

## **Draft All Age Autism Strategy**

**2016-2021**

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## **1. Strategy development process**

Over the past 18 months, Southwark Council and the Southwark NHS Clinical Commissioning Group (CCG) have been talking to people about autism. This has included people with autism and their families/ carers; professionals who diagnose and/ or support people with autism; and organisations that support people with autism and their families/ carers.

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

We have listened to what people have told us and looked at national best practice to develop this draft strategy. We now need you to tell us if the strategy has properly captured all of the issues in Southwark and is suggesting the right actions that need to be taken.

This draft strategy will go through a twelve week period of consultation with local people with autism, parent carers and professionals, before the Strategy is agreed and signed off.

The final Southwark Autism Strategy will provide overarching guidance around the planning and provision of services for people with autism during child and adulthood. There will be two updates to the Strategy between 2016 – 2021. These updates will also be consulted on.

### **Consultation**

The consultation to review this draft strategy will take place from 31 July to 23 October 2015. During the consultation, there will be opportunities to give us your feedback via:

- An online questionnaire (<https://www.surveymonkey.com/r/Southwarkautism>)
- Sending an email to [autismstrategy@southwark.gov.uk](mailto:autismstrategy@southwark.gov.uk)
- Writing to Autism Strategy Consultation, Southwark Council, Children's and Adults' Commissioning Unit, Floor 4/ Hub 4, PO Box 4529, London SE1 5LX
- Attending an event to discuss the draft strategy on 16<sup>th</sup> September (details are on the Council website and Local Offer)

We want your views on the document and how well it reflects your own experiences and issues. In particular, we want to know if you think:

- The strategic aims we have identified are the right ones
- The actions we have identified will address the issues in Southwark
- Which actions should be a priority to be carried out

Once the consultation has finished, we will look over all of the responses we have received, and use them to amend or adjust the draft strategy and develop an action plan. We will then take this to our Council cabinet and CCG governance board to get their agreement. The final strategy will then be made available to everybody.

Every three months, the Learning Disability Partnership Board will look at how well we are carrying out the action plan.

## **2. Introduction and policy background**

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

This draft all age autism strategy for Southwark Council and CCG sets out a local response and explores the development of local services to ensure improved outcomes and quality of life for adults and children with autism, their families and carers<sup>1</sup>.

### **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>.

### **Partnership working**

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

### **Local and National Guidance**

The Southwark Autism Strategy will be 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

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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)

<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>

- 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.

#### 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)

<sup>4</sup> Adult Autism Strategy Statutory Guidance (2015). Available at:

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

<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>

### **3. Development aims in brief**

Southwark has both short and long term goals. Implementation of actions will be planned and monitored by the Learning Disability Partnership Board (LDPB), setting out targets from 2016 for the next five years. Developments will be evaluated by the LDPB each quarter, and detailed in a progress report at the end of every calendar year. This progress report will be published, and made available to the public.

#### **Building on foundations**

There is a range of good autism practice across Southwark, offering some robust and innovative services to local people. Utilising learning and knowledge from these services, and exploring other initiatives taking place nationwide, will allow the area to grow and develop from an informed base. Determined actions will enable steps to be taken to ensure that existing good practice flourishes, and that all services can be of the quality and variety required and expected by local people. A complete list of recommended actions can be found in section six of this document.

Southwark will implement and monitor the autism strategy from January 2016.

#### **Priority short term aims**

- Embedding clear and accessible pathways to diagnosis for children and adults with autism, including post-diagnosis support
- Improving professional understanding of the needs of local people with autism, their families and carers
- Ensuring all frontline staff have access to autism training, demonstrating good autism awareness and knowledge
- Establishing a culture of coproduction in the development of services with people with autism, their families and carers

#### **Priority long term aims**

- Ensuring all those providing services to people with autism have the necessary skills and training
- Ensuring equal access to specialist and mainstream services for people with autism, their families and carers
- Ensuring 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
- Embedding a culture of coproduction in delivery of training with people with autism, their families and carers

#### **4. Development aims in detail**

Key development areas are informed by the National Autism Strategy, NICE Guidelines, and local policies and plans. They are also shaped by consultation with people with autism, families, carers, and professionals and guided by good practice from other localities in England. There is a specific section covering diagnosis, education and transition for children and young people. Other sections reference both children and adults.

##### a) Lifelong care and support

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

There is no single reliable source of prevalence figures for the numbers of people in Southwark with autism. According to national prevalence data, people with autism make up at least 1.1% of the population and have significant, identified needs<sup>7</sup>. At present, the total number of all people with autism in Southwark is estimated to be 3,229<sup>8</sup>.

The lack of comprehensive information on the numbers and needs of adults with autism leads to their exclusion from planning and commissioning processes. While the number of adults age 18-64 is currently approximated as 2,319, there is no data on people age 65 and over. Data from social care indicates there are currently 100 people with autism and a learning disability and six people with autism without a learning disability known to be receiving services. It is not known how many people with autism may receive support through housing, employment, health and other agencies. This points to a significant local adult population who do not receive statutory support. In addition, by 2030, the population of autistic adults in Southwark is expected to rise by 35%<sup>9</sup>.

A specific autism classification has been incorporated into the Southwark social care database which will enable collection of data for those both within and outside the learning disabilities range. Classification for all people currently supported by the Learning Disability service and Transition Team is in process. This data will only cover people who are assessed as eligible for social care support, and other systems and sharing mechanisms should be used to ensure collection of data for the broader autism population.

Mental Health services in Southwark are provided by South London and Maudsley (SLaM) Mental Health Foundation Trust and there is not yet a reporting arrangement to capture autism diagnosis from various SLaM teams. Local GP practices are not currently required to maintain an autism register, and while information on prevalence is recorded this is not shared on an organised basis.

With current identified numbers, as well as an expected growth in population, it is vital that comprehensive quality data is collected to ensure services can accurately expand to required demands.

There should be a comprehensive understanding of needs to avoid the unnecessary duplication of expenditure or the widening of gaps in provision.

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<sup>7</sup> Brugha, T et al. (2012). *Estimating the prevalence of autistic spectrum conditions in adults: extending the 2007 Adult Psychiatry Morbidity Survey*. Leeds: NHS Information Centre for Health and Social Care

<sup>8</sup> Office of National Statistics (ONS) Survey. (2011) Available at: [www.nomisweb.co.uk](http://www.nomisweb.co.uk)

<sup>9</sup> Projecting Adults Needs and Service Information. (2013). Available at: [www.pansi.org.uk](http://www.pansi.org.uk)

Mapping and intelligence are crucial to appropriate planning and commissioning of future services. Clear and consistent data collection, collation and analysis needs to be embedded as a fundamental practice across services for children and adults.

Involvement of a range of stakeholders in any future autism strategy/development group will promote discussions and developments, increasing opportunities for multi-agency partnership working.

### **Recommended Actions**

- Form a working group to develop data sharing practices across relevant health and social care services
- Identify other data collection practices e.g. local autism needs register, and consider implementation locally
- Address data recording methods in services including social care, health, 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 teams 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 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 – either an Autism Partnership Group or sub-group of the Learning Disability Partnership Board
- Undertake a full service mapping exercise to detail range 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; representatives should demonstrate regular attendance and/or engagement

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

All adults with a diagnosis of autism can request an assessment for social care services. Post-diagnosis, adults with autism are referred to the Contact Adult Social Care (CASC) team. This team is the single point of contact for adult social care in Southwark. CASC may link people with the Learning Disabilities service, Transition Team, community services, or provide information and advice. Feedback from people using CASC should be gathered and evaluated to shape future development.

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>10</sup>. This should be supported by provision of training on undertaking assessments for people with autism specifically for care managers and assessors. Comprehensive information about assessments and the support provided by social care services is available online, including contact details. Local information

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<sup>10</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)

hubs/disability organisations should also have access to quality information about the local assessment process that they can share.

The Care Act 2014 and NICE Quality Standard for Autism emphasise the need for Care and Support Plans to be person-centred and completed with comprehensive participation from the person involved, family, friends and carers. 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

The plan 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 the transition from child to adult services. Autism training and awareness for professionals involved in this process will ensure autism-specific needs are understood and considered.

While there are established categories with which to measure someone's quality of life, the most important information is gathered by talking to the person involved. Widespread and regular consultation will assist with this. If services use outcomes models, these should ensure that they are adaptive to an individual, so that the person is getting 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.

### **Recommended Actions**

- Provide specialist autism training to care managers and social workers carrying out assessments of need
- Monitor take up of disability awareness online module and promote necessity of completion to all staff
- Identify specific autism awareness training to roll out to social and health care staff involved in assessments
- Monitor capacity and skills of CASC 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
- Ensure professionals involved in care planning have received recent training in autism
- Establish a formal process by which people with autism and their families will be consulted with about their needs and quality of life, with opportunities at least annually, including monitoring of feedback to develop and improve services



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

It is recognised nationally 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. They are then at risk of being in contact with the Criminal Justice System, excluded from school or employment, suffering the breakdown of family relationships, increased involvement with mental health services, and/or becoming socially isolated.

Two vital services (Early Help Service and Autism Support Team) provide assistance to families going through crisis. These services incorporate a team of professionals including educational welfare, educational psychology, behaviour support and social workers, works with children age 0-19 years and their families, from the early stages of difficulty. This can include children finding it difficult to engage in education, with mental health difficulties, and children with autism under the age of five.

A pilot crisis response service for adults in Southwark has also recently been made permanent. The Enhanced Intervention Service, sitting within the existing Mental Health 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 was set up to support the return of people who were being supported outside of the area, and to prevent this happening in the future. The team works with local services to increase capacity to create appropriate, stable care environments. It does this through providing rapid, intensive assessments and interventions at a point of breakdown or crisis. 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, living within their communities, and there have been positive outcomes for all people that have been supported during points of crisis. The cost-beneficial service demonstrates positive outcomes in terms of strengthening local responses to autism, learning disability and behaviour that challenges. People using the service showed a significant improvement in quality of life, wellbeing, communication and behaviour<sup>11</sup>.

This model should continue to be evaluated to assess how well it is working, and if any learning can be replicated for other age groups. It must be ensured that crisis intervention is available at all ages, and that people have a clear access to appropriate support.

### **Recommended Actions**

- Map key risk areas for children and young people and adults and identify gaps in provision
- Develop a crisis intervention framework for children and adults with autism
- Monitor and evaluate ongoing impact of Enhanced Intervention Service
- Identify gaps in preventative services and development areas

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<sup>11</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.

## **Safeguarding – measures, monitoring**

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 that seek to improve cross-service communication and 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 people with autism, both with and without a learning disability.

When children with autism are subject to child protection plans, there is a need to ensure that the child has 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.

The Safeguarding Adults Partnership Board (SAPB) oversees the adult safeguarding strategy. It is supported in this by the Safeguarding Adults Partnership Team. The additional needs of autistic adults may mean that some are more vulnerable to safeguarding concerns. 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.

When adults with autism are subject to a DoLS plan, there is a 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.

### **Recommended Actions**

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

b) Choice and control

**Assessment and diagnosis – adults**

Getting a diagnosis is a critical step for helping people to 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. There needs to be a clear pathway to diagnosis, which includes referral routes into the service and any post-diagnostic support. The pathway should be promoted and information made available to professionals (particularly those who make referrals) and local people.

While there is an autism diagnostic pathway for adults, the referral process, rates and assessment times are not currently available. 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). For people who do not have learning disabilities, diagnosis is made by the SLaM Autism Service. All referrals and assessments should be completed in line with NICE Guidelines, including 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 identification in trends, supporting commissioners to ensure services meet the pattern and levels of demand.

Post-diagnostic support is incredibly important to 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. Where specific services are not available, comprehensive and timely information and advice is particularly useful to signpost to other sources of support, and empower people with the resources they need to seek further advice. The positive feedback and clear benefits to the family support worker scheme run by the children's diagnostic service offers good opportunity for exploring how elements could be implemented for newly diagnosed adults. Local consultation and observation of diagnostic pathways in other areas indicates that a range of additional post-diagnostic support should be considered, available to people regardless of eligibility for statutory services. This includes psychological therapies, support groups, help to understand social skills/relationships, and family/partner support groups. Consultation with local people with autism, parent carers and professionals will ensure good understanding of local needs and demands.

## **Recommended Actions**

- Clearly define adult diagnostic pathway process including referral, assessment, signposting and post-diagnostic support
- Ensure adult diagnostic pathways deliver 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 accuracy of referrals made (that result in a diagnosis of autism)
- Promote information about adult diagnostic pathways to local people and support organisations
- Consult with adults with autism who have recently gone through the diagnostic assessment process, to understand what post-diagnostic support would most benefit 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**

Increasing awareness and understanding of autism is a priority for local 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 good understanding in recognising the presentation of the condition in children and adults and the needs and difficulties that may arise as a result. Professionals should have good knowledge of referral routes to diagnosis and support. Early identification and intervention, and timely access to appropriate care and support is integral to improving someone's health and quality of life. This can reduce the risk of deterioration to mental health, including depression and anxiety, and associated physical health issues .

In line with the National Autism Strategy, all NHS Bodies and NHS Foundation Trusts should ensure they are involved in the development of local workforce planning, and GPs and primary care practitioners are engaged in the training agenda in relation to autism<sup>12</sup>.

All frontline health staff should have completed autism awareness training as a minimum, and GPs should have access to specialist training. There is a need to increase current training within primary and secondary care services, to better inform the diagnosis and referral processes. A multi-agency training plan should include health services, and training implemented, monitored, and evaluated through this.

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. Multi-agency partnerships will assist commissioning plans, enabling data sharing between services and the identification of potential risks. More effective joint working across services is critical in addressing poor health and preventing the fragmentation of care.

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<sup>12</sup> The National Autism Strategy. (2010). Available at:  
<https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance>

Adults are referred by their GPs to a Community Mental Health Team (CMHTs) if they suspect they have autism and a mental health need. The team is then responsible for diagnosing the person and providing treatment. They can also refer to the specialist funding panel where people can be approved for various support including inpatient, day or outpatient treatment, provided by the specialist SLaM Autism Team.

*My Hospital Passport* is a national resource for people with autism who might need hospital treatment<sup>13</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. Introduction and promotion of the scheme at a local level will support health service awareness of autism, and improve people's experience of hospital.

### **Recommended Actions**

- Ensure health staff access to autism awareness training
- Implement specialist autism training for GP and frontline practitioners and monitor take up
- Engage with identified local GP lead for autism/learning disabilities to feed into any local autism strategy/development group
- Identify gaps in child and adult therapy services and develop action plan to build capacity
- Pilot *My Hospital Passport* scheme in one local hospital and evaluate impact
- Facilitate multi-agency discussions about data covering service users, demand, and gaps; identify actions to improve delivery

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

The needs of people with autism should be addressed in all advocacy provision including mainstream, children, learning disability, mental health and older people. Information about advocacy can be found on the Southwark Council website, as well as other local hubs, with signposting to specific organisations.

Southwark directly commissions a learning disability self advocacy service (Speaking Up Southwark) that is accessible to all adults with autism and their family members. Members within the service have a good knowledge of autism and have received autism training<sup>14</sup>. Children and young people with autism are also able to access a local advocacy service, Cambridge House Advocacy that specifically supports children with disabilities.

Autism training and awareness should be made available to other advocacy services, and specific targets on demonstrable autism knowledge and expertise built into commissioning contract requirements.

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<sup>13</sup> *My Hospital Passport* (2014). Available at: <http://www.autism.org.uk/living-with-autism/out-and-about/my-hospital-passport.aspx>

<sup>14</sup> Southwark Autism Self-Assessment Form. (2014)

Southwark has undertaken various disability- and autism-focused consultations that consider services and support for children with autism and are aimed at parent carers and professionals. Recent engagement has covered SEND reforms and a review of the local transitions pathway, both of which included 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 adults with autism through the planning, delivery and in attendance.

There has been minimal consultation with adults with autism to date. More targeted consultation will enable the specific needs of people with autism to be better understood within the wider context of the provision of community and care services.

In order to enforce a culture of inclusion, and to promote coproduction, consultation with people with autism and families and carers should be ongoing. This will enable developments to be better shaped to local needs, and assist with data collection and service planning.

### **Recommended Actions**

- Identify appropriate autism targets for future advocacy commissioning
- 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, ensuring meaningful engagement with people with autism in development, delivery, implementation and scrutiny
- Ensure good representation of people with autism on relevant statutory strategy and planning groups

### **Information provision**

There is no dedicated information service specifically for people with autism and their families but Southwark Council has a single point of access for universal support. This service offers a comprehensive response to all residents in the borough offering advice, support and directing people to the most appropriate place to meet their needs. All staff in the information service have access to an online disability awareness training module (including autism) so that they can communicate appropriately and signpost effectively. Monitoring take-up and completion rates for the training will ensure good understanding of professional development.

In addition, information can also be accessed through the Contact Adult Social Care (CASC) team, My Support Choices - an online service directory, the Local Offer website, and the Southwark Information Advice and Support (SIAS) team. All provide information about non-statutory, community initiatives and services that people with autism can access, whether they are eligible for statutory service support or not. The latter two services are specifically designed to support families with children age 0-25 with a range of disabilities or Special Educational Needs (SEN).

These services provide advice, information and signposting on the full range of mainstream, universal and specialist services available. This guidance is available online or by telephone, with the SIAS team also providing some training to parent carers.

While existing information resources are comprehensive, there must be widespread knowledge of them for them to be fully utilised. The advertising and promotion of the

resources should include outreach awareness, through universal services such as libraries and community centres, as well as through specialist disability organisations.

### **Recommended 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

### c) Children

### **Needs data**

There are approximately 62,000 children and young people aged 0-19 living in Southwark with 36,000 children being educated in Southwark schools. Identifying the number of children with autism is complex as education settings support both children from Southwark and those from other boroughs who have autism. Autism specialist services are also accessed by children with autism who live within Southwark but who do not go to Southwark schools. However, there are 1,100 children and young people with a diagnosis of autism known to local services in Southwark, and many of these 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>15</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.

### **Recommended Actions**

- Improve collection, analysis and data sharing between child and adult services
- Address data recording methods in children and young people's services, supporting the collection of more comprehensive data on the needs of people with autism

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<sup>15</sup> Learning Disability Profile. (2013). Available at: [www.phe.org.uk](http://www.phe.org.uk)

## Assessment and diagnosis – children

Children of pre-school and school age with suspected autism are referred for assessment to Sunshine House, the Child Development Centre. It carries out assessment and diagnosis for children and young people with autism and other neurodevelopmental disorders through a multi-disciplinary team made up of psychiatrists, psychologists, specialist social workers and therapists. Diagnosis is currently completed on average around six weeks from the point of referral. There is no eligibility criteria for the service, and it caters for all levels of need. As well as diagnosis, the service provides support around mental health problems (through the Child and Adolescent Mental Health Service (CAMHS)) and challenging behaviour. Therapeutic interventions offered include individual, family and group therapies and behaviour modification advice. The service also runs training sessions for parents, and undertakes home visits and visits to schools.

The diagnostic pathway for children receives good feedback from families and professionals, and is working well, with high levels of diagnosis from referral, and quick assessment times, meeting the standards set by NICE Guidelines<sup>16</sup>.

When children and young people receive a diagnosis of autism, a family support worker is available to provide practical support for parents and carers. This service has received very good feedback from families, and includes the provision of information, access to training programmes such as EarlyBird, and advice on giving support at home and creating a good environment<sup>17</sup>.

During the autism diagnosis process, additional health professionals can be brought into provide additional assessments for children, including psychology, speech and language therapy, occupational therapy and others. Post-diagnosis, children may also be referred to these services if they require further input. Other services providing specialist support include a toilet training clinic, Makaton sign language workshops, and physiotherapy.

While there is a range of post-diagnostic support available for children and families, capacity of existing services and gaps should be identified to ensure all needs are being appropriately supported. This could include further training for parent carers, increased access to speech and language therapy, psychological and support-based groups, and help for children and young people to understand social skills. Regular consultation with autistic children and parent carers will ensure good understanding of local needs and demands.

All of this support is widely appreciated by families, however there are some considerable waiting times for CAMHS services, as well as gaps in access to, and frequency of provision, particularly for young people age 14 and over. Communication between services and families should be timely and thorough, to ensure families are not missing out on support because they are not aware it is available.

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<sup>16</sup> NICE Guideline. *Autism Diagnosis in Children and Young People*. Available at: <https://www.nice.org.uk/guidance/cg128>

<sup>17</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)



## Recommended Actions

- Ensure child diagnostic pathways deliver in line with NICE Guidelines
- Ensure all frontline/primary healthcare staff (including GPs) are aware of child diagnostic pathways and can refer appropriately
- Promote information about child diagnostic pathways to local people and support organisations
- Identify data required from diagnostic services and highlight opportunities to share information between services
- Ensure information about available services and referral routes is promoted to families and available to organisations

## Education

Most children and young people in Southwark diagnosed with autism have a statement of Special Educational Needs (SEN)<sup>18</sup>. Autism is the most common primary need listed on a child's statement (610 children)<sup>19</sup>. In addition, there are a further 210 children who are diagnosed with autism but do not have a statement of need. All of these statements will be replaced with Education Health and Care (EHC) Plans over the next few years.

The number of children in schools 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>20</sup>.

Southwark aims to educate children and young people with autism within mainstream schools wherever possible. A specialist autism service, the Autistic Spectrum Disorder (ASD) Support Team works with universal services 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.

Every school in Southwark has at least one child with autism. This illustrates the importance of ensuring that there is understanding, knowledge and experience of autism in every setting. All school staff should receive autism awareness training, to ensure provision of a whole-school environment that is friendly for children with autism. In addition, teaching staff with responsibility for SEN, and/or autism in settings should have specialist autism training.

For some children the provision of alternative or specialist education is required. Within the borough there are 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. While provision is evidently available, demand for places is very high and 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 considerable travel time, and leading to a degree of estrangement from the local community. These placements also come at a high cost to the local authority.

There is also a gap in education provision at both ends of childhood, with not enough early years education for children with autism available to meet needs, and a lack of further education provision for young people with autism who are age 16-25 years.

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<sup>18</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>19</sup> Buckel, M et al. (2014). Southwark Joint Strategic Needs Assessment

<sup>20</sup> Ibid

With demand for specialist provision only likely to increase due to the predicted population rise and high prevalence rate, planning should begin now to address how more children can be educated locally in the future. This will enable good practice to embed as soon as possible.

Southwark is currently exploring proposals to establish a 0-25 pan disability pathway (which would include autism). This should include a review of specialist autism provision to identify whether existing provision meets current needs, and inform future decision making regarding capacity, education and building accommodation across the city. The pathway will need to better address the needs of children and young people whose education needs are not currently able to be met in Southwark, and develop the choice and availability of services and support for young people post-16.

Regardless of current gaps, there is considerable information available to families about existing local education provision and services, including how to get an EHC Plan, how to challenge decisions, and get more support. This can be found on the Local Offer and Southwark Council websites.

Key educational changes arising from the Special Education Needs and Disability (SEND) reforms are currently being implemented locally, and families and carers are encouraged to take an active role in developing and evaluating these either through the Local Offer site, or a local forum such as Southwark Parent Carer Council.

#### **Recommended Actions**

- Review existing autism education provision for age 0-25 years, and identify actions
- Consult with education settings, children and young people with autism, and parent carers to identify existing good practice to share, and better understand current issues and concerns with the system
- Incorporate actions into pan-disability pathway for 0-25 years
- Formulate a five-year plan to build education staff training and skill development
- Identify existing autism training resources for schools available nationally
- Promote existing local autism training available to school staff

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

The Transitions Team supports young people age 14 to 25 years old with disabilities (who are eligible for services), move from child through to adult social care services. The Team's focus is on increasing young people's independence and helping them to plan for the future. This includes developing plans for leaving school, finding work, moving home or finding new interests. The Team works closely with other professionals including health, education and housing, and support is reviewed annually. In year ending March 2014, 25 young people with autism had received support from the Transitions Team.

While this Team clearly demonstrates good practice, many young people with autism currently receiving support from statutory services will not meet the eligibility criteria for adult social care, and will not be able to access the Team's support. There are a large number of young people with autism who do not receive any services, but who still have needs during this life changing period. In addition, there are real difficulties for young people transitioning between child and adult health services (including mental health), with a lack of clear pathways or support to assist the process.

Young people and adults with Asperger syndrome may not have high enough needs to meet service eligibility criteria, but very few other support organisations and groups are currently available. There is a risk resulting in a poor quality of life for young people because of isolation and lack of support, and higher costs to services due to a requirement for costly crisis interventions further down the line.

Southwark Council has produced a number of general resources, providing information about transitions to families and young people. These were created in 2010, and are available hard copy and online. The content should be reviewed and updated as appropriate. Mainstream 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 in this age group, regardless of eligibility, will also assist development with independence and life skills, as well as enabling them to build strong relationships with their peers.

Employment options are prioritised through this transition period. Autistic young people who receive support from the Transition Team have a person-centred assessment process, which 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 part of a local Increasing Employment group, and they and other local schools participated in Increasing Employment Job Fair, ensuring the needs of young people with autism are recognised.

### **Recommended Actions**

- Consult with young people with autism to explore their experiences of transition in more detail and identify development and improvement areas to address
- Increase range of activities available for 14-25 age group
- Develop a transition protocol to address the needs of young people with autism
- Provide autism training to mainstream transition support organisations
- Identify gaps in 16-25 education provision and develop planning process to address
- Ensure clear, up-to-date autism-friendly information and advice about transitions is available, particularly for young people not eligible for social care

d) Employment and training

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

Nationally, adults with autism are significantly under-represented in the labour market: only 15% of adults with autism are in employment (this compares to 48% of people with general disabilities)<sup>21</sup>.

One of the main difficulties adults with autism have to accessing regular employment is a lack of appropriate support. Nationally and locally, there is a range of specialist and mainstream supported employment programmes that people with autism and Asperger syndrome can access, such as Work Choice and Access to Work.

It is vitally important to ensure that information about various sources of employment support is easily available locally and accessible to people with autism, parents and carers.

At present, local employment support services are accessible to adults with autism. Southwark Works is commissioned by the council to deliver employment support to residents with particular needs, including families who are identified as vulnerable. It provides one-to-one support, and can offer a range of employability workshops, including confidence building. This offer could be developed further to address the specific employment needs of people with autism, as well as those who are self-employed and/or employers. The Camden Society also offers employment support for young people and adults, and has strong employer engagement.

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 should be a presumption of employment for all young people and adults with autism, with services exploring creative, flexible and person-centred approaches to developing work experience opportunities. Work experience is an important factor in providing people with skills and experience, helping to attain and sustain employment. The data of young people who are NEET (Not in Employment Education or Training) also needs to be regularly reported on, and shared across services, in order to assist with planning.

The Southwark Employment and Enterprise Development Scheme (SEEDS) helps local employers to give all young Southwark residents new job opportunities. Contracts last 12 months and employers receive a subsidy to help pay 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.

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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

There is one autism-specific employment initiative currently running, as well as several that have operated previously. At present, the local organisation 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, in and outside the hospital, on completion.

In 2012-13, Care Trade also ran a pilot with students from the autism-specialist Spa School, to run a pop-up café. This was well received, and increased skills in all students attending, as well as opening up further opportunities for work experience. It was funded through Southwark Council's Innovation Fund scheme, and provides good learning on which to model future schemes.

Given the success of these schemes and pilots, and the improved outcomes demonstrated for students, consideration should be given to expand existing schemes, and continue the provision of start-up funding (through the Southwark Innovation Fund or others) to boost the growth of new initiatives.

There is a range of other employment services commissioned by Adult Social Care for people with disabilities, including autism, not dependent on eligibility for statutory services. The Increasing Employment project, which includes key stakeholders, delivered an Increasing Employment Job fair in February 2015. This brought together people with autism and/or learning disabilities of all ages, their families, key local services and local employers.

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

### **Recommended Actions**

- Develop an employment pathway for people with autism, clearly setting out routes to services and support
- Identify outcomes of Increasing Employment Job Fair 2015 to inform future planning
- 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 Innovation Fund pilots, and support small-scale employment start-ups on a regular basis
- Provide autism awareness training to local mainstream and disability employment support providers
- 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

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

Many local authorities do not think that care managers receive sufficient training in autism in their initial professional training (71%) or in their ongoing professional training (67%)<sup>22</sup>. A lack of training and subsequent void of understanding can be a major barrier to:

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

The Southwark Autism Strategy will be underpinned by the requirement to ensure commissioners and service providers are skilled, confident, competent and knowledgeable about autism, and understand best practice for working with people with autism.

All staff in Social Work and Transition Teams have an individualised training plan. A requirement is placed on each team member to complete specialist autism training as part of their learning profile. This ensures staff are enabled to carry out effective person-centred assessments of people with autism by recognising and meeting their communication and sensory needs, and to help develop capable environments. This training needs to be delivered on a rolling programme with completion by new staff. Staff should be able to access refresher training as necessary. All community care assessors should have completed autism training of an intermediate level: specific assessment focused training. The impact of this training on practice should also to be measured.

At present, there is an online disability awareness training module, which includes autism, accessible to all council staff. Some staff who work in learning disability services have taken part in autism-specific training, and some other health and social care staff (including Occupational Therapists and staff in older people's services) have taken part in autism awareness training. Training was provided through Southwark Council for only a short period of time. In order to ensure future training best meets needs, a Training Needs Analysis should be completed to identify most appropriate training workshops/formats and current staff needs.

While some training is in place, the numbers of people completing training needs to be monitored (to ensure good take up and that knowledge is regularly renewed) and its impact assessed. The development of a multi-agency training plan will assist with this, to include staff working in autism-specific services, specialised training for frontline staff, and awareness training for universal services. The plan should include statutory services and key stakeholders and partners.

Training content should be informed by people with autism and parent carers, and they should also participate in the delivery of workshops where possible. Cofacilitation ensures the views and experiences of people with autism are directly represented, and is incredibly informative in training staff. Given appropriate support, cofacilitation may also provide people with the skills to deliver autism training on their own.

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<sup>22</sup> Rosenblatt, Mia. (2008) *I Exist: The message from adults with autism in England*. London: The National Autistic Society

There is currently minimal opportunity for professionals to share good practice and troubleshoot concerns, and an online forum or regular network meetings would assist with professional development as well as improving practice, establishing 'autism champions' across the borough.

### **Recommended Actions**

- Undertake a training needs analysis to review all existing provision and identify gaps
- Develop a multi-agency training plan to form a model encompassing all levels of learning, ensuring statutory staff have a basic understanding of autism and creating local experts in autism
- 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 and satisfaction
- 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**

All adults with autism and carers who are eligible for social care services will receive a Personal Budget (PB) to buy or commission services that best meet their needs. This can be managed (solely, or in combination) by themselves, the local authority, or a local organisation.

Local formal and informal consultation with adults with autism and children and families has highlighted the need for increased services including befriending, mentoring, outreach, short breaks and social opportunities. A lack of access to, and suitability of, services can cause social isolation and exacerbate mental health difficulties.

Southwark commissions and supports a wide range of services all of which include the specific remit of supporting people with autism, including those not eligible for statutory services. These services cover a range of support activities including health and wellbeing, peer support/mentoring, and advice and information. A review of these services is currently underway to measure the outcomes achieved.

There are a range of opportunities available for children and adults with autism, including after-school, weekend and holiday activities run by The Camden Society, as well as personalised one-to-one support. Nearby, The Tower Project also has a day opportunities service, offering one-to-one for adults with autism, an evening and weekend service, support to attend appointments, or within the family home, and youth service for young people with autism age 13-19. The Tower Project is accredited by The National Autistic Society Accreditation Scheme. Resources for Autism is a community organisation that runs after school and holiday clubs for children with autism, as well as a youth group for autistic young people. Southwark Autism Support, run by a branch of The National Autistic Society also provides a good information and advice service for local families, including monthly parent carer meetings.

Feedback from parent carers of children and young people in 2014, showed that 62% of felt that there were not enough opportunities for their child to have a social life<sup>23</sup>. This was the most important area of development, and an increase in autism-specific services, as well as access to sports and social activities, were requested. The same consultation showed that 59% of parent carers found it difficult to find out about activities or were not currently aware of any. It is important to note that this was before the Local Offer was introduced in Southwark.

While there are some good services available, they do not appear to be meeting current demand, given the high numbers and needs of children, young people and adults in the borough diagnosed with autism. Mainstream activities should be made more accessible, through staff awareness and training, but development of new autism-specific groups should also be considered.

There is currently very little peer support available for young people and adults with autism, with the only commissioned mentoring service being provided by the Salmon Youth Centre. Peer support is very effective way of enabling people to understand more about their condition, increasing their positivity and empowering them through shared experience. It is also cheap to run, and quick to set up, requiring minimal input from professionals once a group is established. It may be possible to use existing community services with experience in supporting people with autism to assist this development.

The promotion and availability of information about local community services, for adults and children, should be prioritised, to ensure people have awareness and choice with existing provision. The development of an autism benchmark for services will help organisations to reach autism-friendly requirements around communication and approach. If this idea is introduced, it should support quality development, and establish trust between services and local people.

Being engaged in community life reduces social exclusion, isolation and harassment. Universal community services 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 costly statutory health and social care services. Costs will be considered when looking at the commissioning of effective services, however they should not take precedence over the needs of people with autism and the services they actually require.

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<sup>23</sup> Focus Group Report: Autism in Southwark. (2014)



Another barrier for people with autism and their families, can be travel and transport. They may have difficulties using these, further hindering access to existing services and support.

The blue badge scheme and bus passes are invaluable for many. To avoid inconsistent allocation of badges and passes due to lack of understanding of the impact of autism on a person's mobility, autism awareness training should be available for staff working in the travel and transport departments, and with parking enforcement officers. Autism training should also be provided to all escorts working on school or service transport. A standard definition/description of autism, highlighting mobility concerns, should be used consistently when assessing applications for badges and passes. Information about the application process needs to be widely available.

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.

### **Recommended 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
- 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
- Develop a benchmark or 'autism-friendly' criteria in partnership with people with autism, 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 staff providing travel escort staff, and those working in 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

### **Carers**

Without the right support and planning, the health and wellbeing of families and carers can suffer, affecting their ability to continue in their caring roles. This is particularly true of the growing number of older carers. Southwark has a three year plan as part of its Carers Strategy. This references the needs of carers supporting people with autism, and establishes improvements and changes to local services. It also sets out a range of 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 services, including people with autism. This generally takes place alongside a community care assessment or the person with autism's review. However, carers can request an assessment of their needs in their own right, and can currently do this through the Southwark Carers organisation. Southwark Carers are 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.

Consultation with parent carers of children and young people identified that 53% said they would like more support<sup>24</sup>. There are currently gaps in carer support provision, particularly for people who are not eligible for statutory support. There should be a range of support that considers the needs of everyone. This includes out of school care, assistance at home, in the community, during evenings and weekends, and holiday times. Two specific groups of people for whom there is little available support are siblings of children and young people with autism and partners of adults with autism. 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.

### **Recommended Actions**

- Consult with local carers of people with autism about the services currently most useful to them, and those most wanted
- Promote access to carer support through all local networks and universal services
- Provide training to parent carers, siblings and partners about what autism is and how to support someone
- Identify opportunities to develop groups for siblings and partners, to promote peer-support

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

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

The Southwark Learning Disability Accommodation Strategy has recently been reviewed. This used a comprehensive housing needs analysis to look at the support needs of people with learning disabilities and/or autism, and will support the development of a wide range of accommodation service responses to meet these needs over a 10 year plan. This includes bespoke accommodation and support for young people with autism in transition to adulthood, and adults with autism. Southwark's new long-term housing strategy was agreed in early 2015. 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.

Autism needs should be considered when work is done towards 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 the condition is taken into consideration when assessing suitability for placement. Data on the numbers of people with autism using housing services is sparse. Multi-agency planning should include sharing data from housing agencies to assist understanding of needs and demand.

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<sup>24</sup> Focus Group Report: Autism in Southwark. (2014)

Housing staff have completed disability awareness training (which includes autism)<sup>25</sup>. The need for any autism specific training should be identified and implemented through a multi-agency training plan.

### **Recommended Actions**

- Ensure a representative from housing services and support agencies liaises with 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**

Southwark has an economically and ethnically diverse community. There is a high turnover of residents, which means it is difficult to have a consistent picture of local needs. Information from the 2011 Census, and a recent Joint Strategic Needs Assessment (JSNA) indicates that 60.3% of the local population is ethnic minority, with just over 30% of people born outside of the European Union (EU). Southwark is also the 41<sup>st</sup> most deprived local authority in England.

More than half of the children who have a statement for the primary need of autism come from a Black Minority Ethnic (BAME) background, with the majority of those from Black African communities<sup>26</sup>.

Cultural and deprivation considerations impacts on the type and delivery of support and services available.

Local assessment and care planning is individualised and responds to individual needs including those arising from race, ethnicity and culture. All staff receive training in diversity and their responsibilities under the Equalities Act. Support services have been, and are in process of being, developed locally to reduce people from BAME communities being placed out of borough which would often have meant placement in a less culturally-diverse environment<sup>27</sup>.

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

<sup>26</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>27</sup> Southwark SAF. (2014)

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>28</sup>

A National Autistic Society report into the difficulties faced by BAME communities, found that many parents and carers, especially migrants from non-English-speaking countries, face a particular challenge 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>29</sup>.

There is a wide range of BAME services across Southwark, as well as access to organisations in the wider London area. Locally, 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.

Southwark Council has a range of guidance and support for people and families with a low income, including a Hardship Fund, information about healthy eating/cooking, housing, and benefits and welfare advice (in particular Southwark Rightfully Yours, which helps vulnerable residents to claim the benefits they are entitled to). Information is available through the council website, but is scattered across various pages. To support communication and understanding, it will assist the consistency of message and ease the search for information, if all relevant information is stored in one place. While staff working in council information and advice services have access to the online disability awareness training module, the take-up of this training should be monitored. Frontline staff working with BAME and vulnerable communities should have a good understanding of autism and how to communicate, and access to autism training to support this.

Autism training and awareness for staff working in mainstream BAME services will enable professionals to better engage with, and support, people with autism within their local communities. Autism services and assessment processes should be shared and promoted with community and cultural groups, in a variety of formats.

### **Recommended Actions**

- Survey 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 can demonstrate understanding of different cultural needs
- Review Southwark Council website to identify how information could be more clearly presented

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<sup>28</sup> *Missing Out? Autism, Education and Ethnicity: The Reality for Families Today*. London: The National Autistic Society. (2007)

<sup>29</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.

## Aging and Gender

With an aging population, there is national concern about the ability of services to meet the long term needs of adults with autism. As such a high percentage of adults with autism are currently unemployed or on benefits, there will be substantial costs involved in providing support in older age. Many adults with autism also live with their parents or carers, rather than independently, and consideration needs to be given for when this set up may break down due to the death of a carer or the inability of a carer to support the increasing needs of the person with autism. In many cases, those older adults who do have a diagnosis of autism will not have received their diagnosis until relatively late in life. People who have been diagnosed 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>30</sup>.

Capacity should be built into existing services for older people, and training made available, to ensure that professionals have a good understanding of autism.

Planning for the needs of older adults with autism should begin now, with a consistently moderate response, rather than critical reaction, which will have much greater costs. The views and needs of existing younger and older people with autism should be sought to inform the developments required across all services, including housing, social care and health.

Nationally, many women with autism are not being diagnosed and are therefore not receiving the help and support needed throughout their lives. Having a diagnosis is the starting point in providing appropriate support for girls and women on the spectrum. A timely diagnosis can avoid many of the difficulties women and girls with autism experience throughout their lives<sup>31</sup>.

In Southwark, all assessment and support planning responds to individual needs including those arising from gender. With autism being considerably less prevalent in women than in men, consideration should be given to ensure that planning takes full account of the needs of women with autism. This is demonstrated by recent developments to create an in-borough residential facility, where the gender balance of residents is seen as a key priority.

Autism training should include reference to the specific needs of older people with autism, and women with autism.

### Recommended Actions

- Ensure all autism training includes reference to the specific needs and considerations of older people with autism and women with autism
- Include autism training as a contractual requirement for older people's services
- Ensure staff working in older people's services have access to autism awareness training
- Gather information on the numbers of people over 65 with autism in the local area, and include these figures in JSNAs to support planning
- Identify opportunities to address the needs of older people with autism in housing, employment and care strategies

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<sup>30</sup> Boehm, A. (2013) *Getting On. Growing older and autism. Autism and Ageing*. London: The National Autistic Society.

<sup>31</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>

- Identify opportunities to engage with local dementia care initiatives
- Provide specific training to key frontline staff (education, health and social care) on autism and ageing, and autism and women and girls

### **CJS – local needs and provision, engagement with services**

Data on people with autism within the Criminal Justice System (CJS) is sparse. Whilst only a minority of people with autism come into contact with the CJS 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>32</sup>.

Southwark Council has a close relationship with the police, probation and court services in regards to supporting and planning for the needs of people with autism in contact with the CJS. There is good liaison and cooperation through procedures for safeguarding children and adults, and all agencies take a partnership approach to supporting individuals to prevent reoffending behaviours. CJS services have access to local forensic psychiatry and psychology services to ensure effective intervention designed to take into account specific communication and sensory needs.

There are 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.

Police services have had general mental health training, and interview training includes consideration of various needs/vulnerabilities including mental health and learning difficulties, and the use of intermediaries where appropriate. The Missing Persons Unit (MPU) has engaged with an NHS speech and language expert in relation to understanding/communication with regular missing persons with severe 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 CJS<sup>33</sup>. A greater sensitivity to the needs of people with autism is required. Currently, CJS staff in the court, probation and frontline, 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.

In other localities, Autism Alert Card schemes have been successful in improving communication between people with autism and the police, and raising awareness amongst CJS professionals. If this is implemented locally, it will support the process of developing better engagement with police and emergency services in Southwark. It should also aid the police in identifying people with autism more quickly, and assist people with autism in communicating their needs and seeking help.

The safeguarding of children and young people with autism requires an understanding of risk taking behaviours and it may be necessary to increase the relevant knowledge and skills of autism of the police and youth offending services. Data sharing between CJS youth and adult services, and between CJS and health

<sup>32</sup> *Criminal justice system and ASDs*. Available at: <http://www.autism.org.uk/working-with/criminal-justice/criminal-justice-system-and-asds.aspx>

<sup>33</sup> *Autism: A Guide for Criminal Justice Professionals*. London: National Autistic Society. (2008)

and social care services will also ensure better transition of support and understanding of local needs.

### **Recommended Actions**

- Provide autism training to professionals working in the CJS
- Identify opportunities for data collection on young people and adults involved in 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 CJS and autism-specific training and information resources, and consider local implementation

## **5. Summary**

Southwark Council and Southwark CCG are dedicated to improving local services and support for adults and children with autism. Good practice will be shared and built on, developing new services and strengthening existing models. Development priorities and methods of change will be led and shaped by local people with autism, families and professionals.

This draft strategy sets out the direction that Southwark may take. Feedback on the content and selected actions, will be used to inform a final strategy document that will shape delivery over the next five years.

## 6. Actions

### 1. Lifelong care and support

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

- Form a working group to develop data sharing practices across relevant health and social care services
- Identify other data collection practices e.g. local autism needs register, and consider implementation locally
- 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 from SLaM teams 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 placements in- and out-of county, 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 – either an Autism Partnership Group or sub-group of the Learning Disability Partnership Board
- Undertake a full service mapping exercise to detail range 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; representatives should demonstrate regular attendance and/or engagement

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

- Provide specialist autism training to care managers and social workers carrying out assessments of need
- Monitor take up of disability awareness online module and promote necessity of completion to all staff
- Identify specific autism awareness training to roll out to social and health care staff involved in assessments
- Monitor capacity and skills of CASC 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
- Ensure professionals involved in care planning have received recent training in autism
- Establish a formal process by which people with autism and their families will be consulted with about their needs and quality of life, with opportunities at least annually, including monitoring of feedback to develop and improve services



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

- Map key risk areas for children and young people and identify gaps in provision
- Develop a crisis intervention framework for children and adults with autism
- Monitor and evaluate ongoing impact of Enhanced Intervention Service
- Identify gaps in preventative services and development areas

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

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

## **2. Choice and control**

### **Autism diagnosis and assessment – adults**

- Clearly define adult diagnostic pathway process including referral, assessment, signposting and post-diagnostic support
- Ensure adult diagnostic pathways deliver 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 accuracy of referrals made (that result in a diagnosis of autism)
- Promote information about adult diagnostic pathways to local people and support organisations
- Consult with adults with autism who have recently gone through the diagnostic assessment process, to understand what post-diagnostic support would most benefit 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, hospital, primary and secondary care awareness**

- Ensure health staff access to autism awareness training
- Implement specialist autism training for GP and frontline practitioners and monitor take up
- Engage with identified local GP lead for autism/learning disabilities to feed into any local autism strategy/development group
- Identify gaps in child and adult therapy services and develop action plan to build capacity
- Pilot *My Hospital Passport* scheme in one local hospital and evaluate impact
- Facilitate multi-agency discussions about data covering service users, demand, and gaps; identify actions to improve delivery

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

- Identify appropriate autism targets for future advocacy commissioning
- 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, ensuring meaningful engagement with people with autism in development, delivery, implementation and scrutiny
- 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
- Identify opportunities and locations to promote autism resources
- Define a range of hard copy information about assessments and signposting to be made available to local services e.g. libraries, GP surgeries

### 3. Children

#### **Needs**

- Improve collection, analysis and data sharing between child and adult services
- Address data recording methods in children and young people's services, supporting the collection of more comprehensive data on the needs of people with autism

#### **Assessment and diagnosis – children**

- Ensure child diagnostic pathways deliver in line with NICE Guidelines
- Ensure all frontline/primary healthcare staff (including GPs) are aware of child diagnostic pathways and can refer appropriately
- Promote information about child diagnostic pathways to local people and support organisations
- Identify data required from diagnostic services and highlight opportunities to share information between services

#### **Education**

- Review existing autism education provision for age 0-25 years, and identify actions
- Consult with education settings, children and young people with autism, and parent carers to identify existing good practice to share, and better understand current issues and concerns with the system
- Incorporate actions into pan-disability pathway for 0-25 years
- Formulate a five-year plan to build education staff training and skill development
- Identify existing autism training resources for schools available nationally
- Promote existing local autism training available to school staff

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

- Consult with young people with autism to explore their experiences of transition in more detail and identify development and improvement areas to address

- Increase range of activities available for 14-25 age group
- Develop a transition protocol to address the needs of young people with autism
- Provide autism training to mainstream transition support organisations
- Identify gaps in 16-25 education provision and develop planning process to address
- Ensure clear, up-to-date autism-friendly information and advice about transitions is available, particularly for young people not eligible for social care

#### 4. Employment and training

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

- Develop an employment pathway for people with autism, clearly setting out routes to services and support
- Identify outcomes of Increasing Employment Job Fair 2015 to inform future planning
- 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 Innovation Fund pilots, and support small-scale employment start-ups on a regular basis
- Provide autism awareness training to local mainstream and disability employment support providers
- 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

##### **Workforce development – training needs, provision, take-up and evaluation/monitoring**

- Undertake a training needs analysis to review all existing provision and identify gaps
- Develop a multi-agency training plan to form a model encompassing all levels of learning, ensuring statutory staff have a basic understanding of autism and creating local experts in autism
- 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 and satisfaction
- 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

## 5. 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
- Develop a benchmark or ‘autism-friendly’ criteria in partnership with people with autism, that community services are tasked with reaching
- Discuss the development of 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 staff providing travel escort staff, and those working in 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

### **Carers**

- Consult with local carers of people with autism about the services currently most useful to them, and those most wanted
- Promote access to carer support through all local networks and universal services
- Provide training to parent carers, siblings and partners about what autism is and how to support someone
- Identify opportunities to develop groups for siblings and partners, to promote peer-support

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

- Ensure a representative from housing services and support agencies liaises with 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 involve people with autism in the design and review

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

- Survey 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 can demonstrate understanding of different cultural needs

- Review Southwark Council website to identify how information could be more clearly presented

### **Aging and Gender**

- Ensure all autism training includes reference to the specific needs and considerations of older people with autism and women with autism
- Include autism training as a contractual requirement for older people's services
- Ensure staff working in older people's services have access to autism awareness training
- Gather information on the numbers of people over 65 with autism in the local area, and include these figures in JSNAs to 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
- Provide specific training to key frontline staff (education, health and social care) on autism and ageing, and autism and women and girls

### **CJS – 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 in 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 CJS and autism-specific training and information resources, and consider local implementation

## **7. Good Practice**

### **Training**

#### **Cornwall – Training project**

Cornwall has run an autism training project since 2009 and trained over 5,000 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 800 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 APG 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 30 members, and meets at various settings across the county. It has co-produced the autism strategy with the APG 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.