



# Merton Autism Strategy 2018-2023

**August 2018**

# Contents

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Contents .....	2
Foreword.....	3
Executive Summary .....	5
1. Introduction .....	9
2. National and Local context.....	13
The National picture: policy & guidance .....	13
Our population.....	14
Our current services and access to support .....	17
3. Priority Themes .....	27
Multi-agency local leadership & the voice of residents with autism, families & carers .....	27
Theme 1: Awareness training and support for staff and services .....	30
Theme 2: Recognition, support, referral & assessment .....	33
Theme 3: Involving & supporting people with autism.....	36
Theme 4: Preparing for adulthood .....	40
Theme 5: Think Family: involving & supporting families & carers.....	43
Theme 6: Access to information.....	45
4. Governance and delivering the strategy .....	47
5. References.....	48
Glossary .....	50

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## Foreword

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### **Councillor Tobin Byers, Cabinet Member for Adult Social Care and Health and Councillor Kelly Braund, Cabinet Member for Children's Services**

As the Cabinet Members responsible for public health and children, we commend this joint Merton Autism Strategy. Autism touches the lives of many people in our Borough and affects all aspects of life, from school to healthcare to employment and social lives. As such, this strategy covers the whole life-course including children, young people, adults and families and carers.

Making Merton an autism friendly borough in which people with autism are able to live fulfilling and rewarding lives is an important priority for us. We recognise that raising awareness of autism in the wider community and increasing knowledge and understanding is key to succeeding in this. Councillors have an important role to play in this too, which is why we will ensure all elected members are given training on autism.

In developing this strategy we have engaged with, and heard the views of, people with autism, families, carers and partners from across Merton and we want this to continue as the strategy is delivered. The strategy proposes aspirational yet achievable solutions to make Merton a better place to live for people with autism. Delivery of the strategy will require that we work in partnership for and with our communities to ensure its positive ambitions are achieved.

### **Dr Andrew Murray, Chair of Merton NHS Clinical Commissioning Group**

As the chair of NHS Merton CCG and a local GP, I see first hand some of the challenges facing people with autism in Merton. I am therefore pleased that Merton Council has been working closely with NHS Merton CCG and other partners to develop this comprehensive, joint autism strategy.

Autism is a condition which affects someone for their whole life. We want to build on what people can do and where they want to get in life rather than just focusing on what people may find challenging. It is commendable that this strategy considers the whole life-course and takes positive steps to address wide-ranging issues, including the important role of the NHS in supporting people with autism.

The strategy sets out clear objectives and constructive actions to achieve the aim of making Merton an autism friendly borough. It is a useful resource for anyone working with people with autism, as well as residents with autism themselves and their families and carers.

### **About this document**

This document begins with summary of our overall plans (p.5); it then provides an overview of our vision for an autism-friendly Merton and what this might mean for people with autism living in the borough. Section 2 (p.13) gathers facts and figures about autism along with guidance and evidence. It also provides details of services and support currently available to people with autism and their families and carers in Merton and a summary of what stakeholders have said could be improved in the borough.

Section 3 (p.27) sets out details of the six priority themes in our strategy and for each covers: the evidence for change; where we are now; where we want to be and how we will get there – our proposals for improvement. Section 4 (p.47) briefly sets out how we will implement the strategy. A detailed action plan is also available.

### **Note on language**

The terms 'autism', 'autistic spectrum disorder' (ASD) and 'autistic spectrum condition' (ASC) are often used interchangeably and refer to the same spectrum of conditions which includes autism and Asperger syndrome. Asperger syndrome is sometimes referred to as 'high functioning' autism (1). For consistency, we will use the terms 'autism' and 'person with autism' throughout this document.

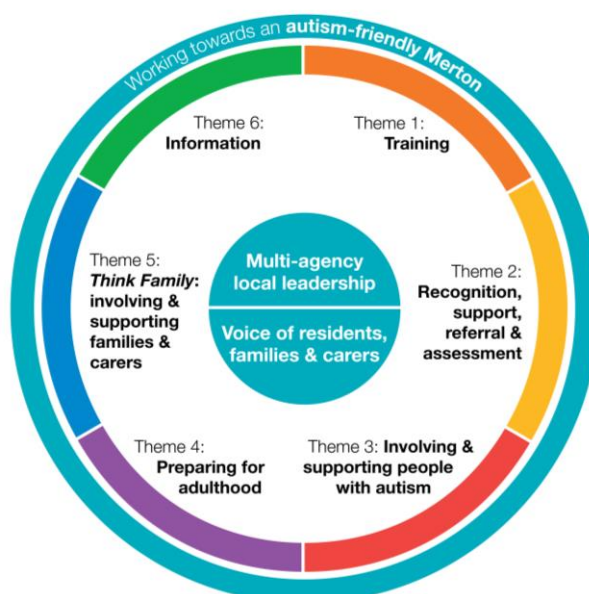
# Executive Summary

We want Merton to be an autism-friendly borough in which people with autism are able to live fulfilling and rewarding lives within a society that accepts and understand them and reach their full potential at all stages of their lives. With this in mind, we have developed a strategy for the next five years which takes a whole life course approach, encompassing children, young people and adults with autism and taking into consideration the needs of families and carers.

We know that autism touches the lives of many people in Merton and demographic data suggests that the number of people with autism is increasing. It is therefore important that we have a strategy which enables us to work in partnership to support people with autism in the most effective way possible. This includes raising awareness and understanding of autism in the wider community, ensuring that people with autism reach their educational potential, gain employment and can access the right support at the right time to be as independent as possible. Additionally, there is a need to ensure our local services are compliant with statutory duties and guidance for local authorities and the NHS in relation to autism.

This is a joint strategy between the London Borough of Merton and Merton NHS Clinical Commissioning Group (CCG) in collaboration with a range of partners, including NHS providers, Merton JobCentre Plus, Schools and the voluntary sector. Public sector services are all facing financial pressures and we need to work in partnership to ensure we use local resources most effectively.

In preparing this strategy we have engaged with a wide range of stakeholders, including people with autism and parents and carers, people working in education, housing, employment and health services to seek their views on what is working well and what needs to improve for people with autism. We have also collected and evaluated a wealth of local and national data and evidence. Through this process we have identified six key themes that we need to address in order to achieve our ambition of making Merton an autism-friendly borough:



### **Theme 1: Awareness training and support for staff and services**

Increasing awareness and understanding of autism is at the heart of this strategy and is fundamental to achieving our ambition of making Merton an autism-friendly borough, in which the general population are aware of autism and have a better understanding of the condition. This means understanding the specific strengths of people with autism, as well as having an awareness of the core social difficulties that those with autism may face. By improving autism awareness in the general population, and not just those who are working directly with people with autism, we hope to counteract unhelpful stereotypes and prejudices.

Summary of actions:

- We will deliver a new autism awareness training programme aimed at the wider CYP workforce.
- We will develop and deliver training to SENCO's and key staff to ensure that CYP in mainstream settings receive appropriate support and access to the curriculum.
- We will work towards all NHS and Merton Council staff undertaking autism awareness training as part of general induction and equality training.
- Utilise training packages which have been co-developed with people with autism and their families and carers e.g. NAS accredited training.

### **Theme 2: Recognition, support, referral & assessment**

We know that the earlier autism is identified, the better the outcomes and we therefore need to ensure that the wider community as well as those working with people with autism are aware of the signs of autism and the local pathways for assessment and diagnosis for people of all ages. We recognise that an autism diagnosis and assessment of needs can offer an understanding of why a child or young person is different from their peers. It can open doors to support and services in education, health and social care, and be a route into voluntary organisations and contact with other children and families with similar experiences. Access to support should however, be guided by need and should not be dependent on a diagnosis.

Summary of actions:

- CCG and Local Authority commissioners, in consultation with residents, will work together to redesign local referral, assessment and support services to meet the needs of children and young people (and their parents or carers) who may need diagnosis of an autistic spectrum disorder.
- We will design services such that access to assessment and diagnosis is available to those who need it, but not a requirement to accessing support.
- We will raise awareness of the diagnostic pathway for adults with autism through a published pathway and training of professionals.
- We will promote 'Autism Champions' in all early years and education settings to raise awareness of autism among staff and support early identification and referral.

### **Theme 3: Involving and supporting people with autism**

No two people with autism are the same and they will have different needs at different times of life, it is therefore key to this strategy that people with autism of all ages in Merton are able to access the right support at the right time. We want Merton to be a borough in which people with autism are fully involved in their care and can participate equally in society, including in their education

setting, the world of work and in leisure activities. It is essential we work with people with autism to ensure the design and delivery of services which are of a high quality, well joined up and available to everyone equally when they need them. We will seek to ensure that there is always opportunity for people with autism to be involved in service developments and delivery.

Summary of actions:

- We will actively involve people with autism, families and carers in co-designing services and take steps to promote equality.
- We will develop a plan for communication and engagement with people with autism over the life-course of the strategy.
- We will work to better support those with lower level needs as well as those with complex needs, including publishing a protocol outlining social care needs assessments for adults with 'high functioning' autism.
- We will develop a support offer for people with autism and complex needs, with early co-ordinated multi-disciplinary support, including transition from children to adult services.
- Work with the voluntary sector to develop a support offer for adults with autism with intermittent, lower level needs. This may include advocacy and advice services, peer support, volunteering programmes, social prescribing etc.
- We will increase the number of places within Specialist Maintained schools and schools with additionally resourced provisions so that CYP with Autism can be educated locally.
- We will promote the South London partnership 'Better Working Futures' programme, Project Search and the government's 'Disability Confident' scheme.

#### ***Theme 4: Preparing for adulthood***

Preparing for adulthood is a recognised challenge. Although the majority of young people with autism will not need specialist services as an adult e.g. adult social care, they will need support as they move towards adulthood in developing independence. This includes learning additional life skills such as travelling independently and seeking opportunities for further education, employment and independent living.

Summary of actions:

- We will ensure transition assessments are structured and use a framework such as the national Preparing for Adulthood framework
- We will work with schools, libraries and adult education to explore their potential for providing more life skills training for young people with autism
- We will work with FE Colleges to increase understanding of the needs of CYP with autism in further education and to improve their access to support within colleges.

#### ***Theme 5: Think Family: involving & supporting families & carers***

Families and carers in Merton have expressed that they would like to be more involved in decision-making about the care and support their loved ones receive. In Merton, families and carers value the existing support services available such as parenting programmes and short breaks, but felt they would benefit from a better continuum of support. In addition, access to clear, comprehensive, up-to-date information about local services has been highlighted as a priority for families and carers.

Summary of actions:

- As part of the development of the CYP 0-18 assessment, diagnosis and support pathway, we will work with partners to identify resources to increase the availability of parenting programmes on offer in the borough-particularly for those with children over 8 years old.
- We will produce clear information about local parenting support as part of the 'local offer'.
- We will promote co-production amongst organisations re-commissioning or delivering new services that support families and carers of people with autism.

### **Theme 6: Access to Information**

Access to comprehensive information about local services is essential in empowering people with autism to make informed choices. High quality information is also crucial to support families and carers of those with autism and staff working in organisations who may be in contact with people with autism. Merton Local Authority publishes a 'local offer' for children and young people with special education needs and disabilities, an online resource containing information about local services, however feedback has identified that this could be improved.

Summary of actions:

- Develop an all-services information hub to provide a single place for information about local services and resources relevant to autism, including the local SEN offer.
- When producing information, stakeholders will consider its accessibility in terms of clarity (easy-read), whether translations into non-English languages are required, and whether cultural factors have been taken into account, seeking to ensure information is widely accessible.

### **Delivering the Strategy**

A time-limited, Merton Autism Steering Group, or similar, will be set up to lead and oversee delivery of this strategy, which is based on working in partnership to use our resources most effectively and seeking opportunities to bring additional resources to the Borough. An Action plan has been produced setting out how and when the actions will be implemented. Progress will be reported to the Health and Wellbeing Board and Children's Trust Board.



# 1. Introduction

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## Our vision & aims

1. We want Merton to be an autism-friendly borough. In line with the Government's vision (2), we want Merton to be a place in which people with autism are able to live *'fulfilling and rewarding lives within a society that accepts and understands them. This means they can get a diagnosis if they choose and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them to make the most of their talents.'*
2. It is estimated that there are more than half a million people with autism in England. This is equivalent to more than 1% of the population, similar to the number of people that have dementia (3) and in Merton there are an increasing number of children and young people with a recorded diagnosis of autism. The National Autistic Society (NAS) estimates autism touches the lives of 2.8 million people in the UK every day (1) (4) and evidence shows that autism is a source of social, economic, and health inequality across England (2).
3. This strategy sets out our plan to achieve our vision for Merton and takes a life-course approach, encompassing children, young people and adults with autism, and taking into consideration the needs of families and carers. It recognises autism affects people in different ways and touches many aspects of their lives. Our ambition is to work in partnership to address the wide range of areas in which residents with autism might be supported, including in health services, education, preparing for adulthood, employment, independent living and the criminal justice system.
4. In implementing the strategy over the next 5 years, our intention is that Merton residents with autism and their families and carers feel more involved in the development and delivery of local services. Residents should expect to:
  - encounter a society which takes a strengths-based view of autism. We will build on what people can do, and where they want to get to in life, rather than a focus on what people may find challenging;
  - participate in decisions about assessment and diagnosis and receive support, information, and advice as early as possible after needs have been identified;
  - understand your diagnosis, if you choose to have one, and what this means to you and your parents/carers on a daily basis;
  - encounter a range of high-quality services that are joined-up, easy to navigate and appropriate for your needs;
  - be able to access clear, comprehensive and up-to-date information about where to go for support, and have a means of sharing knowledge and experiences with others;
  - find staff in relevant services have a clear understanding of autism and are knowledgeable about where to go for more information or help;
  - feel that Merton is a place where you can participate socially and lead an independent life, including reaching your educational potential, gaining and maintaining employment, living close to family and social networks, and have the opportunity to take part in leisure and social activities.

This strategy will act as the roadmap for commissioning intentions and service re-design and improvement initiatives going forward over the next five years.

## **Drivers for change**

5. The need for an Autism Strategy for Merton has been informed by a number of drivers:
  - There has been an increase in the number of children in Merton with autism recorded as their primary type of educational need, which indicates an increasing need for local education, health and other resources.
  - As the population grows older, the number of adults with autism is projected to rise, with an associated increase in the need for care and support for independent living.
  - Recognition that we need to understand better and improve our diagnosis pathway, as we know that our current 0-18 years pathway is not NICE compliant.
  - Stakeholders including service providers, voluntary organisations, people with autism and families and carers have told us they want to see improvements in support and services locally.
  - Preparation for adulthood has been identified as an important transition point for young people with autism, and ensuring this is well planned can have a significant impact on future wellbeing.
  - There are statutory guidance and legal duties for local authorities and the NHS, along with evidence-based quality standards.
  - Public sector services are all facing financial pressures and we need to work in partnership to ensure we use local resources most effectively.

## **Developing Merton's Autism Strategy**

6. This is a joint strategy between the London Borough of Merton and NHS Merton Clinical Commissioning Group. A multi-agency steering group, comprising commissioners and managers from Merton Local Authority, NHS Merton Clinical Commissioning Group (CCG), South West London and St George's Mental Health NHS Trust, and Merton JobCentre Plus, has led its development, with overview provided by senior level boards within Merton Council and NHS Merton CCG.
7. As part of the preparation of this strategy we engaged with a range of stakeholders including people with autism, parents/carers and professionals, through face-to-face meetings, multi-agency workshops, e-mail and on-line questionnaires and sessions with parents and carers.
8. A range of needs assessment information underpins the strategy, including national guidance and evidence, local population data, service mapping information and stakeholder feedback.
9. Through this process the following Merton priorities have been identified;

Figure 1: Strategy themes



## What is autism?

10. We all have differences that affect how we live in the world and relate to our environment. Autism can affect the way a person communicates with, and relates to, other people throughout their life. It affects how a person makes sense of the world around them. It has been stated that autism is neither a learning disability nor a mental health problem, although mental health problems can be more common among people with autism and it is estimated that one in three adults with a learning disability also have autism.
11. Autism is a spectrum of different needs, which means all people with autism are on a different point of the spectrum and affected in different ways. Some people with autism will have good language and communication skills and will be able to live independently, whilst others may have very limited language skills and will require specialist support throughout their lives. Asperger syndrome is on the autism spectrum and is often referred to as 'high functioning' autism, due to the fact that people with Asperger syndrome often have good verbal/language skills, however this can also mask a range of needs.
12. Over the past 40 years the prevalence of autism has increased substantially; greater awareness and diagnosis is thought to have contributed to this rise (5). Autism is more commonly diagnosed in males than females, with most recent estimates suggesting almost eight males have a diagnosis for every one female (6). It has however been suggested the 'true' ratio is narrower and there is under-diagnosis in females (6) (1).

## Features of autism

13. Autism affects how a person understands and interacts with others and the world around them. People with autism can find it more difficult to understand, relate to and communicate with others, and can find the world overwhelming, leading to anxiety and isolation. This can also have a profound effect on their families.

14. Autism is also associated with a range of positive attributes and advantages. People with autism may be better able to understand numbers and patterns than others, giving them an advantage in problem-solving (7). Some studies suggest, compared to the average person, those with autism think more creatively and have better memories (8). These characteristics convey a clear benefit for certain types of work; indeed, case studies show some businesses specifically seek to employ people with autism for the skills they bring.

### *Difficulties associated with autism*

15. People with autism more commonly experience certain health conditions, including generalised anxiety disorder, depression, obsessive compulsive disorder (OCD) and bipolar disorder (9). NAS estimates at least one third of people with autism are experiencing severe mental health difficulties (1). Epilepsy and sleep problems are more common (9), and people with autism can have sensory and motor difficulties including sensitivity to light, sound, touch, balance and pain, which can lead to distressing sensations and behaviours (3).
16. Learning disabilities are more common among those with autism than in the general population. NAS estimates between 44% and 52% of people with autism also have a learning disability (1).
17. Such difficulties, combined with the core features of autism, can result in people having a complex set of needs that may require specialist assessment and support and coordinated care that integrates a range of different services.

### *Social participation*

18. The difficulty people with autism face interacting with others can result in everyday life being confusing and frightening, and leave them feeling isolated (3). The right support can have an enormous impact on the lives of people with autism and their families, and NAS report that, when asked, 70% of people with autism said they would feel less isolated with greater social support (1).

### *A source of inequality*

19. People with autism may face inequality in society; indeed, the Autism Act 2009 was created in response to evidence that many people with autism are socially and economically excluded. People with autism can be stigmatised and the object of discrimination (3) and nationally, many pupils with autism report bullying.
20. National data from January 2016 shows that around 4% of pupils with a diagnosis of autism received at least one fixed period exclusion and about 0.1% were permanently excluded (10). In Merton in 2016, 22% of all permanent exclusions were amongst CYP with autism, however a third of these CYP were only diagnosed with autism after the exclusion.
21. NAS estimates only 15% of adults are in full time, paid work (1).
22. While autism is more commonly identified in males than females, it has been suggested this disparity may in part be due to under-diagnosis of autism in females (6) (1), which can result in unmet need among these individuals and their families. People with autism from Black, Asian and Minority Ethnic (BAME) communities may face additional challenges related to discrimination, engagement and accessing help and support. This may result in some people with autism from BAME communities being particularly disadvantaged.

## 2. National and Local context

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### ***The National picture: policy & guidance***

#### *The Autism Act 2009 & national strategy*

23. The Autism Act 2009 was created in response to evidence that many people with autism are excluded, both socially and economically (11). This act required the Government to create a national Autism Strategy; *Fulfilling and Rewarding Lives, the strategy for adults with autism in England*, which was published in 2010 (2).
24. An updated strategy, *Think Autism* (3) was published in 2014 reflecting progress made and changes in the organisation of public services. Statutory guidance from the Department of Health was then produced in 2015 to assist local authorities and NHS agencies turn the strategy into action (12). This guidance detailed nine priority areas;
  - Training of staff who provide services to adults with autism.
  - Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services.
  - Planning in relation to the provision of services for people with autism as they move from being children to adults.
  - Local planning and leadership in relation to the provision of services for adults with autism.
  - Preventative support and safeguarding in line with the Care Act 2014 from April 2015.
  - Reasonable Adjustments and Equality.
  - Supporting people with complex needs, whose behaviour may challenge or who may lack capacity.
  - Employment for adults with autism.
  - Working with the criminal justice system.
25. The 2015 statutory guidance contains a number of legal duties on local authorities and NHS agencies.

#### *National Institute of Health & Care Excellence (NICE) guidance*

26. The National Institute of Health and Care Excellence (NICE) provides national guidance on health and care, including advice, information, and quality standards to guide the development of best practice in service delivery.
27. The NICE autism pathway brings together all NICE evidence, guidance, quality statements, and other information relating to health and care support for children, young people and adults with autism (13). It recommends the following:
  - service organisation and delivery of care should be led by a multi-agency strategy group;
  - care, assessment and support should be delivered by specialised children and young people and adult autism teams, which consist of professionals from a range of disciplines;
  - partnership working for delivering high-quality and comprehensive local services and support.

28. The NICE guidance contains general principles of care for children and young people and adults including: access for all; fully informed decisions made jointly between professionals, patients, and their families and carers; care delivered by skilled and trained staff; and physical environments designed or adapted to minimise their negative impact. It highlights how smooth transition from young people's to adult services requires advanced planning and a coordinated approach between the two services.
29. NICE quality statements are concise, prioritised statements designed to drive measurable improvements. The NICE autism quality standard (QS51), comprises eight quality statements relevant to the care of CYP and adults with autism. The quality statements are not mandatory (required by law), but are designed to form the basis of local audit criteria to support continuous quality improvement, and should be measured using locally collected data. Table 1 details the quality statements.
30. In Merton it is recognised that we have not yet achieved all the quality statements set out in national guidance and this is challenging. Partners are working towards achieving standards and this strategy identifies priority areas where this will be strengthened.

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

## **Our population**

### *Estimated numbers of Children and Young People (CYP) with autism*

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

- 32. Based on APMS, there were an estimated 541 children and young people aged 0 to 25 with autism resident in Merton in 2017 (14). We need to evaluate the data further within Merton to ensure that we are capturing the CYP who have received a diagnosis 0-5 years, 5-18 years and in adulthood.

### Resident Merton CYP with an Education, Health and Care Plan (EHCP) & autism

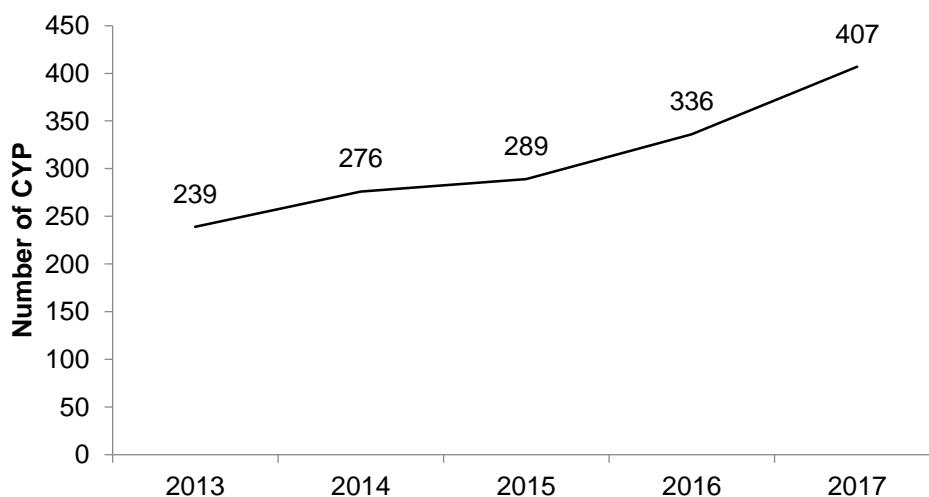
- 33. Merton has an increasing number of resident children and young people with an Education, Health and Care Plan (EHCP) or SEN Statement, with autism recorded as their primary type of special educational need. Of the 1500 CYP who had an EHCP in January 2017, 407 CYP (aged 0 to 25 years) were in this group (15). It is important to note CYP with autism are only captured in this data if they have an Education, Health and Care Plan (EHCP) or SEN Statement, and autism is recorded as their primary, and not a secondary, need.

**Note:** An education, health and care (EHC) plan is for children and young people aged up to 25 who need additional special educational provision to meet their special educational needs than is from SEN support.

EHCPs replaced SEN Statements under the Children and Families’ Act 2014. All Merton CYP with SEN Statements will be moved to EHCPs by the end of March 2018. Throughout this document, the term ‘CYP with an EHCP’ will be used to encompass those with an EHCP or SEN Statement.

- 34. Between 2013 and 2017, the number of CYP with an EHCP and autism as their primary need rose by roughly 60%, from 255 to 407 individuals. This may be due to greater awareness and diagnosis in the region, as well as an overall increase in the 0-19 population (5). In addition, changes implemented following the Children’s and Families Act 2014, in which the age range for SEN provision was extended to include young people aged 19 to 25, contributed to additional young people being captured in the data after 2015.
- 35. Chart 1 displays the rise in Merton CYP with an EHCP and recorded autism between 2013 and 2017.

**Chart 1: number of Merton CYP with ASD recorded as primary type of need, 2013 - 2017**



## Diversity among Merton's CYP with an EHCP & autism

36. Similar to the national picture, there is a difference in prevalence between males and females in Merton; in 2017 85% of CYP recorded with autism were male. It has however been suggested this difference may in part represent under-diagnosis and unmet need among females (6) (1).
37. In 2017, among Merton's CYP with an EHCP and a primary need of autism, and in whom ethnicity was recorded, around half were in a white ethnic group. CYP of Black or Black British origin represented the second largest group, making up 19%. One in seven was Asian or Asian British, just over one in ten was of mixed ethnicity, and 3% were of other ethnic origins. This is comparable to school ethnicity in Merton indicating that ethnic groups are represented equally in terms of autism diagnoses.

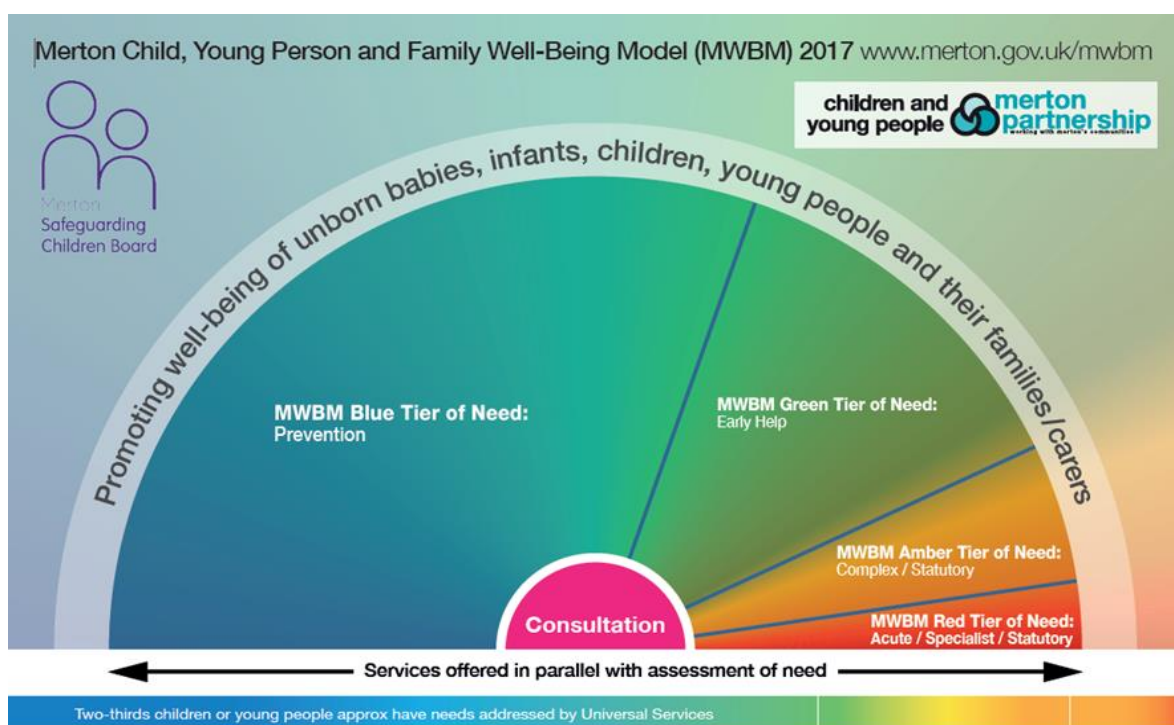
## Estimated numbers of adults with autism

38. Among adult residents (aged 16+), based on the APMS estimates, in 2017 there were around 1,202 Merton adults with autism, including roughly 1,050 men and 150 women. As the population grows, the number is projected to rise, increasing by 14% to reach approximately 1,570 adults in 2030. This implies there will be an associated increase in need for care and support for adults with autism in Merton over time.

## Merton children, young people and family wellbeing model

39. This strategy has been developed in the context of the Merton children, young people and family wellbeing model, which was refreshed in 2017 (see figure 2. below). This sets out our local framework for working with children, young people and families and supports organisations to have a shared understanding of levels of need and work in partnership to address risk and vulnerability.

Figure 2:





## Our current services and access to support

40. This section provides details of the current service provision and support available to people with autism in Merton. An assessment of the strengths and weaknesses of the current services on offer has informed the priorities set out in this strategy. This section provides useful context, however if you would like to read about the strategy priorities please go straight to section 3 (page 27).
41. Further information about resources and accessing services are set out in the Merton 'Local Offer' <https://fsd.merton.gov.uk/kb5/merton/directory/site.page?id=nc00A9s4RpY>

### Recognition, referral & assessment

42. Identification, assessment and diagnosis are important for enabling people with autism and their families to understand their condition and access care and support where needed. Table 2 details current providers and sources of referral for diagnosis.
43. Early Years practitioners including community health, care and education, teachers and GP's are often the first professionals a family will see when investigating assessment/diagnosis for a child who may have delayed language or social skill development. Education settings (e.g. early years, school and colleges) and Primary Care can therefore play a vital role in diagnosis and support pathways for autism. Autism awareness, understanding of referral pathways and sources of support and information are all important for education providers and GP practices to consider.

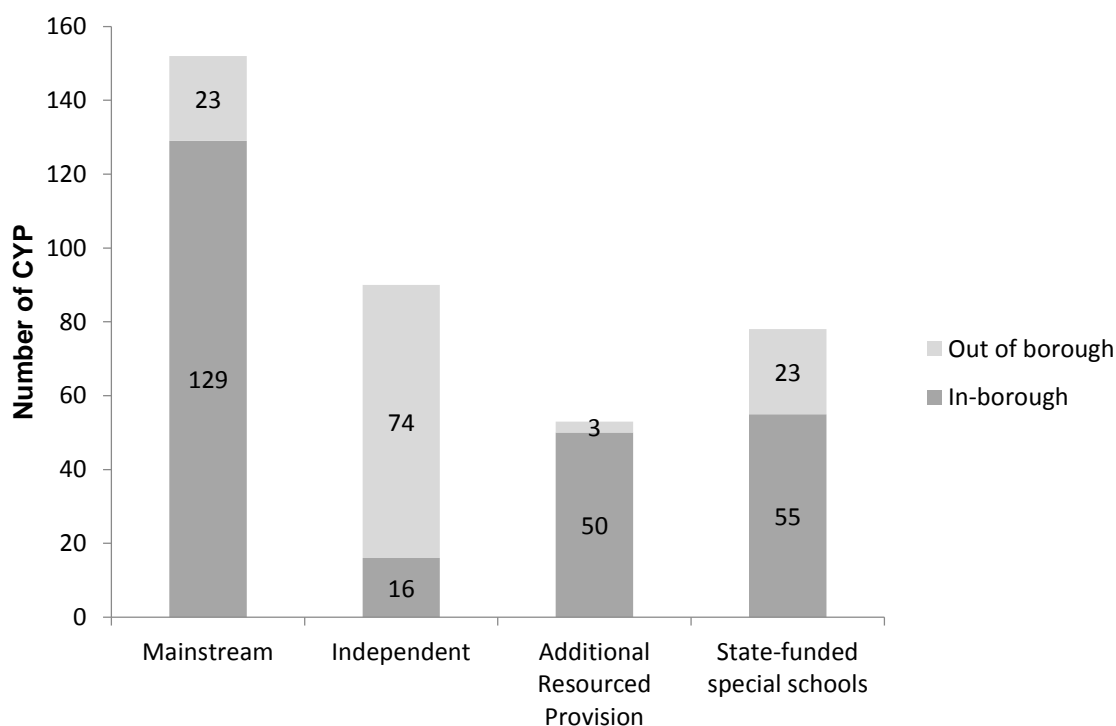
	<b>Commissioner</b>	<b>Provider</b>	<b>Service</b>	<b>Sources of referrals</b>
Under five years	Merton NHS CCG	Epsom and St Helier University Hospitals NHS Trust	Sutton and Merton Community Paediatrics	Direct from health or education professionals
Five to 17 years	Merton NHS CCG	South West London and St George's Mental Health NHS Trust (SWLStG)	CAMHS Neurodevelopmental Service, a dedicated autism and attention deficit hyperactivity disorder (ADHD) service within the Child and Adolescent Mental Health Service	Health or education professionals via CAMHS Single Point of Access
18+	Merton NHS CCG	SWLStG	Adult autism team: for adults without a learning disability	Direct from GPs
	Merton Local Authority	Merton Local Authority	Team for People with Learning Disabilities: for resident adults with a learning disability	Health or social care professionals

## Specialist services for children and young people

### Educational provision & support

44. Appropriate, high-quality support in education settings (e.g. early years, schools and colleges) is crucial for CYP with autism, supporting them to participate, progress and reach their potential. CYP with autism have differing educational needs, and this is reflected in the range of educational provision and services offered in Merton.
45. Many Merton CYP with autism are most suited to mainstream education. In 2017, approximately 40% of Merton CYP with an EHCP and autism attended a mainstream school, representing the largest group. Of those not in mainstream schools, roughly equal proportions attended state-maintained special schools and independent schools, with the lowest proportion attending additional resourced provision (ARP) bases. This distribution of CYP across the different school types indicates a diversity of needs among Merton’s CYP with autism, with different settings most appropriate for different needs.
46. The majority of mainstream, ARP, and state-funded special school placements are in-borough, whereas around 82% of those attending independent schools are placed out-of-borough. Chart 2. displays the numbers of CYP in different types of school, in- and out-of-borough, in 2017.

**Chart 2: Number of CYP with ASD placed in- and out-of borough , by educational establishment, 2017**



47. In recent years small numbers of CYP with autism have been in residential schools. This small yet significant group of CYP is likely to have some of the most complex needs. Almost all residential placements were independent schools out-of-borough, and tended to be high-cost.
48. Support within education provision varies depending on the type and the needs of individual pupils. Merton’s four autism Additional Resourced Provision (ARP’s) including three primary

and one secondary school, provide specialist educational, social and emotional support tailored specifically to CYP with autism. Speech and Language Therapists (SaLT), educational psychologists and Merton Autism Outreach Service (MAOS) work with Merton ARPs to provide additional specialist input, as outlined in EHCP's.

49. Cricket Green and Perseid schools are Merton's two state-maintained special schools, both taking CYP of all schools ages, including a substantial number with autism. Perseid is for CYP with severe and profound learning difficulties, including learners with an additional diagnosis of autism and/or additional physical and/or sensory disabilities. Cricket Green School is for CYP with diverse learning needs. Cricket Green school is involved in leading a number of additional services, including Merton Autism Outreach Service (MAOS) and Project SEARCH.
50. SaLT work with CYP in all schools to help them develop speech and language skills. SaLT can also offer information to parents and teach them specialist techniques to help develop their child's communication skills at home.
51. Merton Educational Psychology Service provides psychological consultation to all Merton schools concerning CYP with special educational needs, including autism. Educational psychologists can also offer training to school staff and deliver evidence-based interventions to support individual pupils, including video interactive guidance (VIG) and cognitive behavioural therapy (CBT). In addition, the service is commissioned by Merton Local Authority to provide psychological advice for EHCPs. This ensures EHCPs best identify and meet the pupils' needs.
52. MAOS helps school staff effectively support pupils with autism. MAOS staff work with head teachers, Special Educational Needs Coordinators (SENCo's), classroom teachers and teaching assistants, in their own school setting, to advise on new strategies tailored to supporting individual pupils. The service mainly works in primary schools although expansion into secondary schools is underway. In order to receive support, schools are required to directly contact MAOS.
53. Merton Sensory Support Service work with CYP in school settings and in the home. Specialist Teachers provide support and advice for CYP with a visual, hearing or multi-sensory impairment to access the curriculum and environment and offer information to teaching staff and families.
54. Children's social care provide support and services to a smaller number of children and young people with autism who have been identified with very complex needs, or who may be children in need, looked after or care leavers. There is a dedicated Children with Disabilities social care team, however children with autism may also be known to other parts of the social care system and wider Children, Schools and Families department including the 0-25s Early Intervention and 'Shortbreaks' service.
55. For children in the early years there are a range of support services available including health visiting, specialist therapists, advisory inclusion work in the child's setting and specialist programmes supporting children's social and communication. Families can be supported through home based specialist family support and have access to specialist parenting and child development programmes.
56. Merton has a specialist 'Shortbreaks' Centre which provides high quality, out of school provision for children and young people with specific needs, including Autism. The Brightwell Specialist Out of School Provision is open after school during term time, and during the day at weekends and school holidays (closed for a maximum of 2 closure weeks and bank holidays) and works with children and young people aged 6 – 18 and their families, in partnership with other specialist agencies.

## Child and Adolescent Mental Health Services

57. Merton CCG commission child and adolescent mental health services (CAMHS) from South West London and St Georges NHS trust (SWLStG). This delivers assessment, diagnosis and management of mental health conditions and services may be accessed by CYP with autism, as well as specialist services including the neurodevelopmental pathway for diagnosis of ASD and ADHD. Services are accessed via a single point of access.

## Parenting programmes

58. Parenting programmes can help parents understand and communicate with their child, and support children with autism to develop social and communication skills. Merton Local Authority and Merton CCG deliver and commission a number of parenting programmes, including autism-specific programmes, such as the NAS 'Early Bird Plus' programme, programmes that are suitable for children with disabilities and/or autism such as the 'Triple P Stepping Stones' programme and general programmes aimed at parents of children with communication or behavioural difficulties, such as 'Social Butterflies' and 'Incredible Years'. Programmes vary in their approaches and aims, and are designed for children of different age groups, ranging from one to eight. Depending on the programme, referrals may come from education, health and social care staff or educational psychologists working in schools, including MAOS.
59. Our ambition in Merton is to ensure there is a full range of parenting programmes to meet diverse needs of local families. In addition, we want to work towards easier access to these programmes.

## Preparing for adulthood

60. People who have received support with autism in childhood may not automatically need support from adult services. This includes a small number of our Looked After Children who will not meet the threshold for adult social care, but who the council may need to continue to support as their corporate parent. Young people sometimes see adulthood as a time to progress to greater independence and may not want an assumption of lifelong need for services, their needs are also likely to change as they move into adulthood and they may need less or more support, particularly if they have secondary diagnoses. Where there is a need for ongoing support, it is essential that the focus of this support is on developing independence and fulfilling their potential.
61. CYP with autism and an EHCP are supported in education provision on the basis of educational needs, whereas adults with autism receive state-funded support on the basis of social care needs under the Care Act 2014, or are supported as Care Leavers under a range of legislation. The majority of CYP with an EHCP and autism will have needs that do not reach the threshold for adult social care, albeit some not reaching that threshold, including Care Leavers, will have significant support needs as young adults in achieving independence.
62. In educational provision, young people with autism and an EHCP receive an annual review. From year nine this review includes 'Preparing for Adulthood', a framework which aims to ensure young people with special educational needs and disabilities (SEND) can reach their full potential as they move into adulthood, including paid employment and higher education, housing options and independent living, good health, friends, relationships, community inclusion and choice and control over their lives and support (16). EHCP outcomes are based on the national 'Preparing for Adulthood' framework.

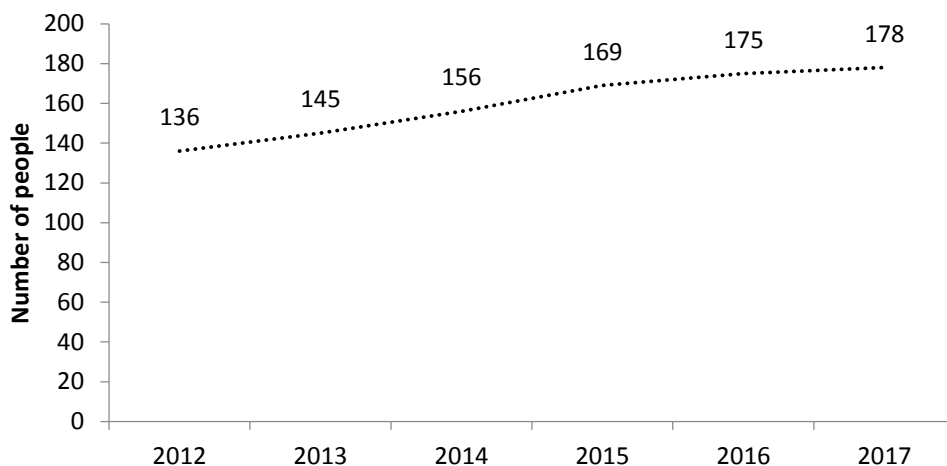
63. For CYP supported by the council's Children with Disabilities (CWD) Social Care team, a transition meeting is held at age 14 to consider whether the young person is likely to be eligible for adult social care. For those identified, the council's CWD and Transitions teams co-work with the young person and their family/ carers from age 16 to plan for transition to adult social care. Young adults transfer to adult social care services at age 18. Care leavers not held in CWD and not meeting the threshold for adult social care will be supported through to independence as Care Leavers by the council's Children, schools and families department.
64. Merton Council offers a wide range of courses in partnership with South Thames College which have specialist teaching, and a support team to work with young people and adults with a wide range of disabilities. It also runs Merton-specific 'Towards Independence' courses which are daytime courses for adults (people over 18), who have a learning disability or difficulty and include life skills, looking after yourself, arts & crafts, etc.
65. The Aurora Centre is Merton College's specialist, non-residential centre for young adults aged 16-25 with autism and complex needs. It runs courses focusing on three key areas: living, work and community. Students are also able to take part in supervised work experience.
66. Project SEARCH, an initiative originally developed in the USA, is provided in Merton, led by Cricket Green School. This programme provides practical work experience and prepares a cohort of young people with learning disabilities, including those with autism, for the world of work. The programme places roughly 6 students per year within an organisation where they gain on-the-job training and additional employment support. The current host organisation is St Georges Hospital. Although numbers of participants are relatively low, the success rates are high with 76% of participants gaining on-going employment after the project.

## **Specialist Services for adults**

### *Adult social care & support*

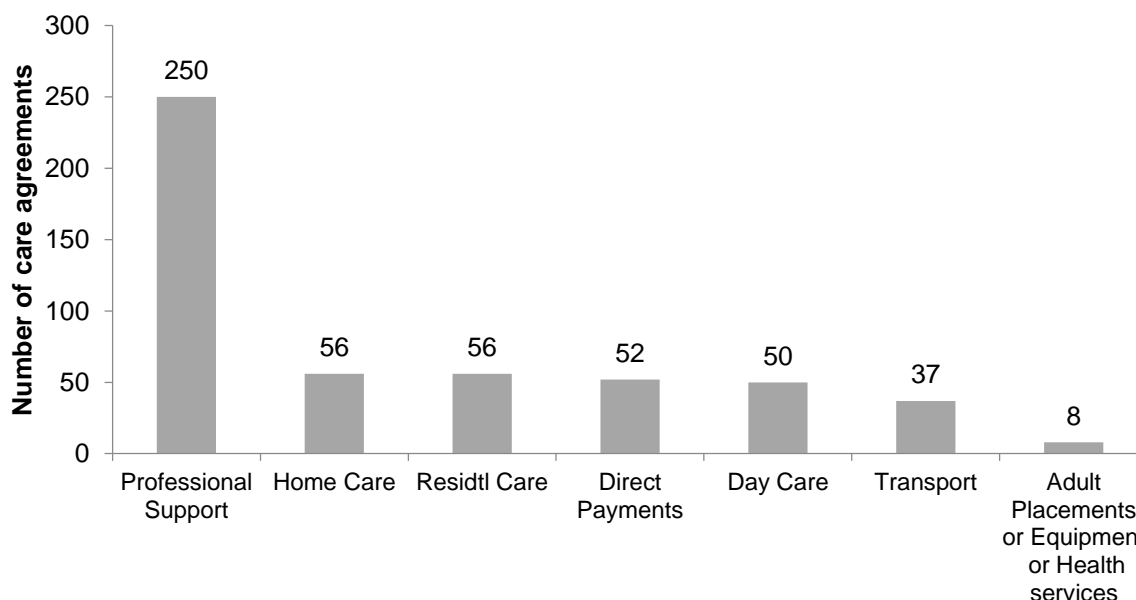
67. Merton Council's Team for People with Learning Disabilities and Transition is a multi-disciplinary health and social care team working with adult residents. Where eligible, the team supports adults with autism through professional health services and social care, including conducting needs assessments under the Care Act 2014 and commissioning support to meet individuals' social care needs.
68. In January 2017, 178 adults (aged 16+) with a diagnosis of autism were receiving adult social care and support. The number of adults with autism receiving adult social care has gradually increased year on year since 2012, as chart 3 depicts.

**Chart 3: Number of adults with autism receiving adult social care**



69. The number of care agreements in place ranged from one to nine per person, demonstrating varied levels of need among the group. Approximately 75% of service users were receiving at least one professional service, which may be support from social workers or health professionals. 30% were being supported in residential care, and around one quarter were receiving home care. Chart 4 displays the total numbers and types of services being delivered to service users with autism in January 2017.

**Chart 4: number of care agreements among adult social care users with autism, by service type, Jan 2017**



### Adult mental health services

70. Merton CCG commissions South West London St Georges NHS Mental Health Trust (SWLStG) to provide adult mental health services, which deliver assessment, diagnosis and management of adults with mental health conditions. This is a universal service, and routinely cares for residents with autism and co-existing mental health needs.

71. Social workers work within SWLStG adult mental health services fulfilling adult social care functions under the Care Act 2014, for example carrying out social care needs assessments. This allows a multi-disciplinary approach to supporting people with mental health needs, including those with autism.

### *Support for training, employment & independent living*

72. At Mitcham JobCentre Plus, a Disability Employment Advisor and work coach support people with disabilities, including those with autism, into training and employment. Merton Local Authority Employment Team for People with Learning Disabilities also offers support to adults with autism who have a learning disability.
73. The London Borough of Merton is aiming to support young people with a learning disability to be able to travel independently between home and their place of education or training. The aim is to provide young people with the skills they need to confidently travel on their own, removing the need for transport to be provided for them and supporting their greater independence. Merton Mencap currently provides this service to students attending schools and colleges in Merton (and some surrounding areas), including Cricket Green School, Raynes Park High, Ricards Lodge High, Rutlish, South Thames Crossroads and Carshalton College.
74. A new South London partnership 'Better Working Futures' programme, which is being jointly commissioned by 5 councils across South London started in Spring 2018. The programme aims to help people who have been unemployed for longer than two years, or who have struggled to get into work due to health problems or disability, into jobs. Furthermore it will also address other difficulties including a lack of basic education, debt and homelessness.
75. Merton Local Authority Library and Heritage Service provides opportunities for people with autism to participate in activities and programmes in these facilities. Library staff are trained to understand the basics of many common conditions, including autism, in order to support service users.

## **Services relevant to residents of all ages**

### *Access to mainstream health services*

76. As well as specialist services, people with autism need to be able to access universal services such as GP practices and hospitals. Using these services can be more difficult for people with autism. A lack of awareness amongst staff of the features of autism, and inappropriate or stressful environments are likely to be contributing factors. For example, waiting areas in hospital A&E departments are often loud, brightly lit and some staff working in these departments may be unaware of how best to communicate with people with autism. GP practice reception areas may be crowded and appointments may not run to time. Such environments may deter people with autism from using these services. Putting in place reasonable adjustments (such as booking a person with autism for the first morning appointment or booking with the same doctor) and raising awareness can ensure that people with autism are able to benefit fully from mainstream public services and live independently and healthily.

### *Respite & short breaks services*

77. Merton's children and young people special educational needs and disabilities integrated service co-ordinate short breaks services for children and young people. The adult social care team co-ordinates short breaks services for adults and their families/carers. Eligible

carers can have a break from their caring role for a few hours each week by having someone support their loved one either in a community provision or at home, or could receive an allocation of day/overnight respite stays throughout the year. The carer can organise this support as and when they need this. Carers looking after an adult could also be entitled to a grant (of up to £100 per annum) to support their caring role, which they could use for a short break. Families with children and young people up to the age of 18, could be eligible for a short break with a focus on supporting the child's development through a recreational activity as well as providing the parent with a short break.

78. Merton Shared Lives Scheme offers an accommodation based service for adults with a learning disability or mental health issue that need some support in their everyday lives. The Shared Lives Carer provides help and support, either by sharing their own home with the client, or by offering 'floating support' by regularly visiting a service user who resides in another property.

### *Social prescribing*

79. In 2017, Merton Partnership, the CCG and Merton Public Health jointly commissioned a pilot for social prescribing. Social prescribing is a mechanism for linking patients in primary care with non-medical sources of support within the community. The pilot is currently active in two GP practices in the east of the borough and is due to be rolled out across the rest of Merton in 2018.
80. For people with autism and their families and carers, social prescribing could help to reduce social isolation and support people with autism to access a wide range of community organisations, including sports and leisure clubs, befriending services and adult learning. Social prescribing co-ordinators are also trained to provide information and advice on housing, employment, debt and benefits, and support people with low to moderate mental health issues, including those with autism.

### *Voluntary sector services*

81. The voluntary sector plays a key role in Merton, providing opportunities for people with autism to participate socially, particularly outside the school day, and fostering networks of local families and carers through which information and support can be shared. Merton Mencap runs Talk Autism, which provides monthly information and support sessions for parents of people with autism. Merton National Autistic Society holds monthly coffee mornings for families and carers, and is in the process of setting up regular social groups for CYP and adults with autism. Carers Support Merton, Carers Partnership Group and Merton Centre for Independent Living support residents concerning a range of needs, including autism. Merton Voluntary Service Council provides supported volunteering, befriending and training placements for young people in the borough, including those with autism.

### *Services in the criminal justice service*

82. People with autism may be witnesses or victims of crime. They may also commit crimes and be detained. People with autism appear to be over-represented in the criminal justice system (17) (18) nationally, and national guidance highlights the importance of ensuring the needs of people with autism are met in all custodial settings and as they move between settings.
83. Merton CCG commissions SWLStG to provide assessment and support for detained young people. A CAMHS worker screens all young people receiving a youth court order, and fully assesses individuals who may have care and support needs, including due to autism.



## *Social, Leisure and Community Resources*

84. This strategy adopts an approach that expects children and adults with autism to be able to take advantage and enjoy all that their local communities have to offer. Some local organisations are already taking steps to promote inclusion for all and reduce barriers. There are also local facilities that people with autism will be able to use along with everyone else, and this strategy will work to promote the development of community assets.
85. Examples of existing leisure activities which are autism friendly include Wimbledon Theatre's creative learning programmes and Uptown Youth Services which is run from the High Path community centre and hosts activities 3 nights a week for children with and without learning difficulties.

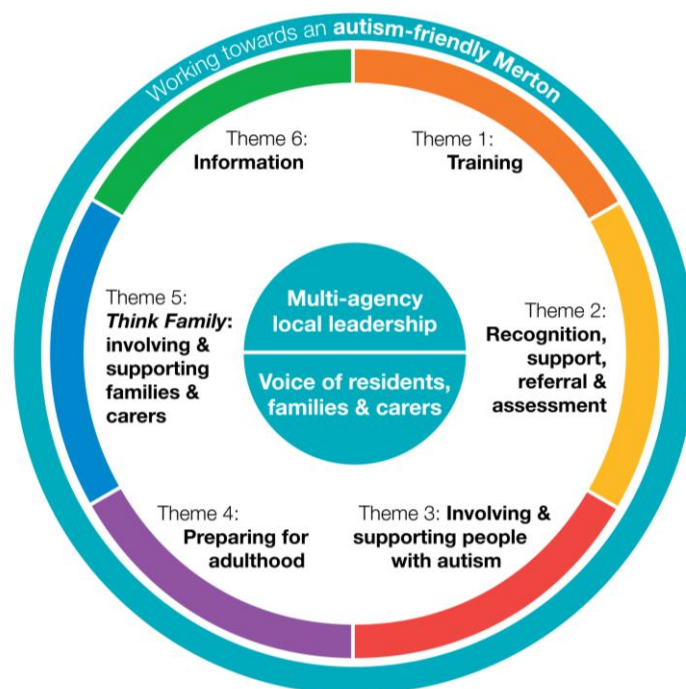
## **What stakeholders say**

86. Stakeholders provide a unique and valuable insight into local challenges, priorities, and potential solutions. Information provided by local stakeholders has been critical to developing this Autism Strategy and identifying themes and priorities.
87. Initial engagement included a survey of stakeholders; a workshop involving 35 partners; presentations and discussion at community and voluntary sector groups and forums involving people with autism, parents and carers; engagement with young people with autism about the assessment and diagnosis process; presentations and discussion at health and partnership groups.
88. Stakeholder views were incorporated in the sections on priority themes that follow. Key themes that were identified from initial engagement included:
  - the need for better multi-agency collaboration;
  - the need to involve people with autism and families and carers better;
  - the need for clearer support pathways and information;
  - the need to increase staff awareness;
  - the need to create appropriate environments that enable people with autism to participate socially;
  - the need to strengthen training and employment opportunities and support;
  - the need to recognise the needs of people with autism from Black and minority ethnic groups and the needs of girls and women with autism.
89. Following the development of a draft strategy, wider public engagement took place over 6 weeks to seek stakeholders' views on the draft, identify any issues which had not been addressed and ascertain priorities for action. This engagement period involved two strands; written engagement via a structured on-line survey and paper easy-read survey; verbal engagement through facilitated feedback sessions with stakeholders including people with autism, parents and carers and professionals. 146 participants engaged in this process.
90. The feedback received was used to inform the final version of the strategy. Key issues from engagement on the draft strategy that have been incorporated in the final strategy include;
  - the need to increase awareness of autism in the wider community and promote inclusion;
  - the need to ensure our aims are achievable and set clear priorities for action;

- the need for further emphasis on early intervention and training for front-line staff;
- the need for improved access to diagnostic services and availability of post-diagnostic support;
- the need to prioritise services which are inclusive for people with autism and enable social participation and independent living;
- the need to listen to parents and carers, whilst ensuring the voice of people with autism is still at the forefront of decision-making.

## 3. Priority Themes

91. The following section considers our priority themes in turn, for each describing the evidence for change, current situation in Merton, our aspirations for where we want to be and what we will do to achieve our ambitions. These are all underpinned by multi-agency local leadership and working with our resident children, young people, adults and their parents/carers.



### **Multi-agency local leadership & the voice of residents with autism, families & carers**

92. Multi-agency local leadership underpins the planning and delivery of support for people with autism in Merton. A range of services and organisations have important roles to play in making Merton an autism-friendly borough, and should therefore be involved in designing and delivering local services as well as being accountable for their commitments.
93. The voice of residents with autism and their families and carers should be central to the delivering and monitoring the strategy. In seeking the views of service users, families and carers, local organisations should be willing and able to take these views into account in designing and delivering services in line with the strategy.

### *Governance*

94. We will establish a time-limited, multi-agency Merton Autism Steering Group, or similar, to lead implementation of the strategy and monitor progress against an action plan. The Group will include representation from the local authority, NHS, education, voluntary sector, Job Centre and engage people with autism and families and carers.

95. We will develop effective and sustainable methods for engaging with, and collecting the views of, people with autism to ensure user voice is heard and taken into account and helps drive continuous improvement.
96. Methods used to collect the views of people with autism need to take into account their specific needs. For example, some people with autism may not wish to attend meetings or focus groups and may prefer to provide their feedback via email or online questionnaire. We will therefore use a range of ways to engage people with autism and ensure we feedback to them on how their views are used to influence local plans.

### Promoting equality

97. Based on evidence that many people with autism are socially and economically disadvantaged, this strategy is likely to have a positive impact on equality through seeking to address the needs of residents with autism.
98. In addition, an equality analysis detailed a number of specific opportunities to further promote equality. Table 3 summarises these opportunities and where they are addressed in the strategy.

Table 3: opportunities to promote equality	
Equality issue	Themes where addressed
<b>Age</b>	
<b>Early years:</b> awareness, diagnosis and intervention in early childhood may improve long-term outcomes. Without early diagnosis, children may miss the opportunity to benefit from intervention and support.	Theme 2 Recognition, support, referral & diagnosis Theme 1 Training
<b>Young adults:</b> transition from children to adulthood is a recognised challenge and, without appropriate planning and support, young adults can face particular difficulties after they enter adult life.	Theme 4 Preparing for adulthood
<b>Sex</b>	
Although autism is more common in males, it has been suggested there may be under-diagnosis in females, which may lead to unidentified and unmet needs in this group.	Theme 2 Recognition, support, referral & diagnosis Theme 1 Training
<b>Race</b>	
People affected by autism from BAME communities may face additional challenges related to different cultural perspectives, varying levels of knowledge and understanding about the condition, and difficulty accessing services and information due to language or other barriers (19). This may result in some people with autism from BAME communities being particularly disadvantaged.	Theme 2 Recognition, support referral & diagnosis Theme 3 Involving & supporting people with autism Theme 4 <i>Think Family:</i> involving & supporting families

	and carers
Theme 6	Information
Theme 1	Training

99. The Steering Group and its member organisations should take joint responsibility for promoting equality by collecting data on protected characteristics of service users, interpreting the data and acting upon the findings.

# Theme 1: Awareness training and support for staff and services

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## Evidence for change

- I00. Improving training around autism is at the heart of the national autism strategy ‘*Think Autism*’, for all public service staff but particularly for those working in education, health and social care. This includes not only general autism awareness training, but also different levels of specialist training for staff in a range of roles.
- I01. Staff autism training can bring wider benefits to residents with autism through increasing awareness and understanding of the condition throughout society, leading to an autism-friendly population. This applies to staff from a range of settings having access to training, including education, health and social care, transport, criminal justice and local businesses.
- I02. This means understanding the specific strengths of people with autism, as well as having an awareness of the core social difficulties that those with autism may face, thereby counteracting unhelpful stereotypes and prejudices.
- I03. Finding employment can be a challenge for people with autism, and lack of awareness among local employers about the value employees with autism can bring to the workplace may contribute to this. In addition, employers may not be aware of their duty to make reasonable adjustments for people with autism under the Equality Act 2010 (22). Autism training and education for local employers can improve the employment prospects of people with autism.

## Where we are now

- I04. Stakeholders passionately expressed that training and raising awareness of autism is fundamental to achieving the strategy’s aims of making Merton an autism-friendly borough.
- I05. A substantial number of education, social care and health staff across Merton regularly interact with CYP and adults with autism. Many have received training to raise their awareness and understanding of the condition.
- I06. Merton Local Authority offers free autism awareness training to all education, health and social care employees. In addition, the council has delivered training to other local practitioners including providers of adult social care services and GPs. Local NHS Mental Health Services (SWLStG) have established ‘Autism Champions’ throughout the trust to increase awareness among staff.
- I07. Training helps increase staff knowledge of local services available and how to refer, enabling them to seek timely, appropriate support for service users. Stakeholder feedback has highlighted the need for more routine training for relevant education, health and social care staff to increase autism awareness and knowledge of local support available. This could lead to earlier diagnosis and intervention, reduced risk of under-diagnosis in females, improved equality, and higher quality support provided more consistently across Merton.
- I08. Many stakeholders feel training should be co-developed with people with autism, quality-assured and evaluated to measure its impact and enable improvement over time.

- I 09. Stakeholders identified the following key groups for autism training; employers, children and young people and front line staff in schools and health settings.

## **Where we want to be**

Merton is committed to being an autism-friendly borough in which:

- I 10. The general population are aware of autism and have a basic level of understanding of the condition. This contributes to people with autism feeling understood, accepted, having equal opportunity to live independently and participate socially.
- I 11. All education, health and social care staff are aware of autism, understand the importance of recognition and referral, and know where to go for more information.
- I 12. Staff working with CYP or adults with autism have a more in-depth understanding of the condition, its related equality issues, and local services available. This enables them to provide high-quality support.
- I 13. Local employers understand the value people with autism can bring to the workplace and ensure residents with autism have equal opportunity to gain and stay in fulfilling employment.
- I 14. People with autism interacting with the criminal justice system are treated appropriately by staff who understand the condition and know how to access additional support where necessary.

## **How we will get there**

In the first year we will:

- I 15. Deliver a new programme of autism training for CYP workforce. This will include targeted training for Early Years workforce on recognising the signs of autism, including recognition in girls, to enable early intervention.
- I 16. Deliver general awareness training for wider CYP workforce, including education, health, social care and third sector. This will include anxiety and sensory training.
- I 17. Develop and deliver training to SENCO's and key staff to ensure that CYP in mainstream settings receive appropriate support and access to the curriculum.
- I 18. Utilise the existing early-years accredited SENCO training programme
- I 19. Utilise training packages which have been co-developed with people with autism and their families and carers e.g. NAS accredited training.
- I 20. Review opportunities and seek funding to educate children and young people about autism and identify champions.

Over the life of the strategy we aim to:

- I 21. Work towards all NHS and Merton Local Authority staff undertaking autism awareness training as part of general induction and equality training.

- I22. Seek opportunities to deliver training to GP's and health professionals in recognising and managing co-existing mental health issues in people with autism e.g. ADHD/anxiety.
- I23. Promote uptake of autism awareness training among local employers. This training should include information about employers' duty to make reasonable adjustments for people with autism under the Equality Act 2010.
- I24. Explore how social care staff can be better supported when working with people with autism with very complex needs.
- I25. Work with the Police and encourage work with partners to deliver training to relevant staff groups.



## Theme 2: Recognition, support, referral & assessment

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### **Evidence for change**

- I26. We know that the earlier autism is identified, the better the outcomes. We therefore need to ensure that the wider community as well as those working with people with autism are aware of the signs of autism and the local pathways for diagnosis and assessment for people of all ages.
- I27. NICE highlight that an autism diagnosis and assessment of needs can offer an understanding of why a child or young person is different from their peers. It can open doors to support and services in education, health and social care, and a route into voluntary organisations and contact with other children and families with similar experiences (20). All of these can improve the lives of the child or young person and their family. Access to support should not however, be dependent on a diagnosis and should be guided by need.
- I28. NICE publish guidelines for recognition, referral and assessment for 0-19's and for adults. The guidelines include the following recommendations;
- Improving early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training.
  - Making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services.
  - Formation of a multi-disciplinary 'local autism team' who have the skills and capabilities to carry out an autism diagnostic assessment, and communicate with children and young people and adults with suspected or known autism, and with their parents and carers, and sensitively share the diagnosis with them.
  - People having a diagnostic assessment for autism should also be assessed for coexisting physical health conditions and mental health problems.
- I29. Additionally, the guidelines for recognition, referral and assessment for 0-19's recommend;
- An autism diagnostic assessment should be started within 3 months of the referral to the autism team.

### **Where we are now**

- I30. Earlier identification and diagnosis among CYP has been highlighted by stakeholders as a local priority, since early intervention may improve long-term outcomes (21).
- I31. Demand currently exceeds capacity and waiting times have been lengthening inappropriately. Added to this, the current process is not currently NICE compliant so the pathway needs significant revision.

- I 32. This position has led to a number of workshops and 'listening events' with parents and commissioners about how the needs of CYP, particularly those seeking an assessment and diagnosis without specific mental health needs, can best be met.
- I 33. Some local stakeholders are concerned that there is a lack of awareness among local staff and residents around the routes to diagnostic assessment for adults. This may prevent adults receiving appropriate assessment and support. A lack of post-diagnostic support was also raised during stakeholder engagement.
- I 34. Stakeholders have fed back that access to support should be on the basis of need and there should be wider awareness that you do not have to wait until a diagnosis has been made to access support.
- I 35. Additional opportunities to promote equality in recognition, referral and diagnostic services include taking steps to reduce the risk of under-diagnosis in females and considering the needs of people from BAME backgrounds.

## **Where we want to be**

Merton is committed to being an autism-friendly borough in which:

- I 36. All people are treated with sensitivity and respect by staff with the right skills and understanding and are able to access universal and other services appropriately.
- I 37. Assessment takes place in a timely manner, particularly for children, where effective early intervention may improve long-term outcomes.
- I 38. Pathways to autism assessment, diagnosis and support are clear, published and equally accessible to all residents where needed.
- I 39. Assessments are efficient and high-quality, conducted by multi-disciplinary teams, build on assessments which have already been conducted and meet NICE quality standards (QS51).

## **How we will get there**

In the first year we will:

- I 40. Work together to redesign local referral, assessment and support services to meet the needs of children and young people (and their parents or carers) who may need a diagnosis of autism.
- I 41. Create an assessment, diagnosis and support pathway for CYP 0-18 year olds, which is easily understood by referrers, parents, and (as appropriate) by children and young people, where assessment and diagnosis is available to those who need it but not a requirement to accessing support.
- I 42. Promote autism champions in all education settings to raise awareness amongst staff, enable early identification of autism and ensure that staff provide appropriate support.
- I 43. Raise awareness of the diagnostic pathways for adults with autism through a published pathway and training of professionals.

Over the life of the strategy we aim to:

- I44. Ensure the newly designed pathway for CYP 0-19 is fully embedded, has sufficient capacity to meet demand and work towards quality that complies with NICE guidelines.
- I45. Audit the new pathway against NICE autism quality standard (QS51), using this as a tool for continuous quality improvement.
- I46. Use the SEN Quality Assurance framework to ensure that staff provide appropriate support.
- I47. Engage staff and clients of adult services to explore options for post-diagnostic support

## Theme 3: Involving & supporting people with autism

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### **Evidence for change**

- I49. Autism is a spectrum disorder, meaning that different people will be affected in different ways, and therefore will require differing levels of support throughout life. For example, some CYP may only need help to understand a diagnosis, others may need a one-off service, whereas others will need more enhanced support at various ages, stages, transitions or life events. A small number will need on-going intensive education, health and social care support.
- I50. The 2014 Care Act states that local authorities must involve individuals (including those with autism and their carers) when carrying out certain care and support functions in respect of them, such as when conducting needs or carers assessments, preparing care and support, or support plans.
- I51. Employment among adults with autism is low nationally (1), and supporting adults with autism into training and employment is a key priority highlighted in statutory guidance and NICE guidelines. In 2017, fewer than one in twelve Merton adult social care users with autism were recorded as being in any type of work, including unpaid and paid work.

### **Where we are now**

#### *Supporting CYP through education, health & social care*

- I52. Merton's CYP with autism attend different types of education provision as appropriate for their needs. Certain types of specialist provision are only available out of borough. For example, a small yet significant group of CYP are in residential placements, which may be for education, health and social care needs, these provisions are out of borough and are often independent establishments. In line with Merton Council's Special Educational Needs and Disabilities (SEND) place planning, keeping CYP closer to home is a key priority for the borough.
- I53. The current SEND Placement Planning is taking into account the increase in autism and we are expanding capacity in both Cricket Green and Perseid schools and reviewing our ARP's with the view of expansion.
- I54. The importance of life skills training for CYP with autism is recognised. Such training can help people with autism manage unknown situations, in turn enabling them to live more independently, particularly after they transition into adulthood.
- I55. Some CYP with autism will meet the criteria for a Short Break. There are different levels of Short Breaks to meet the different needs of CYP with a disability and their families/carers which include Universal, Targeted and Specialist Services. Merton's Short Breaks Services Statement can be found on the Local Offer.

#### *Supporting adults through education, health & social care*

156. The majority of adults with autism in Merton will have needs that do not reach the threshold to receive adult social care support. Stakeholder engagement identified the need to consider opportunities to support all adults with autism to live independently and participate in society, regardless of their eligibility for adult social care. This includes wider aspects of life such as employment services, social and leisure activities, peer support and advocacy, and appropriate physical environments. Support in these areas also contributes to a preventative approach, increasing resilience and independence, with the aim to reduce demand for social care and crisis intervention.
157. Stakeholder engagement has highlighted the need to improve the social care needs assessment pathway for adults with high functioning autism, in order to improve the experience of those waiting for assessments and strengthen efficiencies in the referral and assessment process. Stakeholders have identified the need to clarify responsibilities of different teams.
158. Merton Council Adult Social Care service supports a number of adults with autism in residential care. Concerns have been expressed that there may be an over-reliance on residential support, which may limit the individual's ability to live independently and participate in social and family life. In January 2017 this represented the largest social care cost among service users with autism (excluding the cost of professional support).
159. An Autism Trust Lead at SWLStG works to ensure CYP and adult mental health services are autism-friendly. Every clinical team in the trust has an 'Autism Champion' with responsibility for raising awareness of autism among staff and ensuring the individual needs of people with autism are taken into account during their care. In addition, the Trust has a system for making staff aware when a person with autism is under their care to ensure reasonable adjustments are made.

### *Supporting adults into employment*

160. A key challenge for people with autism seeking employment has been identified as a lack of understanding among employers of the positive impact people with autism can have in the workplace. Suggested approaches to address this include engaging local employers and promoting autism awareness training, utilising the new Better Working Futures programme and promoting the government's Disability Confident scheme among local businesses.

### *Wider settings that support CYP & adults*

161. Merton's libraries and voluntary sector provide wider social and educational opportunities that can support people with autism to live independently and participate socially. Many stakeholders have suggested it would be valuable to build on or expand existing services to increase the breadth and capacity of support available for CYP and adults with autism. Suggestions include expanding peer support and advocacy networks such as Autism First, leisure activities, traineeships and volunteering schemes, alert-card schemes and social prescribing, which is currently being developed more widely in Merton.

### *Joined-up services*

162. A number of local services across a range of organisations support residents with autism. Local stakeholders have suggested more joined-up working between relevant organisations could help to improve awareness and access the range of services in a coordinated and timely way (see also Theme 6: Access to Information).

## **Where we want to be**

Merton is committed to being an autism-friendly borough in which:

- I 63. Merton CYP with autism are able to access appropriate, effective interventions in a timely manner, including in, and out of, school support.
- I 64. All residents with autism (diagnosed or undiagnosed) can access appropriate support to participate socially and live independently. This includes ensuring autism-friendly leisure and social opportunities are available, supporting adults into training and employment, and preventing people going into residential care where possible.
- I 65. Residents with autism are involved in the planning of their own support and care, and actively involved in co-creating local services.

## **How we will get there**

In the first year we will:

- I 66. Develop a plan for communication and engagement with people with autism over the life-course of the strategy, which links with existing forums e.g. the SEN user voice forum.
- I 67. Regularly engage and seek feedback from people with autism on the priorities within this strategy, and its implementation to frontline services.
- I 68. Finalise and publish a protocol outlining social care needs assessments of adults with 'high-functioning' autism.
- I 69. Develop a support offer for people with autism and complex needs, with early co-ordinated multi-disciplinary support, including transition from children to adult services.
- I 70. Promote the new South London partnership 'Better Working Futures' programme, which helps people with a disability or those who have been out of work for a period of time to find and maintain work.
- I 71. Promote the government's Disability Confident scheme among local organisations and businesses.
- I 72. Work with the voluntary sector to develop a support offer for adults with autism with intermittent, lower level needs. This may include advocacy and advice services, peer support, volunteering programmes, social prescribing etc.
- I 73. Increase the number of places within Specialist Maintained schools and additionally resourced provisions so that CYP with Autism can be educated locally.

Over the life of the strategy we aim to:

- I 74. Promote co-production amongst organisations re-commissioning or delivering new services that support people with autism, and take steps to promote equality.
- I 75. Encourage relevant services, including health services, education settings, libraries and transport providers, to consider how their physical environments may be improved to better meet the needs of people with autism.

176. Ensure there is equal access to housing options for people with autism.

## Theme 4: Preparing for adulthood

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### **Evidence for change**

177. Supporting young people as they prepare for adulthood, including those who transition between children's and adult services is a key priority nationally and locally. Preparing for adulthood is however a recognised challenge. Differing eligibility criteria between children's and adult services is believed to contribute to some of the difficulties that can arise.
178. Advanced planning and coordination of care, is a means of ensuring young people's needs are identified and, where appropriate, plans are put in place to meet these needs as young people move into adult life. However, the majority of CYP with autism in Merton will not be eligible for adult social care services, and transition planning needs to focus on the development of independence as young people move towards adulthood.
179. NICE set out a number of key recommendations in relation to those young people who are eligible for transition to adult services. These include:
- Local autism teams should ensure that young people with autism who are receiving treatment and care from child and adolescent mental health services (CAMHS) or child health services are reassessed at around 14 years to establish the need for continuing treatment into adulthood.
  - If continuing treatment is necessary, make arrangements for a smooth transition to adult services and give information to the young person about the treatment and services they may need.
  - As part of the preparation for the transition to adult services, health and social care professionals should carry out a comprehensive assessment of the young person with autism.
  - Involve the young person in the planning and, where appropriate, their parents or carers and provide information about adult services.

### **Where we are now**

180. The current provision of transition assessments for young people with an EHCP, or CYP known to the council's Children with Disabilities (CWD) Social Care team are detailed in the 'current services and access to support' section of this document.
181. Most young people with autism will not be eligible for adult social care services. As such, stakeholders feel that a key role of transition planning needs to be to enable people with autism to make informed choices as they move from children's to adults services.
182. Local stakeholders have identified that transition planning needs to have more of a focus on developing independence, through post-16 education opportunities, life skills training, travel training and housing support. Some examples of this kind of support already exist in Merton and are detailed in section 2, page 20.
183. Engagement identified that young people felt that it is easy to pigeon-hole young people with autism into specific courses or programs designed for SEND and this is sometimes limited in its offer. They felt more should be done to either increase the offer of subjects available in SEND provisions or further enable inclusion into mainstream courses.



## **Where we want to be**

Merton is committed to being an autism friendly borough in which:

184. Preparing for adulthood is a priority, and there are systems in place to ensure young people's needs are met as they move into adulthood. This should be the case whether or not the person with autism has social care needs.
185. There will also be a focus on supporting independent living, maintaining good health in adult life, and participation in society.
186. CYP with autism and their families and carers feel well informed regarding the transition from children's services to adulthood including the difference in eligibility criteria between children's and adult services, and are given advice on where to go to access further information about services available to them.
187. There are a range of services available and published in our 'local offer', to support CYP as they prepare for adulthood, and these services are easily accessible. Examples include life skills development, housing support and support with employment.
188. The expectation is that the EHCP will serve as the coordinating plan for young people with the highest levels of SEN up to the age of 19, by which time planning for their adulthood in terms of employment, care, health and community involvement should be secure. Between the ages of 16 and 19 the SEN team will identify education and training outcomes that support employability. Some of these outcomes may need to continue after the young person reaches the age of 19.
189. As young people with an EHCP move into adulthood it will be important to support their aims for employment and training, for independent living, for good health and community involvement.

## **How we will get there**

In the first year we will:

190. Maintain our ambition for all CYP with special educational needs and disability and recognise the importance of ensuring a smooth transition to adulthood for such children and young people.
191. For those with the most complex needs, we will continue our commitment to providing an integrated approach across education, social care and health to ensure a smooth transition into adult services.
192. Ensure transition assessments are structured and use a framework such as the national *Preparing for Adulthood* framework.
193. Ensure assessments involve the CYP and their families, and provide clear and comprehensive information to enable CYP and their families and carers to make informed choices as they move from children's services to adulthood.

Over the life of the strategy we aim to:

194. Develop a new programme of work experience within the council for vulnerable cohorts, including those with autism.
195. Work with further education colleges to increase understanding of the needs of CYP with autism in further education and to improve their access to support.
196. Work with schools, libraries and adult education to explore their potential for providing more life skills training for young people with autism e.g. interview training, extended work experience opportunities, financial management training and cooking classes.

## Theme 5: Think Family: involving & supporting families & carers

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### **Evidence for change**

197. *Think Autism* highlights that 'Local Authorities should ensure that their local Autism Strategies are linked to local carer's strategies (or equivalent). Involvement of self-advocates and family carers directly is essential to support a joined up approach across the strategies.'
198. The availability of in-home support that complements parenting programmes and in-school services is a priority area for local families and carers and other key stakeholders. Interventions such as video interaction guidance (VIG) and outreach services can support people with autism and families and carers in their home and outside of the school day, thus widening support.
199. Merton CCG, in partnership with Merton Mencap, has recently undertaken a review of the views of parents and carers of CYP with autism on family support needs. The results of this work will inform future commissioning.

### **Where we are now**

200. Local engagement has highlighted that families and carers would like to be more involved in decision-making about the care and support their loved ones receive, and contribute to shaping local services. This would enable them to feel reassured that their relatives will receive high-quality long-term support and mean local services are designed with the needs of people with autism, and their families and carers, at the centre.
201. In Merton several parenting programmes and child development programmes help parents and children with autism to interact and develop communication and social skills. This includes universal, targeted and specialist support services delivered in a range of settings (Children's Centres, childcare, early education provision and the family home). Parents and carers did however feel that parenting programmes need to be more widely available, recognising that parental understanding is key to improving outcomes for children with autism.
202. Stakeholders felt there is a need to recognise the emotional challenges associated with being a parent/carer of someone with autism, and the impact on the wider family. It was suggested that counselling or peer-support should be promoted and utilised to address these needs.
203. Families and carers value the opportunity for short breaks, and feel there is a need locally for a better continuum for support.
204. A number of voluntary sector services support families and carers by fostering peer networks through which members can support and learn from each other. Family and carer representatives have emphasised the value these peer networks offer, and have suggested families and carers would benefit from greater access to peer support and advocacy.
205. Families and carers also feel a key priority is having access to clear, comprehensive, up-to-date information about the local services and resources available. This is addressed in Theme 6: Information.

206. Stakeholders also noted that some families and carers from BAME backgrounds may face additional challenges due to varying levels of knowledge and understanding of the condition, stigma and difficulties accessing services and information.

## **Where we want to be**

Merton is committed to being an autism-friendly borough in which:

207. Families and carers of people with autism are informed and involved in making decisions about the care and support of their loved ones and contribute to designing local pathways and services.
208. Families and carers have ready access to information, advice, advocacy and peer support networks.
209. Safe and high-quality support services for carers and families are available (subject to assessed needs) and parents are guided to those that best meet their needs.
210. Wherever possible interventions/programmes are evidence based to ensure effectiveness of the support offered to parents.

## **How we will get there**

In the first year we will:

211. Produce clear information about local parenting support as part of the 'local offer'.
212. As part of the development of the CYP 0-19 assessment, diagnosis and support pathway, we will work with partners to identify resources to increase the availability of parenting programmes on offer in the borough-particularly for those with children over 8 years old.
213. Promote support available to carers of adults with autism and the 'Thinking Ahead' plan.
214. Promote co-production amongst organisations re-commissioning or delivering new services that support families and carers of people with autism.

Over the life of the strategy we aim to:

215. Explore opportunities for improving the availability of counselling and emotional support for parents and carers of people with autism. This could include raising awareness of the Merton IAPT service or supporting autism champions to facilitate peer support groups for parents.
216. Look for opportunities to increase training for staff in evidence based interventions, such as 'video interaction guidance' (VIG).

## Theme 6: Access to information

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### **Evidence for change**

217. Statutory guidance states; 'It is important that parents, young people and adults with autism can access information that is relevant to them to help them make choices about the type of support they can receive.' (12)
218. In addition, Section 4 of the Care Act 2014 states that 'it is important that all people with autism, whatever their level of need, can easily access information in their local area about what support from peers, charities or other community groups is available.'
219. For staff working in local services, better information may assist them to make appropriate referrals and more effectively support people with autism. This applies to professionals working in health, education, social care and the criminal justice service, who cite access to information as a key priority, as well as staff who may interact with people with autism in wider settings, such as transport and local businesses.

### **Where we are now**

220. Following SEND reforms resulting from the Children and Families Act 2014 and changes to the SEND code of practice 2015, Merton Local Authority provides the 'local offer', an online resource containing information for residents, families, carers and key stakeholders about the local services available for CYP with special educational needs and disabilities.
221. A wealth of local knowledge exists among Merton staff and residents, and facilitating information sharing could benefit many people affected by autism in the borough, particularly parents of children newly diagnosed.
222. There are a number of valuable services and resources available for people with autism and their families and carers in Merton. However, stakeholders have identified the need to improve access to clear, comprehensive information about these services and how they can be accessed.
223. It is possible to search for autism-specific services on the 'local offer' website, however there is a need to ensure the information in the 'local offer' is easy to understand, up-to-date and that local people know it exists and how to find it.

### **Where we want to be**

Merton is committed to being an autism-friendly borough in which:

224. Merton staff and residents can access easy to understand, comprehensive, up-to-date information that is available via a single location online (as well as other formats where appropriate).
225. Relevant staff and residents know where to go for information.
226. Key groups, including people with autism and family/ carer organisations, can share their local knowledge and resources with the community.

## **How we will get there**

In the first year we will:

227. Develop an all-services, electronic information hub to provide a single place for information about local services and resources relevant to autism, including the local SEN offer.
228. When producing information, stakeholders will consider its accessibility in terms of clarity (easy-read), whether translations into non-English languages are required, and whether cultural factors have been taken into account, seeking to ensure information is widely accessible.

Over the life of the strategy we aim to:

229. Hold an 'autism fair' to promote autism-friendly services and activities in the borough and increase wider awareness.
230. Explore opportunities for a system to enable key groups, including people with autism and their families/ carers, to share local information with the community. This may involve partnership working with local voluntary sector organisations.

## 4. Governance and delivering the strategy

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231. A time-limited Merton Autism Steering Group, or similar, will be established to oversee the strategy and implementation of an action plan. A range of agencies will be represented on the Steering Group including senior commissioners, managers and practitioners, as well as people with autism and families/ carers.
232. An action plan has been developed for the life of the strategy and reviewed annually. This sets out timescales and leads for implementing actions and expected benefits and outcomes.
233. The Steering Group will monitor progress against the action plan, and report to Merton Children's Trust Board and the Health and Wellbeing Board.
234. The delivery of the strategy is based on working in partnership to use resources within the system more effectively in order to achieve our ambitions to develop *'an Autism friendly borough, where people with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them'*. We will also look to enhance delivery by seeking opportunities to lever in additional resources to the borough.

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## Glossary

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ARP	Additional Resourced Provision	School which has been given extra funding to support children who have additional learning needs, including speech, language and communication difficulties.
ASC	Autism Spectrum Condition	
ASD	Autism Spectrum Disorder	
Autism Champion		Staff member or person who has been given autism training and can cascade this learning to a wider group.
BAME	Black, Asian and Minority ethnic	used to refer to members of non-white communities in the UK
CAMHS	Child and Adolescent Mental Health Services	CAMHS are the NHS services that assesses and treat young people with emotional, behavioural or mental health difficulties.
Care pathway		A 'Care Pathway' describes the process of best practice to be followed in the care and support of a patient or group of people with a particular condition.
CBT	Cognitive Behavioural Therapy	Cognitive behavioural therapy (CBT) is a talking therapy that can help manage problems by changing the way people think and behave. It is most commonly used to treat anxiety and depression, but can be useful for other mental and physical health problems
CCG	Clinical Commissioning Group	Clinical Commissioning Groups (CCGs) were created following the Health and Social Care Act in 2012, and replaced Primary Care Trusts on 1 April 2013. They are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area.
CWD team	Children with Disabilities team	The Children with Disabilities service supports children up to the age of 18 who have learning disabilities, a physical or sensory impairment or who have particular mental health difficulties
CYP	Children and Young People	
Diagnosis		Identification or recognition of a disease or condition

EHCP	Education, Health and Care Plan	An education, health and care plan (EHCP) is for children and young people aged up to 25 who need additional special educational provision to meet their special educational needs than is from SEN support.
High-functioning autism		High-functioning autism (HFA) is a term sometimes applied to people with autism who are deemed to be cognitively "higher functioning" (with an IQ of 70 or greater) than other people with autism. High-functioning autism and Asperger syndrome are often used interchangeably.
Life course		A person's whole life
Local offer		Information about support and services for children and young people with Special Educational Needs and disabilities and their families
MAOS	Merton Autism Outreach Service	Merton Autism Outreach Service (MAOS) supports the inclusion of pupils with Autism Spectrum Disorder (ASD) and Social Communication Difficulties in mainstream settings.
NAS	National Autistic Society	The leading UK charity for autistic people (including those with Asperger syndrome) and their families.
NICE	National Institute of Health and Care Excellence	The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care
Reasonable adjustments		Employers have a duty to change their procedures and remove barriers that people with disabilities could face. The Equality Act 2010 calls this the duty to make reasonable adjustments
SaLT	Speech and Language Therapy	The care, support and treatment for children and adults who have difficulties with communicating, eating, drinking and swallowing.
SEND	Special Educational Needs and Disabilities	
SWLStG	South West London St Georges Mental Health Trust	NHS mental health trust
VIG	Video Interactive Guidance	A tool to enhance communication and relationships by recording interactions and reflecting on the positive attributes.