

# Children and young people with autism spectrum disorder

## Case for change and recommendations for London

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## **Executive Summary**

This document is intended as a guide for Healthy London Partnership when considering a programme to support commissioners and providers in delivering better care for children and young people with autism spectrum disorder and their families and carers.

Autism spectrum disorder, or autism as it is more commonly known, is a developmental disability that affects how people communicate with people and experience the world. Diagnoses are on the rise and it is estimated that approximately one in every 100 children in the UK has autism. It is thought that for every three children with a diagnosis of autism there are another two children who have the condition but have not been given a formal diagnosis.

An increase in diagnosis rates has led to an increased focus within national programmes and on the governmental agenda, however children and young people (CYP) and their families are still struggling to access diagnostic and support services across the country.

CYP with autism and their families are subject to health inequalities such as access of diagnostic and support services and 'diagnostic overshadowing' where other physical health concerns are put down to their diagnosis of autism. Within education, children with special educational needs such as autism are almost seven times more likely to be excluded from school than children with no additional needs.

Healthy London Partnership (HLP) CYP Programme undertook a project aimed at further understanding the issues that CYP with autism and their families face in London and to recommend how these issues can be addressed on a pan-London level. We carried out engagement events with parents, spoke with commissioners, providers and managers and undertook a mapping exercise in North West London to do this.

Families told us that waiting times are too long to get a diagnosis; it is often difficult to access support during this time as well as once a diagnosis has been made and that there is sometimes a lack of understanding from health professionals of how to manage autism, making visits to hospital more stressful. Commissioners also told us that there is limited support for families; multiple and confusing diagnostic pathways and long waiting times as services cannot keep up with demand. Service mapping helped to identify some areas of good practice across London and elsewhere and this should be harnessed and shared on a wider scale.

Across London, work can begin to create a joined up vision with health, social care, education and the voluntary sector for CYP with autism and their families. It has been recommended that at a pan-London scale, HLP could facilitate events to share best practice across London, support the development of autism training for health professionals, design standardised family support guides for roll out across London, help to facilitate stronger relationships between the education system and support commissioners to improve and develop local pathways.

## **Background information**

The National Autistic Society describes autism as a 'lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them'.<sup>1</sup> Autism, also known as autism spectrum disorder (ASD), is a spectrum condition meaning it affects people in different ways. People with autism may experience differences and impairments in social interaction and communication, together with restricted interests and repetitive and rigid behaviours, which often have a lifelong impact. People with autism also frequently experience a range of learning, language, cognitive, medical, emotion and behavioural problems. These can encompass the need for routine and difficulty understanding other people's intentions, feelings and perspectives.<sup>2</sup>

Although autism is not a learning disability or a mental health problem, mental health difficulties are common among people with autism and approximately one in three adults with a learning disability also have autism.<sup>3</sup> The spectrum nature and complex co-morbidities that autism often brings can leave people with autism and their families feeling isolated, under supported and struggling to manage.

Over the last 30 years, there has been a 25-fold increase in the diagnosis of autism and it is estimated that over 1% of the UK's population are autistic, with around 700,000 people on the autism spectrum living in the UK today.  $^4$ 

The Government has responded to the increasing diagnosis rates, with The Autism Act 2009 binding them to produce a strategy for adults with autism. In 2010, the first autism strategy for England, *Fulfilling and rewarding lives,* was published with the vision to ensure that 'all adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them'.<sup>5</sup> The strategy was updated in 2014 and renamed *Think Autism,* which expanded on the original themes as well as identifying new key proposals.

#### What about children and young people?

It is estimated that approximately one in every 100 children in the UK has autism, with four times as many boys being diagnosed than girls.<sup>6</sup> <sup>7</sup> Although diagnosis rates have increased over the years, many children with autism still remain undetected. A study led by Professor Simon Baron-Cohen of primary school children in Cambridge found that for every three children who have been diagnosed with autism there are two more who have the condition but have not been given a formal diagnosis.<sup>8</sup> This would mean that there are an additional 300,000 children in the UK who have not yet been identified.

The National Institute for Health and Care Excellence (NICE) recognised the need to develop specific clinical guidelines for children and young people with autism and in 2011 published a clinical guideline for recognition, referral and diagnosis with a second clinical guideline in 2013 including the support and management of under 19s with autism spectrum disorder. <sup>9 10</sup>

The last 6 years have seen numerous national programmes and policies to help transform the way in which children and young people with autism should be treated. The challenge arises as everybody's business becomes no-one's priority and this needs to change. Other programmes and reports that cover or are relevant to children and young people with autism include:

#### The Children and Families Act 2014 <sup>11</sup>

- Reform of the special educational needs and disability (SEND) system, covering education, health and social care, giving children, young people and their parents greater control and choice up to 25.
- Children who have SEN should have a single assessment, an Educational, Health and Care Plan and the option of a personal budget.

#### National Standards Framework for Children, Young People and Maternity Services <sup>12</sup>

- The Department of Health Standard for Disabled Children and Young People and those with Complex Health Needs (2004) sets out the government's quality standards for children who are disabled and/or those with complex health needs including those with autism spectrum disorders and/or learning disabilities.
- The standard promotes coordinated, high-quality child and family-centred services which are based on assessed needs, social inclusion and, where possible, the ability for families to live ordinary lives.

#### Transforming Care<sup>13</sup>

National programme jointly led by NHS England, the Care Quality Commission (CQC), Local Government Association (LGA), Health Education England (HEE), the Association of Adult Social Services (ADASS), and the Department of Health (DH) to improve services for people with learning disabilities and/or autism, who display behaviour that challenges, including those with a mental health condition.

#### These are our children<sup>14</sup>

- Published in 2017, this Department of Health commissioned review was led by Dame Christine Lenehan and focused on care and support for children and young people with complex needs involving mental health, learning disabilities and/or autism.
- Dame Lenehan makes 11 recommendations for government departments and partners at a national level on how to improve the system.

#### Five Year Forward View for Mental Health<sup>15</sup>

- Five year programme published in 2016 to transform mental health care in England.
- Vulnerable children feature within the 'Next steps' document with transforming care for those with a learning disability and/or autism lined up for a national programme.

#### Challenging Behaviour Foundation Early Intervention Programme<sup>16</sup>

- Department of Health funded project which aims to deliver better outcomes across the country for children with learning disabilities whose behaviour challenges.
- The project defines what needs to happen to increase effective early intervention and shares best practices.

#### The Westminster Commission on Autism – A spectrum of obstacles<sup>17</sup>

- Inquiry into access to healthcare for people with autism
- Identified a number of challenges to access including inadequate training of health professionals and poor understanding of autism. The report makes a number of recommendations and calls on the Government and NHS England to take action.

## What are the issues?

A survey of 264 parents and carers in 2014 highlighted the scale of challenges they face when caring for children and young people with ASD, both in relation to the behaviours and health problems but also when accessing adequate services for support.<sup>18</sup> Only 11% of respondents felt that NHS professionals understood their worries about the behaviour and healthcare issues of their child, and 70% of parents and carers had experienced 'diagnostic overshadowing', feeling that their child's symptoms were attributed to ASD, rather than being worthy of investigation with the potential for treatment. Almost all respondents (80%) had sought help privately.

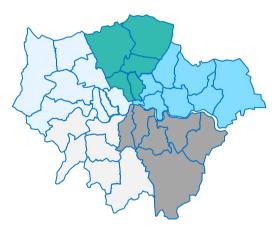
The challenges within education are also profound. Around 71% of children with autism are educated in mainstream schools however 60% of teachers in England feel that they have not had adequate training to teach children with autism.<sup>19 20</sup> Exclusions are common, and government statistics in 2014/15 show that pupils with an Education, Health and Care plan or a statement of special educational needs were almost seven times more likely to receive a fixed period exclusion than pupils with no identified SEN.<sup>21</sup>

The cost of supporting children with autism spectrum disorders in the UK is estimated to be £3.1 billion each year. <sup>22</sup> These costs are largely driven by direct non-medical costs, such as special education, and indirect non-medical costs, such as parental productivity loss.

#### **London Issues**

Healthy London Partnership Children and Young People's Programme has driven this work to identify what can be done on a pan London scale to improve the lives of children and young people with autism living in London, and their families.

A quarter of Londoners are children and young people, with this figure set to rise by 13% by 2022. In 2016, statistics from the Department of Education indicated that 205,039 children and young people in London were identified as having



special educational needs, of which 81% receive support in school. Autism Spectrum Disorder was noted to be the primary type of need for London pupils in 40,243 cases, which accounts for 19.6% of all pupils with special educational needs in London.<sup>23</sup>

Recent joint local area SEND inspections highlighted 'unacceptable' waiting times for some pupils to acquire a formal diagnosis for their autism spectrum disorder, delaying how quickly they are able to access support in a special school. It is known that these lengthy waiting times for assessment are present across London.<sup>24</sup>

There is a significant need for action within London to ensure children and young people with autism and their families are receiving the best support, care, and access to services.

### **Engagement with parents**

Navigating through the health, social care and education systems in London in order to receive the best care and support for a child with autism can be highly complex and frustrating. Healthy London Partnership ran two parent carer events and engaged with approximately 30 parents in East London to hear of their experiences.

Some key issues that were highlighted by parents and carers included:

- Some areas have no early intervention support programme for parents
- Lack of speech therapy available to children
- Long waits for ASD diagnosis with little or no support while waiting
- Long waits to access CAMHs, often this doesn't happen before crisis point
- Difficulty in accessing hospital services e.g. A&E departments and phlebotomy due to unsuitable waiting areas and lack of flagging that children have ASD
- No challenging behaviour support
- Some healthcare staff have a lack of understanding of how to manage children with a learning disability and/or autism

#### **Patient case study**

#### **Alex's story**

Mary Busk, a parent representative and founding member of the National Network for Parent Carer Forums (NNPCF) shared her story of looking for answers when her second child Alex was developing differently to normal and her families struggle to get a diagnosis and the relevant support.

Mary and her husband noticed quite quickly that Alex was not developing in the same way as their first child had and was very passive, not babbling or making sounds, had sickness and couldn't sit still. The family began to look for answers and as all parents would, relied on their GP and other health experts for support.



The family found themselves in a 'whole new world' faced with comments such as:

<text>

#### Alex's story continued...

Mary and her family were struggling to cope with Alex's behaviours as he began to get older and was able to run around and exhibit challenging behaviours such as biting and kicking family members. Not being able to access the correct support not only had a negative impact on Alex but also seriously affected the whole family. Alex was barely eating or sleeping and had other physical health conditions and Mary and her husband didn't know why.

Alex was eventually referred to the local child development team by a health visitor who was visiting Alex's younger sister. He was diagnosed with a 'speech and language disorder' following a uni-professional assessment.

Much like other desperate parents, Mary and her family paid privately for speech and language therapy as, despite Alex's diagnosis, they were unable to access the service. Diagnostic overshadowing is something that Alex was often subject to with his sickness passed off as being due to asthma and his eating difficulties ignored for a long period. He was eventually referred to GOSH feeding and eating disorders service who made reasonable adjustments and tailored their programme to meet Alex's needs.

Alex went to a mainstream primary school and was diagnosed with autism a year later when he was 6. This was followed by a learning disability diagnosis aged 10. Alex moved into a special school for secondary education as his needs were recognised as more than could be provided by a mainstream school.

Mary highlights a number of things that need to happen to help parents and families like her to receive the best care for their children:



#### **Engagement with commissioners and providers**

In order to understand how best to support commissioners to improve local provision for families, Healthy London Partnership conducted an online survey. The purpose of the survey was to establish what services were currently commissioned, whether they were NICE compliant and to understand areas of need. The survey was conducted online through survey monkey and a link was emailed to 90 CAMHS and children's commissioners across all London boroughs. 15 responses were received and 5 commissioners (as well as 1 provider and 1 voluntary organisation) completed the whole survey. It is likely this reflects the strong need for more focus and support for local clinical commissioning groups and local

authorities to develop ASD pathways and services. It could also be reflective of the lack of data that is held centrally for children and young people with autism, meaning commissioners were unable to gather the information needed to input into the survey. The questions within the survey were all mandatory and therefore this also may have been a stumbling block to responses.

Pre and post diagnostic support for children and young people and their families was noted as an urgent challenge for nearly all of the respondents to the survey, with pathway development and waiting times also high on the agenda (see table 1). Other key themes identified from the survey responses are collated below.

Challenges that are of the most urgent need of improvement within local areas	Percentage of respondents that outlined this as a problem
Pre and/or post diagnostic support	83%
Developing pathways	67%
Waiting times for assessment	50%
Transition and access to adult services	33%
Staffing	33%

#### **Key themes**

- Services are commissioned for ASD but often do not meet NICE guidelines
- Waiting times for assessments are often up to 18 months
- Diagnostic pathways are dependent on age and/or the presence of mental health concerns
- Not all areas carry out multidisciplinary assessments with some more focused on paediatrician or psychology input dependent on the pathway
- There are limited support services commissioned for children and young people and their families both before and after diagnosis
- Multi-agency meetings are held to engage with children's social care, education and the third sector
- Transition is a problem for young people who do not meet thresholds for adult social care and may be seen as 'high functioning'.

Healthy London Partnership also set up a number of ad hoc conversations with providers and commissioners around this subject and it was felt that overall the *key to success* for children and young people with ASD is *a joint vision from health, social care, and education.* This can often be lost across all of the systems as all face the current climate of financial pressures and organisational restructuring.

## **Service Mapping**

As part of the exploration, a mapping exercise was undertaken across North West London to understand the diagnostic pathways and support services available to children and young people with autism and their families. The results were variable. Some areas had well established pathways with multidisciplinary assessments and some had a comprehensive 'local offer' available online signposting to numerous support services.

The below key challenges were noted:

- Historical commissioning arrangements often meant that multiple diagnostic pathways have been formed causing duplication within the system and confusion for parents.
- Lack of support for CYP and parents and families during long waits for assessments as well as after diagnosis.
- Transition to adult services is often disjointed or non-existent.

A number of recommendations were highlighted for the region:

- Local services to be benchmarked against NICE guidance to better understand borough specific gaps and improvements that can be made locally.
- Ensure multiagency assessment is available in all boroughs in North West London.
- Develop better relationships with social care and education to provide a more joinedup approach for families.
- Develop regional support networks to extend a fair support offer for children, young people and their families across the whole of NWL.

Although this exercise was only conducted for 8 North West London boroughs, it is likely that the challenges across the rest of London will be similar. South West London have begun work on redesigning their pathways however what this will look like in practice is yet to be determined.

## **Best practice examples**

A number of exemplar services have been identified within London and beyond for children and young people with autism and their families. Below is a summary of these findings.

## **Diagnostic Services**

## Camden MOSAIC

#### Background

Making our Services All Integrated in Camden (MOSAIC) is the integrated service for disabled children, young people and their families from birth to 18 years of age, providing assessment, therapy and family support, including short breaks. The service provides multiagency assessment, diagnosis and support for disabled children and their families, including a specific Social Communication Assessment Service (SCAS) for ASD. The service contributes to better outcomes by supporting families to care for their disabled

children and for their children to remain living at home and as part of their local community wherever possible.

#### Aims

To enable families to help their children with complex needs to participate in family and community life by:

- Working with families to develop a greater understanding of their child's needs and to agree a family support plan that is reviewed over time.
- Making sure that relevant services are available to all children, young people and their families, based on their individual needs.
- Listening to and learning from the experiences of children, young people and their families who use the service.
- Being a community resource that shares specialist knowledge and skills with families, other organisations and the wider community.

#### Target patient groups

Children aged under 18 who reside in Camden and have a permanent and substantial disability including autism spectrum disorder.

#### The service model

Camden MOSAIC offers a diagnostic service for children with potential ASD. If the child is under 5 this is carried out by the child development team. Children of school age are seen by the SCAS.

Children who have difficulties with communication, imagination, relationships and flexibility may be seen by MOSAIC for a multidisciplinary SCAS assessment. Following the assessment a feedback meeting is held to discuss the diagnosis where parents are referred to the Early Bird plus programme and educational advice, support and interventions are discussed. If no diagnosis is given or the referral is not accepted, the team will continue to observe the child and give advice or refer to an alternative diagnostic referral.

#### Staffing

- Paediatrician
- Child Psychotherapist
- Clinical Psychologist
- Physiotherapist
- Child Psychiatrist
- Social Workers

- Family Support Worker
- Paediatric Dietician
- Occupational Therapist
- Speech and Language Therapist
- Specialist Health Visitor
- Family Therapist

#### Who can refer

A referral should be made by someone who knows the child's special needs well, such as their GP, school or another health professional.

#### More information

More information can be found on the CNWL website.

#### Lorna Wing Centre for Autism

#### Background

The National Autistic Society's Lorna Wing Centre for Autism is located in Kent and was the first centre in the country to provide a complete diagnostic, assessment and advice service for children, adolescents and adults with social and communication disorders throughout the UK. The centre started in 1991 in response to parents of children with autism having major problems trying to get a diagnosis or explanation for their child's behaviour. A second Lorna Wing Centre for Autism is opening in Essex in the near future.

#### Target patient groups

The Lorna Wing Centre will assess patients of any age.

#### The service model

Children, together with their parents or carers are seen for a whole day to undertake a full diagnostic assessment. Detailed developmental history is taken using the Diagnostic Interview for Social and Communication Disorders (DISCO). At the same time, an in-depth neuropsychological assessment is carried out with the child. Information is also collected from previous assessments and any other relevant sources.

The diagnosis and recommendation of needs is formulated into an in-depth report. The team considers interventions that are already in place and give guidance about new interventions for consideration by the family.

#### Staffing

- Consultant Specialist Educational Psychologist
- Consultant Clinical Psychologist
- Specialist Educational Psychologist

#### Who can refer

There are three ways that people are referred to the service for an assessment:

- Referral by an NHS medical professional (likely if the person has a complex presentation of difficulties)
- Commissioned referral by block contract with a public sector service
- Private referral

#### More information

More information can be found on the National Autistic Society website

- Business and Office Manager
- Administrator

## **Support services**

#### Kensington and Chelsea CAMHS Behaviour and Family Support Team (BFST)

#### Background

The BFST team was set up in 2005 as a new initiative initially funded by a two year government grant, but is now funded jointly by the Local Authority and the CCG. The BFST team is a specialist CAMHS service for children with autism and/or moderate to severe learning disabilities, who have emotional, behavioural or mental health problems. It is a community-based multidisciplinary team which has an outreach approach, working in partnership with parents and with all the systems around the child, including social work, education, paediatrics, respite services and mainstream CAMHS.

#### Aims

To meet the gap identified by the children's National Service Framework (2004) regarding CAMHS services for children with disabilities by extending and improving access to CAMHS for these children and their families

To provide a borough wide service that builds on existing initiatives (including generic CAMHS and local Child Development Services) and offer a specialist service for children with disabilities who present with challenging behaviours

To improve, stabilise and help manage challenging behaviour by:

- Sustaining educational placements
- Preserving family and peer relationships
- Minimising placements away from home
- Contributing to multi-agency co-ordination of family support
- Addressing transition issues

To contribute towards establishing an integrated service for disabled children in Kensington and Chelsea in line with the expectations and outcomes of Every Child Matters.

#### Target patient groups

Children aged 5-18 with a diagnosis of moderate to severe learning disabilities and/or ASD and Asperger's Syndrome.

#### The service model

The multidisciplinary service concentrates on emotional, behavioural and mental health needs with an intervention approach as a focus, as opposed to diagnostic assessment.

The team provides support to the whole family using an approach which allows for more outreach and indirect work/liaison and being involved for a longer period. They work in partnership with parents and with all the systems around the child, including social work, education, paediatrics, respite services and mainstream CAMHS.

This flexible and intervention focused service is highly regarded by parents not only for the support they provide to children but to the whole family. Post diagnosis support is an area that is often lacking and therefore this service is a great example of the effects that this support can have for everyone.

#### Staffing

- Two Consultant Clinical
   Psychologists / Managers (1 wte)
- Three Clinical Psychologists (2 wte)
- Speech and Language Therapist (0.2 wte)
- Trainee Clinical Psychologist (0.6 wte)
- Occupational Therapist (0.3 wte)
- Consultant Child and Adolescent Psychiatrist (0.1 wte)
- Assistant Psychologist (1 wte)
- Business Support Officer (0.2 wte)

#### Who can refer

Referrals can come from all avenues including health, education, social care and parents.

#### More information

More information can be found on the NICE website for shared learning.

## Brent Outreach Autism Team (BOAT)

#### Background

BOAT supports mainstream schools working with children and young people who have been diagnosed on the autism spectrum. The service is primarily school based with some advice and support offered to families.

#### Target patient groups

Children with ASD up to the age of 16 years who attend a Brent mainstream school, or up to 19 years if the young person attends a mainstream provision 6<sup>th</sup> form. BOAT also supports some out of borough placements where the Brent resident child has a Statement of Educational Need or an Education Health and Care Plan.

#### The service model

The service is tailored to facilitate a multi-agency approach with a range of support offered including:

- Observations of the child or young person in various settings
- Face to face discussions
- Advice on target setting with reviews and updates
- Modelling behaviour/approaches and positive interactions
- Support for students in understanding their diagnosis
- Peer support work
- Inset training for staff

- Facilitation of an online autism network for professionals
- Transition days to support 11 plus and 16 plus transition
- Post diagnostic parent training sessions
- Telephone and email support
- Home visits in exceptional circumstances

#### Staffing

- Autism Outreach Coordinator
- Autism Support Worker
- Three Autism Outreach Teachers

#### Who can refer

A referral can be made directly to the team by any professional working with the child or young person. Referrals cannot be accepted from parents.

#### More information

More information can be found on the Brent Local Offer

## Bexley Early Autism Service (BEAS)

#### Background

BEAS provides support for very young children who are recognised to be on the autism spectrum. It provides support tailored to individual children and families and is delivered by members of a trained and experienced team in the home and/or pre-school or nursery setting. This early intervention approach is crucial for the social, emotional and educational development of young children with complex social communication difficulties.

BEAS was highlighted as good practice on the joint local area SEND inspection in Bexley in 2016.

#### Aims

For children:

- To provide an individualised programme that focuses on developing communication, attention, early learning and play skills.
- To provide trained specialist support assistants to work both directly with you and your child at home and collaboratively with pre-school staff in the pre-school/nursery.
- To model effective strategies and approaches for you to follow on in your day to day life with your child.

For parents:

- To provide information to further their understanding of the autism spectrum.
- To enable them to develop effective strategies to address their child's daily needs.
- To support their role in promoting communication, attention, early learning and play.

For nurseries/pre-schools:

- To provide training and support for staff to enable them to further their knowledge and skill in working with children on the autism spectrum.
- To work regularly and collaboratively with preschool/nursery staff to achieve consistency across settings.
- To support communication between home and educational settings.
- To support the child's transition to reception at the appropriate time.

#### Target patient groups

Children aged between 2 ½ years and 4 years who have been identified as having complex social communication needs indicating, or who is diagnosed with, autistic spectrum disorder.

#### The service model

The service provides a programme of support for the family, their child and the preschool/nursery with an agreed number of sessions each week with a specialist BEAS team member. The programme will help the family to apply successful strategies in their everyday lives with their child. Regular casework meetings are held to monitor the programme, review the child's progress and to set new targets. The service can also provide specialist teaching materials.

#### Staffing

- Autism Outreach Coordinator
- Autism Support Worker
- Three Autism Outreach Teachers

#### Who can refer

A referral can be made directly to the team by any professional working with the child or young person. Referrals cannot be accepted from parents.

#### More information

More information can be found on the Bexley local offer

## Recommendations

Transforming care for children and young people with autism needs to happen on a systemwide scale as complex relationships and integrated working is required between health, social care and education to enable change. The recommendations below begin to address this on a pan-London scale.

Children and young people with autistic spectrum disorder come into contact with many aspects of physical and mental health services and therefore a separate programme of work for autism should be established within Healthy London Partnership Children and Young People Programme. Dedicated project management resource and clinical leadership will be required to enable implementation of the below recommendations with links to the local authority also essential.

Sharing best practice	<ul> <li>Run a London-wide autism event with attendance from clinicians, managers and commissioners from health, social care, education and the voluntary sector to share best practice across London.</li> </ul>
Training and support	<ul> <li>Support the delivery of autism training for health professionals to increase awareness and understanding across the system. Training should aim to build confidence in autism much like 'We Can Talk' is doing with mental health for physical health staff.<sup>25</sup> The training sessions should be co-produced and co-delivered with children and young people with autism wherever possible.</li> <li>GP specific training has been identified as an initial area to focus. This could be in the form of a toolkit that could be rolled out across all London GPs (some local changes would be needed).</li> </ul>
Supporting families	<ul> <li>Lead on the development of guides for families that increases understanding of ASD, what support is available to them, what they're entitled to and what to expect at an ASD assessment (local editions would be needed).</li> </ul>
Building better relationships	<ul> <li>Facilitate the strengthening of relationships with education and the voluntary sector to aid integration.</li> <li>Run regional events with attendance from health, social care, education, parents and carers with the aim of bringing everyone together to facilitate networks and to gain understanding of what support is needed in order to implement NICE guidance locally.</li> </ul>
Strategy and pathways	<ul> <li>Support the setup of local strategy groups across London to focus on pathway redesign and collaborative commissioning plans for autism (CCG, LA, specialised commissioners)</li> </ul>

## **Appendix 2 - References**

<sup>1</sup> National Autistic Society. *What is autism?* (June 2016) (<u>http://www.autism.org.uk/about/what-is.aspx</u>)

<sup>2</sup> National Institute for Health and Care Excellence. Autism. (January 2014) (<u>https://www.nice.org.uk/guidance/qs51/chapter/introduction</u>)

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<sup>5</sup> Department of Health. *Fulfilling and rewarding lives: the strategy for adults with autism in England*. (March 2010)(<u>http://webarchive.nationalarchives.gov.uk/20130104203954/http://www.dh.gov.uk/en/Public ationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_113369)</u>

<sup>6</sup> Green, H., McGinnity, A., Meltzer, H., Ford, T., and Goodman, R. The Office for National Statistics. *Mental health of children and young people in Great Britain, 2004.* (August 2005) (<u>https://digital.nhs.uk/catalogue/PUB06116</u>)

<sup>7</sup> Knapp, M., Romeo, R., and Beecham, J. *Economic cost of autism in the UK*. Autism. (May 2009) (<u>http://journals.sagepub.com/doi/pdf/10.1177/1362361309104246</u>)

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<sup>9</sup> National Institute for Health and Clinical Excellence. *Autism spectrum disorder in under 19s: recognition, referral and diagnosis.* NICE guideline (CG128). (September 2011) (<u>https://www.nice.org.uk/guidance/cg128)</u>

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