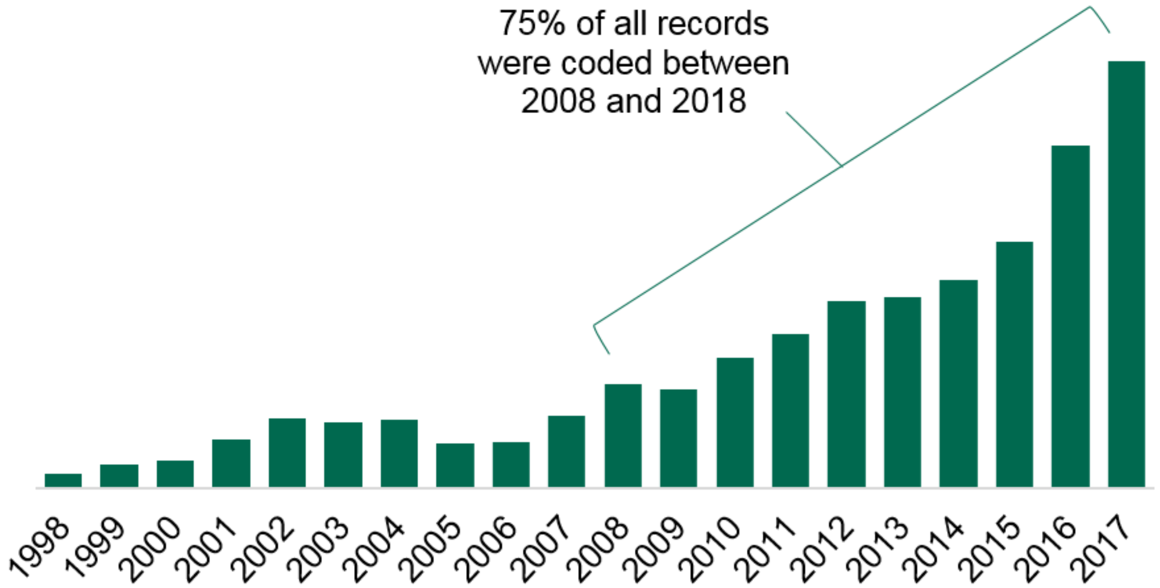
4.2.2 GP records

The data used in this section includes GP patients who live within Hackney and the City of London, and who are registered at a GP practice within the City of London, Hackney, Newham, Tower Hamlets or Waltham Forest. Twenty-six different clinical (READ) codes were included to identify patients with autism.

There are a total of 1,417 GP patients of all ages with a coding of autism in the City and Hackney, comprising 0.34% of the total registered patient population.

The majority (75%) of patients were recorded with autism in the past 10 years reflecting the relatively recent increase in awareness of the condition. There are clear demographic trends to the data which reflect the inconsistency in recording of autism in primary care, these trends are explored in **section 5.3 Local inequalities data** and **section 5.4 Comparison with other areas and over time**.

Figure 5: Number of new recordings of autism in City and Hackney GP practices, by year (1998 to 2017)



Source: Clinical effectiveness group (2018). [93]

4.2.3 Social care (adults)

Historically, autism and other health-related conditions were not routinely collected in adult social care data systems in a meaningful way; this meant local authorities were unable to see which health conditions most affected social care clients. In recent years (since the Autism Act and the political emphasis towards improving the integration of health and social care systems), efforts have been made to capture health information of social care clients in a more systematic way. To account for this in the needs assessment, data analysts within Hackney performed a free text analysis of Mosaic records to estimate the level of underreporting of autism in social care data. The free text analysis aimed to improve the reflection of autistic people in contact with local services along with any differences between people confirmed as having an autism diagnosis (using the ‘health condition’ field in Mosaic), people likely to have autism (based on free text description) and those who may be affiliated with an autistic person (based on free text description).

Hackney Mosaic record identification methods

A social care record is created when an individual makes contact with local services. Each record should represent one person in contact with services[8]. The record could reflect a range of services, from a straight forwards telephone call involving general advice and signposting to a person receiving comprehensive domestic support arrangement to meet their needs.

The Hackney Performance and Improvement Team provided a data extract for all clients ever recorded on Mosaic (system implemented in September 2014) with a mention of an autism-related word.

A list of autism-related words was compiled by a GP trainee following a rapid literature review and collaboration with social care commissioning leads (Table 5). When discussing records identified using this method, this document will refer to records with ‘autism’.

The Hackney Data and Insight Team performed the second stage of free text analysis to indicate the likelihood of the word ‘autism’ being attributed to the individual or another person (such as a friend or relative). The analysis used Python software to explore the 20 words surrounding each appearance of an ‘autism’ term, and number of times it was mentioned. This produced a likelihood score of between one and five, where five is highly likely and one is very unlikely. A record was attributed as the individual being ‘likely autistic’ where the likelihood score was either four or five (where the majority of mentions of autism terms did not co-occur with a mention of a relation, friend or carer within the surrounding 20-word “window”).

Table 5: Autism-related words used in the free-text search of mosaic records

Autis*
Asperg*
‘pervasive development disorder’
ASD
PDD
HFA (‘high functioning autism)

The free text analysis identified 6,513 records mentioning ‘autism’; after removing duplicates and records where insufficient data was available 4,243 records remained (recorded between September 2014 and March 2019). [94]

Using this method, there were 3,804 individuals who made contact with Hackney Adult Social Care between September 2014 and March 2019 who were likely to be

---

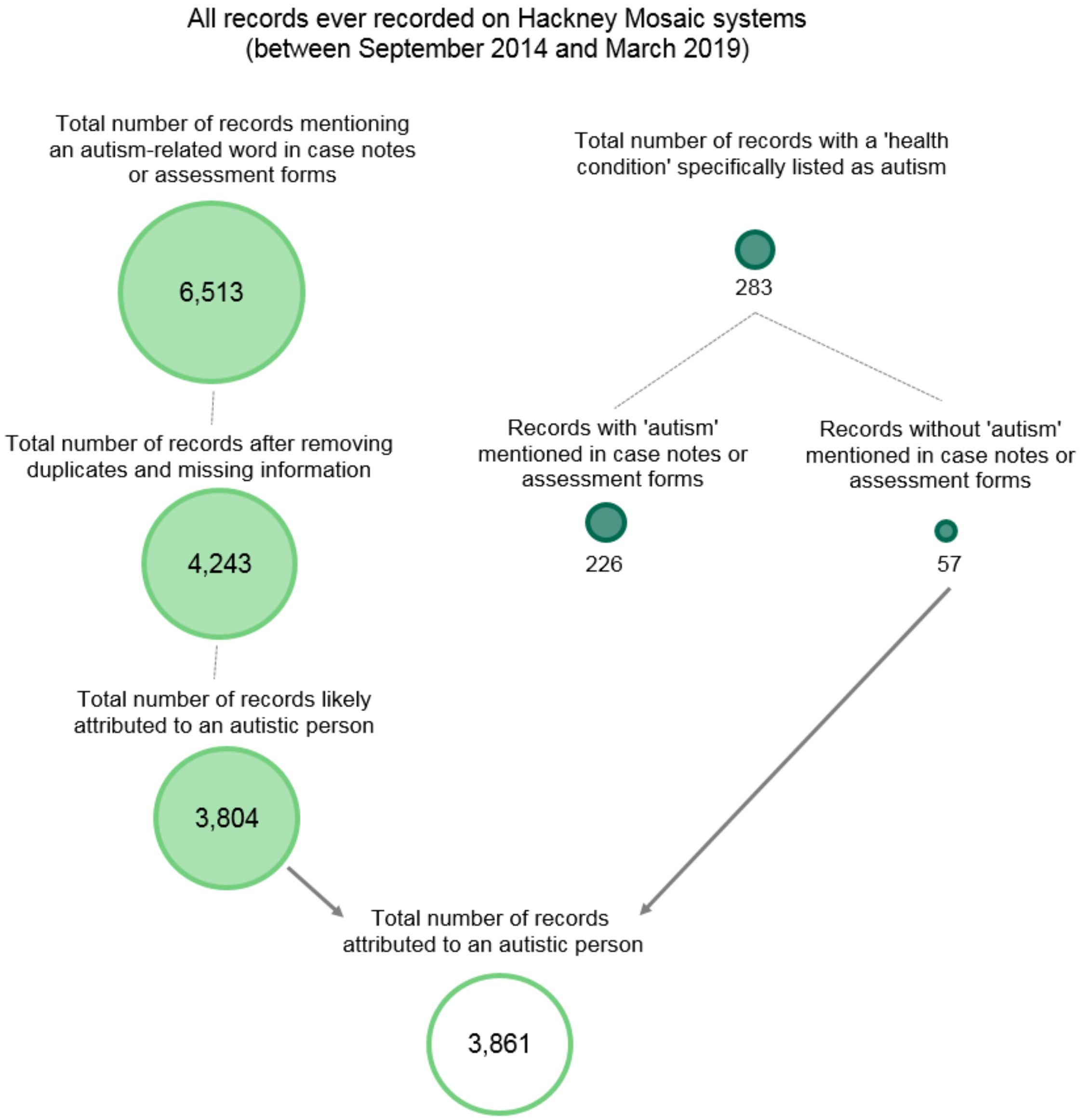
[8] Despite the system being designed to reflect one record per client, it is possible for a person to make multiple contacts with adult social care with different circumstances which can create duplicate records for the same individual.

autistic. The remaining 449 records are thought to relate to another person in contact with an autistic person (such as a relation, friend or carer).

Before the free text analysis there were 283 individuals with a health condition explicitly recorded with autism. Of these, 226 also had ‘autism’ mentioned in the case notes or assessment forms. The remaining 57 records were combined with the free text identified clients who were likely to have autism, resulting in a total dataset of 4,300 records (3,861 of which are likely attributed to an autistic individual).

Of the free text records that discuss ‘autism’ but are not attributed to the individual, the most commonly associated term associated with the record was “mum” or “mother” which was mentioned in 47.7% of records (generally in the context of being the mother of someone with autism).

Figure 6: Overview of the record identification process used to reflect adults in contact with Hackney adult social care



Hackney local data

Of all Mosaic records recorded by Hackney adult social care between September 2014 and March 2019, 3,861 individual records were attributed to an autistic person (using the method outlined in the previous section).

Of the records identified by this method, 157 autistic adults were eligible for adult social care support and received a service[9] from during the 2018/19 financial year. All of the people receiving a service had a health condition validated client record of autism.

From the information available for this this report we are unable to determine how many people had made contact but did not receive services in this financial year. Despite this, the remaining 3,705 'likely autistic' individuals who made contact with adult social care between 2014 and 2018 (96% of all 'likely autistic' contacts) did not receive a service at any point during this time. [94]

City of London

Due to the small numbers of autistic adults, further information cannot be disclosed for this locality due to the potentiality of identification of individuals. [95]

4.3 Local inequalities data

Notes on the data

Data in this section comes from three main sources: 1) GP records, as mentioned earlier, 2) SEND data from the Hackney Learning Trust, and 3) data from social care. GP records were examined using the methodology described in section 1.2.2 and so comprises those individuals living within the City and Hackney and being registered at a GP within Hackney, the City, Tower Hamlets, Waltham Forest, or Newham. Data from the Hackney Learning Trust reflects the number of student records held by the Capita system – this is different to the total number of students reflected by the school census (which is a snapshot of pupils taken in January each year) and is more comprehensive as it covers information on demographics and school exclusions not available elsewhere. This means that, due to differences in the total school age- population denominators, data is not directly comparable to sections 1.2.1 or 1.4.1. One limitation with the Capita data is that it does not reliably reflect autistic students with a SEND support who do not have an EHCP. As the data for social care does not have a reliable denominator, we are unable to provide prevalence rates for inequality strands but have presented the number of unique adults social care records that are either confirmed or likely* to be relating to an autistic person. The data has been presented in this section according to broader equality strands and provided for where data is available.

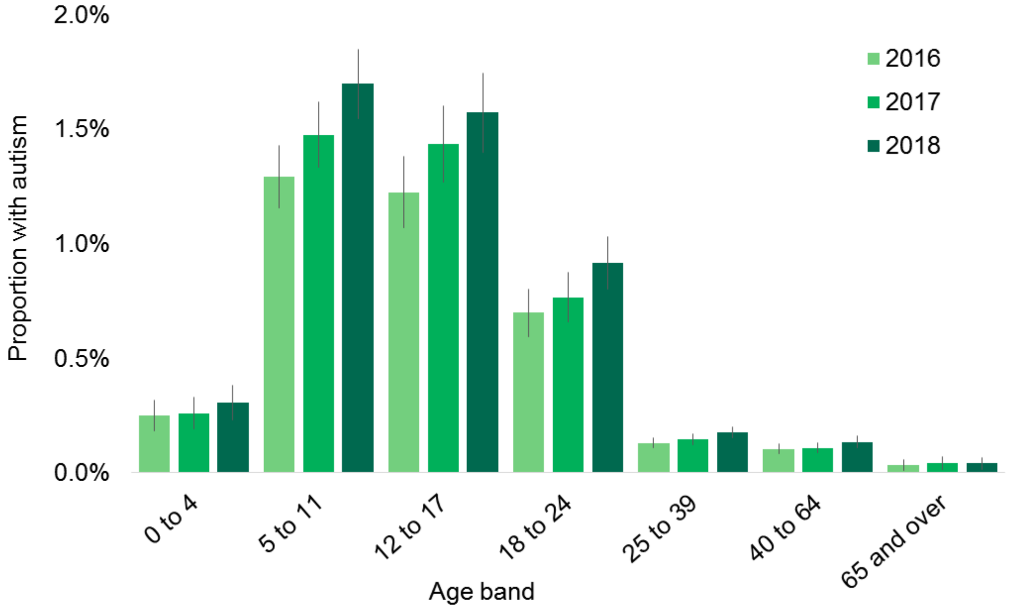
---

[9] The list of services includes; long term care (home care, care home, day care), telecare or reablement received by clients during the financial year. It includes people receiving direct payments. It does not include people receiving carer services.

4.3.1 Age

GP records show that the highest proportion of autistic patients in City and Hackney are in the 5 to 11 age band. The proportion of residents with autism has been increasing in the period from 2016 to 2018, with the highest incremental increases seen in the age bands covering ages 5 to 24. Given that autism is a lifelong condition, it would be expected that the proportion of residents with autism would remain fairly stable across age bands. Nevertheless, as there has been an increase in understanding (and therefore, diagnosis) of autism over the last couple of decades the low proportion of residents with autism aged 25 and over (particularly in the 65 and over group) suggests there may be a high proportion of older people who remain undiagnosed.

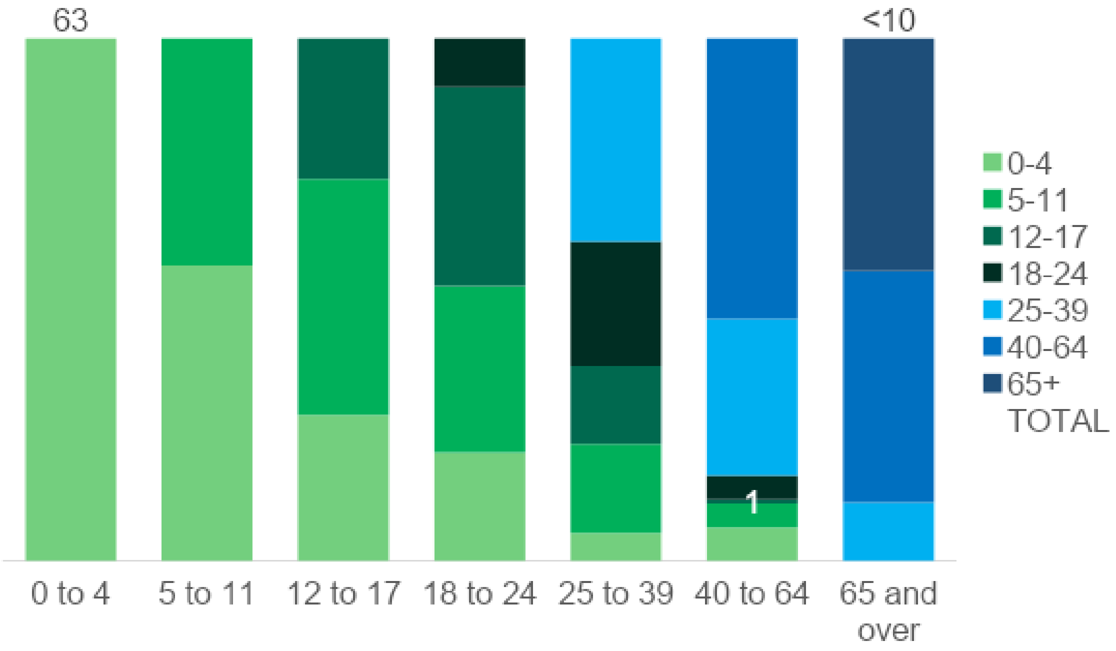
Figure 7: Proportion of City and Hackney (resident) patients with autism, by age band (2018)



Source: Clinical effectiveness group (2018). [93]

Figure 8 shows the proportion of City and Hackney residents with autism, by current age band and age band at diagnosis. Most children up to the age of 11 are diagnosed when they are under 4 years old. In older age bands there is a greater variation in age at diagnosis, with more children being diagnosed between the age of 5 to 11, and 12 to 17. Older residents (25 and over) are more likely to have been diagnosed later on in life, i.e. during adulthood. No residents over 65 received their diagnosis under the age of 25. It is likely that those diagnosed in adulthood will not have been able to benefit from the additional educational support they would have been entitled to.

Figure 8: Proportion of City and Hackney (resident) patients with autism, by current age band (x axis) and age band at diagnosis (see key; 2018)



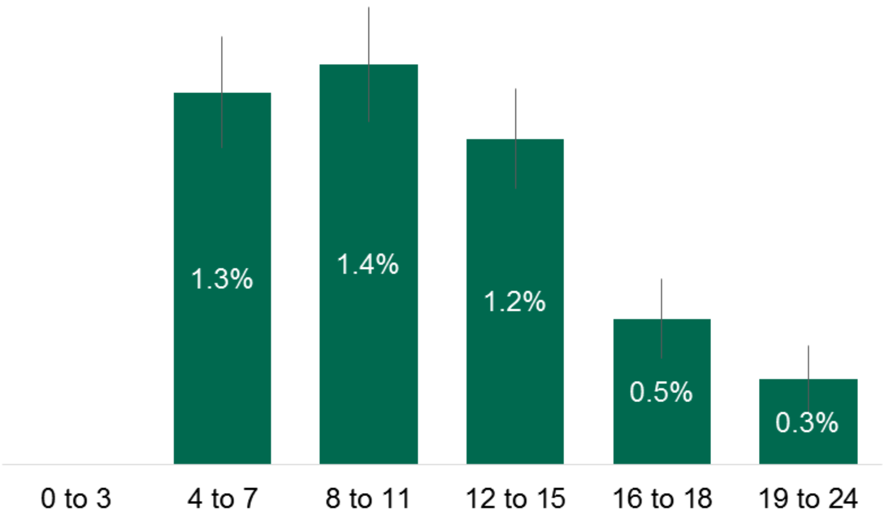
Source: Clinical effectiveness group (2018). [93]

Analysis of data from HLT of student records of those with SEND with autism, shows that the prevalence of autism by age band follows a similar pattern to the overall distribution of students by age. There is significantly lower prevalence of autism in students aged 16 to 24 in comparison to those under the age of 16.

Some of the reasons driving the lower prevalence of autism in students aged 16+ include:

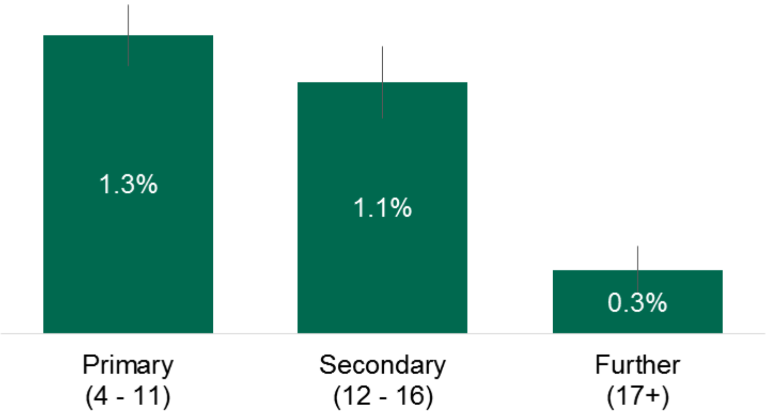
- a smaller number of students attending 16+ education results in harder-to-identify SEND
- a higher educational level may not be appropriate for some students already with SEND support for autism
- students with autism no longer stated as having a need for EHCP, but this doesn't preclude their having a need for additional support as once involvement in needing an ECHP is closed they may not be picked up in reporting
- students attending 16+ education may have support provided through their college/institute of further education and thus may apply for an EHCP
- those who are post 16 and not in education may have their EHCPs ceased and thus would not be recorded

Figure 9: Proportion of student records in Hackney with SEND of autism, by current age band (2018/19)



Source: Hackney Learning Trust (2018/19). [92]

Figure 10: Proportion of student records in Hackney with SEND of autism, by school setting (2018/19)

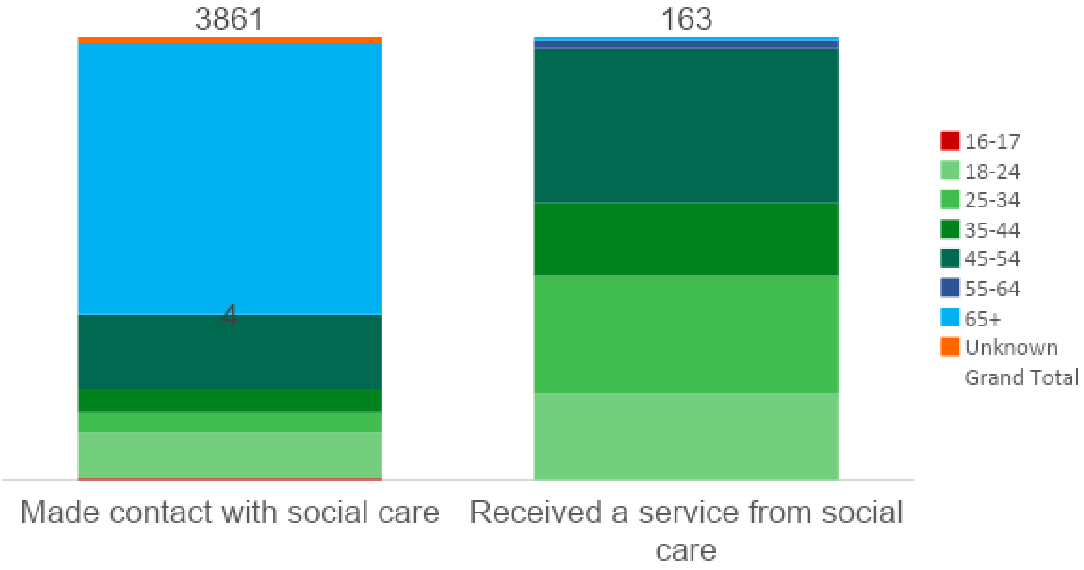


Source: Hackney Learning Trust (2018/19). [92]

We do not have reliable denominator information to present prevalence rates by demographic group in social care and as such, therefore the section below describes the distribution of data instead. The data reflects the number of unique adults social care records that are either confirmed or likely* to be relating to an autistic person

The majority of people making contact with adult social care (who are likely to be autistic) are over the age of 65.

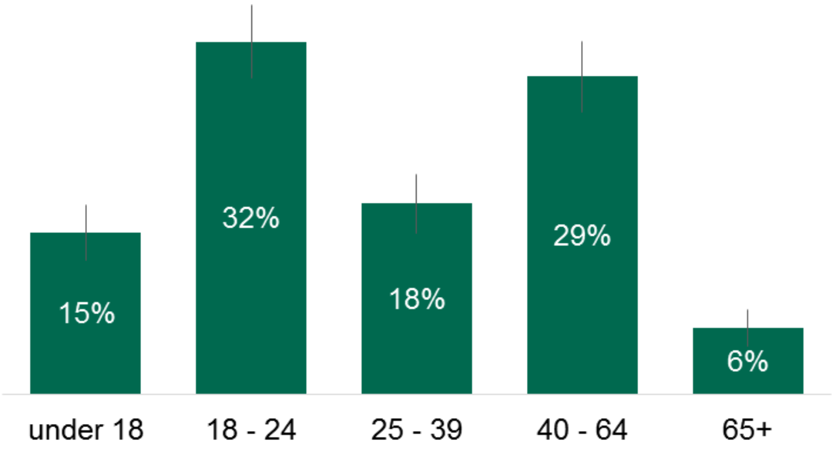
Figure 11: Proportion of those with confirmed or likely autism accessing adult social care (2018/19, 16+)



Source: Hackney Performance Team (2019). [94]

Adult social care records show two thirds (65%) of autistic clients are under the age of 40 and a very small proportion (around 1 in 20) are aged 65+.

Figure 12: Proportion of records by age group (2014 – 2019)



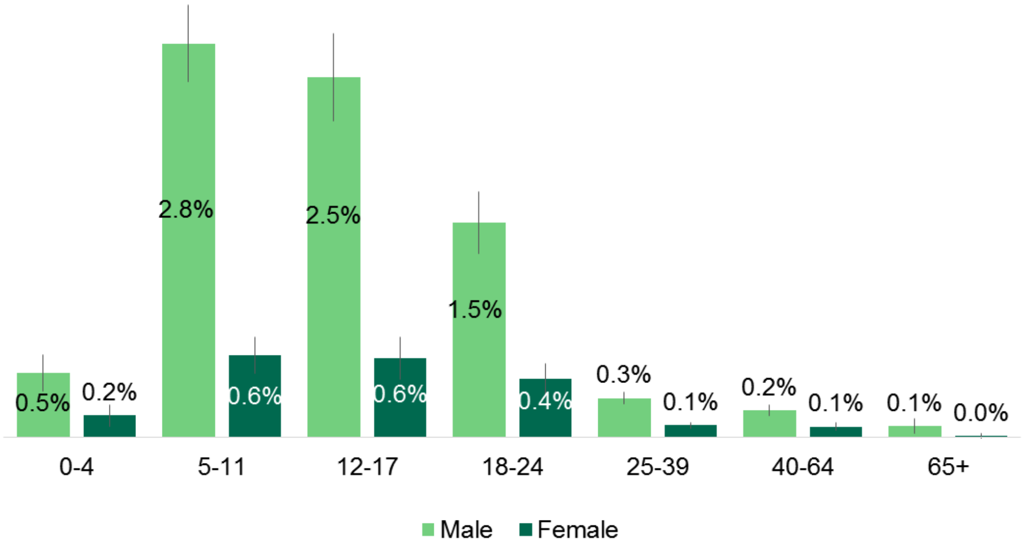
4.3.2 Gender

The gender distribution of City and Hackney residents with autism identified on GP records is similar to that seen in national population data, with a male: female ratio of approximately 4:1. This is also similar to other areas in East London.

Figure 13 shows that the proportion of male patients with autism is greater than female patients with autism across all age groups.

The all-age gender ratio between autistic patients is approximately 3:1 male:female in the City and 4:1 in Hackney. This different ratio in the City likely reflects the low numbers of autistic patients resident in the City.

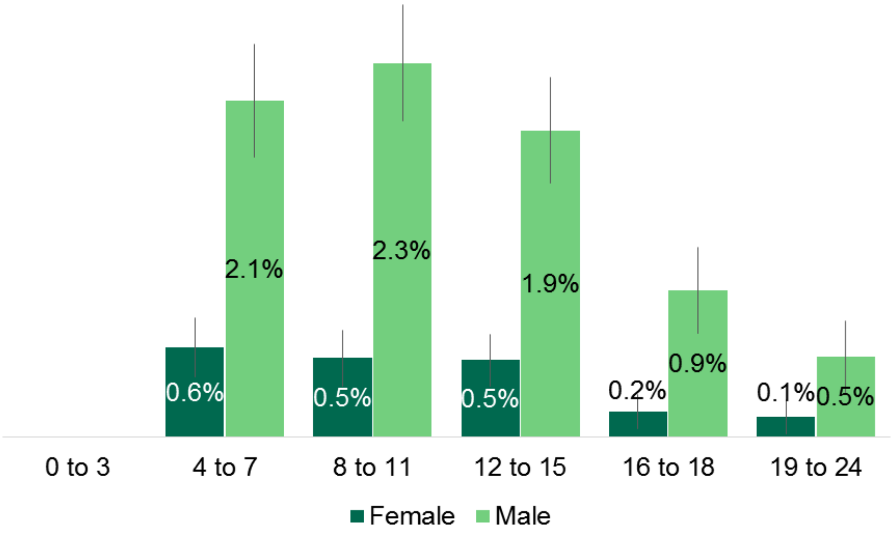
Figure 13: *Proportion of City and Hackney (resident) patients with autism, by gender and age group (2018)*



Source: Clinical effectiveness group (2018). [93]

When examining data from HLT on autism amongst the student population, the gender distribution of autism is broadly consistent with that reported nationally. [96] Figure 14 shows the proportion of student records by gender with the overall gender ratio is 4.2 males for every 1 female. This gender difference may reflect the differences in presentation of autism between boys and girls and subsequent under- or delayed diagnosis in among girls, as discussed in Section 3.5

Figure 14: Proportion of student records by age band and gender (2018)

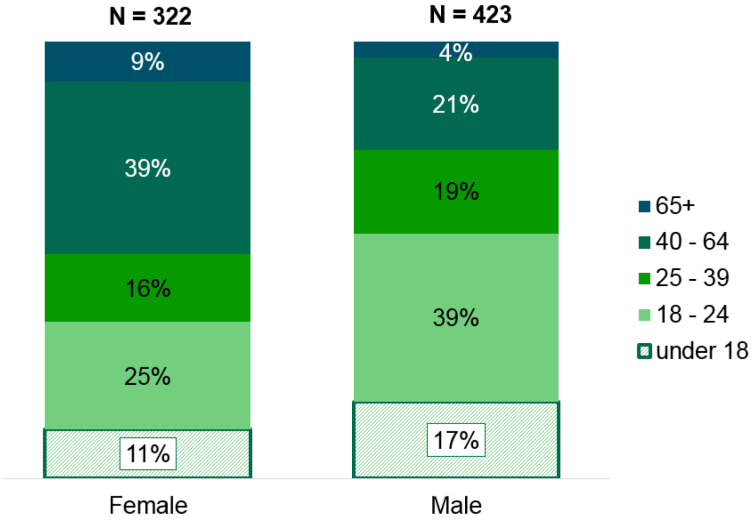


Source: Hackney Learning Trust (2018/19). [92]

When looking at those who are accessing adult social care, there are differences in age trends by gender, particularly in the 18-24 and 40-64 age groups.

The overall gender ratio of autistic social care clients is 1.3 males for every 1 female. An interesting finding from the data extract exercise is that the gender ratio of cases exclusively confirmed with a health condition of autism (as opposed to including those with 'likely autism' based upon free text record search) shows a larger male:female gender ratio of 3.4:1. This suggests gender differences are more likely to be observed among cases known to local learning disability service, who are more likely to be recorded with autism as a health condition.

Figure 15: Proportion of records by gender and age group (2014 – 2019)



Source: Hackney Performance Team (2019). [94]

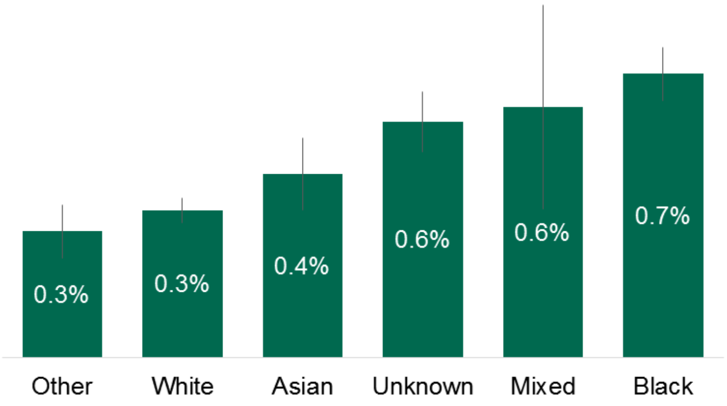
4.3.3 Ethnicity

Figure 16 shows the distribution of City and Hackney patients identified with autism broken down into broad ethnic groups. The highest prevalence of autism is observed in Black patients - this rate is significantly higher than people from Asian, White or Other ethnic backgrounds.

Figure 17 explores the prevalence by detailed ethnic category, however given the low number of individuals per group we cannot be statistically confident that the observed differences are true (as shown by the overlapping black lines on the figure that relate to the 95% confidence interval).

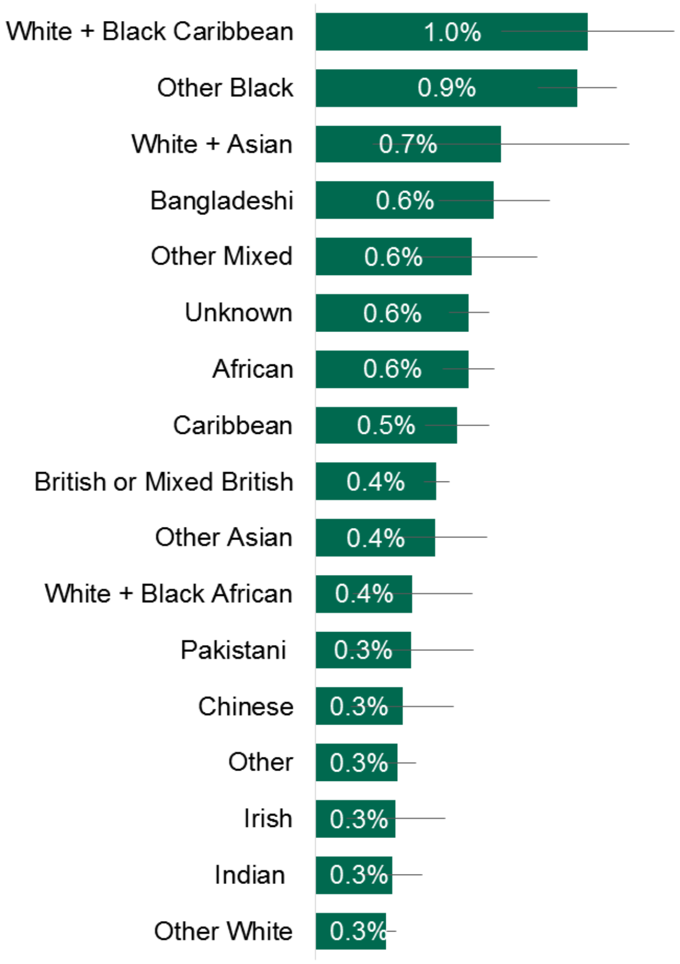
In total 17% of all autistic GP patients do not have an ethnic group recorded (either not stated, unclassified or blank). This high percentage of missing ethnic group records could relate to younger patients (who form the majority of the autistic patient population) as ethnic group may not be captured as accurately in children. This work could be explored further by public health team or the local GP confederation.

Figure 16: Proportion of City and Hackney (resident) patients with autism, by broad ethnic group (2018)



Source: Clinical effectiveness group (2018). [93]

Figure 17 : *Proportion of City and Hackney (resident) patients with autism, by detailed ethnic group (2018)*



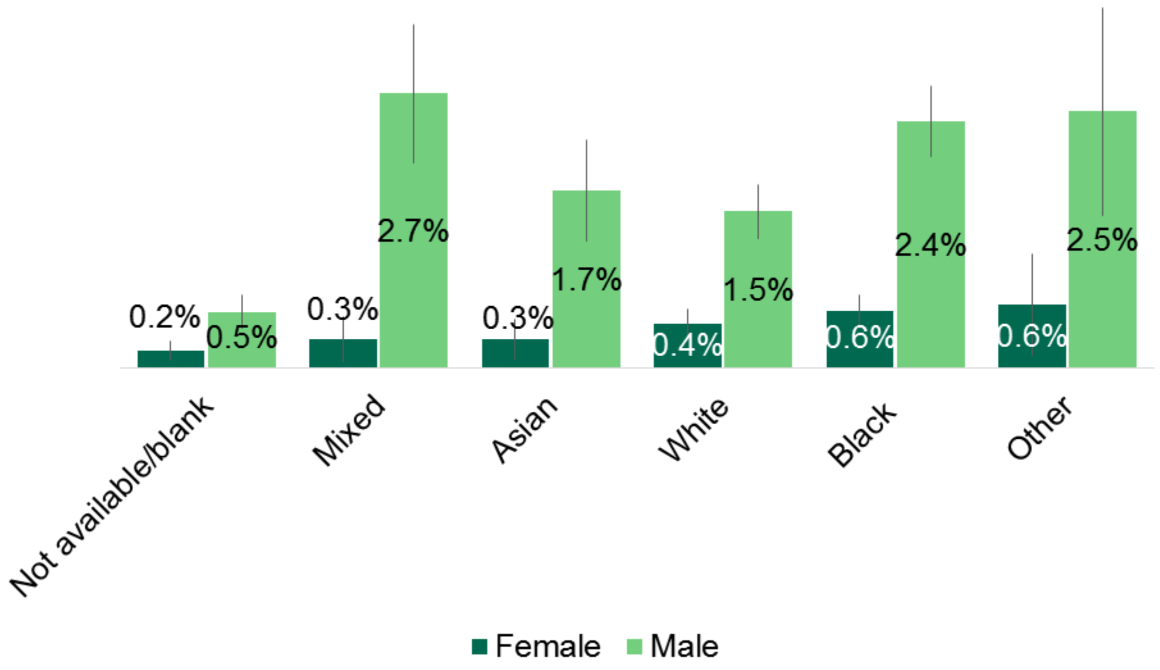
Source: Clinical effectiveness group (2018). [93]

National reporting shows students from Asian ethnic backgrounds are significantly less likely to be recorded with an SEN relating to autism than White British students and Black Caribbean and Black Other student are more likely to be recorded with autism. [96] Despite these national trends, no existing prevalence estimates adjust values for ethnic group, generally because of low number of autistic people in research meaning sub-group analysis cannot be robustly measured.

Local Hackney data reflects the patterns found in national reporting as shown by Figure 18 below with a higher recorded prevalence of autism in students from Black and Mixed ethnic backgrounds than students from White backgrounds. There is also a significant difference between the prevalence of autism in Asian students compared to Black students locally. The difference in prevalence by ethnic group is only evident in male students and is not visible in females, this may be due to:

- underreporting of autism in females which masks any gender differences
- recording bias exposing ethnic bias
- a true difference in the prevalence of autism by gender and ethnic group

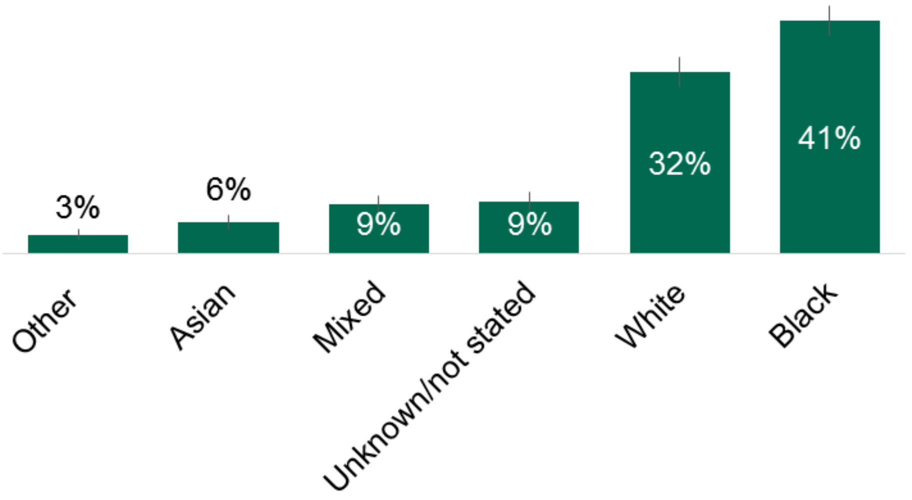
Figure 18: Proportion of student records by broad ethnic group and gender (2018/19)



Source: Hackney Learning Trust (2018/19). [92]

The majority (73%) of autistic adult social care records reflect clients from White or Black ethnic backgrounds.

Figure 19: Proportion of records by age group (2014 – 2019)



Source: Hackney Performance Team (2019). [94]

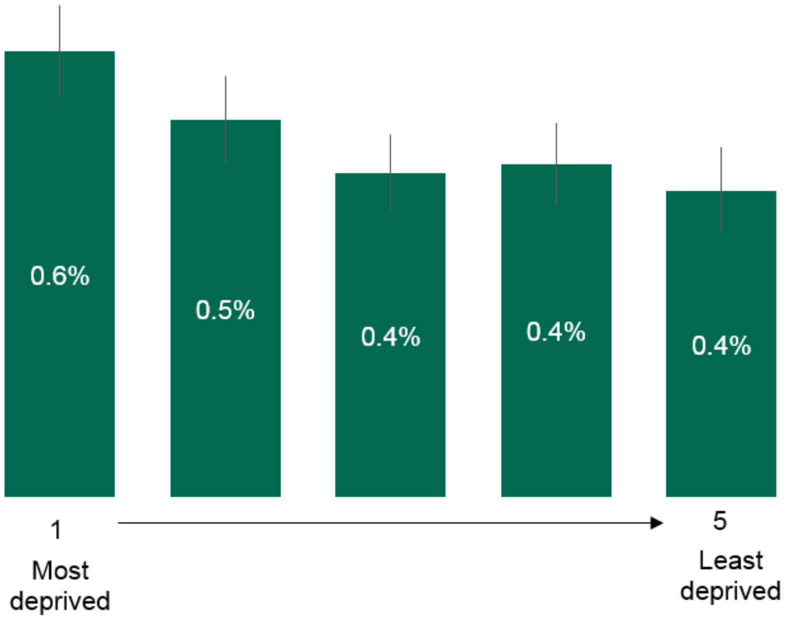
Unfortunately as only 20% of records had a detailed ethnic group recorded, we are unable to reliably reflect a further ethnic breakdown. The majority of records that do have a detailed ethnic group recorded fall into the following 5 detailed categories:

- White British
- Jewish
- Caribbean
- Black British
- African

4.3.4 Socio-economic status

The English Indices of Multiple Deprivation (IMD) measure relative levels of deprivation in 32,844 small areas called Lower-layer Super Output Areas (LSOA) [10], in England. It measures 7 domains (income, employment, health deprivation and disability, education skills and training, barriers to housing and services, crime and living environment) and produces a total score for each local authority. Most of the indicators used for these statistics are from 2015. Data from GP records (see Figure) indicates that a higher proportion of autistic residents live in the most deprived areas compared to the least deprived areas.

Figure 20: Proportion of City and Hackney (resident) patients with autism, deprivation quintile[11] (all ages, 2018)



Source: Clinical effectiveness group (2018). [93]

---

[10] A small area with a defined population that can be used provide an overview of information about that population. In 2010, the average LSOA in London covered a population of 1722 people.

[11] Quintile – any of five equal groups into which the population is divided according to the IMD (see note) scale of most and least deprived in England

Figure 21, a map of the City and Hackney geographical area, provides a visual representation of the distribution of patients with autism by the LSOA in which they reside.

Figure 21: Proportion of City and Hackney (registered) patients with autism, by total lower super output area population (all ages, 2018)

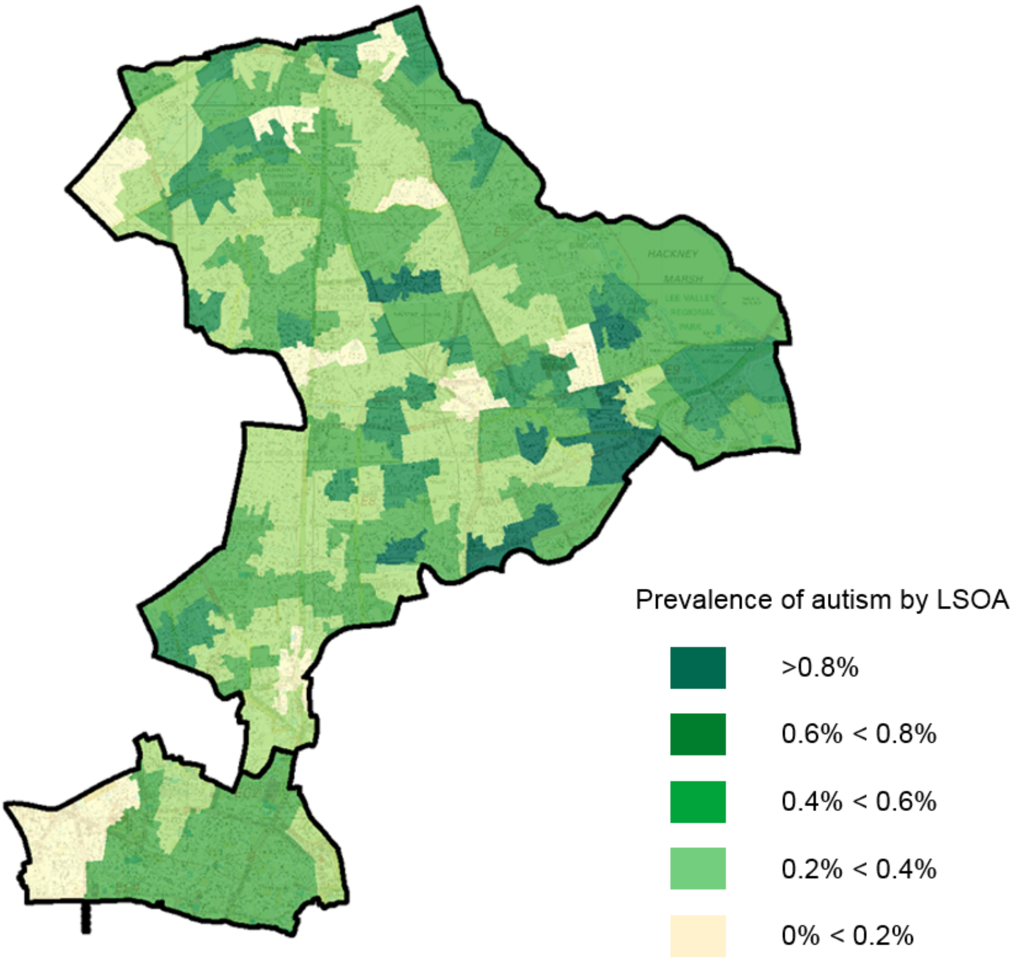
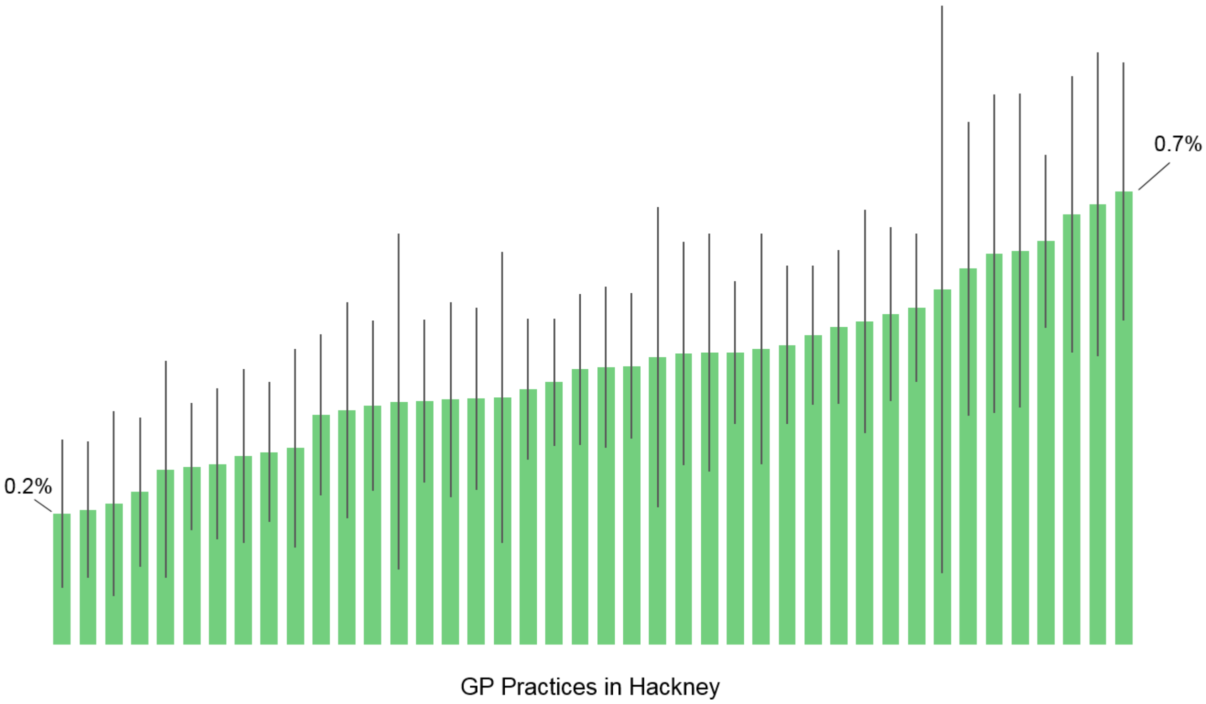


Figure 22 shows the proportion of patients with autism residing in City and Hackney by GP practice. The practice with the highest proportion (0.7%) of registered patients with autism has a proportion that is nearly 4 times higher than that of the practice with the lowest (0.2%). Looking at the practice demographics, the practice with the highest proportion of patients with autism is on the most deprived centile for deprivation. The practice with the lowest proportion of patients with autism is on the third most deprived centile for deprivation.

Figure 22: Proportion of City and Hackney (registered) patients (per GP practice) with autism (all ages, 2018)



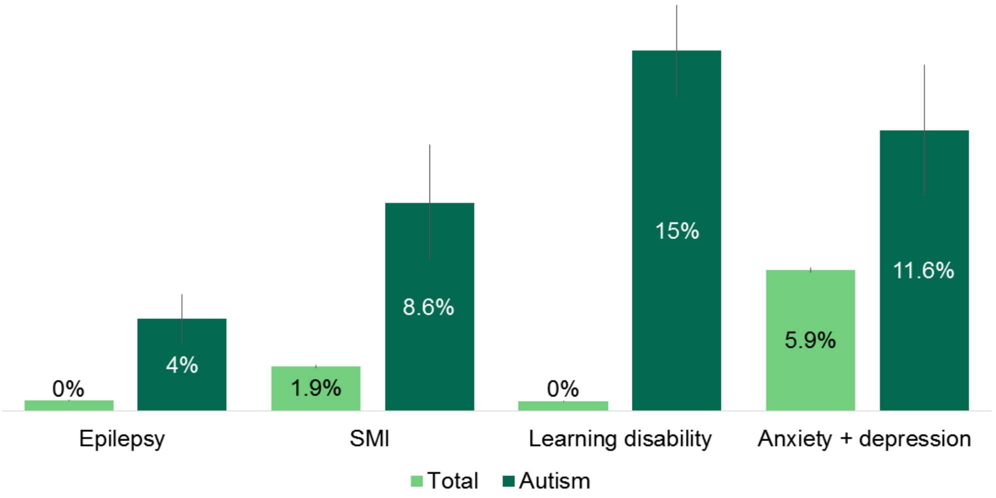
Source: Clinical effectiveness group (2018). [93]

There is insufficient data to draw conclusions about the local associations between student deprivation and the prevalence of autism.

4.3.5 Other health conditions

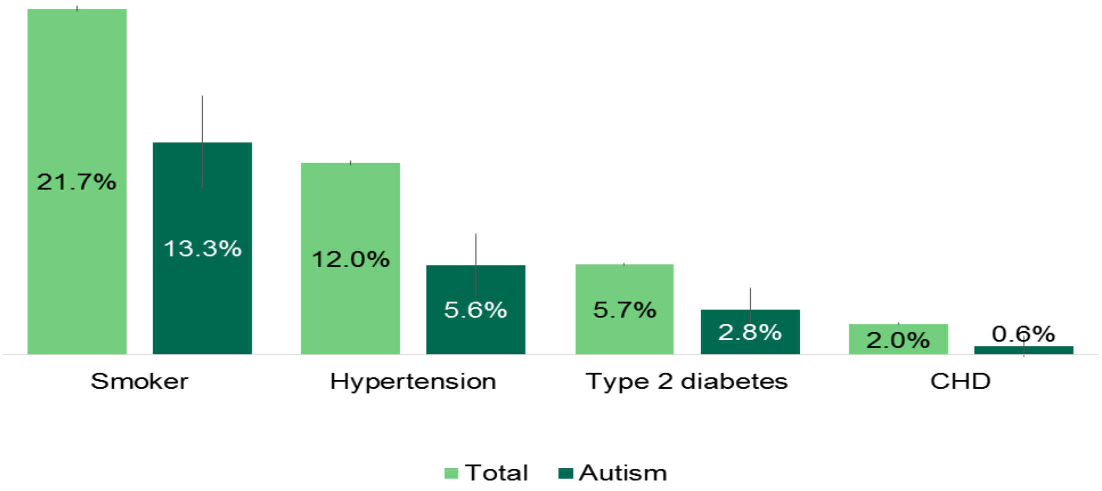
As discussed in SECTION 3.2 published literature shows that a number of clinical conditions are more prevalent in autistic people; however most of these studies were performed in the United States or Europe and not within the UK. Local data (see Figure 23) shows that the rates of recorded epilepsy, serious mental illness (SMI), learning disability and anxiety and depression are significantly higher in the autistic patients when compared to the general population. The higher rates of anxiety and depression amongst autistic individuals are supported in the literature. [98]

Figure 23: Proportion of City and Hackney (registered) autistic patients with selected clinical conditions (age 18+, 2018)



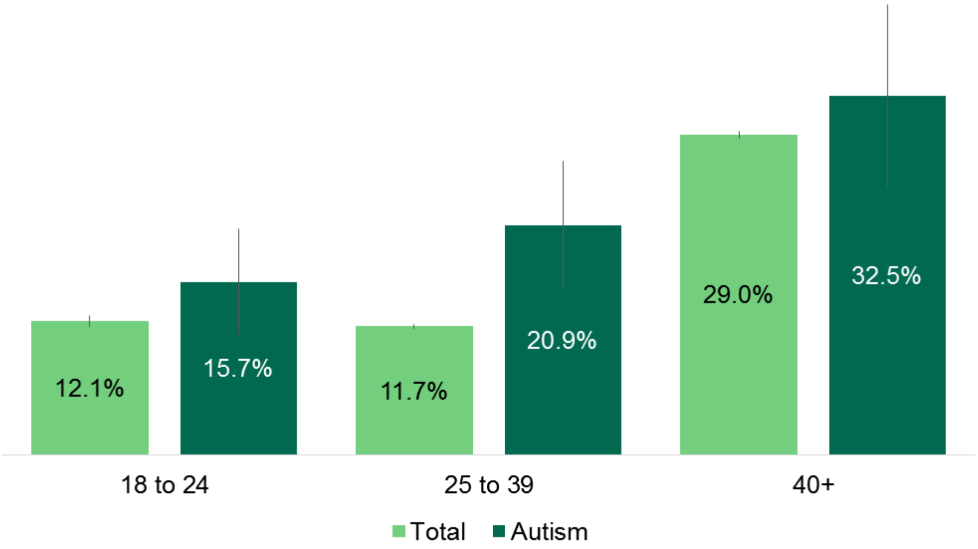
Smoking, hypertension and type 2 diabetes are risk factors for cardiovascular disease (CVD), a term encompassing multiple conditions with a similar drivers of disease, including coronary heart disease (CHD), cerebrovascular disease (include stroke) and peripheral vascular disease. In contrast to published studies, local rates of coronary heart disease, hypertension and type 2 diabetes are lower in autistic patients compared to the total patient population [98] [99]. It is likely the difference in recorded prevalence reflects the younger age of patients recorded with autism locally in comparison to the population reflected in the literature. CVD risk factors include behavioural, lifestyle and environmental factors that accumulate to disease overtime, therefore our younger recorded population would not have been exposed to risk factors for a significant duration to affect disease.

Figure 24: Proportion of City and Hackney (registered) autistic patients with risk factors for cardiovascular disease (age 18+, 2018)



Autistic patients are more likely to have their BMI recorded than the total patient population, with 82% and 76% of patients having their BMI measured, respectively. Figure 25 shows a higher prevalence of obesity in all age bands among autistic adults – however it only appears to be a significant difference in the 25 to 39 age band. These data should be interpreted with caution given the small sample sizes particularly in the 40+ age band and the high likelihood of recording bias. Given the increased prevalence of co-morbidity in the autistic population, individuals may be more likely to present to healthcare services for non-related reasons and have opportunistic checks of other parameters, e.g. blood pressure.

Figure 25: Proportion of City and Hackney (registered) autistic patients with obesity (BMI 30 or above) (age 18+, 2018)



Source: Clinical effectiveness group (2018). [93]

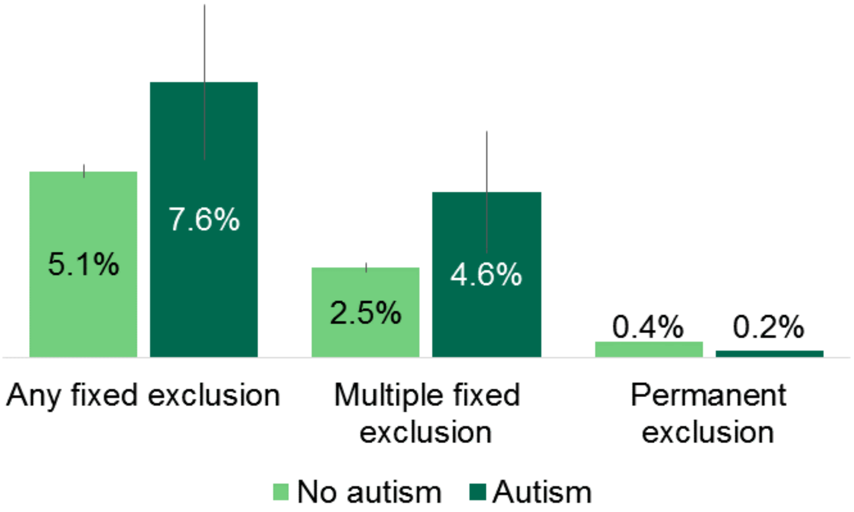
Note: The denominator for obesity prevalence is derived from patients who have ever had a BMI score recorded by their GP practice. This method is likely to underestimate the prevalence of obesity locally, in particular in people who are less likely to attend at GP practices (such as younger males, recent migrants, traveller and gypsy communities).

4.3.6 School exclusions

School records data shows students with a SEND relating to autism may be more likely to have a fixed term or multiple fixed term exclusions than other students, however this finding cannot be confirmed due to the overlapping confidence intervals (shown in Figure 26 below) which show this finding could be due to chance.

The data does not indicate whether the exclusion occurred before or after the student was recorded with autism. A review of SEND data flows would improve ability to reflect understanding on this topic.

Figure 26: Proportion of students who have been excluded from school (2015-18)



Source: Hackney Learning Trust (2018/19). [92]

4.3.7 Limitations

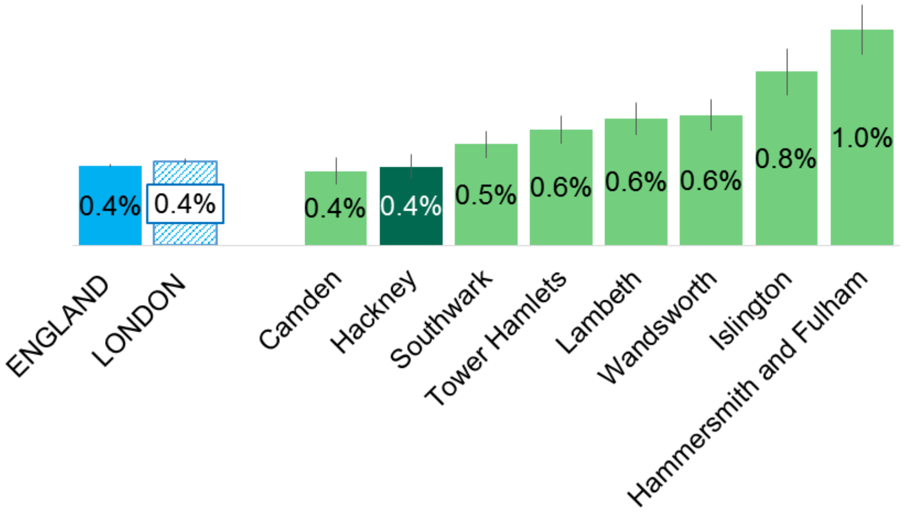
As described in SECTION 3.9 being autistic may affect an individual's ability to access to employment and housing provision. It was not possible to reflect these particular areas of need in this needs assessment, as data on specific subtype of disability is not routinely captured by employment agencies or by housing services. Though it may be collected for some individuals, the data set is likely to be incomplete and therefore unreliable.

4.4 Comparison with other areas and over time

4.4.1 Special educational needs and disability (SEND)

Figure 27 shows the proportion of students with a SEN of 'ASD' attending state primary and secondary schools in Hackney, compared to neighbouring boroughs, London and England proportions overall. **Students who have been issued with an EHCP are not included.** Locally, 99% of children with ASD have been issued with an EHCP. The low proportion of students (0.4%) in Hackney with a SEN of ASD who have not been issued with an EHCP is comparable to the London and England levels.

Figure 27: Proportion of students attending state-maintained primary and secondary schools who have an SEN of ASD[12] (2018)



Source: Department for Education (2018). [97]

4.4.2 GP records

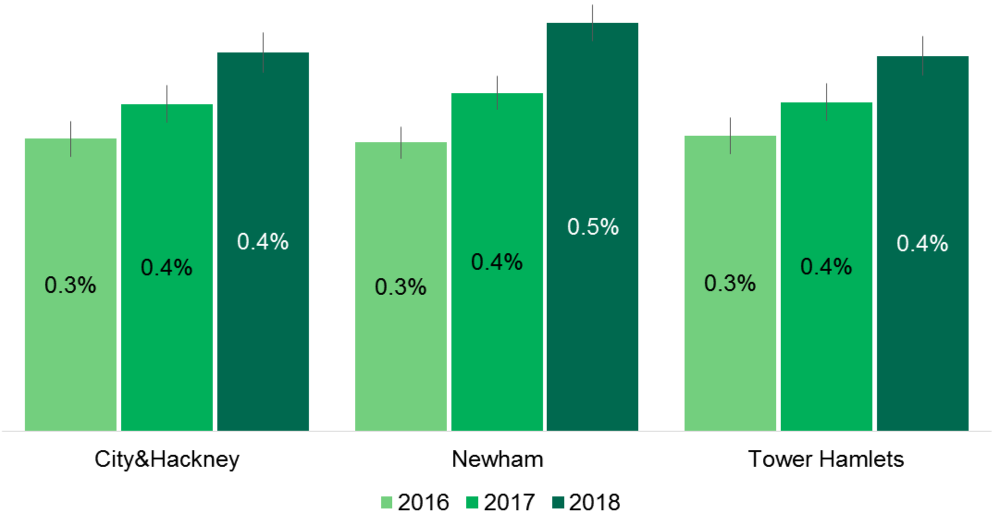
In comparison to the two neighbouring boroughs of Newham and Tower Hamlets, the City and Hackney has similar rates of autism in GP patients (between 0.4% and 0.5% of resident patients). Data is not available for all statistically comparable areas therefore we are unable to determine whether the rates in east London are similar elsewhere.

There has been a significant increase in the recorded prevalence of autism, each year, for each of the east London areas shown by Figure 28 below. Given the improved awareness and understanding of the condition throughout education, health and care systems it is likely that this increased prevalence observed in GP data reflects improved recording as opposed to increased prevalence of the condition in the population.

---

[12] Excludes pupils with a statement or EHCP relating to ASD.

Figure 28: *Proportion of resident GP patients recorded with autism (2016-2018)*



Source: Clinical effectiveness group (2018). [93]

5 Local services and support

5.1 Introduction

This chapter aims to identify the key health and support services available to autistic children and adults (and their families) living in Hackney and the City of London. The list has been compiled based on consultation with local stakeholders including commissioners, service providers and clinicians. It is not an exhaustive list of every service available but highlights the most commonly referenced services. Where possible service descriptions including caseload have been included. Reference to the best practice recommendations described in Chapter 4 will be made where appropriate, and any gaps in service provision noted.

The intention has been to describe services that are more specifically geared towards autistic people. Given the prevalence of concurrent conditions including learning disability and mental health conditions (reported in Chapter – Health and wellbeing impacts) autistic people may also come into contact with/be eligible for other services. Detailed descriptions of services available for autistic children and adults with a concurrent learning disability can be found in the Adults learning disabilities and Disabled children and young people JSNA chapters. Relevant mental health services are described within the Mental health and substance misuse chapter of City and Hackney's Health and Wellbeing Profile.

5.2 A note on services for City of London residents

Arrangement and provision of social care and housing services for City of London residents is separate to that for residents of Hackney. There are no autistic adults known to Adult Social Care residing in the City. If there was an individual eligible for social care/housing services it is assumed services would be spot-purchased on an individual basis, as is common when numbers are small. As such, these services are not generally described in detail in this chapter, although where possible relevant support has been highlighted.

Hackney and the City each have their own SEND teams, responsible for SEN provision for children and young people residing in each area.

Local support services for autistic children and adults residing in the City of London have been described where possible. Support services available to those who live and work in Hackney may not be available to those who live and work in the City, and vice versa.

The City and Hackney Clinical Commissioning Group (CCG) commission health services for both areas. People who work or reside in the City and are registered with a City and Hackney GP would be entitled to health services commissioned by the City and Hackney CCG in Hackney.

Of note there will be residents in the City of London who are registered not with a City and Hackney GP but with a Tower Hamlets GP and so this group will technically only be eligible for healthcare services commissioned by the Tower Hamlets CCG.

5.3 Prevention

This section will look at the support services aiming to prevent escalating care needs and to improve the health and wellbeing of autistic people.

5.3.1 Targeting support to known inequality groups

As discussed in the Evidence and best practice section, autistic people from BAME communities can face additional challenges when accessing diagnostic and post-diagnostic services.

There are no targeted support services to BAME communities or older people with autism in Hackney or City of London.

5.3.2 The Autism Alliance Board

Following statutory recommendations, the City and Hackney have an Autism Partnership Board, known locally as the Autism Alliance Board. The board meet bi-monthly. There is a strong emphasis on co-production; the board is co-chaired by an Autistic resident and the Director of Adult Social Services. The main purpose is to oversee production and development of the first Hackney and City of London local Autism Strategy and its implementation going forward. The Board has created the following work groups: Education, Training and Employment; Experts by Experience; Data, Health and Social Care, Criminal Justice and one for the wider community and local retailers. Representatives from across the fields of Health, Social Care and Education attend, including commissioners, the CCG and clinicians from the specialist autism diagnostic services. Autistic individuals ('experts by experience'), parents, and community partners are represented.

5.3.3 Supporting independence and the needs of people who may not qualify for statutory social support

Local authorities have a duty to *provide preventative support for people in their communities*. [59] As part of this duty they are required to consider the needs of those people who have autism but do not meet the eligibility threshold for social care.

Specialist Autism Social Worker

Hackney council funds a specialist autism social worker to work with newly diagnosed autistic adults who *do not have a coexisting learning disability*.

The majority of referrals are from the Autism Diagnostic Service but referrals from other health and social care professionals are accepted. The Autism Social Worker offers:

- guidance, advice and signposting to appropriate services that may help with the individual's well-being – for example, arranging an occupational therapist to assess mobility; or support to apply for benefits or the housing register.
- social care needs assessments where appropriate, including support for the whole family if required. Eligibility for social care is defined in the Care Act, 2014 (see links/additional information below).
- support with transitions for young people as they near the age of 18 and transfer into adult social care.
- contribute to the development of Hackney's offer of support services to autistic adults.
- providing a weekly drop-in offering information and advice to anyone over the age of 16 who works or lives in Hackney, who either has a diagnosis of autism or works with or cares for someone who does. Information and advice may include - a social care needs assessment, enquiries about autism-friendly areas, advice on using public transport, etc.

The service is commissioned to be time-limited; however, there may be autistic people who need an extended service

These services are limited to those who live or work in Hackney. Residents or workers in the City are not eligible.

Assistive technology

Reasonable adjustments may also include using new technology to help increase and maintain independence. For adults, these are considered on a case by case basis with the autism social worker. Children and young people up to the age of 25 may be able to access assistive technology as part of their EHCP if they remain in education or training.

Links/additional information:
Hackney local offer – Social Worker for adults with autism [100]
The Care Act 2014 – EasyRead version [101]
The Care Act 2014 was passed in the House of Lords in May 2013, with the aim of modernising adult social care laws in England. The key section that refers to a person's eligibility for care is summarised in The Care Act 2014. [59]

5.3.4 Education

Most children with autism in Hackney and the City are educated in mainstream schools with additional SEN support. A child with more complex needs which cannot be met by SEN support can access specialist autism provision (in mainstream schools), or may be accepted by a special school, after the statutory assessment process and when the appropriate educational provision is named on the child's EHCP.

In Hackney there are three primary schools and one secondary school that have additional specialist provision for children with autism:

- Tyssen Community Primary School
- Millfields Community School
- Shoreditch Park Primary School (previously called Whitmore Primary School)
- Mossbourne Community Academy

There are currently three community state-funded special schools in Hackney, there are none in the City of London. More information on these schools can be found via the Links below.

Further information about these schools and independent schools in Hackney is available on the Hackney Local Offer website.

Hackney Learning Trust have published a plan of intent to use special provision capital funding to support the following:

1. the development of specialist post 16 provision at The Garden for young people with ASD, and
2. the development of an additional resourced provision at Queensbridge Primary School for primary aged children with ASD.

There is an EHCP administrator at Hackney Ark who is a single point of contact for education, coordinating EHCP requests and reporting against the 20 week target timeframe

Links/additional information:
Hackney local offer: special schools [102]

5.3.5 Employment support

Mainstream provision of employment seeking support is through Jobcentre Plus. Jobcentre Plus, part of the Department of Work and Pensions, aims to help people of working age find employment. They offer information about training opportunities for people who have been long-term unemployed, and administer claims for benefits. Appointments may be face-to-face, digital or by telephone, at the discretion of the work coach and selected based on the individual’s requirements.

The scope of Jobcentre Plus’s role includes working with local employers and advocacy groups to create opportunities for employment. It is unlikely that undiagnosed autistic people will be identified through mainstream employment support channels, but for those with a diagnosis of autism, disability employment advisors can offer assistance.

A specialist disability employment advisor (DEA) operates at each Jobcentre Plus site, of which there are three in Hackney and one in the City of London. Rather than having their own caseload, DEAs offer advice, training and support to work coaches interfacing directly with jobseekers with the aim of upskilling of all work coaches in their interactions with autistic people. Training also aims to raise awareness among staff on how autism presents and how to ask about disability particularly when it is not disclosed by the individual. DEAs attend community forums including parent-carer forums to improve awareness of their services. There are links with the adult autism diagnostic service, who signpost to these employment services.

Autism is not routinely captured on client management systems and so it is not possible to quantify the number of autistic clients who are receiving support from Jobcentre Plus locally. Individuals may not disclose their diagnosis. Moreover, there is currently no process for sharing data between DEAs and Adult social care or the Autism social worker. As such, there may be autistic adults who are not receiving the additional employment support to which they are entitled. Anecdotally, there needs to be earlier links made between autism services for young people and employment services – often autistic young people do several college courses or voluntary work and then access employment services later. There is a small number of young people accessing benefits who have been assessed as able to work but, anecdotally, families are reluctant to support this because of their perceived vulnerability. In such cases DWP grants such as Access to Work are available which fund reasonable adjustments to support people with disabilities into work. Parental education on the additional funding options and potential reasonable adjustments available may be beneficial.

There are two main provisions through the DWP: the Working Health Programme (WHP) and the Specialist Employability Support Programme (SESP). The WHP is a local government funded 15 month programme which supports people in going back to work. Individuals are supported in finding work programmes and accessing services, e.g. dietetics. Support continues for 182 days while the person is in employment. 75% of people supported by this scheme have a disability. The SESP is a 12 month service for people with disabilities and more complex needs who aspire to work.

The work coach identifies the provision that is most appropriate for the service user. There are other non-contracted services funded by local authority (see below Supported Employment offer) and by third sector organisations – if the individual meets the specifications the work coach can refer to these.
Challenges include finding appropriate employment provision for people with complex needs. There is no autism specific employment service.

City and Hackney Jobcentre Plus branches are grouped in the East London district. Each district runs at least two ‘Calm and Quiet’ sessions per year, where reasonable adjustments are made in terms of appropriate lighting and removal of auditory distractions. Service users are given the opportunity to look around and understand what to expect from the service. These sessions are open to people from other boroughs. Support is offered to the jobseeker on how to disclose a diagnosis. The sessions are advertised through the local adult autism diagnostic service as well as through supporting into adulthood transitions services and other third sector organisations designed to help people with disabilities find employment.

For an individual claiming benefits there are often set conditions that need to be met. ‘Easements’ are reasonable adjustments that are made when it is acknowledged that the conditions may be difficult for that individual to meet in view of their disability. Easements for an autistic person can include: ensuring continuity (seeing the same work coach each visit); flexibility around timekeeping but acknowledgement also of the importance to some of good timekeeping, and clear, unambiguous verbal or written communication.

Hackney Works offer - Supported Employment service. The Hackney Supported Employment Service, Hackney Works, provides services that include vocational profiling, sourcing of employment opportunities, assistance with CV preparation and interviews as well as support through the application process and beyond, while the individual is in employment. The service also negotiates suitable job goals and recruitment methods with the employer and provides support for the employer in recognising the skillset of people with health and social care needs.
The service is available for adult social care customers who reside in Hackney.

Links/additional information:
Hackney Works: Supported Employment [103]

5.3.6 Access to services

Public organisations are required by the Equality Act to take into account of how the experience of their services may differ for autistic people and make reasonable adjustments so that this population are not at a disadvantage. *[4]* Examples of services include healthcare, education, leisure and transport.

In Hackney and the City there are no locally held data sources on the frequency of use of reasonable adjustments.

In the 2018 Self-assessment framework[13] questionnaire responses for City and Hackney, local autistic adults reported that the phlebotomy service at Homerton Hospital was very accessible and that the post-diagnostic support for adults included some reasonable adjustment work with employers/schools/colleges.

City Hackney Autism Communication Cards
The Autism Alliance Board have co-produced a credit-card sized card which allows the autistic individual to alert others to the fact they are autistic and may have additional needs. They have been developed for autistic young people and adults to use in situations when communication may be difficult. The autistic person can decide when and where to show their card. Data is not held on card holders.

As described in chapter 2, NAS have produced an autism hospital passport document, which individuals can complete take with them to appointments. We do not have local data from primary or secondary care services on the use of these in the local population.

---

[13] The Autism Self-Assessment is intended to review progress, around the country, in implementing the Government's Autism strategy 'Think Autism'. Organisations (including commissioners and local residents) are asked to review progress on the principal areas covered by the strategy.

5.3.7 Housing support

Local authorities are required under the Equality Act to consider the needs of disabled adults, including those with autism, when considering housing provision. [4]

At present, there is no service which specifically considers the needs of autistic people looking for housing. The national autism strategy recommends taking the autistic individual's needs into consideration when applications are made. This is done to some extent locally, where individual autistic need are taken into account with regard of the suitability of a property where they are serious enough for the property to be potentially unsafe for the individual. Autistic individual are not easily identified through the local housing register in Hackney or the City so it is not possible to give a breakdown of the range of categories of housing in which our autistic population resides.

Floating support services

Floating support services provide preventative housing-related support to vulnerable adults to help them manage their accommodation, sustain stable tenancies/homeowners agreements and continue to live independently. Hackney has commissioned a floating support service which is due to start in September 2019. Autism has been added to the list of support needs that confer eligibility for the service. Support workers working with autistic adults will be required to make reasonable adjustments in accordance with this. Self-referrals can be made to the service. This is a time-limited service of up to 12 months duration.

The service may be delivered one-to-one in the home or on the premises of the referring agency. Advice and support may be provided on paying bills, understanding tenancy agreements, access to external services such as education and employment and crisis or dispute resolution (for example as short term interventions in areas like homelessness, debt or benefits payments).

5.3.8 Community involvement

Think Autism, the updated national autism strategy, highlighted the need for community environments to be autism-friendly. This can be achieved by having an awareness of the needs that autistic people may have and by making reasonable adjustments to provide for these.

Hackney Picturehouse

Hackney Picturehouse cinema has ‘Autism-friendly’ screenings once a month. Adjustments made include:

- no trailers or advertisements
- lights left on low throughout the film
- reduced volume
- freedom to move around, make noise and sit where you like
- the freedom to take a break and leave the screen when needed
- tickets are at the reduced rate of £2.50 per person
- a relaxed and welcoming environment where staff are sensitive to the needs of children and families with autism

The films selected are usually those aimed at younger audiences.

Hackney Museum and Archives

Hackney Museum has anecdotally been recognised as a welcoming, safe and accessible place for people with learning disabilities and/or autism and staff report that many carers and disabled groups using the museum on a regular basis.

In this service mapping exercise we did not identify any other businesses or organisations in City or Hackney who are currently employing strategies to raise autism awareness or make environments more autism-friendly.

5.3.9 Advocacy

Advocacy, as defined in the Evidence and best practice chapter, is a process by which an individual is supported in communicating their views, gathering information and reaching a decision while ensuring their rights are secured. As explained in section 4.3.6 local authorities have a duty to offer support from an independent advocate, if required, to enable people to be involved in decisions about them and their care and support. [59]

All referrals for community advocacy services go through the Council's commissioned lead provider service The Advocacy Project.

Links/additional information:
The Advocacy Project in Hackney [104]

5.4 Identification and early intervention

NICE recommend that every area have a clear, consistent pathway for diagnosis, followed by the offer of a personalised needs assessment. [82]

5.4.1 Diagnostic pathway – adults

The City and Hackney Autism Service is a commissioned diagnostic service that has been active since February 2015. The service comprises a multidisciplinary team including consultant psychiatrists, a manager/ senior practitioner, an occupational therapist and a peer support worker. It offers diagnostic assessments, brief interventions and advice to adults (18 or over) registered with a City and Hackney GP who have not had a previous diagnosis of Autism Spectrum Disorder or have a coexisting learning disability.

16 weeks was the average waiting time from referral to assessment from April 2017 to March 2018.

NICE guidance is followed for the diagnostic process. This is followed by onward referral, for example, to the psychology services, specialist autism social worker, and signposting to other services.

The City and Hackney Adult Autism Service provides time-limited post-diagnostic support for those who receive a diagnosis in the form of:

1. Post diagnostic course – twice a year
2. Monthly peer support group for up to 18 months
3. Reasonable adjustments appointment resulting in a Reasonable Adjustment letter to share with employer/educational establishment. Some of these appointments result in referral to an employment service, e.g. supported employment services.

In 2018 73% of newly diagnosed autistic adults (n=35) engaged in at least one of these.

5.4.2 Diagnostic pathway – children

Hackney and the City have a well-established children's autism diagnostic service. The table below summarises the organisations involved. The following sections will describe the diagnostic pathway in more detail.

Table 6: Organisations involved in children's diagnostic pathway

Organisation	Description
Homerton University Hospital Foundation Trust (HUHFT) Acute and Community Services providing services across Hackney and the City of London	Hackney Ark: Children and young people's centre for child development and disability. It offers multi -disciplinary and multi -agency care pathways. The ASD diagnostic pathways for Under 5s and Over 5s with a primary Learning Disability are based at The Ark Services involved in these pathways are: ● Paediatrics ● Child and Adolescent Mental Health Services for children with Learning Disability (CAMHS Disability; provides educational psychology (EP) input to schools ● Children's Speech and Language Therapy ● Children's Occupational Therapy
East London Foundation Trust (ELFT) Mental Health Foundation Trust providing services to a large core area including City of London, Hackney, Newham and Tower Hamlets and, Bedfordshire and Luton	Specialist Child and Adolescent Mental Health Services (CAMHS) Carry out ASD assessments for YP over the age of 14-18 years. Involved in ASD diagnostic assessments for children over 5 who DO NOT have a learning disability. This is through the Social Communication Assessment Clinic (SCAC). The SCAC pathway sits across ELFT, HUHFT, and CSC and involves the following services: Paediatrics Specialist CAMHS (including Psychiatry and Psychology) Educational Psychology (EP) Children's Speech and Language Therapy Clinicans from the CSC clinical team
London Borough of Hackney	Social Care CAMHS team are involved in in the SCAC assessment pathway
Hackney Learning Trust (HLT)	Provide information regarding children that they are working with as part of the assessment process

Autism assessments for all children aged 2-13 years take place at the Hackney Ark. Most new referrals to the Hackney Ark are discussed at a Multi-agency referrals (MARs) meeting; some are direct referrals from schools. MARs meetings involve a team of professionals from Health, Social Care and Education, who determine and arrange initial assessment and support for children and families referred. Social Care CAMHS referrals for autism also come through this pathway.

Children under 5 years are usually referred by a health visitor, GP or speech and language therapist with speech and/ or communication difficulties. They are initially seen in neurodevelopmental clinic by a consultant paediatrician and then referred to the Complex Communication Clinic if appropriate.

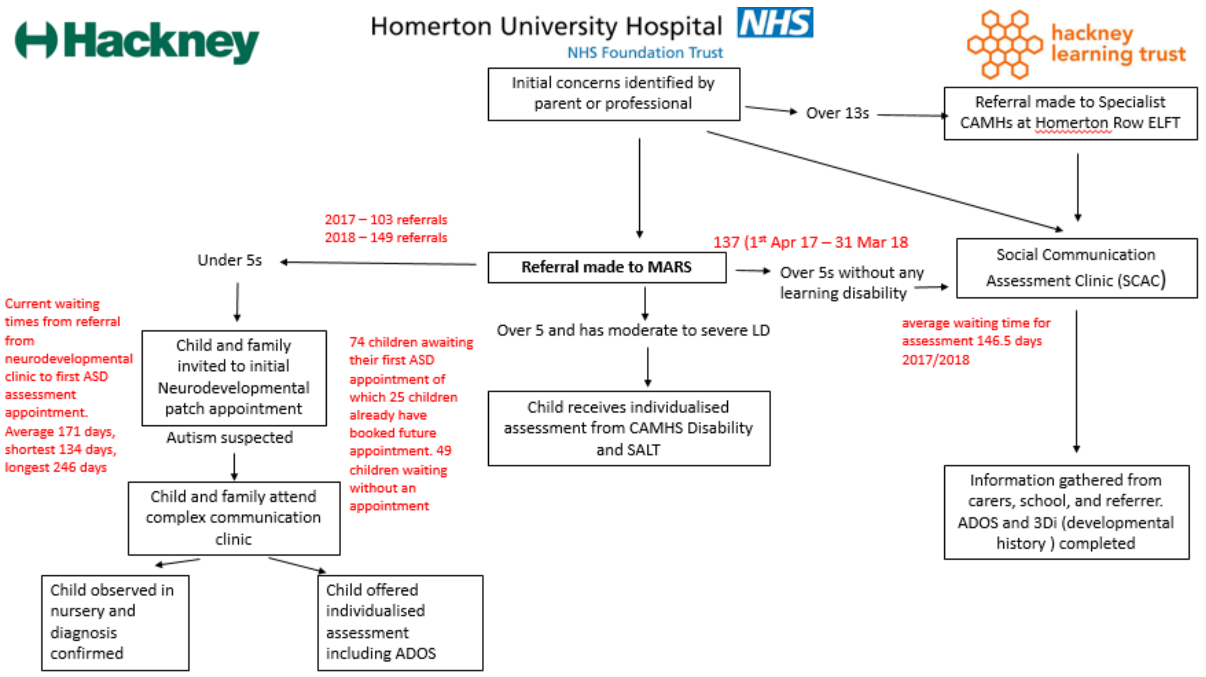
Children aged 5-13y without a primary learning disability are seen in The Social Communication Assessment Clinic (SCAC), which is a joint pathway by Hackney Ark clinicians, Specialist mental health CAMHS (ELFT); Social Care CAMHS and CAMHS Disability. This is an individualised assessment with an MDT including Paediatrician, Psychiatrist, Clinical Psychologist, Educational Psychologist and Speech and Language Therapist.
The CAMHS Disability Team, based at Hackney Ark, performs assessment of 5 -19y school age children and young people with primary learning disability. CAMHS Disability provide educational psychology (EP) input to educational settings/schools.

In the SCAC section of the children's diagnostic pathway for children aged over 5 years, the EP provides consultation and support to schools / settings to plan interventions and offer guidance for SEN support plans and EHC plans

All young people aged 14 or over with suspected autism are assessed at Specialist CAMHS (ELFT) due to overlay with mental health needs.

The diagnostic pathway is as shown in Figure 29.

Figure 29: Childrens' autism diagnostic pathways



There is input from education at all stages of assessment to ensure adequate provision of SEN support while the child or young person is having their assessment. The target timeframe from referral to the autism diagnostic service to assessment is 3 months. [82]

5.4.3 Awareness and frontline staff training

Hackney Adult Social Care provides a comprehensive autism multi-agency training programme. They provide bi-monthly awareness sessions to staff. Training is provided on autism and ageing, autism and dementia, dual diagnoses of mental health problems and learning disability. Between 2015 and 2018 over 400 staff members had attended a training course. Training is open to staff working in the City. This is delivered in part internally by the Learning and Development team. Additional external specialist speakers can be commissioned when necessary. Use of autistic trainers is prioritised where possible. Attendees include representatives from the public and private sector including the local Hackney police force.

Autism training is not compulsory for staff working in Homerton University Hospital or East London Foundation Trusts. Staff from the adult diagnostic service at ELFT have run training events open to NHS staff and local partners including training to Jobcentre Plus staff. The Royal College of GPs offers an Autism toolkit on its website, which contains links to useful resources, and offers an online learning course to its members, but it is not known how many GPs have completed this locally. [105] [106]

Records are kept on attendees and which departments they represent. From these, areas where uptake is relatively low include the probationary service and sport and leisure services. There is no council-wide policy in regards to training. The Hackney Learning Trust (HLT) and Children's Social Care teams do not receive this programme of teaching but source their training elsewhere.

The Inclusion and Specialist Support Team (ISST) at HLT provide a central training offer (Autism awareness over two days) to school and setting staff. There is a charge for teachers and setting staff to attend.

The ISST, the Educational Psychology Service (funded by HLT) and the Speech and Language Therapy Team (jointly funded by health and education) offer bespoke training to schools, which schools would pay for. Other boroughs including City can access the above training at a cost.

There is not a standard offer for HLT staff, but if there is capacity ISST can provide training to teams on request.

Parent training can be provided through EarlyBird – this is a joined up offer between HLT and teams from Hackney Ark. There are also post diagnostic sessions and further drop-in training / support sessions for parents following their child being given a diagnosis of autism and the CYGNET programme which is run for older children (8 years plus). These will be discussed in Section 6.5.2.

5.4.4 Data collection

Computerised health information systems are used in most of the major health providers in Hackney and the City. GP practices in Hackney and the City use EMIS.[14] Homerton University Hospital uses the Cerner PowerChart[15] system. The children's diagnostic service for under 5s and over 5s both use the RiO[16] system but the systems are separate.

The diagnostic service has coded children with Autism on their system in 3 processes. For the last 5+ years - all children under 5 years old newly diagnosed with autism have been coded as having autism on RIO. ICD10 codes are currently being used.

Children diagnosed in the over 5 diagnostic service have also been coded on their RIO system but anecdotally recording for this age group has been less consistent.

Recently all children with an EHCP who the Hackney Learning Trust had labelled as having ASD were also coded. While coding to date has been inconsistent senior staff in the under-5s diagnostic pathway report that this is now being done in their service with more rigour. Data collection on ethnicity is not mandatory on the system and is likely to be user-dependent.

---

[14] EMIS Health is one of the electronic patient record systems commonly used in primary care in the United Kingdom.

[15] Cerner's PowerChart is an Electronic Medical Record (EMR) system used by clinicians in hospitals and ambulatory facilities.

[16] Rio is an electronic patient records system for community, mental and child health providers.

5.5 Treatment, care and support

The diagnostic pathways for children and adults have been discussed. As mentioned both are time-limited. This section will detail the local services available in Hackney and the City for those who have a diagnosis.

5.5.1 Crisis services

As described in the Health and Wellbeing Section, autistic children and adults can at time experience periods of crisis, which can be triggered by worsening anxiety or depression. As discussed, there is a higher prevalence of anxiety and depression among autistic people. NICE guidance states treatment for these may need to be adapted for autistic people following consultation from a specialist autism team. There is no specialist autism post-diagnostic service for Hackney and the City. For an autistic child or adult who presents with anxiety or low mood initial presentation is usually to the GP, who may then refer to child or adult mental health services in secondary care.

City and Hackney Child and Adolescent Mental Health Services (CAMHS)
CAMHS provide services for children and young people with mental health problems. Autistic children or young people may be referred to CAMHS if they are felt to have a co-existing mental health presentation such as anxiety or depression and the problems do not go away or they begin to seriously interfere with their everyday lives (e.g. not going to school, not eating or sleeping). Referrals are accepted from the GP or school SEN coordinator. This is not an autism-specific service.

Adult mental health services
Following initial presentation to the GP, the individual may be managed in primary care, signposted to local services, or referred to secondary care mental health services.

Individuals who may benefit from talking therapies are signposted online to the IAPT (Improving Access to Psychological Therapies) website for City and Hackney where they can self-refer. They will then be contacted at a later date for a further telephone assessment and plan.

City and Hackney have crisis services in the form of a crisis line telephone number (to talk to a professional at any time of day if in severe distress) and a walk-in Crisis Café which runs every day in a location next to Homerton Hospital.

The City and Hackney Mental Health Referral and Assessment Service (CHAMHRAS) team offer a one-stop single point of referral for routine and non-urgent referrals of adults aged 18-65 to secondary mental health services.

As with children and young people, there is no autism specialist service for autistic adults post-diagnosis.

5.5.2 Carer support

Adults

Adult Carers caring for adults aged 18+ can access a variety of services within Hackney. These include information, advice, signposting, peer support groups, training, events, a carers discount card and 'what if' planning. A statutory carers assessment can also be undertaken which may result in a direct payment and/or support plan depending on the identified and eligible needs of the carer.

All services offered are person-centred and focused on the wellbeing on the carer to support empower them to continue caring for their loved one(s) and live a fulfilled life for years to come.

Children and young people

Short Breaks allow a disabled young person to have a break away from their main carer and give their carer a break from their caring responsibilities. Children and young people are eligible if they are 5-17 years old, are resident in Hackney and in receipt of certain benefits (disability living allowance at middle rate or above or personal independence payments at intermediate or advance rate).

The number of hours offered may vary depending upon levels of funding available, levels of demand and the capacity of the services. There are a variety of activities available and suitable for children with autism. Hours can be used for once-weekly activities such as boating, or for longer periods of time – all-day activities in school holidays, for example.

Links/additional information:
Short Breaks Hackney [107]
Short Breaks Service City of London *[108]*

ASD Family Intervention Worker

The Inclusion and Specialist Support Team is part of the Hackney Learning Trust and is formed of specialist teachers with SEND experience. They provide a range of services including delivering training and advice to schools. Within this team is an ASD Family Intervention Worker who works with families of children who have a diagnosis of autism. They work with families experiencing challenging circumstances, for example marital breakdown, breakdown in relationship between school and family, anxiety and school refusal. They can offer support in the home or in another chosen venue. The number of sessions and nature of the support required is individually discussed and agreed with the families and young people.

Specialist CAMHS

Autism parent information sessions

CAMHS hold monthly parent groups for parents of autistic children and young people living in Hackney in order to offer professional advice and support. The groups are run between Clinical Psychology, Occupational Therapy and Speech and Language Therapy and cover a different topic each month. There is a rolling programme of range of topics throughout the year, such as parental stress, communicating with schools and developing independence.

PEGASUS

PEGASUS is a psychoeducation group available to parents of children who have been recently diagnosed with autism in Hackney. It comprises a time-limited intervention of two 3 hour sessions and aim to help parents understand more about autism, learn ways of managing their child's difficulties related to autism and to help parents build a support network and plan for how to manage things in the future. Referrals are accepted from the diagnosing autism assessment team if they feel it would be of benefit. It is funded through the CCG via Specialist CAMHS.

CAMHS Disability

The Child and Adolescent Mental Health service (CAMHS) for children with disabilities and emotional / behavioural and mental health concerns is based at Hackney Ark and runs specialist assessment and intervention groups for children with autism, including:

1. Next Steps group which is a group for parents of children (up to 5 years) who have been recently diagnosed with autism
2. Earlybird courses for parents with children (up to 8 years) with a diagnosis (or who have just received a diagnosis) of autism. It is run twice a year by a multi-disciplinary team.
3. CYGNET, a parenting support programme aimed at parents/carers of children (over 8 years) who have recently received a diagnosis of autism or who would like more support in understand their child's autism and how to meet their needs.
4. monthly autistic parents' coffee morning

These interventions are time-limited, with the exception of monthly coffee mornings.

The following services are for children and young people and their families with SEND and not exclusive to those with autism.

Parent Carer Forums

Since 2008 parent carer forums have been set up in most local authority areas of England, with help from the Department for Education, who provide a small grant.

The Hackney Independent forum for Parents/Carers of Children with Disabilities (HiP) is the parent carer forum for Hackney. The group is represented in a number of committees, including the Autism Alliance Board and the SEND Partnership Board. They also run information sessions on a variety of special needs related topics.

The City Parent Carer Forum is the parent-carer forum for the City.
Parents and carers of children and young people who have an EHCP meet once a term with local authority officers to discuss expanding service provision for children and young people. Longer term goals include involving parents and carers of children and young people with SEND regardless of whether they have an EHC plan. The group organises activities for children and families, events and training days and links with other forums nationally to share ideas.

Other parent support groups for parents of children with SEND are available and more can be found on the Hackney Local Offer website.

Hackney SEND Information, Advice and Guidance Service (SENDIAGS)
The Hackney SEND Information, Advice and Guidance Service is an arm's length service providing impartial and confidential information, advice and support to parents and carers of children with SEND and young people and children with SEND. SENDIAGS run weekly face-to-face drop in sessions.

Links/additional information:
Autism: Information and Support [109]

5.5.3 Transition to adult services

NICE have produced guidelines on transitioning children and young people under children's services to adult services. [88] As part of the requirements from the Children and Families Act both Hackney and the City each have a local offer website, which lists and describes the available local services for children and young people with SEND. [62]

Young people with autism over 18 years of age may be eligible for a mix of adult services and children's services from Education, Health and Social Care.
Support with an EHCP is provided until 25 years if the young person is still in education or training. The EHC Plans are reviewed annually and maintained on the basis that the YP still requires support/provision via an EHC plan and that they remain in education. Those that leave education would have their EHCPs ceased. Those that go on to further education (ie: university, college, etc) may have support offered at those institutions and might not necessarily apply for/receive and EHCP.

Targeted Health Outreach Team

The Targeted Health Outreach Team is part of Hackney Ark's Child Development & Disability Service, funded by the CCG. They run services for young people with SEND who live in Hackney or the City, providing support around developing independence and improving health and wellbeing. The team works with those aged 14 to 19 years who have SEN support or an EHCP. They can work with young people who receive DLA or PIP benefit and who may already get short breaks but cannot work with young people who already have an allocated social worker and care package through social services. This service is available until the individual's 20th birthday.

The service runs several activities:

- a monthly film club,;
- a weekly social club where members can all take part in a hobby or activity together;
- school holiday group activities, involving day trips for activities and visits to local partners, for example, the Geffryre Museum;
- relationship groups, supported by local youth support service Young Hackney, where attendees can discuss dating, sexual health and relationships in a safe environment
- 1:1 support can be used to prepare individuals for transition to college / work / further education. Initially offered for six sessions, this can include visiting possible post-16 education or training providers and travel training.

Links/additional information:
Targeted health outreach website [110]

Supported Internships

A supported internship is a structured study programme designed to support young people aged 16-24 with an EHCP who wish to go into sustainable paid employment but need additional support to do so. Through learning in the workplace the programme is designed to equip learners with the skills they need in a work environment. Supported internships are unpaid, and last for a minimum of six months.

Each local authority receives a government funding allocation to deliver supported internships for learners with EHCPs. The below programmes are available to Hackney residents. In Hackney there are young people who have SEN support in school but who did not meet the threshold for an EHCP. They are assessed on an individual case basis with the potential for them to access a supported internship if they have the desire to work and it is clear they would benefit from the service. Only those who have an EHCP are eligible for the Education Funding Agency funding, the main source of funds, but there are other potential funding sources the local authority can use. Some internships can also be funded from the individual's personal budget (if entitled to this).

Project SEARCH – Hackney

Project SEARCH is a supported internship programme based on an international model that originated in the USA. To be eligible the individual must be either a Hackney resident or looked after by Hackney.

Internships take place on the Homerton Hospital site. A Tutor and a Job Coach support interns for three periods of approximately eight weeks over the academic year in a programme comprising classroom learning and work placements.

For some individuals it may not be appropriate to rotate around changing hospital settings. There is potential for the model to be used in different settings, the local authority for example. Traditionally the model has been used in hospitals, as these generally are the largest employer in a given area.

The Tower Project's Hackney Supported Internship Offer

In the Tower Project Job Enterprise Training (JET) Service’s supported internship programme, the partner employers providing work placements are all based in East London’s hospitality and leisure sector.

After an initial induction, most of the remaining time is spent undertaking the work placement arranged by JET and supported by JET Job Coaches. The programme is delivered 3 days per week throughout the length of the academic year.

Depending on the work placement, interns will be supported and trained to undertake a range of work tasks with the aim of working to the same standards as their colleagues. Travel training sessions are available.

Ellingham Supported Internships

The Ellingham supported Internship for young people in Hackney is a one year programme. Bespoke placements are set up that are individually tailored to the requirements of the young person. Travel training is available.

Interns are supported in undertaking a role at a commercial employer in their local community. Towards the end of the course the participants may be supported into paid employment, traineeships, apprenticeships, or signposting to other SEND programmes to continue receiving support. Ellingham also run an Education and Skills Funding Agency NEET (not in education, employment or training) programme.

Hackney Museum projects – work placements

The Hackney Museum works with autistic young people on an ad hoc basis, such as work experience placements for school pupils. The museum runs an art class for people with learning disabilities that runs every Wednesday and some of the participants have autism, but it is mainly adults and adolescents participating in those sessions.

6 Recommendations

6.1 Planning and delivering health and care services

- Healthcare services should audit themselves against best practice resources such as the Greenlight toolkit, to ensure they are making appropriate reasonable adjustments for autistic people. This includes settings such as GP practices and outpatient clinics in secondary care.

- Efforts should be made within Homerton Hospital, and amongst health and care professionals more broadly, to raise awareness of the “Hospital Passport” and autism more generally to support improved identification/diagnosis and provide a better understanding of relevant health and wellbeing needs. Regular training of health and care staff is required to meet the needs of this patient group – including raising staff awareness regarding their employment and housing needs. Additional training would also be useful regarding “diagnostic overshadowing” and “masking” in relation to under-diagnosis of autism in women and ethnic minorities as well as post-referral pathways. Support and ancillary staff should also receive training. Autistic individuals and parents should be encouraged and supported to disclose the autism diagnosis and this should prompt staff to make reasonable adjustments, such as offering early or extended appointments, for example, to meet the needs of the individual. There should be greater collaborative working with mental health crisis teams to ensure that staff are trained in the needs of autistic individuals and that services are accessible to autistic users.

- After 2014’s SEND reforms as part of the Children and Families Act (*reference*) the City’s SEND board identified that further work was required in communication and partnership working. The City educational psychologist has close links with both the Hackney and Tower Hamlets educational psychologists and documentation and practice is shared for consistency. For some children, initial contact is from these area professionals before City professionals become involved. Communication and shared planning should continue to take place.

- The City SEND board has committed to an ongoing programme of autism training for staff in settings across the borough to ensure the appropriate level of ASD knowledge and expertise are brought into future strategy planning.

- There is a need to ensure carers of autistic people are offered carers assessments and advice on support.

- Some services which have anecdotally been referenced positively by parents and service users - for example, the ASD family support worker and the Targeted Health Outreach team - are running at capacity and do not have the resources to work with more young people. The Targeted Health Outreach team is one of the few services eligible to young people who do not meet the criteria for statutory support. Efforts should be made to ensure that the service should be available to all eligible young people who could potentially benefit from it.

- Following the SEN reforms and changes in personnel, the SEND Service identified that, whilst there is good practice in the City, documentation and partnership working needed further development.

6.2 Housing and promoting independent living

- Local authority housing plans should take account of the housing needs of the local autistic population, recognising the future need for independent housing options for the growing number of autistic adults living with ageing parents. Future housing needs of those living with older parent carers should be planned well in advance to avoid emergency or crisis situations. Housing pathways should be redesigned to ensure continuity and security in housing accommodation.

- The specific needs of autistic adults should be taken into account when housing services are allocating properties in choice based lettings, as per recommendations from Think Autism, the national autism strategy.

- Autistic adults who can and wish to live independently should be supported in doing so.

- Increase awareness of autism amongst Homeless and Rough Sleeper services so that the needs of autistic individuals are understood, and that a pathway is developed for referrals to autism assessment services

6.3 Education and employment

- Autistic adults should be supported in navigating the benefits system, to ensure they are claiming all support to which they are entitled. Reasonable adjustments should be made to tailor the process to the individual's specific needs, i.e. continuity of advisor, option for face to face interview, a quiet environment.

- There is a need for timely planning for post-16 educational provision if the individual wishes to work. Early identification of young people who are at risk of NEET should take place so that local authorities can develop and plan appropriate provision.

- Early links should be made between schools and mainstream employment services should be made if the individual wishes to work. There should be increased awareness of specialist employment support and funding available through these services. Jobcentre Plus has links with the adult diagnostic service but young people who already have a diagnosis may not be accessing services or funding they may be entitled to. Increased awareness among autistic people (as well as their families and schools) should be promoted on what funding (and support with reasonable adjustments) they could be entitled to if they wish to work. This may help to allay parental anxieties about the transition of their child to adulthood and moving into a work environment.

- The supported employment programme commissioned by Hackney Council is only eligible to adult social care customers. Supported employment options should be available to all autistic adults to help them gain and retain paid work, taking into account both the needs of the employee and employer.

- Autistic individuals can continue to experience stigma and discrimination in various situations despite Equalities legislation. It is therefore imperative to share best practises and guidance regarding reasonable adjustments and accommodations amongst wider environments, particularly education and employment settings. In employment settings, there could be further promotion and uptake of the "Disability Confident" scheme

6.4 Community and social support

- Continue to work with Hackney and City community groups and existing autism support groups and charities

- There is a need to encourage development of health education and messaging regarding autism and autism awareness amongst minority communities, particularly given the challenges of low awareness of autism in minority communities and differences in diagnostic prevalence.

- There should be an emphasis on reducing social isolation amongst autistic individuals and carers. Leisure and entertainment facilities should be made more accessible to people with autism. This may include providing transport options. There is a paucity of data on whether reasonable adjustments are being made in Council run community settings - for example, leisure centres. In terms of private businesses, there are infrequent 'autism-friendly' screenings in a local cinema, of films mainly aimed at children. Local shops and businesses should be encouraged and potentially incentivised (for example, with an award and increased publicity) to make their environments more accessible. Thus, there continues to be a need to promote accessibility amongst arts, social, and leisure services to promote autistic friendly environments

- There is scope for greater use of assistive technology in promoting independence. There are apps available that can help young people form social groups; this could be explored further to assess whether these and similar telecare support services could be more widely offered as preventative support to autistic residents in Hackney and the City.

- There is a need to embed autism training within equality and diversity training across all public services, and employ specialist training amongst health and social care staff, employment and education, and criminal justice

- Mandatory autism awareness training should be implemented across all Council departments where there is face-to-face contact with members of the public, including sports and leisure. Currently training delivered at the Hackney Learning Trust and in Children's Social Care is different to that offered by Adult Social Care. Information could be shared between departments on existing training packages offered and taken up and departments could collaborate with each other when commissioning training packages. This would allow for more options for training dates but could result in reduction in overall expenditure. Managers should support staff members in attending training. One of the key areas for development identified by the City is to provide an ongoing programme of autism training for staff in settings across the borough to ensure the appropriate level of ASD knowledge and expertise are considered into future strategy planning.

- There should be wider representation on the Autism Alliance Board from services like the Criminal Justice System, Sports and Leisure facilities. Attendance at board meetings has been variable. Efforts should be made to seek valuable input from these services and raise awareness of autism to improve the experiences of autistic people accessing them. There is representation from both Hackney and the City of London on the workstreams set up by the Autism Alliance Board to help produce a joint all-ages local autism strategy. An area of future development agreed by the City of London is to incorporate the strategy into the Local Offer website. Ongoing collaboration and joint working between Hackney and the City will be required to meet the short and long term goals within the strategy.

- From discussion with stakeholders including parents, carers and autistic people and in the course of undertaking this needs assessment it was apparent that there appear to be service-level barriers preventing autistic residents' needs from being adequately met. There is a need for meaningful consultation with stakeholders and qualitative research which is representative of the local population. A consultation in the form of a questionnaire was circulated recently, with around 100 respondents of which approximately 20 were autistic residents. Unfortunately, the format of the questionnaire meant it was not possible to differentiate between autistic person/child/carer in some of the responses. In addition, there were no respondents to questionnaire who identified as being Charedi Jewish; given that 20% of the children living in the local population of interest are within this community it is clear that further work needs to be done to canvas their views.

6.5 Dedicated autism services

- There should be a dedicated autism service in order to provide ongoing support to young people and adults who have a diagnosis of autism. Despite educational provision with an EHCP potentially going until the age of 25, for services such as psychology, input from a children's psychologist ends at the age of 18 (continuity is not practical as adult psychology is a distinct specialism). There should also be further development of post-diagnosis pathways and support. Post-diagnostic support offered by the adult diagnostic team is time-limited and does not have the resources to support a caseload of patients. There are no autism-specific commissioned mental health or crisis services in Hackney or the City. Given the higher prevalence of anxiety and depression in autistic people, services that are able to provide support to prevent escalation to crisis should be commissioned. NICE guidelines on the management of coexisting mental health disorders advise that conventional treatment may need to be adapted for autistic people following consultation from a specialist autism team. At present there is no specialist autism team able to provide this input.

- The Targeted Health Outreach team offers support up until the individual's 20th birthday. Following this, there is no further support in terms of picking up work that has been done previously with the young person. A designated support worker working with young people about to leave the service could help bridge this gap. While services are still lacking for adults this may serve only to delay the 'cliff-edge' where the number of services available drops. Therefore for this to be effective, services for adults need to be available – with the support worker aiding in the transition process.

- There is a need to ensure parents are aware of what services their children are (and are not) eligible to receive. Parents have reported inconsistency (between children in different families) in what is offered by CAMHS in terms of counselling and post-diagnostic support

6.6 Data collection and data sharing

- All new and existing diagnoses of autism (and related conditions on the autism spectrum) should be coded. The SNOMED coding system should be used as per the Government's plan of implementation across all health settings by 2020. (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/384650/NIB_Report.pdf) Consistency of coding will improve the quality and accuracy of the data set and facilitate data linkage between healthcare settings.

- Anecdotally it has been fed back that the Autism Alert cards have been helpful. Feedback from individuals on which settings they have found the card useful could inform service improvements, for example awareness training for public sector staff or reasonable adjustments in council-run environments.

- Systems should be improved within services to enable more effective sharing of information between health and social care teams - to optimise coordination of care and support to better meet service user needs. This recommendation applies to data sharing between local authority children's and adult services to improve transition planning.

- A significant challenge when carrying out this work was the difficulty in accessing data. Of the core data sources that it would have been desirable to access, the only sources of data available were school record data, GP data and adult social care data. There was no access to secondary care data, though the yield from this data may not have been be significant given that recording of autism has historically been suboptimal within this data set. Accessing data from the childrens' and adults' diagnostic services has not been possible within the time constraints of this work. There should be a defined agreement or protocol for sharing data between services to inform robust analysis and intelligence on the needs and inequalities amongst autistic individuals. Frontline clinicians may not be aware of how to extract a defined dataset from their computer system but each service should have or be able to signpost to a designated data handler, i.e. a named contact who is able to provide a data extract within a certain timeframe.

7 References

[1] National Autism Society, “What is autism?,” [Online]. Available: https://www.autism.org.uk/about/what-is.aspx.

[2] UK Parliament, “Autism Act,” 2009. [Online]. Available: www.legislation.gov.uk/ukpga/2009/15/contents. [Accessed February 2019].

[3] American Psychiatric Association, Diagnostic and statistical manual of mental disorders (5th ed., Arlington, VA: American Psychiatric Publishing, 2013.

[4] UK Parliament, “Equality Act,” 2010. [Online]. Available: http://www.legislation.gov.uk/ukpga/2010/15/contents. [Accessed February 2019].

[5] National Audit Office, “Supporting people with autism through adulthood,” 2009. [Online]. Available: https://www.nao.org.uk/report/supporting-people-with-autism-through-adulthood/. [Accessed February 2019].

[6] Department of Health and Social Care, “THINK AUTISM: Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update,” 2014. [Online]. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf. [Accessed February 2019].

[7] Dahlgren and Whitehead , “ Policies and Strategies to Promote Social Equity in Health.,” Institute for Futures Studies, Stockholm, 1991.

[8] T. Hirvikoski, A. Mittendorfer-Rutz and M. Boman, “Premature mortality in autism spectrum disorder.,” *British Journal of Psychiatry,* 2016.

[9] D. Bilder, E. L. Botts and K. R. Smith, “Excess Mortality and Causes of Death in Autism Spectrum Disorders: A follow up of the 1980s Utah/UCLA Autism Epidemiologic Study,” *Journal of Autism and Developmental Disorders,* vol. 43, no. 5, pp. 1196-1204, 2013.

[10] F. M. Besag, “Epilepsy in patients with autism: links, risks and treatment challenges,” *Neuropsychiatr Dis Treat.,* vol. 14, pp. 1-10, 2017.

[11] S. Cassidy, P. Bradley and J. Robinson, “Suicidal ideation and suicide plans or attempts in adults with Asperger’s syndrome attending a specialist diagnostic clinic: a clinical cohort study,” June 2014. [Online]. Available: https://www.thelancet.com/pdfs/journals/lanpsy/PIIS2215-0366(14)70248-2.pdf. [Accessed March 2019].

[12] Department of Health and Social Care, “Think Autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update.,” 2014. [Online]. Available:

https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy. [Accessed February 2019].

[13] National Institute of Clinical Excellence, “Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum (NICE Clinical Guidelines, No. 128.) 7, Assessment of coexisting conditions,” 2011. [Online]. Available: https://www.ncbi.nlm.nih.gov/books/NBK92989/. [Accessed February 2019].

[14] S. Broder-Fingert and K. Brazauskas, “Prevalence of Overweight and Obesity in a Large Clinical Sample of Children With Autism,” *Academic Pediatrics,* vol. 14, no. 4, pp. 408-414, 2014.

[15] A. Presmanes Hill and K. E. Zuckerman, “Obesity and Autism,” *Pediatrics,* vol. 136, no. 6, 2015.

[16] G. Baird, E. Simonoff, A. Pickles, S. Chandler, T. Loucas, D. Meldrum and T. Charman, “Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP),” *Lancet,* vol. 368, no. 9531, pp. 210-5, 2006.

[17] G. O'Brien and J. Pearson, “Autism and learning disability,” *Autism,* vol. 8, no. 2, pp. 125-140, 2004.

[18] K. Gadow, C. DeVincent and J. Pomeroy, “ADHD Symptom Subtypes in Children with Pervasive Developmental Disorder,” *Journal of Autism and Developmental Disorders,* vol. 36, no. 2, pp. 271-283, 2006.

[19] K. Johnston, A. Dittner, J. Bramham, C. Murphy, A. Knight and A. Russell, “Attention deficit hyperactivity disorder symptoms in adults with autism spectrum disorders,” *Autism Research,* vol. 6, no. 4, pp. 225-236, 2013.

[20] E. Hanson, B. Cerban and C. M. Slater, “Brief Report: Prevalence of Attention Deficit/Hyperactivity Disorder Among Individuals with an Autism Spectrum Disorder,” *Journal of Autism and Developmental Disorders,* vol. 43, no. 6, pp. 1459-1464, 2013.

[21] S. M. Meier, “Obsessive-Compulsive Disorder and Autism Spectrum Disorders: Longitudinal and Offspring Risk,” *PLoS One,* vol. 10, no. 11, 2015.

[22] M. J. Hollocks and J. W. Lerh, “Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis,” *Psychological Medicine,* vol. 39, no. 4, pp. 559-572, 2019.

[23] S. W. White and D. Oswald, “Anxiety in Children and Adolescents with Autism Spectrum,” *Clin Psychol Rev.,* vol. 29, no. 3, pp. 216-229, 2009.

[24] L. A. Croen, O. Zerbo and Y. Qian, “The health status of adults on the autism spectrum,” *Autism,* vol. 19, no. 7, p. 814–823, 2015.

[25] CIty and Hackney Public Health Team , “Joint Strategic Needs Assessment; Adult Health and Illness; Use of health and care services,” 2018. [Online]. Available: https://hackneyjsna.org.uk/wp-content/uploads/2018/12/Use-of-Services-1.pdf . [Accessed February 2019].

[26] City and Hackney Public Health Team , “Joint Strategic Needs Assessment: Children and Young People: use of clinical services,” 2018. [Online]. Available: https://hackneyjsna.org.uk/wp-content/uploads/2018/05/Use_of_clinical_services.pdf. [Accessed February 2019].

[27] Public Health England, “Autism Self-Assessment Exercise 2016 Personal Stories,” 2017. [Online]. Available: https://dera.ioe.ac.uk/29444/2/autism_self_assessment_framework_personal_stories_2016.pdf. [Accessed February 2019].

[28] The Westminster Commission on Autism, “A Specutrum of Obstacles: An Inquiry into Access to Healthcare for Autistic People,” 2016 July. [Online]. Available: https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011_ncg-autism-report-july-2016.pdf. [Accessed April 2019].

[29] NHS England, “NHS Change Day: Lucy's story - understanding autism,” NHS Change Day, March 2018. [Online]. Available: https://www.nhs.uk/video/Pages/nhs-change-day-lucy.aspx?searchtype=video&searchterm=&offset=145&#. [Accessed March 2019].

[30] P. Sims, “Barriers to health care for autistic people,” February 2018. [Online]. Available: https://network.autism.org.uk/sites/default/files/ckfinder/files/Barriers%20to%20Health%20for%20Autistic%20People%20-%20PDF%20ready(1).pdf. [Accessed March 2019].

[31] S. Dern and T. Sappok, “Barriers to healthcare for people on the autism spectrum,” *Advances in Autism,* vol. 2, no. 1, 2016.

[32] Department of Health, “Autism Self-Assessment Exercise 2016 Detailed report and thematic analyses,” 2017. [Online]. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/621233/Autism_self_assessment_framework_2016_report.pdf. [Accessed February 2019].

[33] City and Hackney Public Health Team, “Joint Strategic Needs Assessment; Lifestyle and Behaviour,” 2016. [Online]. Available: https://hackneyjsna.org.uk/articles/lifestyle-behaviour/. [Accessed February 2018].

[34] J. Underwood, “Autism spectrum disorder diagnosis in adults: phenotype and genotype findings from a clinically derived cohort,” *The British Journal of Psychiatry,* 2019.

[35] S. Bejerot and L. Nylander, “Low prevalence of smoking in patients with autism spectrum disorders,” *Psychiatry Research,* vol. 119, no. 1-2, pp. 177-182, 2003.

[36] L. Nylander, A. Axmon and P. Bjorne, “Older Adults with Autism Spectrum Disorders in Sweden: A Register Study of Diagnoses, Psychiatric Care Utilization and Psychotropic Medication of 601 Individuals,” *J Autism Dev Disord. ,* vol. 48, no. 9, pp. 3076-3085, 2018.

[37] P. J. Santosh and A. Mijovic, “Does pervasive developmental disorder protect children and adolescents against drug and alcohol use?,” *Eur Child Adolesc Psychiatry,* vol. 15, no. 4, pp. 183-8, 2006.

[38] B. Sizoo and W. van den Brink, “Treatment seeking adults with autism or ADHD and co-morbid Substance Use Disorder: Prevalence, risk factors and functional disability,” *Drug and Alcohol Dependence,* vol. 107, pp. 44-50, 2010.

[39] L. G. Bandini, S. E. Anderson and C. Curtin, “Bandini LG, Anderson SE, Curtin C, et al. Food selectivity in children with autism spectrum disorders and typically developing children. J Pediatr. 2010;157(2):259-64.,” *J Pediatr,* vol. 157, no. 2, pp. 259-264, 2010.

[40] R. A. Jones and K. Downing, “Physical activity, sedentary behavior in children with Autism: A systematic review,” *PLoS ONE,* vol. 12, no. 2, 2017.

[41] D. Umberson and J. K. Montez, “Social Relationships and Health: A Flashpoint for Health Policy,” *J Health Soc Behav,* vol. 51, no. Suppl, pp. 54-66, 2010.

[42] H. Tager-Flusberg, P. Rhea and A. Klin, “Language and Communication in Autism,” in *Handbook of Autism and Pervasive Developmental Disorders* , 2013.

[43] F. Sedgewick, V. Hill and R. Yates, “Gender Differences in the Social Motivation and Friendship Experiences of Autistic and Non-autistic Adolescents,” *Journal of Autism and Developmental Disorders,* vol. 46, no. 4, pp. 1297-1306, 2016.

[44] M. Dean, R. Harwood and C. Casari, “The art of camouflage: Gender differences in the social behaviors of girls and boys with autism spectrum disorder,” *Autism,* vol. 21, no. 6, pp. 678-689, 2017.

[45] National Autistic Society, “Meltdowns,” March 2016. [Online]. Available: https://www.autism.org.uk/about/behaviour/meltdowns.aspx. [Accessed April 2019].

[46] A. Churchard, M. Ryder, A. Greenhill and W. Mandy, “The prevalence of autistic traits in a homeless population.,” 2018. [Online]. Available: https://doi.org/10.1177/1362361318768484. [Accessed February 2019].

[47] All Party Parliamentary Group on Autism, “Autism and education in England 2017. A report by the All Party Parliamentary Group on Autism on how the education system in England works for children and young people on the autism spectrum,” 2017. [Online]. Available: https://www.autism.org.uk/~/media/nas/documents/get-involved/held-back/appga-autism-and-education-report.ashx?la=en-gb. [Accessed February 2019].

[48] Department of Education, “Special educational needs in England: January 2018,” July 2018. [Online]. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/729208/SEN_2018_Text.pdf. [Accessed February 2019].

[49] National Autistic Society, “The autism employment gap: Too much information in the workplace,” 2016. [Online]. Available: https://www.autism.org.uk/get-involved/tmi/employment.aspx. [Accessed February 2019].

[50] Department of Health, “Strategy for adults with autism: progress report,” 2016. [Online]. Available: https://www.gov.uk/government/publications/progress-report-on-strategy-for-adults-with-autism. [Accessed February 2019].

[51] BIBIC, “BIBIC research on ASBOs and young people with learning difficulties and mental health problems,” BIBIC, Bridgewater, 2005.

[52] World Health Organisation, “Prisons and Health,” 2014. [Online]. Available: http://www.euro.who.int/__data/assets/pdf_file/0005/249188/Prisons-and-Health.pdf?ua=1. [Accessed April 2019].

[53] F. Myers, “On the Borderline? People with Learning Disabilities and/or Autistic Spectrum Disorders in Secure, Forensic and Other Specialist Settings,” 2004. [Online]. Available: https://www2.gov.scot/Publications/2004/06/19505/38853. [Accessed February 2019].

[54] P. McAdam, “Knowledge and understanding of the autism spectrum amongst prison staff,” *Prison Service Journal,* pp. 26-30, 2004.

[55] NHS Information Centre for health and social care, “Autism Spectrum Disorders in adults living in households throughout England. Report from the Adult Psychiatric Morbidity Survey 2007,” 2009. [Online]. Available: https://digital.nhs.uk/data-and-information/publications/statistical/adult-psychiatric-morbidity-survey/adult-psychiatric-morbidity-in-england-2007-results-of-a-household-survey. [Accessed February 2019].

[56] P. Scragg and A. Shah, “Prevalence of Asperger’s syndrome in a secure hospital.,” *Br J Psychiatry,* 1994.

[57] Social Care Institute for Excellence, “The pressures for carers of people with autism,” January 2017. [Online]. Available: https://www.scie.org.uk/autism/carers/the-pressures. [Accessed April 2019].

[58] D. Catalano, L. Holloway and E. Mpofu, “Mental Health Interventions for Parent Carers of Children with Autistic Spectrum Disorder: Practice Guidelines from a Critical Interpretive Synthesis (CIS) Systematic Review,” February 2018. [Online]. Available: https://www.mdpi.com/1660-4601/15/2/341. [Accessed February 2019].

[59] UK Parliament, “Care Act,” 2014. [Online]. Available: http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted 8. Health and Social Care Act. UK Parliament 2012. Available from: www.legislation.gov.uk/ukpga/2012/7. [Accessed February 2019].

[60] Department of Health, ““Fulfilling and rewarding lives” The strategy for adults with autism in England,” 2010. [Online]. Available: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/docu ments/digitalasset/dh_113405.pdf. [Accessed February 2019].

[61] Department of Health, “Implementing “Fulfilling and rewarding lives” Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy,” 2010. [Online]. Available: https://www.gov.uk/government/publications/implementing-fulfilling-and-rewarding-lives. [Accessed February 2019].

[62] UK Parliament, “Children and Families Act,” 2014. [Online]. Available: http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted. [Accessed February 2019].

[63] University College London, “Preventative co-ordinated low-level support for adults with high-functioning autism Systematic review and service mapping,” 2016. [Online]. Available: https://eppi.ioe.ac.uk/CMS/Portals/0/PDF%20reviews%20and%20summaries/Autism%20support%202016%20Lorenc%20report.pdf. [Accessed February 2019].

[64] Department of Health, “Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy,” 2015. [Online]. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/42 2338/autism-guidance.pdf. [Accessed February 2019].

[65] National Autistic Society, “Diverse Perspectives,” 2014. [Online]. Available: https://www.autism.org.uk/~/media/nas/about-autism/nas-diverse-perspectives-report.ashx?la=en-gb. [Accessed April 2019].

[66] Department of Health and Department of Work & Pensions, “Improving Lives: The Future of Work, Health and Disability,” November 2017. [Online]. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/663399/improving-lives-the-future-of-work-health-and-disability.PDF. [Accessed March 2019].

[67] National Institute for Health and Care Excellence, “Autism spectrum disorder in adults: diagnosis and management,” June 2012. [Online]. Available: https://www.nice.org.uk/guidance/cg142. [Accessed March 2019].

[68] National Autistic Society, “My Hospital Passport,” 2017. [Online]. Available: https://www.autism.org.uk/about/health/hospital-passport.aspx. [Accessed February 2019].

[69] Department of Health, “Green Light Toolkit 2013,” November 2013. [Online]. Available: https://www.ndti.org.uk/uploads/files/Green_Light_Toolkit_22_Nov_2013_final.pdf. [Accessed April 2019].

[70] Social Care Institute for Excellence, “Support for carers of people with autism,” January 2017. [Online]. Available: https://www.scie.org.uk/autism/carers/support. [Accessed May 2019].

[71] National Institute of Health and Care Excellence, “NICE Quality and Outcomes Framework indicator,” July 2017. [Online]. Available: https://www.nice.org.uk/standards-and-indicators/qofindicators/the-practice-establishes-and-maintains-a-register-of-all-patients-with-a-diagnosis-of-autism. [Accessed April 2019].

[72] NHS England, “Report of the Review of the Quality and Outcomes Framework in England,” July 2018. [Online]. Available: https://www.england.nhs.uk/wp-content/uploads/2018/07/05-a-i-pb-04-07-2018-qof-report.pdf. [Accessed April 2019].

[73] National Health Service, “The NHS Long Term Plan,” January 2019. [Online]. Available: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf. [Accessed February 2019].

[74] UK Parliament, “Disability Discrimination Act 1995,” 1995. [Online]. Available: http://www.legislation.gov.uk/ukpga/1995/50/contents. [Accessed March 2019].

[75] UK Parliament, 2017. [Online]. Available: https://www.gov.uk/guidance/homelessness-code-of-guidance-for-local-authorities/overview-of-the-homelessness-legislation. [Accessed April 2019].

[76] Department of Justice Northern Ireland and The National Autistic Society Northern Ireland, “Autism: a guide for criminal justice professionals,” 2014.

[Online]. Available: https://www.justice-ni.gov.uk/publications/autism-guide-criminal-justice-professionals. [Accessed February 2019].

[77] National Autistic Society, “Autism: a guide for police officers and staff,” 2017. [Online]. Available: https://www.autism.org.uk/~/media/nas/documents/publications/autism-a-guide-for-police.ashx. [Accessed April 2019].

[78] C. L. M. S. H. T. C. P. W. D. M. A. Maras KL, “Brief Report: Autism in the Courtroom: Experiences of Legal Professionals and the Autism Community,” *J Autism Dev Disord,* vol. 47, no. 8, pp. 2610-2620, 2017.

[79] The Advicate's Gateway, “Intermediaries: step by step,” December 2016. [Online]. Available: https://www.theadvocatesgateway.org/images/toolkits/16-intermediaries-step-by-step-2016.pdf. [Accessed April 2019].

[80] Department of Health and Social Care, “Open consultation: Learning disability and autism training for health and care staff,” February 2019. [Online]. Available: https://www.gov.uk/government/consultations/learning-disability-and-autism-training-for-health-and-care-staff. [Accessed March 2019].

[81] UK Parliament, “Health and Social Care Act 2012,” 2012. [Online]. Available: http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted. [Accessed April 2019].

[82] National Institute for Care Excellence, “Autism Quality Standard [QS51],” 2014. [Online]. Available: https://www.nice.org.uk/guidance/qs51/chapter/Quality-statement-1-Diagnostic-assessment-by-an-autism-team. [Accessed February 2019].

[83] National Institute for Health and Care Excellence, “Autism spectrum disorder in under 19s: recognition, referral and diagnosis,” September 2011. [Online]. Available: https://www.nice.org.uk/guidance/cg128. [Accessed March 2019].

[84] National Institute for Health and Care Excellence, “Autism spectrum disorder in under 19s: support and management,” August 2013. [Online]. Available: https://www.nice.org.uk/guidance/cg170. [Accessed March 2019].

[85] National Autistic Society, “Anxiety in autistic adults,” November 2017. [Online]. Available: https://www.autism.org.uk/about/behaviour/anxiety.aspx. [Accessed March 2019].

[86] E. Emerson, Challenging Behaviour: Analysis and intervention in people with learning disabilities, Cambridge: Cambridge University Press, 2001.

[87] National Institute for Health and Care Excellence, “Challenging behaviour and learning disabilities: prevention and interventions for people with learning

disabilities whose behaviour challenges," May 2015. [Online]. Available: https://www.nice.org.uk/guidance/NG11. [Accessed March 2019].

[88] National Institute for Health and Care Exellence, "Transition from children's to adults' services for young people using health or social care services," 2016 February. [Online]. Available: https://www.nice.org.uk/guidance/ng43. [Accessed March 2019].

[89] B. Emerson, "The estimated prevalence of autism among adults with learning disabilities in England," Improving Health and Lives: Learning Disabilities Observatory, 2010.

[90] NHS Digital, "Adult Psychiatric Morbidity Survey (APMS): Autism spectrum disorder," NHS Digital , 2014.

[91] B.-C. S, "Prevalence of autism-spectrum conditions: UK school-based population study," *The British Journal of Psychiatry ,* vol. 194, pp. 500-509, 2009.

[92] Hackney Learning Trust, "Bespoke date extract (extracted 16th April 2019)," 2019.

[93] Clinical Effectiveness Group , "Bespoke data extract (1st April 2018)," London, 2019.

[94] Hackney Performance Team, "Bespoke data extract (extracted on 28th February 2019)," 2019.

[95] City of London Department of Community and Children's Services, "Autism Strategy Report," 2019.

[96] L. A. Strand S, "University of Oxford Department of Education," 20 December 2018. [Online]. Available: http://www.education.ox.ac.uk/wp-content/uploads/2018/08/Executive-Summary_2018-12-20.pdf?platform=hootsuite. [Accessed 13 June 2019].

[97] L. A. Z. O. Q. Y. M. M. L. R. S. S. S. &. K. C. Croen, "The health status of adults on the autism spectrum," *Autism,* vol. 19, no. 7, pp. 814-823, 2015.

[98] C. V. S. S. C. K. M. T. A. S. &. J. A. K. Tyler, "Chronic disease risks in young adults with autism spectrum disorder: forewarned is forearmed.," *American journal on intellectual and developmental disabilities,,* vol. 116, no. 5, pp. 371-380, 2011.

[99] Department for Education, "Special educational needs in England: January 2018," Department for Education, 2018.

[100] Hackney local offer, "Social worker for adults with autism," 2019. [Online]. Available:

https://www.hackneylocaloffer.co.uk/kb5/hackney/localoffer/service.page?id=K3Pn6kcMNzw. [Accessed April 2019].

[101] Department of Health, “The Care Act EasyRead version,” October 2014. [Online]. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/365345/Making_Sure_the_Care_Act_Works_EASY_READ.pdf.

[102] Hackney local offer, “Special schools in Hackney,” July 2018. [Online]. Available: https://www.hackneylocaloffer.co.uk/kb5/hackney/localoffer/service.page?id=AWcqHL-80S8. [Accessed May 2019].

[103] Hackney Council, “Hackney Works Supported Employment,” 2019. [Online]. [Accessed May 2019].

[104] “The Advocacy project in Hackney,” 2018. [Online]. Available: https://www.advocacyproject.org.uk/news/the-advocacy-project-in-hackney/. [Accessed July 2019].

[105] Royal College of General Practitioners, “Autistic Spectrum Disorders Toolkit,” [Online]. Available: https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/asd-toolkit.aspx. [Accessed May 2019].

[106] Royal College of General Practitioners, “RCGPLearning Autistic Spectrum Conditions,” May 2011. [Online]. Available: http://elearning.rcgp.org.uk/course/info.php?id=78. [Accessed May 2019].

[107] Short Breaks Hackney, “Short Breaks Hackney,” [Online]. Available: http://www.shortbreakshackney.com/. [Accessed May 2019].

[108] City of London Corporation Family and Young People's Information Service, “Short Breaks Service,” [Online]. Available: http://fyi.cityoflondon.gov.uk/kb5/cityoflondon/fyi/service.page?id=cRTePmKTQak&familychannel=7. [Accessed May 2019].

[109] Hackney Local Offer, “Autiusm: Information and Support,” 2019. [Online]. Available: https://www.hackneylocaloffer.co.uk/kb5/hackney/localoffer/advice.page?id=fLQ-DCX9nyc. [Accessed July 2019].

[110] Homerton University Hospitals NHS Foundation Trust, “Targeted health outreach team,” [Online]. Available: http://www.homerton.nhs.uk/our-services/services-a-z/c/childrens-services-in-the-community/targeted-health-outreach-team/. [Accessed May 2019].

[111] Department of Health, “Towards fulfilling and rewarding lives: the first-year delivery plan,” 2010. [Online]. Available:

https://webarchive.nationalarchives.gov.uk/20130105045211/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_115121.pdf. [Accessed February 2019].

[112] Department of Health and Social Care, “How DHSC and other organisations monitor the updates to the progress of the autism strategy,” 2018. [Online]. Available: https://www.gov.uk/government/publications/think-autism-strategy-governance-refresh-2018. [Accessed February 2019].

[113] National Institute for Health and Care Excellence, “National Institute for Health and Care Excellence Indicator Development Programme Consultation Report,” 2017. [Online]. Available: https://www.nice.org.uk/Media/Default/Standards-and-indicators/QOF%20Indicator%20Key%20documents/NM153%20NICE%20public%20consultation%20report.pdf. [Accessed February 2019].

[114] Department of Health and Social Care, “A manual for good social work practice: supporting adults who have autism,” 2015. [Online]. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/467392/Pt1_Autism_Learning_Materials_Accessible.pdf. [Accessed February 2019].

[115] National Autistic Society, “Local Voices, Local Choices: A guide to consulting young people with autism on your local offer,” 2014. [Online]. Available: www.autism.org.uk/~/media/NAS/eCommerce/G-M/Local Voices Local Choices.ashx. [Accessed February 2019].

[116] Ofsted, “Ofsted Annual Report 2017/18: education, children’s services and skills,” 2018. [Online]. Available: https://www.gov.uk/government/publications/ofsted-annual-report-201718-education-childrens-services-and-skills. [Accessed February 2019].

[117] M. A. Dzuik , J. C. Larson, A. Apostu, E. M. Mahone, M. B. Denckla and S. H. Mostofsky, “Dyspraxia in autism: association with motor, social, and communicative deficits,” *Developmental Medicine & Child Neurology,* vol. 49, no. 10, pp. 734-739, 2007.

[118] B. S. Bram, “Cognitive behavioural therapy and mindfulness based stress reduction may be equally effective in reducing anxiety and depression in adults with autism spectrum disorders,” *Research in Developmental Disabilities,* vol. 64, pp. 47-55, 2017.

[119] W. L. Mangerud, “Smoking, alcohol consumption, and drug use among adolescents with psychiatric disorders compared with a population based sample,” *Journal of Adolescence,* vol. 37, pp. 1189-1199, 2014.

[120] All Party Parliamentary Group on Autism, “The right start: reforming the system for children with autism. A Report on improving the Special Educational Needs and Disabilities System,” [Online]. Available:

https://www.autism.org.uk/~/media/nas/documents/get-involved/the-right-start-autism-friendly-version.ashx?la=en-gb. [Accessed February 2019].

[121] Department for Work and Pensions and Department of Health. , “Work, Health and Disability Green Paper Data Pack,” 2016. [Online]. Available: www.gov.uk/government/statistics/work-health-and-disability-green-paper-data-pack. [Accessed March 2019].

[122] R. Mills and J. Francis, “SCIE research briefing 32: ‘Access to social care and support for adults with autistic spectrum conditions (ASC)’,” 2010. [Online]. Available: https://www.scie.org.uk/publications/briefings/briefing32/. [Accessed February 2019].

[123] R. Loomes and L. Hull, “What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis.,” *J Am Acad Child Adolesc Psychiatry,* vol. 56, no. 6, pp. 466-474, 2017.

[124] S. Woolfenden, V. Sarkozy and G. Ridley, “A systematic review of two outcomes in autism spectrum disorder - epilepsy and mortality,” *Developmental Medicine and Childr Neurology,* vol. 54, pp. 306-12, 2012.

[125] I. Mavranezouli, O. Megnin-Viggars and N. Cheema, “The cost-effectiveness of supported employment for adults with autism in the United Kingdom,” *Autism,* vol. 18, no. 8, pp. 975-984, 2014.

[126] UK Parliament, “Housing Act,” 1996. [Online]. Available: https://www.legislation.gov.uk/ukpga/1996/52/contents. [Accessed April 2019].

[127] UK Parliament, “Housing Act,” 2004. [Online]. Available: https://www.legislation.gov.uk/ukpga/2004/34/contents. [Accessed April 2019].

[128] The British Psychological Society, “Learning Disability: Definitions and Contexts,” 2000. [Online]. Available: https://www.bps.org.uk/sites/bps.org.uk/files/Member%20Networks/Faculties/Intellectual%20Disabilities/Learning%20Disability%20Definitions%20and%20Contexts%20%282000%29.pdf. [Accessed April 2019].

[129] Brain in Hand, “Brain in Hand,” 2019. [Online]. Available: https://braininhand.co.uk/. [Accessed April 2019].

[130] Choice in Hackney, “Choice in Hackney,” 2016. [Online]. Available: http://www.choiceinhackney.org/. [Accessed May 2019].

[131] L. Kenny, C. Hattersley and B. Molins, “Which terms should be used to describe autism? Perspectives from the UK autism community,” *Autism,* vol. 20, no. 4, pp. 442-462, 2016.