



## **All Age Autism Strategy**

**2016-2021**

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## **1. Introduction and background**

Southwark is invested in supporting people with autism, families and carers for the full length of their lifetime.

Many people with autism and their families are socially and economically excluded, and services are currently unable to meet their range of needs.

The All Age Autism Strategy (the Strategy) for Southwark Council and Southwark NHS Clinical Commissioning Group (CCG) sets out our response to improve the outcomes and quality of life for children and adults with autism, their families and carers<sup>1</sup>.

Over the past 18 months, we have been talking to people about autism. This has included people with autism and their families and carers, professionals who diagnose and/or support people with autism, and organisations that support people with autism and their families and carers.

We have asked what improvements or changes need to be made to improve the services and support for people with autism to ensure they lead fulfilling and active lives and achieve their full potential.

With the support of an external consultant, we have looked at our local services, listened to what people have told us and identified national best practice. The Strategy has developed as a result of this work, and provides guidance around the planning and provision of services for all people with autism.

Southwark will implement and monitor the autism strategy from January 2016. We will formally update the Strategy twice by 2021, but are continually seeking people's views about whether their needs are being met.

### **Autism**

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. Autism is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Asperger syndrome is a form of autism and people with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language<sup>2</sup>.

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<sup>1</sup> The term 'autism' is used in this document to mean all people with an autistic spectrum condition. A specific area on the spectrum will be referred to if relevant. The term 'behaviour that challenges' is also used as a definition of children or adults who can display a range of behaviours that sometimes challenge families, professionals and themselves. The descriptions of 'autistic people' and 'people with autism' will be used in this document, in reflection of different preferences of self-identification.

<sup>2</sup> The National Autistic Society. Available at: [www.autism.org.uk](http://www.autism.org.uk)

## Local and National Guidance

The Southwark Autism Strategy is influenced by national and local policy and research, with particular reference to the following:

### National Autism Strategy<sup>3</sup>

Autism services for adults are shaped by the National Autism Strategy for Adults, *Fulfilling and Rewarding Lives*. This has five main areas for development:

- Increasing awareness and understanding of autism
- Developing pathways for diagnosis and personalised needs assessment
- Improving access to support services in the local community
- Helping people with autism into work
- Enabling local partners to plan and develop appropriate services

The refreshed national strategy, *Think Autism* (2014), maintains a similar focus for development, with three new key proposals. These are:

- Autism Aware Communities - Think Autism community awareness projects will be established in local communities and there will be pledges/awards for local organisations to work towards
- Autism Innovation Fund - funding for projects that promote innovative local services and projects, particularly for lower-level preventative support
- Better data collection and more joined up advice and information services - including a new way of social care staff recording someone's condition as autism, and a commitment to make it easier for people with autism to find information online about how their local authorities are performing

### Statutory Guidance<sup>4</sup>

The statutory guidance has been published to ensure the implementation of the adult autism strategy. It tells local authorities, NHS bodies and NHS Foundation Trusts what actions should be taken to meet the needs of people with autism living in their area.

Latest guidance was published in March 2015, which replaced the previous guidance from 2010.

It clearly states that local authorities and the NHS:

- Should provide autism awareness training for all staff
- Must provide specialist autism training for key staff, such as GPs and community care assessors
- Cannot refuse a community care assessment for adults with autism based solely on IQ
- Must appoint an autism lead in their area
- Have to develop a clear pathway to diagnosis and assessment for adults with autism
- Need to commission services based on adequate population data.

As the guidance is statutory, local councils and local health bodies have a legal duty to implement it. Some actions must be done, and others should be carried out unless there is good reason not to do so.

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<sup>3</sup> Adult Autism Strategy (2014). Available at: <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

<sup>4</sup> Adult Autism Strategy Statutory Guidance (2015). Available at: <https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance>

### Care Act (2014)<sup>5</sup>

The Care Act aims to put people and their carers in control of their care and support, including introducing:

- A national minimum eligibility threshold for care
- The right to a personal budget for people and their carers who meet eligibility criteria
- New rights for carers, including a right to an assessment and support if they are eligible
- A duty for councils to consider the physical, mental and emotional wellbeing of people needing care, and to provide preventative services

### National Institute for Clinical Excellence (NICE)<sup>6</sup>

Guidelines

- *Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum* CG128 (2011)
- *Autism: The Management and Support of Children on the Autism Spectrum* CG120 (2013)
- *Autism: Recognition, Referral and Diagnosis of Adults on the Autism Spectrum* CG142 (2012)

Quality Standard

- *Autism* QS51 (2014)

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<sup>5</sup> Care Act (2014). Available at: <https://www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation>

<sup>6</sup> NICE Guidelines (2011-2014). Available at: <http://www.nice.org.uk/guidance/conditions-and-diseases/mental-health-and-behavioural-conditions/autism>

## **2. Development aims in brief**

Southwark has both short and long term goals. We will set targets from January 2016, and they will be monitored four times a year by the Learning Disability Partnership Board. We will also produce a progress report at the end of every calendar year, and make this available to residents.

### **Building on foundations**

We have identified a range of good autism practice across Southwark, offering some robust and innovative services. We will use our knowledge of these services, and explore other initiatives taking place nationwide, to ensure that existing good practice flourishes, and all services are of high quality.

A complete list of the actions we will take to achieve this can be found in section five of this document.

### **Priority short term aims**

- Clear and accessible diagnostic pathways for children and adults with autism, including post-diagnostic support
- All education, employment, health, social care, community, housing and criminal justice services have access to information about the needs of local people with autism, their families and carers
- All frontline staff have access to autism training, demonstrating good autism awareness and knowledge
- Services are developed with the full inclusion of people with autism, their families and carers

### **Priority long term aims**

- All staff providing services to people with autism have the necessary skills and training
- Equal access to specialist and universal services for people with autism, their families and carers
- A smooth, well-coordinated transition to adulthood for young people with autism regardless of eligibility for statutory services
- Creating autism friendly communities within the borough where people with autism are understood and supported
- Developing opportunities for new initiatives across education, employment, criminal justice, housing, community, social care and health services
- Training is delivered with the full inclusion of people with autism, their families and carers
- Services are commissioned to meet local needs, using accurate data collected from across organisations

### **3. Development aims in detail**

Historically the needs of people with autism without a learning disability or mental health need have been less well addressed. We want to ensure there are specialist autism services accessible to people with all levels of need, as well good autism knowledge and understanding in universal, learning disability and mental health services.

Key actions are informed by:

- Consultation with people with autism, families, carers and professionals
- Good practice from other localities in England
- The National Autism Strategy
- National Institute for Health and Care Excellent (NICE) Guidelines
- Local policies and plans.

Information about children and young people can be found in section a). Later sections also contain content relevant to their support and development.

#### **a) Children**

##### **Needs data**

*Aspiration: Southwark has comprehensive knowledge of the needs and numbers of children and young people with autism*

There should be good data recording and sharing in children's services across health, social care and education. This will help us to make sure children with autism are given the opportunities and support they need, and can be used when services are expanded or developed. Data should also be shared with adult services to assist with planning for future needs.

There are approximately 62,000 children and young people aged 0-19 living in Southwark with 36,000 children educated in Southwark schools. Identifying the precise number of children with autism is complex, as education settings support children from other boroughs as well as Southwark. Autism specialist services are also accessed by children with autism who live within Southwark but do not go to Southwark schools. However we are aware that there are currently 1,100 children and young people with a diagnosis of autism known to local services in Southwark, and many will be residents.

The incidence of autism in Southwark's children and young people is among the highest in England, and the number accessing local schools is increasing every year<sup>7</sup>. This may be due to an actual increase in prevalence, or professionals' better understanding of autism and a clear local diagnostic pathway.

This figure is a significant number of children and young people who may require a level of support in the future, whether from statutory or voluntary services.

##### **Actions**

- Improve collection, analysis and sharing of data between children's health, social care and education services
- Improve data sharing between child and adult services

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<sup>7</sup> Learning Disability Profile. (2013). Available at: [www.phe.org.uk](http://www.phe.org.uk)

## Assessment and diagnosis

*Aspiration: Southwark provides a timely assessment and diagnostic service, and offers a range of post-diagnostic support*

Children age 0-17 years with suspected autism are referred to the Autism and Related Disorders Clinic at Sunshine House, the Child Development Centre. The Clinic carries out assessment and diagnosis for children and young people with autism and other neurodevelopmental disorders. It is made up of a team of paediatricians, psychiatrists, psychologists, specialist social workers, speech and language therapists and others. Diagnosis is currently completed on average six weeks from the point of referral. There is no eligibility criteria for the service.

The diagnostic pathway for children receives good feedback from families and professionals, with high levels of diagnosis from referral, and quick assessment times, meeting the standards set by NICE Guidelines<sup>8</sup>.

During the autism diagnostic process, additional health professionals can be brought into provide further assessments for children. After diagnosis, children may be referred to other services including psychology, speech and language therapy and occupational therapy if they require further support.

When children and young people receive a diagnosis of autism, they are referred to the Autism Post-Diagnostic Support worker. Their role is to help parent carers understand their child's diagnosis and they can provide simple support strategies in the period before other services become involved. In addition they provide information about autism, can signpost to other services and offer emotional support. Support is not time-limited. The service has received very good feedback from families although capacity is currently limited due to resources<sup>9</sup>.

While there is some support available after diagnosis for children and families, we need to look at the capacity of existing services and identify gaps to ensure everyone is supported appropriately. Additional services could include further training for parent carers, increased access to speech and language therapy, psychological and support groups, and help for children and young people to understand social skills. Specialist autism guidance on sleep, nutrition, toileting and evidence-based interventions may also be required.

We want to make sure that autistic children and families have opportunities to share their experiences of diagnosis.

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<sup>8</sup> NICE Guideline. *Autism Diagnosis in Children and Young People*. Available at: <https://www.nice.org.uk/guidance/cg128>

<sup>9</sup> *Evaluation on the Autism Post Diagnosis Support service for the families of children newly diagnosed with autism/Asperger syndrome*, Southwark Children and Young People's Development Centre. (2012)

## **Actions**

- Ensure child diagnostic pathways deliver in line with NICE Guidelines
- Ensure all frontline healthcare staff (including GPs) are aware of diagnostic pathways and can refer appropriately
- Promote information about diagnostic pathways to local people and support organisations
- Identify gaps in post-diagnostic support and resources required to meet demand
- Identify data required from diagnostic services and share with health, social care and education services

## **Support and crisis services**

*Aspiration: Southwark has a range of preventative and crisis services to meet key risks*

Families with children with autism may need support for a variety of reasons. There should be a range of services with minimal wait for support. We recognise that where there are early intervention and low-level services, there is less demand for crisis support. However, crisis services should be available to access quickly when families and children are going through difficult situations. The development of a local crisis pathway will help to identify key support services and an appropriate response. All staff working in children's social care and health services should have access to the appropriate level of autism training and awareness.

We need to regularly ask people for feedback about the services they are using.

Southwark has good autism support for early years. The Early Years Autism Support Team is part of Southwark's Special Educational Needs Team. It is made up of autism support officers, speech and language therapists, an educational psychologist and a post-diagnostic autism support worker.

It works with pre-school children (age 0-5 years) with a diagnosis of autism, focusing on supporting learning and development in relation to communication, social interaction, self-help and independence. All children who receive a diagnosis through the Autism and Related Disorders Clinic are notified about the Team and placed on a waiting list for support.

The Team provides a parent training course called Next Steps to help families understand the diagnosis of autism. It also offers support at home and pre-school settings. This support is limited to a specific number of sessions. Training is also offered to early years practitioners and local organisations (such as HomeStart, KIDS Home Learning and the school transport team).

Local support for children older than five years is more fragmented although help at home or in education can be provided through social care, educational welfare, CAMHS and the SEN Team. Sunshine House, the Child Development Centre, provides access to various specialist support including a toilet training clinic, Makaton sign language workshops, occupational therapy, speech and language therapy and physiotherapy.

The Children with Disabilities and Complex Needs Team provides assistance to children and young people who are eligible for social care support. Clear information about access and eligibility should be widely available for families. Social workers should have knowledge and understanding of autism and the impact this can have on children and families.

The Child and Adolescent Mental Health Service (CAMHS) provides support for children and young people with mental health needs and/or behaviours that can challenge. Therapeutic interventions include individual, family and group therapies and behaviour modification advice. Waiting times and gaps in access need to be reduced, frequency of provision increased, and services available for children of all ages. CAMHS should run as a preventative as well as crisis service.

There are a range of social opportunities available for children and young people. The Camden Society runs after-school, weekend and holiday activities for young people age 12-19 years. The Tower Project has a youth service for young people with autism age 13-19 and is accredited by The National Autistic Society. Resources for Autism is a community organisation that runs after school and holiday clubs for children with autism age 8-19 years, as well as a youth group for autistic young people age 19-25 years. Southwark Autism Support, run by a branch of The National Autistic Society, also provides a good information and advice service for local families with a child of any age, and monthly parent carer meetings.

There are opportunities for us to increase the range of activities for children younger than 12, particularly those under five years old. In 2014, feedback from parent carers of children and young people showed 62% felt that there were not enough opportunities for their child to have a social life<sup>10</sup>. We would like to offer more autism-specific services, and better access to mainstream sports and social activities. This will require autism training and awareness for staff as well as funding for additional support workers.

The same consultation showed 59% of parent carers found it difficult to find out about activities or were not currently aware of any. The Local Offer is now available and provides lots of information about services and support. This, and other information sources, should be well promoted to families.

Salmon Youth Centre provides mentoring support for children and young people over the age of nine years (as well as a range of other activities and groups), including for children with autism. Mentoring and peer support are empowering and can increase positivity. Southwark will look at how this model can be used more widely and whether community services with experience supporting people with autism can assist.

We need to make sure that people are able to access the right support quickly. We can do this by having clear pathways and referral routes into services. Good communication between services and families will help families to be aware of the help available, and for children to be supported as they grow.

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<sup>10</sup> Focus Group Report: Autism in Southwark. (2014)

## **Actions**

- Map key risk areas for children and young people
- Develop a crisis intervention pathway for children and young people with autism
- Ensure professionals working in health, education and social care services for children have access to the appropriate level of autism training and awareness
- Identify gaps in preventative services and areas of development
- Ensure information about services and referral routes is promoted to families and organisations
- Identify resources and developments required to reduce waiting lists for services including CAMHS and the Early Years Autism Team
- Identify resources and developments required to increase capacity of Autism Post-Diagnostic Support Worker post
- Identify good practice examples of children and young people's activity/support groups running in other areas, and investigate local potential
- Provide autism awareness resources or training to mainstream children's activity groups

## **Safeguarding**

*Aspiration: Southwark prioritises the safeguarding and welfare needs of children and young people with autism*

The Southwark Safeguarding Children's Board manages safeguarding processes and policies for children in the borough. Multi-Agency Safeguarding Hubs (MASH) are a new initiative to improve communication across services and increase support for children at risk. The additional needs of autistic children and young people may mean that some are more vulnerable to safeguarding concerns. Safeguarding and child protection training should include the specific needs and vulnerabilities of children with autism, both with and without a learning disability.

When children with autism are subject to child protection plans, Southwark will ensure that they have access to appropriate advocacy and/or communication support, with people who understand any specific needs relating to their autism. The Safeguarding Children's Board should have oversight of the needs of children with autism, and make reference to specific recommendations in relevant policies and plans.

## **Actions**

- Local safeguarding and child protection training to include the needs of children and young people with autism
- Ensure appropriate advocacy and suitable representative training is available for children on child protection plans
- Identify autism-specific safeguarding resources and review suitability for local use

## Education

*Aspiration: Southwark provides a range of education provision and services to support children and young people to attend the setting they need*

Most children and young people in Southwark diagnosed with autism have a statement of Special Educational Needs (SEN)<sup>11</sup> and autism is the most common primary need listed on a child's statement (610 children)<sup>12</sup>. In addition, there are a further 210 children who are diagnosed with autism but do not have a statement of need. All statements are being replaced with Education Health and Care (EHC) Plans over the next few years. Families should have clear and comprehensive information about this process.

The number of school children with a diagnosis of autism is increasing every year, and the borough has a much higher number of 0-4 year olds than average in England or the rest of London. This youngest section of the population is projected to rise by 25% over the next 20 years<sup>13</sup>.

We aim to educate children and young people with autism within mainstream schools wherever possible. The Early Years Autism Team (part of the SEN Team) provides advice and training to early years settings. The Autistic Spectrum Disorder (ASD) Support Team works with mainstream and special education services for children and young people age 5-18 years (up to 25 years if still in education) to gain greater knowledge and confidence in supporting children and young people with autism. It does this by providing information, advice and training to school settings, supporting them to integrate pupils successfully.

Some children do require alternative or specialist education. Within the borough we have autism resource bases at five schools, one special school for young people with autism, and three schools for children with a range of learning disabilities. Demand for places is very high and there are not enough for all local children. Consequently a number of children are currently placed in schools outside of Southwark. This is not a satisfactory arrangement for children or their families, involving a lot of travel time, and decreasing access to the local community. These arrangements are also costly for us to support.

We recognise that there is currently a gap in the range of education provision at both ends of childhood, with not enough early years education for children with autism or further education for young people with autism age 16-25 years. We are aware that the demand for specialist provision is only likely to increase due to the predicted rise in population and rate of diagnosis of autism.

We have already started planning to address how more children can be educated in the setting they need, close to home and are working to establish a 0-25 pan disability pathway (which will include autism). This will include a review of specialist autism provision. The pathway should address the needs of children and young people whose education requirements are not currently met in Southwark, and help develop choice and availability of services and support.

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<sup>11</sup> About 80% of children with autism have a statement of SEN. *Communicating Better a Strategy for Children with Autistic Spectrum Conditions and their Families, 2009-2014*. Southwark. (2009)

<sup>12</sup> Buckel, M et al. (2014). Southwark Joint Strategic Needs Assessment

<sup>13</sup> Ibid

There is a wide range of information available to families about existing local education provision and services on the Local Offer website and Southwark Council website. This includes how to get an EHC Plan, how to challenge decisions, and how to get more support. Southwark Information Advice and Support (SIAS) can also assist parent carers to help identify local schools as well as providing information about EHC Plans.

Every school in Southwark has at least one child with autism. This shows the importance of ensuring that there is understanding, knowledge and experience of autism in every setting. The Early Years Autism Team runs an Introduction to Autism training course for early years practitioners several times a year and can also offer bespoke workshops. The ASD support team provides bespoke training to schools and colleges. All setting staff should receive autism awareness training so that they can provide a whole-school environment that is friendly for children with autism. Teaching staff with responsibility for SEN, and/or autism, and support staff working directly with pupils with autism, should have specialist autism training.

Southwark is already making key educational changes through the Special Education Needs and Disability (SEND) reforms. We are encouraging families and carers to have an active role in developing and evaluating these through the Local Offer website, and local forums such as Southwark Parent Carer Council.

### **Actions**

- Review existing autism education provision for age 0-25 years, and identify development actions
- Ensure information about the EHC Plan process is accessible and clear
- Consult with education settings, children and young people with autism, and parent carers to identify existing good practice, and understand current issues and concerns
- Incorporate actions into a pan-disability pathway for 0-25 years
- Encourage all education settings to have at least one module covering autism as part of staff induction (for every role)
- Identify existing autism training resources for schools available nationally and how these can be implemented locally
- Promote existing local autism training to setting staff
- Formulate a five-year plan to increase education staff training and skill development

### **Transition – specialist support, information, opportunities**

*Aspiration: Southwark provides a smooth transition between child and adult services and works with young people to achieve their aspirations*

Southwark recognises that young people moving from childhood to adulthood face considerable change in their lives. Where young people are eligible for health (including mental health) and social care, there should be clear pathways and guidance for young people transitioning between child and adult services.

The Transitions Team supports young people age 14 to 25 years old with disabilities (who are eligible for services) to move from child to adult social care services. The Team's focus is on increasing young people's independence and helping them to prepare for the future. This includes developing plans for leaving school, finding work, moving home or finding new interests. The Team works closely with health, education, housing and employment professionals, and young people have an annual review to see how life is progressing for them. Between April 2013 and March 2014, the Team supported 25 young people with autism.

There are many young people with autism who do not meet the eligibility criteria and cannot access the Transitions Team. However they may still require support during this life changing period to ensure they have the same opportunities and can reach their goals. Having the right support means that there is less risk of young people becoming isolated, developing mental or physical health problems, or requiring crisis interventions. We need to have a good range of services for young people of all levels of need, including those with Asperger syndrome.

Southwark Council has a number of general transition information resources for families and young people. These were created in 2010, and are available in hard copy and online. The content should be regularly reviewed and updated as appropriate.

Employment options are prioritised through this transition period. Careers and guidance services, such as Connexions, should receive autism training, and be aware of the specific needs of young people with autism. An increase in the support activities available for young people, regardless of eligibility, will also assist development with independence and life skills, as well as enabling them to build strong relationships.

Autistic young people who receive support from the Transitions Team have a person-centred assessment process that assists them to identify opportunities for paid and unpaid work they might want to pursue. This is helping to develop a pathway for young people with autism that involves appropriate training, work experience, education and other opportunities for development. Southwark special schools are also part of the local Increasing Employment group, and along with other local schools participated in the Increasing Employment Job Fair, ensuring the needs of young people with autism are represented.

### **Actions**

- Consult with young people with autism about their experiences of transition to identify development and improvement areas
- Increase range of activities available for young people age 14-25 years
- Develop a transition protocol to address the needs of young people with autism
- Provide autism training to transition, careers and guidance organisations
- Ensure clear, up-to-date, autism-friendly information and advice about transitions is available, particularly for young people not eligible for social care

## b) Lifelong care and support

### **Needs data – collection methods, sharing, quality and quantity**

*Aspiration: Southwark has comprehensive knowledge of the needs and numbers of people with autism*

To make sure we have enough services in Southwark to support people with autism to live fulfilling lives, we need to know how many people there are with autism and what help they need.

We know that people with autism make up at least 1.1% of the population nationally. If we apply that figure to Southwark, then around 3,229 people have autism. This is expected to rise by 35% to 4,359 by 2030.

There is no easy way to count the number of people with autism using our services because we don't always record that they have autism. Southwark Council's adult social care team has started to record when people have autism, but this will only count people who are eligible for social care support.

We have looked at how the different services record when people have autism:

- Adult social care – 100 people recorded to have autism and a learning disability and six people with autism receiving support.
- Guys and St Thomas' (GSTT) Learning Disability Team (health care) – recorded a similar number of people (108 people with autism and a learning disability, 12 people with autism)
- South London and Maudsley Mental Health Foundation Trust (SLaM) – the mental health service does not have a way to record when someone they work with has an autism diagnosis
- Local GP practices – do not have to keep an autism register
- Housing services – do not record when someone they work with has autism
- Employment support services – do not record when someone they work with has autism

We know that a significant number of adults do not receive any statutory support, but these current identified numbers are very low. When we have good information about our services and who they are being used by we are able to plan and commission well. Clear and consistent data collection, collation and analysis needs to be embedded as a fundamental practice across services for children and adults. This will help us to reduce gaps in services, and avoid unnecessary duplication of expenditure.

We will involve professionals, people with autism and parent carers in discussions about how to improve data collection and multi-agency partnership.

## **Actions**

- Progress Autism Multi-Disciplinary Team membership and meetings to further develop data sharing practices across relevant health and social care services
- Share and compare existing data from SLaM, GSTT, and Southwark Council
- Address data recording methods in services including social care, health, and employment, supporting the collection of more comprehensive data on the needs of people with autism
- Develop a reporting arrangement to ensure accurate and timely sharing of data between SLaM, GSTT and Southwark Council
- Include autism as an identified need when capturing information in primary care (GP surgery) data audits
- Identify and collect information on people living in residential placements in and out of borough, including NHS accommodation, and people resettled to local provision from long-term residential homes
- Identify group to provide oversight and scrutiny of data and development
- Identify other data collection practices, and consider implementation locally e.g. local autism needs register
- Undertake a full service mapping exercise to detail offer and identify gaps in provision
- Develop an action plan to address service gaps and form solutions
- Ensure any autism strategy/development group has representatives from housing, employment, criminal justice organisations, education, social care, health and education, people with autism and parent carers; representatives should demonstrate regular attendance and/or engagement

## **Access to statutory care services – assessment, eligibility, personalised care plans**

*Aspiration: Southwark has a clear pathway to services; services have good understanding and awareness of autism*

All adults with a diagnosis of autism can request an assessment for social care services. We know that if people can quickly access the support that they need, they can have an improved quality of life.

All social workers and care managers undertaking assessments for adults must have a clear understanding of the needs of people with autism and good knowledge of the condition. This is a requirement of the 2015 National Autism Strategy Statutory Guidance<sup>14</sup>. We need to support this by providing specific training for care managers and case assessors undertaking assessments for people with autism.

Information about assessments and the support provided by social care services is available online through Southwark Council website and the Local Offer website. Local disability organisations should have access to quality information about the local assessment process.

In Southwark, adults with autism are referred to the Contact Adult Social Care (CASC) team after diagnosis. This team is the single point of contact for adult social care in Southwark. The CASC team may link people with the Learning Disabilities service, Transition Team, community services, or provide information and advice. If people are eligible for services, a Care and Support Plan will be created with them, to identify how their needs will be met.

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<sup>14</sup> *Statutory Guidance for Local Authorities and NHS organisations to support implementation of the adult autism strategy.* (2015). Available at: [www.gov.uk/doh](http://www.gov.uk/doh)

Care and Support Plans should be person-centred and completed with comprehensive participation from the person involved, family, friends and carers<sup>15</sup>. A personalised plan should be based on an assessment of needs, taking into account the person's strengths, skills, learning ability, family and social context including:

- Any post-diagnostic support that the person and their family and carers need
- What interventions, support and timescales are most appropriate for the person; these include clinical interventions and social support, such as support in relation to education, employment or housing
- Preventative action to address triggers that may provoke behaviour that challenges
- Any further interventions for identified coexisting conditions

Plans should also include a risk management plan for people with behaviour that challenges or have complex needs. For young people under 18 years the plan should also include managing transition from child to adult services. We need to make sure that professionals involved in support planning have accessed autism training.

People with autism should be supported to achieve the outcomes that they want, not that have been determined by someone else. Processes for monitoring quality of life outcomes should include reference to autism, and demonstrate an understanding of autism needs.

### **Actions**

- Provide specialist autism training for care managers and social workers carrying out assessments of need
- Monitor take up of online disability awareness training module and promote necessity of completion to all staff
- Identify autism awareness training to roll out to social and health care staff involved in assessments
- Ensure professionals involved in care planning have received recent training in autism
- Monitor capacity and skills of the CASC team to ensure quality and quantity of support meets local demand
- Improve access to, and quality of, information about assessments (online and through other sources)
- Identify opportunities for including specific autism needs within existing quality of life monitoring systems
- Establish a formal process by which people with autism and their families are consulted with at least annually about their needs and quality of life; including monitoring of feedback to develop and improve services

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<sup>15</sup> The Care Act 2014 and NICE Quality Standard for Autism

## **Crisis intervention – management, response model**

*Aspiration: Southwark has a range of preventative and crisis services to meet key risks*

We know that if there is increased investment in low-level and early intervention services, crisis management is less likely to be required. Despite this, there will always be a number of people with autism who have difficulties coping in the community or in school. We want to make sure that they have the right support, so that they will not be at risk of being in contact with the Criminal Justice System, excluded from school or employment, suffer a breakdown of family relationships, experience increased involvement with mental health services, and/or becoming socially isolated.

We have recently created a permanent crisis response service for adults after a successful pilot. The Enhanced Intervention Service provides assistance to autistic adults and their families and carers, offering rapid, flexible, intensive assessment and intervention at times of crisis or potential family/carer breakdown. It also supports people to return to Southwark who are being supported outside of the area, and to stay within their community. The team works in partnership with speech and language therapists, community nurses and other professionals within the Guys and St Thomas' (GSTT) Adult Learning Disability Team to create appropriate, stable care environments.

Psychological and behaviour support professionals work with people with autism, families and organisations to improve peoples' quality of life, and ensure they are appropriately supported. To date, five people have returned to Southwark to live in their community, and there have been positive outcomes for all people that have been supported during points of crisis. People using the Service showed a significant improvement in quality of life, wellbeing, communication and behaviour<sup>16</sup>. The Service is also cost-beneficial, and helps increase partnership working across services so that we can provide a consistent response.

We will continue to evaluate the Service to assess how well it is working, and if we can use any learning for other age groups.

### **Actions**

- Map key risk areas for adults
- Identify gaps in preventative services and development areas
- Promote information about the crisis intervention pathway for adults with autism
- Monitor and evaluate ongoing impact of Enhanced Intervention Service

### **Carers**

*Aspiration: Southwark understands the needs and responsibilities of carers and provides a range of support services*

We know that with the right support and planning, the health and wellbeing of families and carers can thrive. If this is not in place, it can affect people's ability to continue in their caring role. This is particularly true of the growing number of older carers.

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<sup>16</sup> Findings from evaluation of service January 2014-March 2015, overseen by Southwark Council, SLaM NHS Foundation Trust, and Guy's and St Thomas' NHS Foundation Trust.

Southwark has a three year plan as part of our Carers Strategy. This references the needs of carers supporting people with autism, and sets out improvements and changes to local services. It also identifies services that eligible carers may be able to access, including flexible short break care, assistive technology, and telecare support. Southwark Council works closely with carer support services, including Southwark Carers Service and Southwark Parent Carer Council, to have a good understanding of local needs and demands.

Carer assessments are offered to all carers of people who use statutory services, including people with autism. This generally takes place alongside a community care assessment or an annual review for the person with autism's. Carers can also request an assessment of their needs in their own right through Southwark Carers. Southwark Carers is commissioned by Southwark Council to provide a range of support to all carers including advice and information, advocacy, counselling, health liaison, carers groups, grants and emergency planning.

Where at all possible, families are supported to stay together. When children are in the care of the local authority, foster carers and family link workers are all able to access a variety of autism training.

Some parent carers of children and young people told us that they would like more support<sup>17</sup>. There are gaps in carer support, particularly for people who are not eligible for statutory services. We also know that siblings of children with autism, and partners of adults with autism currently have no specific support services. Southwark would like there to be a range of support that considers the needs of everyone. This includes out of school care, assistance at home and in the community, and care during evenings, weekends and holiday times. There should also be opportunity for carers to increase their knowledge and understanding of autism and specific needs, to support them to be confident in their caring role.

### **Actions**

- Consult with local carers of people with autism about the services they use and need
- Promote access to carer support through all local networks and services
- Increase speed of access to parent training including Next Steps and Cygnet courses
- Provide training to parent carers, siblings and partners about what autism is and how to support someone
- Identify opportunities to develop new carers groups, including for siblings and partners, to promote peer-support

### **Safeguarding – measures, monitoring**

*Aspiration: Southwark prioritises the safeguarding and welfare needs of people with autism*

The additional needs of autistic adults may mean that some are more vulnerable to safeguarding concerns. The Safeguarding Adults Partnership Board (SAPB) oversees the adult safeguarding strategy. It is supported in this by the Safeguarding Adults Partnership Team. Safeguarding and Deprivation of Liberty Safeguards (DoLS) training should include the specific needs and vulnerabilities of people with autism, both with and without a learning disability.

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<sup>17</sup> 53% of respondents. Focus Group Report: Autism in Southwark. (2014)

When adults with autism are subject to a DoLS plan, we need to ensure that they have access to an appropriate representative and/or communication support, with people who understand any specific needs relating to their autism.

The SAPB should have oversight of the needs of adults with autism, and make reference to specific recommendations in relevant policies and plans.

### **Actions**

- Local safeguarding and DoLS training to include the needs of people with autism
- Ensure appropriate advocates and representatives supporting adults going through the DoLS process have had autism training
- Identify autism-specific safeguarding resources and review suitability for local use

### c) Choice and control

#### **Assessment and diagnosis**

*Aspiration: Southwark provides a timely assessment and diagnostic service, and offers a range of post-diagnostic support*

Getting a diagnosis is a critical step to help people understand their condition and why they may have difficulties. Adults who do not have a clear or recognised diagnosis of autism may be prevented from accessing services across health, education, employment, housing and others, leading to increased vulnerability. We want to have a clear pathway to diagnosis that includes referral routes to the service and post-diagnostic support. The pathway should be promoted and information made available to professionals (particularly those who make referrals) and local people.

Southwark has an autism diagnostic pathway for adults. People with learning disabilities are diagnosed by the Mental Health in Learning Disabilities service within the South London and Maudsley Mental Health Foundation Trust (SLaM). The SLaM Autism Service carries out diagnostic assessments for people who do not have learning disabilities.

Details of the referral process, rates and assessment times are not currently available. We want all referrals and assessments to be completed in line with NICE Guidelines. This includes using autism-specific diagnostic tools, with assessments completed by trained and competent professionals. Data from the diagnostic pathway should be collated and shared across health and social care. This will enable our commissioners to ensure services meet the pattern and levels of demand.

Access to post-diagnostic support can assist people in the early stages of a diagnosis, helping them to better understand themselves and their condition and supporting families and carers to provide appropriate care. At the very least, people should have comprehensive information and advice, including signposting to other sources of support. Southwark does not currently have a clear offer of post-diagnostic support, although people are given information and guidance, and can be referred to other services. We want to make sure that we can offer people the support that they need.

We want to look at whether the positive feedback and benefits of the Autism Post-Diagnostic Support Worker post (for families with a newly diagnosed child) offers opportunity for exploring how elements could be implemented for newly diagnosed adults. Local people have told us that they would like a range of post-diagnostic support, regardless of eligibility for statutory services. This includes psychological therapies, support groups, help to understand social skills and relationships, and family/partner support groups.

We will continue to talk to local people with autism, parent carers and professionals about their experiences of diagnosis, and what support they need afterwards.

### **Actions**

- Clearly define the diagnostic pathway process including referral, assessment, signposting and post-diagnostic support
- Ensure diagnostic pathway delivers in line with NICE Guidelines
- Ensure all frontline/primary healthcare staff (including GPs) are aware of adult diagnostic pathways and can refer appropriately
- Monitor referral rates across the borough, and the number of referrals that result in a diagnosis of autism
- Promote information about adult diagnostic pathway to local people and support organisations
- Consult with adults with autism who have recently been through the diagnostic assessment process, to understand what post-diagnostic support would be of most benefit to them
- Explore opportunities for developing post-diagnostic support for adults, including access to psychological therapies, speech and language therapy, occupational therapy and social skills groups
- Identify data required from diagnostic services and highlight opportunities to share information between services

### **Access to health services – mental health, primary and secondary care**

*Aspiration: Southwark provides a range of autism-aware health services accessible to people with autism with a variety of needs*

Early identification and intervention, and timely access to appropriate care and support is integral to improving health and quality of life for people with autism. This can reduce the risk of mental health deterioration, including depression and anxiety, and associated physical health issues.

Increasing awareness and understanding of autism is a priority for Southwark's health service staff. GPs and Health Visitors are often the first point of contact for people with autism and their families. There needs to be a good understanding of how the condition can present in children and adults and the needs and difficulties that may arise as a result. We want our local professionals to have knowledge of referral routes to diagnosis and support.

In line with the National Autism Strategy, all NHS Bodies and NHS Foundation Trusts should ensure they are involved in local workforce planning, and GPs and primary care staff are included in the development of autism and related training<sup>18</sup>. We can improve our diagnostic and referral processes by increasing training for health care services. At a minimum, all frontline health staff should have completed autism awareness training. GPs should have access to specialist training. We need to understand the training required by staff, and how we can implement and monitor it.

People with autism can easily fall between gaps in services, or find themselves shuttled back and forth between agencies that are not able to best meet their needs. More effective joint working across services can improve health and prevent fragmentation of care. We want to increase multi-agency partnerships between services to assist commissioning, enable data sharing, and identify risk areas.

Southwark is working to improve access to GPs and health services for people with learning disabilities. There should be a holistic assessment of people's needs to help identify any physical issues, and reasonable adjustments made to ensure services are accessible for people with autism.

Adults are referred by their GPs to the Community Mental Health Team (CMHT) if they suspect they have autism and a mental health need. The CMHT is then responsible for diagnosing the person and providing treatment. Southwark has some specialist services but there is little or no community mental health provision for people with less critical needs. Increased medical time, including provision for expert nursing and social care will support this gap. In addition, we need to look at our local provision (and accessibility) of psychological therapies to make sure there is the capacity and skill to support adults with autism. We also want our other mental health teams (e.g. the Eating Disorders Service) to have good knowledge of autism to help identify correct referral and/or treatment and support.

When people have more severe mental health needs, the CMHT can refer them to the specialist funding panel where they can be approved for various support. This may include inpatient, day or outpatient treatment, provided by the specialist South London and Maudsley (SLaM) Autism Team.

Southwark has three hospitals in the borough (St Thomas', Guy's, and King's College). We want to make sure that people with autism have a positive experience of care there. *My Hospital Passport* is a national resource for people with autism who might need hospital treatment<sup>19</sup>. It is designed to increase the understanding of someone's needs when they are treated in hospital. This is endorsed by the Department of Health and promoted by NHS England. We will look at how we can introduce and promote the scheme locally to support awareness of autism, and improve people's hospital care.

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<sup>18</sup> The National Autism Strategy. (2010). Available at:

<https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance>

<sup>19</sup> *My Hospital Passport* (2014). Available at: <http://www.autism.org.uk/living-with-autism/out-and-about/my-hospital-passport.aspx>

## **Actions**

- Ensure all health staff have access to autism awareness training
- Implement specialist autism training for GP and frontline practitioners and monitor take up
- Promote awareness of autism in all community and specialist mental health services
- Identify resources to increase capacity and expertise of community mental health teams to support people with autism
- Engage with identified local GP lead for autism/learning disabilities to feed into any local autism strategy/development group
- Ensure local access to psychological therapies – identify gaps and develop plan to build capacity
- Pilot *My Hospital Passport* scheme in one local hospital and evaluate impact
- Facilitate multi-agency discussions to identify actions to improve delivery

## **Engagement - advocacy, consultation**

*Aspiration: Southwark works together with people with autism and parent carers to develop services and support*

Southwark wants people with autism and their families to be fully included in services. Everyone should be supported to have their thoughts and experiences heard.

Some people with autism may need to use advocacy services so that their rights and wishes are respected. Southwark does not have an autism-specific advocacy service but we want all advocacy organisations to understand the needs of people with autism. This includes services supporting children, people with a learning disability, people with mental health needs and older people. Southwark directly commissions Speaking Up Southwark, a learning disability self-advocacy service that is accessible to all adults with autism and their families. Staff within the service have a good knowledge of autism and have received autism training<sup>20</sup>. Children and young people with autism are also able to access a local advocacy service, Cambridge House Advocacy, which specifically supports children with disabilities. Southwark provides information about advocacy on the Southwark Council website and through local information hubs, with signposting to specific organisations.

We need to make sure autism training and awareness is available to all locally funded advocacy services, and include autism knowledge and expertise as a requirement of securing funding.

Over the past few years we have carried out several disability and autism consultations. Recently we covered the Special Educational Needs and Disability (SEND) reforms and reviewed the local transitions pathway, involving a number of parent carers and young people with autism. In addition, a range of other local engagement activities (including development days, a Pathway to Employment planning event, and an autism conference) have enabled strong contacts to be developed with parent carers, young people and some adults with autism through the planning and delivery.

We want to strengthen our engagement with adults with autism so that we can better understand their experiences and see what changes we need to make to the provision of community and care services.

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<sup>20</sup> Southwark Autism Self-Assessment Form. (2014)

Southwark should promote a culture of inclusion, and encourage the involvement of people with autism and families and carers in the development, review and provision of services. We want to shape our services to local needs and improve people's quality of life.

### **Actions**

- Identify appropriate autism-related targets for future commissioning of advocacy services
- Provide access to autism awareness training for all advocacy providers
- Promote local advocacy services through autism networks
- Ensure funded advocacy services appropriately meet the needs of people with autism
- Develop a local consultation strategy, setting out how meaningful engagement with people with autism will be achieved at all stages of service development and delivery
- Ensure good representation of people with autism on relevant statutory strategy and planning groups

### **Information provision**

*Aspiration: Southwark provides a comprehensive range of information about local services and support*

When people have access to good quality information, they are given choice and control over the support they can access.

Southwark Council has a single point of access for information. People can get advice and support, and are directed to the most appropriate service to meet their needs. All Council staff have access to an online disability awareness training module (that includes autism) to support them to communicate appropriately and effectively. We need to monitor take-up and completion rates for the training to see whether it is having a positive impact.

Information about services and support can also be accessed through the Council's Contact Adult Social Care (CASC) team and online service directory My Support Choices. They provide information about community initiatives and services that people with autism can access, regardless of eligibility.

Southwark Information Advice and Support (SIAS) team and the Local Offer website specifically support families with children age 0-25 with a range of disabilities or Special Educational Needs (SEN). As well as signposting they provide details about how people can access support and the different ways of accessing/applying for services.

All of the information services provide advice, information and signposting on the full range of local universal and specialist services. This guidance is available online or by telephone. We want to make sure information is kept up-to-date, relevant and easily accessible.

Southwark does not have a dedicated information service specifically for people with autism and their families. This means that we need to make sure our existing information resources are comprehensive and that autism information is clearly identifiable. Advertising and promotion of resources should include universal services such as libraries and community centres, as well as specialist disability organisations.

## **Actions**

- Analyse existing provision of autism information available on the Southwark Council website and identify gaps
- Incorporate information about, and relevant to, autism onto a single easy access web page with links
- Ensure information websites meet good practice guidelines for access by people with autism
- Define a range of hard copy information about assessments and signposting to be made available to local services e.g. libraries, GP surgeries
- Identify opportunities and locations to promote autism resources

## **d) Employment and training**

### **Employment – young people, adults, projects**

*Aspiration: Southwark provides opportunities for people with autism to find and secure employment, and be supported in the workplace*

With the right support and understanding, many people with autism are very successful employees and employers, with a wide range of skills and abilities. Southwark wants to promote people's abilities and provide support to attain qualifications and employment.

We know that adults with autism are significantly under-represented in the national labour market: only 15% of adults with autism are in employment (this compares to 48% of people with general disabilities)<sup>21</sup>. We need to make sure that people with autism in Southwark have greater opportunities to find and secure work, which means identifying the right support required.

Autism training should be available locally to all employment support providers and staff working for the Department of Work and Pensions (DWP) including JobCentre Plus, so that people with autism accessing these services can have their needs better understood and supported.

There are national specialist and universal supported employment programmes that people with autism and Asperger syndrome can access locally, such as Work Choice and Access to Work. Information about these programmes should be easily available and accessible to people with autism, parents and carers.

Southwark has a presumption of employment for all young people and adults with autism. We want our services to offer creative, flexible and person-centred approaches, developing apprenticeship and work experience opportunities. These can give people skills and experience, helping them to attain and sustain employment. We need to understand the numbers of young people with autism who are Not in Employment Education of Training (NEET) and the reasons why. Where possible, we also want to identify the number of adults with autism who are not in work. This information should be shared across services so that we can plan and develop appropriate support.

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<sup>21</sup> Reid B. (2006). *Moving on up? Negotiating the transition to adulthood for young people with autism*. London: The National Autistic Society

We currently have one autism-specific employment initiative, (and experience of several others previously). Care Trade works in conjunction with Guys and St Thomas' NHS Foundation Trust to provide The Autism Project. This is a pioneering student internship for young people with autism who would like to be employed but need to build their confidence, experience and skills. The Project offers a 36-week course, learning in real work settings alongside hospital staff. The aim is for students to be ready to apply to paid employment, inside and outside the hospital, on completion.

From 2012-13, Care Trade ran a pilot with students from the autism-specialist Spa School to run a pop-up café. This was well received, and increased skills for all students attending, as well as opening up further opportunities for work experience. It was funded through Southwark Council's Innovation Fund scheme, and we will look at how we can use our knowledge from running this to develop future schemes.

Southwark has a wide range of local employment support services that can be accessed by adults with autism. We will look at whether these services can be expanded or replicated to address the specific employment needs of people with autism, including those who are self-employed and/or employers.

Southwark Works is commissioned by the council to deliver employment support to residents with particular needs, including vulnerable families and people with health issues. It provides one-to-one support and can offer a range of employability workshops, including confidence building. The Camden Society also offers employment support for young people and adults, and has strong employer engagement.

The Southwark Employment and Enterprise Development Scheme (SEEDS) helps local employers to give young Southwark residents new job opportunities. Contracts last 12 months and employers receive a subsidy to help pay staff the London Living Wage. At the end of the year, they are supported to take on the trained employee or help them find further employment. This innovative project offers good opportunity to engage with employers around supporting young people with autism through training and awareness raising, potentially increasing the employment prospects for autistic adults.

Other employment services have been commissioned by Adult Social Care in Southwark Council. These are for people with disabilities, including autism, and are not dependent on eligibility for statutory services.

We also have our Increasing Employment project involving many different local partners, which held an Increasing Employment Job fair in February 2015. This brought together people of all ages with autism and/or learning disabilities, families, key local services and local employers.

Southwark also offers support to set up a small business (Mind Your Own Business for young people, and Southwark Partnership Investment Readiness and Enterprise (SPIRE) for adults) and a project to develop employer engagement in the borough. Southwark's Economic Development Team commissions an umbrella employment organisation which has a number of disability-specific organisations sitting within it.

We want to make sure that our local employment schemes have enough knowledge and awareness to support people with autism. We will look at how we can expand existing schemes, and continue to provide start-up funding to increase new initiatives. To do this successfully, we need to make sure we have opportunities to share experiences and resources between services, and promote good practice.

## **Actions**

- Develop an employment pathway for people with autism, clearly setting out routes to services and support
- Provide autism awareness training to local universal and disability employment support providers
- Track the employment path of people with autism already known to services, to inform local service planning and development
- Report data on young people who are NEET
- Explore opportunities to further small funded pilot schemes, and support employment start-ups on a regular basis
- Investigate potential for supported internships and work experience opportunities with further education providers, specialist schools and school commissioners
- Ensure employment is included on all young people's Education Health and Care (EHC) Plans with links to local employment services
- Engage with the SEEDS project to identify opportunities to raise autism awareness amongst local employers
- Identify opportunities to establish autism employment forum (either separately or as a subgroup of an autism strategy group) for local statutory and voluntary sector employment support services
- Identify existing employment initiatives that could be opened up to people with autism and/or replicated specifically for people with autism
- Explore opportunity to make a specific number of apprenticeships in health, education and social care available to young people with autism

## **Workforce development – training needs, provision, evaluation/monitoring**

*Aspiration: Southwark provides a range of autism training and awareness to have informed and knowledgeable staff and services*

People with autism should be supported by staff that understand their needs. We Southwark wants to have commissioners and service providers that are skilled, confident, competent and knowledgeable about autism, and understand best practice for working with people with autism.

If we do not make sure that there is understanding of autism, and access to autism training, there are risks to:

- Building trust and relationships with people with autism, parents and carers
- Correctly carrying out needs assessments
- Signposting to suitable provision
- Developing appropriate services

We want staff to be able to recognise and meet the communication and sensory needs of people with autism and carry out effective person-centred assessments. Southwark Council provides an online disability awareness training module for all council staff. This includes information about autism. The Council has also run autism training workshops although there is not a regular programme. All frontline staff in Southwark Council's Community Learning Disability and Transition Teams have an individualised training plan. Each is required to complete autism training. Some other social care staff (including Occupational Therapists and staff in older people's services) have also attended autism training.

Autism training should be delivered on a rolling programme so that it is quickly accessible by new starters, and people requiring a refresher. All community care assessors should also have completed specific training focusing on carrying out assessments for people with autism.

We will talk to people with autism who have received support from social care and health teams to see how training is having a positive impact on staff practice.

On its own, online training will not provide the level of autism knowledge required by staff. We need to identify the most appropriate training workshops/formats for professionals, and how we can monitor and review attendance. This will allow us to develop a multi-agency training plan that can include staff working in autism and universal services, specialist training for frontline staff, and awareness training for others. The plan should include statutory services and key partner organisations.

Training content should be informed by people with autism and parent carers, and they should also participate in the delivery of workshops where possible. We need to enable people with autism to directly represent their views and experiences. This can be a powerful training experience for staff. It may also help people with autism to develop skills to become autism trainers.

Southwark understands that we can develop our staff skills and practice by giving professionals the opportunity to share good practice and discuss concerns. We will look at how online forums or meetings could be established so that we can have a network of 'autism champions' across services. This will assist professional development and improve practice.

### **Actions**

- Undertake a training needs analysis to review all existing training and identify gaps
- Develop a multi-agency training plan encompassing all levels of learning, ensuring statutory staff have a basic understanding of autism and creating local experts
- Review online training module to ensure content on autism is comprehensive and up-to-date
- Provide ongoing Level 1 autism training to all frontline health, social care and education staff
- Provide ongoing Level 2 autism training to care managers, assessors and key autism workers
- Provide specialist autism training for clinicians and GPs
- Monitor and evaluate take up of training to ensure high attendance, satisfaction and impact
- Identify opportunities for combined training for adult and children's workforce
- Ensure all community care assessors have undertaken intermediate level autism training and assess the impact of the training upon their practice
- Identify opportunities to increase involvement of people with autism in training delivery
- Ensure training/awareness about autism is available for people with autism, parents and carers through post-diagnostic support services
- Identify opportunities for professional development, including forums for sharing information – across education, health and social care

## e) Living in the community

### **Community services – variety, accessibility, sustainability**

*Aspiration: Southwark supports people to develop skills and access support to live the life they choose*

Being engaged in community life reduces social exclusion, isolation and harassment. People with autism need to have information about services and a choice of support, so that they can live successful, fulfilling lives.

Universal community services in Southwark should be supported to have understanding of autism so that they can better understand the needs of local people. Community services are cost effective: they improve the quality of life for people with autism and reduce dependence on more expensive statutory health and social care services. When we are commissioning services we consider costs, but the needs of people with autism and the services they require takes precedence.

We currently commission and support a wide range of services that include the specific remit of supporting people with autism, including people not eligible for statutory services. The services cover areas including health and wellbeing, peer support/mentoring, and advice and information. We are currently reviewing how well these services are working, so that we can understand the outcomes achieved. When people with autism and carers are eligible for social care support, they receive a Personal Budget to buy or commission services that best meet their needs. This can be managed (solely, or in combination) by themselves, Southwark Council, or a local organisation.

Southwark has some community opportunities specifically for adults with autism, The Camden Society provides personalised one-to-one support. The Tower Project has a day opportunities service, offering one-to-one for adults with autism, an evening and weekend service, and support to attend appointments or within the family home. The Tower Project has received accreditation from The National Autistic Society. While there are some good services available, there is a broader demand. Local people have told us that we do not have enough services to meet their needs, and there is a high number of adults in the borough diagnosed with autism. They would like to be able to access more support including befriending, mentoring, outreach, short breaks and social opportunities. We want to increase the range of services available and their accessibility to people with autism, to reduce the risk of social isolation and increased health difficulties. We will look at how mainstream activities can be made more accessible through staff awareness and training, as well as the potential for the development of new autism-specific groups. As part of this, we need to identify what autism-friendly requirements we have for universal services, and if we should introduce an autism 'standard' to support quality development. This would also increase trust between services and local people.

In order to make sure people can access community activities, we want to improve travel and transport for people with autism and their families.

Many people with autism and their families use a Blue Badge and/or have a bus passes. We want Badges and passes to be allocated correctly according to need, and autism awareness training should be available for staff working in travel and transport departments and parking enforcement officers. Autism training should also be provided to all travel escorts working on school or service transport. A standard definition or description of autism that highlights relevant mobility concerns should be used when assessing applications. We also need to provide clear information about the application process and eligibility to people with autism.

Some travel issues can be supported through the provision of travel training for young people and adults with autism. This increases confidence and self-reliance, and improves independence. Southwark will look whether there are opportunities for introducing this locally.

### **Actions**

- Map existing community services to identify gaps
- Consult with adults with autism to determine whether existing services meet needs
- Establish a plan for developing new services, including using the Innovation Fund model
- In partnership with people with autism, develop a benchmark or 'autism-friendly' criteria, that mainstream and specialist community services are tasked with reaching
- Discuss the development of adult peer support (including social groups, mentoring and befriending) with local people with autism, and existing autism and disability networks/organisations
- Promote existing services through local networks and online information hubs
- Provide autism training to services providing travel escort staff, and local transport departments
- Produce a definition of autism that is adopted by travel and transport staff when assessing applications
- Identify travel training opportunities for young people and adults through school/youth and social groups

### **Housing – accommodation, data/needs identification**

*Aspiration: Southwark provides a range of housing and support services to enable people with autism to live safely in their community*

The right kind of housing and support varies according to what someone with autism specifically needs to be able to lead a safe, independent life. The provision of suitable housing is imperative for people to feel supported in, and engaged with, their local community.

We should consider autism needs when discussing or developing any of the four main housing options: private rented, home ownership, supported living and social housing. In addition, autism should be recognised as a specific need on the statutory housing register, to ensure it is taken into consideration when assessing suitability for placement.

At the moment, Southwark has very little data on the numbers of people with autism using housing services. We need to collect data from housing agencies and services and share as part of planning with other services, to help our understanding of needs and demand.

We have recently reviewed the Southwark Learning Disability Accommodation Strategy and carried out a comprehensive housing needs analysis. The Strategy looks at the support needs of people with learning disabilities and/or autism, and will support the development of a wide range of accommodation options to meet these needs over the next ten years. Particular areas focusing on autism include creating bespoke accommodation, support for young people with autism in transition to adulthood, and housing needs of adults with autism.

We have also introduced our new long-term housing strategy. This sets out our housing plan up to 2043. People with autism are directly referenced, including in relation to promoting person centred housing alternatives to people with autism, such as the Shared Lives Scheme.

Southwark housing service staff have completed disability awareness training (which includes autism)<sup>22</sup>. We should identify what other housing support services may benefit from this, as well as talking to people with autism and staff to understand their experiences and understanding. The need for any further autism specific training should be identified and implemented through a training plan.

### **Actions**

- Ensure there is representation from housing services and support agencies at any autism strategy/development group
- Provide autism awareness training for housing service staff to address specific housing needs relating to autism
- Promote and monitor take up of autism training with statutory housing staff, and housing support providers
- List autism as a specific need on Southwark housing register
- Develop links with housing services to ensure needs of autistic people are recognised and considered in all new housing developments
- Ensure new- and existing-build provision for people with autism considers environmental/sensory needs and involves people with autism in the design and review

### **Community needs – cultural groups, deprivation**

*Aspiration: Southwark respects and recognises the different community and cultural needs of people with autism*

Southwark has an economically and ethnically diverse community. We have a high turnover of residents, which means it is difficult to have a consistent picture of local needs. Cultural and deprivation considerations impacts on the type and delivery of support and services available.

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<sup>22</sup> Southwark JSNA. (2014)

Just over 60% of our local population is ethnic minority, with just over 30% of people born outside of the European Union (EU)<sup>23</sup>. More than half of our children who have a statement of Special Educational Need (SEN) with a primary need of autism come from a Black Minority Ethnic (BAME) background, and the majority of those from Black African communities<sup>24</sup>.

We carry out assessment and care planning according to individual needs including those arising from race, ethnicity and culture. All of our staff receive training in diversity, which covers their responsibilities under the Equalities Act. We are currently developing local support services to reduce people from BAME communities being placed out of borough, which would often have meant placement in a less culturally-diverse environment<sup>25</sup>.

Some of the main issues for people with autism from an ethnic minority are that:

- Evidence about the prevalence of autism in various communities is inconsistent
- Communities are not aware of their rights or relevant services
- Services that are available do not always meet the needs of ethnic minority communities<sup>26</sup>

A report by The National Autistic Society into the difficulties faced by BAME communities, found that many parents and carers, especially migrants from non-English-speaking countries, face challenges when trying to understand autism and what services are available. In particular, specific behaviours within cultures are sometimes misunderstood, leading to delays in providing appropriate support<sup>27</sup>. We need to recognise these barriers when we are planning and delivering support and services.

We have a wide range of BAME services across Southwark, and organisations in neighbouring London areas are also accessible. Southwark Carers signposts to specific BAME carer organisations. Lambeth and Southwark Mind has a broad section of BAME services on its website, and there is also the Afro-Asian Advisory Service based in Southwark itself. Southwark Council also has a comprehensive translation service, able to translate documents and information into over 70 languages and dialects. We need to look at whether there is local need for specific BAME autism support and how we can provide autism awareness and training to universal services.

Southwark is the 41<sup>st</sup> most deprived local authority in England and we have developed guidance and support for people and families with a low income. This includes a Hardship Fund, and information about healthy eating and cooking, housing, and benefits and welfare advice. Southwark Rightfully Yours specifically helps vulnerable residents to claim the benefits they are entitled to. Information about this support is available through Southwark Council website across several pages.

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<sup>23</sup> Information from the 2011 Census, and the recent Joint Strategic Needs Assessment (JSNA)

<sup>24</sup> 35% of children with a statement of SEN for autism are from Black African communities, which account for 16.4% of the borough's resident population. Southwark Children's Joint Strategic Needs Assessment. (2013)

<sup>25</sup> Southwark SAF. (2014)

<sup>26</sup> *Missing Out? Autism, Education and Ethnicity: The Reality for Families Today*. London: The National Autistic Society. (2007)

<sup>27</sup> Slade, Guy. (2014) *Diverse Perspectives. The challenges for families affected by autism from Black, Asian and Minority Ethnic communities*. London: The National Autistic Society.

We should make sure this is easy to find so that people can access all relevant information quickly.

We want our frontline staff working with BAME and vulnerable communities to have a good understanding of autism and how to communicate. They need to have autism training to support this. This will enable them to better engage with, and support, people with autism within their local communities. We will look at training opportunities and how we can promote them to staff and services. Information about autism services, diagnostic and assessment processes should also be shared and promoted with community and cultural groups.

### **Actions**

- Consult existing services working with BAME communities and vulnerable people to understand current autism awareness and identify gaps in knowledge
- Provide autism awareness training to staff working with BAME communities, and BAME organisations and services
- Provide autism awareness training to staff working with low-income and vulnerable people and families
- Ensure autism-specific services have a good awareness and understanding of different cultural needs
- Review Southwark Council website to identify how information for vulnerable people could be more easily accessed

### **Aging and Gender**

*Aspiration: Southwark recognises and support specific needs of people with autism that might arise through gender or age*

With an aging population, there is national concern about the ability of services to meet the long term needs of adults with autism. We want to provide local services that can meet the needs of people with autism at all stages in their life.

In many cases, older adults with a diagnosis of autism did not receive their diagnosis until relatively late in life. People who have been diagnosed with autism later in life report that the diagnosis is immensely valuable, with many saying that it enables them to understand themselves fully for the first time<sup>28</sup>. We should have services for older people with the capacity to support people with autism, and training for staff to ensure that they have a good understanding of autism.

We will work to support people with autism to have sustained employment, however we know that there are likely to be substantial costs involved in providing for adults in older age due to a number who will require welfare support. Many adults with autism also live with their families, rather than independently, and we need to consider how to offer support when this be affected by the death of a carer or their difficulties providing ongoing care for the person with autism.

Southwark will start planning for the needs of older adults now, so that we are able to prepare and develop services as the age of many of our residents increases. We will seek the views and experiences of younger and older people with autism to inform any developments across services including housing, social care and health in particular.

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<sup>28</sup> Boehm, A. (2013) *Getting On. Growing older and autism. Autism and Ageing*. London: The National Autistic Society.

Nationally, many women with autism are not being diagnosed and are therefore not receiving the help and support needed throughout their lives. Southwark recognises the different ways that autism can impact women and girls, and will monitor data from diagnostic services on the numbers diagnosed. We want diagnosis to be the starting point in providing appropriate support, and a timely diagnosis can avoid many of the difficulties women and girls with autism experience throughout their lives<sup>29</sup>.

In Southwark, all of our assessment and support planning responds to individual needs including those arising from gender. Autism is less prevalent in women than in men but we want our planning to take full account of the needs of women with autism. We have recently done this in a new local residential facility, where the gender balance of residents is seen as a key priority.

Autism training should include reference to the needs of older people with autism, and women with autism to help professionals to understand how best to provide support.

### **Actions**

- Ensure all autism training includes reference to the specific needs of older people and women with autism
- Include autism training as a contractual requirement when commissioning services for older people
- Ensure staff working in older people's services have access to autism awareness training
- Provide specific autism and ageing, and autism and women and girls training to key frontline staff (education, health and social care)
- Gather information on the numbers of people over 65 with autism in the local area, and include this data in support planning
- Identify opportunities to address the needs of older people with autism in housing, employment and care strategies
- Identify opportunities to engage with local dementia care initiatives

### **Criminal Justice System – local needs and provision, engagement with services**

*Aspiration: Southwark recognises the vulnerability of, and risks to, people with autism, and has a criminal justice system with good knowledge and understanding of autism*

People with autism are vulnerable due to their social and communication difficulties, so they have a particular need for understanding and appropriate support from the Criminal Justice System (CJS)<sup>30</sup>. We want the CJS to have greater sensitivity to the needs of people with autism. We have a close relationship with the police, probation and court services regarding supporting and planning for the needs of people with autism in contact with the CJS. There is good liaison and cooperation through safeguarding procedures for children and adults, and all agencies take a partnership approach to prevent people's reoffending behaviours. CJS services have access to

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<sup>29</sup> Gould, J and Ashton-Smith, J. (2011). *Women and girls on the autism spectrum*. Available at: <http://www.autism.org.uk/about-autism/autism-an-introduction/gender-and-autism/women-and-girls-on-the-autism-spectrum.aspx>

<sup>30</sup> *Autism: A Guide for Criminal Justice Professionals*. London: National Autistic Society. (2008)

local forensic psychiatry and psychology services to ensure effective intervention designed to take into account specific communication and sensory needs. There are also a number of witness care units that specifically address the needs of witnesses who have autism, including arranging for an independent self-advocate supporter if the victim or witness indicates that they are unable to self-advocate. Prosecuting lawyers liaise with the unit to ensure that pre- and post-court support is available to help people to deal with the emotional and practical impact of being a witness.

We do not currently have good data on people with autism within the CJS. Whilst only a minority of people with autism come into contact as a suspect or offender, it is anticipated that future research will demonstrate that people with autism are over-represented in data relating to victims of crime<sup>31</sup>. We need to understand how people with autism are involved in the CJS, so that we can develop appropriate support. The safeguarding of children and young people with autism also requires an understanding of risk taking behaviours. Data sharing between CJS youth and adult services, and between CJS and health and social care services will also ensure better transition of support and understanding of local needs.

Southwark wants to make sure our CJS has professionals with good knowledge and understanding of autism. Our local police services have had general mental health training, and their interview training includes consideration of various needs/vulnerabilities including mental health and learning difficulties, and the use of intermediaries where appropriate. Southwark Missing Persons Unit (MPU) has also worked with an NHS speech and language expert in relation to improving understanding of autism and communication needs, to support missing persons with autism.

Currently, the majority of CJS staff in the court, probation and frontline (including youth offending), do not engage with specific autism training. This should be available to ensure CJS staff have an understanding of communication and social difficulties related to autism, and included in any multi-agency training plan developed.

We need to look at how we can increase autism awareness generally in the CJS. Autism Alert Card schemes have been successful in other areas in improving communication and awareness between people with autism and the police. This supports the process of developing better engagement with police and emergency services. We should consider whether this would be of benefit to Southwark, to aid the police in identifying people with autism more quickly, and assist people with autism in communicating their needs and seeking help.

### **Actions**

- Provide autism training to professionals working in the CJS
- Identify opportunities for data collection on young people and adults involved with the CJS as an offender, witness or victim
- Ensure representation from various CJS agencies on any autism strategy/development group
- Investigate potential for developing a local autism alert card scheme
- Identify national CJS and autism-specific training and information resources, and consider local implementation

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<sup>31</sup> *Criminal justice system and ASDs*. Available at: <http://www.autism.org.uk/working-with/criminal-justice/criminal-justice-system-and-asds.aspx>

#### **4. Summary**

We are dedicated to improving local services and support for children and adults with autism. We will continue to build on our good practice and strengthen our existing services as well as introducing new. Our development priorities and plans will be shaped and led by the thoughts and views of local people with autism, families and professionals. We want to support people with autism in Southwark to lead the lives that they choose.

## **5. Actions**

### **a) Children**

#### **Needs data**

- Improve collection, analysis and sharing of data between children's health, social care and education services
- Improve data sharing between child and adult services

#### **Assessment and diagnosis**

- Ensure child diagnostic pathways deliver in line with NICE Guidelines
- Ensure all frontline healthcare staff (including GPs) are aware of diagnostic pathways and can refer appropriately
- Promote information about diagnostic pathways to local people and support organisations
- Identify gaps in post-diagnostic support and resources required to meet demand
- Identify data required from diagnostic services and share with health, social care and education services

#### **Support and crisis services**

- Map key risk areas for children and young people
- Develop a crisis intervention pathway for children and young people with autism
- Ensure professionals working in health, education and social care services for children have access to the appropriate level of autism training and awareness
- Identify gaps in preventative services and areas of development
- Ensure information about services and referral routes is promoted to families and organisations
- Identify resources and developments required to reduce waiting lists for services including CAMHS and the Early Years Autism Team
- Identify resources and developments required to increase capacity of Autism Post-Diagnostic Support Worker post
- Identify good practice examples of children and young people's activity/support groups running in other areas, and investigate local potential
- Provide autism awareness resources or training to mainstream children's activity groups

#### **Safeguarding**

- Local safeguarding and child protection training to include the needs of children and young people with autism
- Ensure appropriate advocacy and suitable representative training is available for children on child protection plans
- Identify autism-specific safeguarding resources and review suitability for local use

## **Education**

- Review existing autism education provision for age 0-25 years, and identify development actions
- Ensure information about the EHC Plan process is accessible and clear
- Consult with education settings, children and young people with autism, and parent carers to identify existing good practice, and understand current issues and concerns
- Incorporate actions into a pan-disability pathway for 0-25 years
- Encourage all education settings to have at least one module covering autism as part of staff induction (for every role)
- Identify existing autism training resources for schools available nationally and how these can be implemented locally
- Promote existing local autism training to setting staff
- Formulate a five-year plan to increase education staff training and skill development

## **Transition – specialist support, information, opportunities**

- Consult with young people with autism about their experiences of transition to identify development and improvement areas
- Increase range of activities available for young people age 14-25 years
- Develop a transition protocol to address the needs of young people with autism
- Provide autism training to transition, careers and guidance organisations
- Ensure clear, up-to-date, autism-friendly information and advice about transitions is available, particularly for young people not eligible for social care

## **b) Lifelong care and support**

### **Needs data – collection methods, sharing, quality and quantity**

- Progress Autism Multi-Disciplinary Team membership and meetings to further develop data sharing practices across relevant health and social care services
- Share and compare existing data from SLAM, GSTT, and Southwark Council
- Address data recording methods in services including social care, health, and employment, supporting the collection of more comprehensive data on the needs of people with autism
- Develop a reporting arrangement to ensure accurate and timely sharing of data between SLAM, GSTT and Southwark Council
- Include autism as an identified need when capturing information in primary care (GP surgery) data audits
- Identify and collect information on people living in residential placements in and out of borough, including NHS accommodation, and people resettled to local provision from long-term residential homes
- Identify group to provide oversight and scrutiny of data and development
- Identify other data collection practices, and consider implementation locally e.g. local autism needs register
- Undertake a full service mapping exercise to detail offer and identify gaps in provision
- Develop an action plan to address service gaps and form solutions
- Ensure any autism strategy/development group has representatives from housing, employment, criminal justice organisations, education, social care,

health and education, people with autism and parent carers; representatives should demonstrate regular attendance and/or engagement

### **Access to statutory care services – assessment, eligibility, personalised care plans**

- Provide specialist autism training for care managers and social workers carrying out assessments of need
- Monitor take up of online disability awareness training module and promote necessity of completion to all staff
- Identify autism awareness training to roll out to social and health care staff involved in assessments
- Ensure professionals involved in care planning have received recent training in autism
- Monitor capacity and skills of the CASC team to ensure quality and quantity of support meets local demand
- Improve access to, and quality of, information about assessments (online and through other sources)
- Identify opportunities for including specific autism needs within existing quality of life monitoring systems
- Establish a formal process by which people with autism and their families are consulted with at least annually about their needs and quality of life; including monitoring of feedback to develop and improve services

### **Crisis intervention – management, response model**

- Map key risk areas for adults
- Identify gaps in preventative services and development areas
- Promote information about the crisis intervention pathway for adults with autism
- Monitor and evaluate ongoing impact of Enhanced Intervention Service

### **Carers**

- Consult with local carers of people with autism about the services they use and need
- Promote access to carer support through all local networks and services
- Increase speed of access to parent training including Next Steps and Cygnet courses
- Provide training to parent carers, siblings and partners about what autism is and how to support someone
- Identify opportunities to develop new carers groups, including for siblings and partners, to promote peer-support

### **Safeguarding – measures, monitoring**

- Local safeguarding and DoLS training to include the needs of people with autism
- Ensure appropriate advocates and representatives supporting adults going through the DoLS process have had autism training
- Identify autism-specific safeguarding resources and review suitability for local use

## c) Choice and control

### **Assessment and diagnosis**

- Clearly define the diagnostic pathway process including referral, assessment, signposting and post-diagnostic support
- Ensure diagnostic pathway delivers in line with NICE Guidelines
- Ensure all frontline/primary healthcare staff (including GPs) are aware of adult diagnostic pathways and can refer appropriately
- Monitor referral rates across the borough, and the number of referrals that result in a diagnosis of autism
- Promote information about adult diagnostic pathway to local people and support organisations
- Consult with adults with autism who have recently been through the diagnostic assessment process, to understand what post-diagnostic support would be of most benefit to them
- Explore opportunities for developing post-diagnostic support for adults, including access to psychological therapies, speech and language therapy, occupational therapy and social skills groups
- Identify data required from diagnostic services and highlight opportunities to share information between services

### **Access to health services – mental health, primary and secondary care**

- Ensure all health staff have access to autism awareness training
- Implement specialist autism training for GP and frontline practitioners and monitor take up
- Promote awareness of autism in all community and specialist mental health services
- Identify resources to increase capacity and expertise of community mental health teams to support people with autism
- Engage with identified local GP lead for autism/learning disabilities to feed into any local autism strategy/development group
- Ensure local access to psychological therapies – identify gaps and develop plan to build capacity
- Pilot *My Hospital Passport* scheme in one local hospital and evaluate impact
- Facilitate multi-agency discussions to identify actions to improve delivery

### **Engagement - advocacy, consultation**

- Identify appropriate autism-related targets for future commissioning of advocacy services
- Provide access to autism awareness training for all advocacy providers
- Promote local advocacy services through autism networks
- Ensure funded advocacy services appropriately meet the needs of people with autism
- Develop a local consultation strategy, setting out how meaningful engagement with people with autism will be achieved at all stages of service development and delivery
- Ensure good representation of people with autism on relevant statutory strategy and planning groups

### **Information provision**

- Analyse existing provision of autism information available on the Southwark Council website and identify gaps
- Incorporate information about, and relevant to, autism onto a single easy access web page with links
- Ensure information websites meet good practice guidelines for access by people with autism
- Define a range of hard copy information about assessments and signposting to be made available to local services e.g. libraries, GP surgeries
- Identify opportunities and locations to promote autism resources

#### d) Employment and training

##### **Employment – young people, adults, projects**

- Develop an employment pathway for people with autism, clearly setting out routes to services and support
- Provide autism awareness training to local universal and disability employment support providers
- Track the employment path of people with autism already known to services, to inform local service planning and development
- Report data on young people who are NEET
- Explore opportunities to further small funded pilot schemes, and support employment start-ups on a regular basis
- Investigate potential for supported internships and work experience opportunities with further education providers, specialist schools and school commissioners
- Ensure employment is included on all young people's Education Health and Care (EHC) Plans with links to local employment services
- Engage with the SEEDS project to identify opportunities to raise autism awareness amongst local employers
- Identify opportunities to establish autism employment forum (either separately or as a subgroup of an autism strategy group) for local statutory and voluntary sector employment support services
- Identify existing employment initiatives that could be opened up to people with autism and/or replicated specifically for people with autism
- Explore opportunity to make a specific number of apprenticeships in health, education and social care available to young people with autism

##### **Workforce development – training needs, provision, evaluation/monitoring**

- Undertake a training needs analysis to review all existing training and identify gaps
- Develop a multi-agency training plan encompassing all levels of learning, ensuring statutory staff have a basic understanding of autism and creating local experts
- Review online training module to ensure content on autism is comprehensive and up-to-date
- Provide ongoing Level 1 autism training to all frontline health, social care and education staff
- Provide ongoing Level 2 autism training to care managers, assessors and key autism workers
- Provide specialist autism training for clinicians and GPs
- Monitor and evaluate take up of training to ensure high attendance, satisfaction and impact
- Identify opportunities for combined training for adult and children's workforce

- Ensure all community care assessors have undertaken intermediate level autism training and assess the impact of the training upon their practice
- Identify opportunities to increase involvement of people with autism in training delivery
- Ensure training/awareness about autism is available for people with autism, parents and carers through post-diagnostic support services
- Identify opportunities for professional development, including forums for sharing information – across education, health and social care

#### e) Living in the community

##### **Community services – variety, accessibility, sustainability**

- Map existing community services to identify gaps
- Consult with adults with autism to determine whether existing services meet needs
- Establish a plan for developing new services, including using the Innovation Fund model
- In partnership with people with autism, develop a benchmark or ‘autism-friendly’ criteria, that mainstream and specialist community services are tasked with reaching
- Discuss the development of adult peer support (including social groups, mentoring and befriending) with local people with autism, and existing autism and disability networks/organisations
- Promote existing services through local networks and online information hubs
- Provide autism training to services providing travel escort staff, and local transport departments
- Produce a definition of autism that is adopted by travel and transport staff when assessing applications
- Identify travel training opportunities for young people and adults through school/youth and social groups

##### **Housing – accommodation, data/needs identification**

- Ensure there is representation from housing services and support agencies at any autism strategy/development group
- Provide autism awareness training for housing service staff to address specific housing needs relating to autism
- Promote and monitor take up of autism training with statutory housing staff, and housing support providers
- List autism as a specific need on Southwark housing register
- Develop links with housing services to ensure needs of autistic people are recognised and considered in all new housing developments
- Ensure new- and existing-build provision for people with autism considers environmental/sensory needs and involves people with autism in the design and review

##### **Community needs – cultural groups, deprivation**

- Consult existing services working with BAME communities and vulnerable people to understand current autism awareness and identify gaps in knowledge
- Provide autism awareness training to staff working with BAME communities, and BAME organisations and services

- Provide autism awareness training to staff working with low-income and vulnerable people and families
- Ensure autism-specific services have a good awareness and understanding of different cultural needs
- Review Southwark Council website to identify how information for vulnerable people could be more easily accessed

### **Aging and Gender**

- Ensure all autism training includes reference to the specific needs of older people and women with autism
- Include autism training as a contractual requirement when commissioning services for older people
- Ensure staff working in older people's services have access to autism awareness training
- Provide specific autism and ageing, and autism and women and girls training to key frontline staff (education, health and social care)
- Gather information on the numbers of people over 65 with autism in the local area, and include this data in support planning
- Identify opportunities to address the needs of older people with autism in housing, employment and care strategies
- Identify opportunities to engage with local dementia care initiatives

### **Criminal Justice System – local needs and provision, engagement with services**

- Provide autism training to professionals working in the CJS
- Identify opportunities for data collection on young people and adults involved with the CJS as an offender, witness or victim
- Ensure representation from various CJS agencies on any autism strategy/development group
- Investigate potential for developing a local autism alert card scheme
- Identify national CJS and autism-specific training and information resources, and consider local implementation

## **6. Good Practice**

### **Training**

#### **Cornwall – Training project**

Cornwall has run an autism training project since 2009 and trained over 6,000 professionals. It is currently funded by Cornwall Council, delivered by The National Autistic Society, and run by a part-time coordinator. The project provides free, multi-level autism training, on a range of topics, to health and social care professionals from the statutory, private and voluntary sectors who may be in contact with young people and adults with autism. Bespoke workshops are also provided for a range of organisations.

In 2010, 20 people with autism, parents and carers completed an accredited training course, enabling them to present at, and co-deliver training workshops. They are also regularly involved in the development of workshops and the running of the overall project. This coproduction gives workshops considerable added value.

A draft training strategy has been developed from a training needs analysis, which is guiding future developments. Evaluations of workshops are consistently positive, and more detailed work is currently taking place looking at the impact of training on organisational and individual practice, and the difference it makes to people using services.

#### **Gloucestershire – Training**

A range of training is provided in Gloucestershire, including trainer-led workshops for professionals, and e-learning, which is available free for anyone living in the county. Over 1,000 staff have been trained from a range of organisations, and the awareness of autism in services and the general population appears to have been raised. Funding has been allocated to implement an integrated workforce development strategy for autism. The aims are to:

- Identify and allocate responsibility for leadership and coordinated delivery of the multi-agency strategy, recruiting to the new multi-agency training coordinator post
- Review and enhance the role of the multi-agency Autism Workforce Development Group in order to secure partner engagement, sign up for the strategy, and oversee implementation
- Promote e-learning, awareness and intermediate level training
- Introduce monitoring and reporting of training take up
- Complete a workforce needs analysis in order to develop a prioritised implementation plan
- Develop a 'Train the Trainer' cascade model
- Support commissioning review of provide contracts/performance requirements for autism workforce knowledge and skills
- Develop the blended learning pathway and ensure organisational sign up to training
- Work with the NHS trust to align specialist training
- Develop an evaluation process, with particular focus on the transfer of learning into practice, to evidence impact of improved awareness and understanding

## **Assessment, Diagnosis and post-diagnosis support**

### **Bristol – Bristol Autism Spectrum Service (BASS)**

BASS provides a comprehensive assessment, diagnostic and post-diagnostic support service for adults on the autism spectrum. It has a small multi-disciplinary staff team which also supports services working with adults with autism. The service can:

- Assess and diagnose people who are referred by their GP
- Support colleagues in mental health services to assess and diagnose
- Provide social support assessments to people who have been diagnosed by the team
- Offer an a with groups on mindfulness, managing anxiety, social cognition and interaction, as well as an opportunity to book one to one sessions with staff
- Provide post-diagnosis support including psycho-education, coping strategies and signposting
- Deliver training in Asperger syndrome and autism, ranging from one hour awareness sessions to a full day's training.

It currently accepts referrals for people within Bristol, North Somerset, Bath and North East Somerset and South Gloucestershire. Referrals outside of these areas can be seen on a cost per case basis, subject to funding being agreed by the referring clinical commissioning group.

### **Awareness**

#### **Wiltshire – Awareness campaign**

In November 2012, Wiltshire Council launched a year-long campaign to raise awareness of autism, showing how autism affects people in different ways so that a person's actions and behaviours are understood in Wiltshire communities, and to encourage businesses to recognise the skills and talents of people with autism.

The range of awareness methods includes:

- Video – a short five-minute film involves people with autism talking about their life experiences; this is available via the council website and YouTube
- Presentations
- Editorial in Wiltshire resident's magazine
- Exhibition at County Hall
- Road shows – during National Autism Week in April, Wiltshire Council hosted well attended outdoor road shows in four major towns, which enabled people to find out more about autism and provided an opportunity to gain information and advice
- Website – the Wiltshire Council website has been updated to provide good signposting to advice and support services for people with autism and professionals
- Internal communications
- Business breakfasts
- Media campaign
- An 'at a glance' flyer describing what autism is, how you can support someone with autism and highlighting particular myths and facts

The campaign was very successful, and the most impacting elements continued through 2014 to carry on raising awareness across the county.

## **Autism Hub**

### **Cambridgeshire – Chitra Sethia Centre**

The centre provides a base for autism services in the Cambridge area, including:

- Diagnostic support for adults through the Cambridge Lifespan Asperger Syndrome Service (CLASS) clinic based at the centre
- Post diagnosis support through information, advice and signposting services
- Drop-in facilities for help and support
- Information seminars for people and their families
- Links across the geographical area to raise awareness of autism and opportunities for employment, leisure and education
- A meeting space for local autism support organisations and groups
- Voluntary and supported employment opportunities
- Access to research volunteers for Cambridge University's Autism Research Centre (ARC)

## **Engagement**

### **Gloucestershire – Involvement of people with autism**

The Autism Network Group (ANG) runs alongside the Gloucestershire Autism Partnership Board (APB). It supports the positive involvement of people with autism, parents and carers, and allows two-way communication and feedback. The ANG reminds the APB about what is most important for people with autism. Through it, people with autism are empowered to get involved and members also meet socially outside of the formal ANG meetings – increasing local social support opportunities. The ANG is chaired by a parent/carer, and currently has over 50 members, and meets at various settings across the county. It has co-produced the autism strategy with the APB and also developed an easy-read version.

## **Youth Services**

### **Sheffield – Aspergers Children and Carers Together (ACCT)**

ACCT is a very successful parent-led support group for children and families affected by Asperger's syndrome and High Functioning Autism. It runs activity groups for children and teenagers with Asperger's and Autism, as well as family days out and other trips. Siblings are welcome too. It also hosts weekly drop-in sessions and monthly meetings for parents and carers. Members are invited to all ACCT activities, receive a quarterly newsletter and have use of a library of resources. Membership is free

A children's club and youth club meets weekly. There is a cross-over with ages, to enable young people to have a smooth transition between groups. The groups run general activities, but also cover social skills and other topics requested by young people.

## **Health**

### **Cornwall – Acute Liaison Nurses**

There are three Acute Liaison Nurses operating in the Royal Cornwall Hospitals Trust. They provide support to people with learning disabilities and/or autism who require inpatient or outpatient treatment. Due to the success of the service, it has expanded to support children and adults. One nurse has also been funded to complete a post-graduate certificate in autism, increasing the team's expertise. The nurses provide adjustments and ensure access to care pathways across the Trust, promoting the use of communication booklets, and advising hospital staff on appropriate support and adaptations.