SOMERSET AUTISM STRATEGY

June 2014

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# SOMERSET AUTISM STRATEGY

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1 Introduction

This Strategy has been produced by the Somerset Autism Planning Group which is a multi-agency group, chaired by Somerset County Council. It brings together different agencies and stakeholders, spanning health and social care commissioning, relevant health and social care services, children’s services, the National Autistic Society (NAS). Representation from people with autism and people who care for someone with autism has also happened through the Planning Group and by running a range of surveys.

The Strategy sets out our strategic priorities here in Somerset and has been written in response to ‘Fulfilling and Rewarding Lives: the strategy for adults with autism in England.” It has been developed during a time of organisational change within statutory services and also at a time when health and social care services are under financial constraints. The outcomes identified within this Strategy will therefore have to be achieved using available resources, within the statutory agencies.

The multi agency group have also been guided by recent recommendations from the Department of Health regarding Winterbourne View and NHS Commissioners are working to meet the requirements of a national timetable of actions, to redesign the care and support provided for people with learning disabilities or autism and mental health conditions, or behaviours described as challenging.

It is recognised that adults’ and children’s services need to work together to put in place the necessary changes needed.

2 Defining Autism

Autism is a spectrum condition meaning the condition affects people in different ways. Some exhibit mild characteristics of autism and live largely independent lives, while others with more severe autism or coexisting conditions may require more intensive support.

The term autism describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact. In addition to these features, people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems, including: a need for routine; difficulty understanding other people, including their intentions, feelings and perspectives; sleeping and eating disturbances; dyspraxia or motor coordination problems; and mental health problems such as anxiety, depression, problems with attention, sensory sensitivities, self-injurious behaviour and other challenging, sometimes aggressive, behaviours. Asperger syndrome is a form of autism that affects how people process information and relate to other people. While there are similarities with autism, people with Asperger syndrome have fewer problems with speaking and are often of average or above average intelligence.

Some older people have lived with autism for their entire life without ever getting a formal diagnosis. This was because autism wasn’t widely known or understood when they were younger.
Living with autism can substantially affect a person’s quality of life and that of their families or carers. Many carers of people with autism face significant daily challenges and the pressures of living with and supporting people who see the world very differently, who can appear unresponsive or who can present with behaviour that challenges at times can be considerable. When caring for a person with autism, the caring role can sometimes be lifelong and can persist whether or not the person with autism lives with their carer or not. The person with autism can also lack insight into their condition and can reject care and support services that are intended to support the carer.

A significant proportion of adults with autism across the whole autistic spectrum experience social and economic exclusion. Autism has life-time consequences, with a range of impacts on the health, economic well-being, social integration and quality of life of individuals with the condition and also their parents, families and the wider community. Many of these impacts can be expressed as economic costs.

Autism is not a curable condition. This strategy reflects the NAS view that “this does not mean, however, that nothing can be done for a person with autism. There is a growing movement among adults with autism, who don’t think in terms of ‘curing’ autism, but instead, of celebrating difference.”

3 The National and Local Context

Nationally, around 700,000 people may have an autistic spectrum condition which is just above 1:100 in the population. The population of Somerset is 530,000, so it is estimated that approximately 5,300 people may have autism.

Around four times more men than women have diagnosed autism, although this may be due to under recognition in women.

Autism often co-exists with other learning disabilities/difficulties, physical disabilities and mental health problems. Around 50% of people with autism have a learning disability. National figures estimate that 70% of individuals with autism also meet diagnostic criteria for at least one other (often unrecognised) mental and behavioural disorder, and 40% meet diagnostic criteria for at least 2 disorders, mainly anxiety, attention deficit hyper activity disorder (ADHD) and oppositional defiant disorder (ODD).

In Somerset, of the 367 children and young people recorded as High Needs (School Action Plus) or a Statement with autism as the primary need in 2013; 26% have a secondary need of which Speech, Language & Communication Needs and Behaviour, Emotional & Social Difficulties are the main ones (7% and 6% respectively).

Latest figures from the National Autistic Society indicate that for someone with high-functioning autism, or Asperger syndrome, the lifetime cost is £3.1m and for someone with autism and a learning disability, the cost was 50% higher at £4.6m. These figures include the “hidden” costs of family carers and voluntary services.

Research shows only 15% of people with autism are in full-time employment and 9% are in part-time employment, while 79% of people with autism on out-of-work
benefits say they would like to work, with the right support. What's more, 26% of graduates with autism are unemployed; around twice the proportion of any other disability group, according to the Association of Graduate Careers Advisory Services.

At the end of 2012 there were 1,659 people diagnosed with a condition in the autistic spectrum and recorded on Somerset GP clinical systems. This figure is about a third of that suggested above and may reflect low recognition of the condition, especially in the older population. Rates of diagnosed ASD are much higher in young people, and there are 4 times as many male patients as female. Just over 40% of the diagnoses were for Asperger syndrome.

There is variation in the prevalence in different parts of the county, with a particularly high concentration in the North Sedgemoor Federation area and a particularly low concentration in Bridgwater Bay Health Federation area. This may be because of a true difference in the proportion of people with such conditions and/or the proportion of cases that are diagnosed. There was no evidence of the rate of diagnosed ASD increasing or decreasing by increased deprivation. There is a summary of data in Appendix 2 Data.

In Somerset there is a need to improve the collection of information and data about autism, across the age spectrum with a range of agencies and people with autism and carers. This will be used to inform future planning and change.

4 National Policies

4.1 The Autism Act 2009

The Act became law in November 2009 and was the first ever condition-specific piece of legislation in England and Wales. The Act placed new responsibilities on NHS bodies and local authorities for the planning and provision of services for adults with autism. The Act does not apply to children, but does cover the transition period into adult services so does cover young people from age 14 +.

4.2 ‘Fulfilling and Rewarding Lives’ – Autism Strategy for Adults

The first national autism strategy for adults was published by the Department of Health in March 2010 and statutory guidance for local authorities and NHS organisations followed in December 2012. The Strategy was reviewed in 2014 and the Think Autism response published, noting all the existing recommendations and duties from Fulfilling and Rewarding Lives still apply to local authorities and NHS bodies. The Strategy sets out a clear framework for all mainstream services across the public sector to work together for adults with autism. The vision states:

“....for all adults with autism to be able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and accept support if they need it, and they can depend upon mainstream public services to treat them fairly as individuals, helping them to make the most of their talents.”

The National Strategy highlighted five core areas for development and action:

- Increasing awareness and understanding of autism across all public services
• The development of clear, consistent pathways for diagnosis in every area, which is followed by the offer of a personalised needs assessment by the local authority

• Improving access for adults with autism to mainstream public sector services and the support they need to live independently within the community

• Helping adults with autism into work

• Building capacity and capability at a local level to enable local partners to plan and develop relevant services for adults with autism to meet identified needs and priorities.

These core areas are equally important in relation to children with autism.

There are three new key proposals in the updated Think Autism Strategy additional to the 2010 Strategy and are expected to make the biggest difference to the lives, services and support for adults with autism over the next 5 years:

  - **Autism aware communities** – Think Autism community awareness projects will be rolled out. There will be pledges/awards for local organisations to work towards to show that they are autism-aware.
  
  - **The Autism Innovation Fund** – there will be funding available for projects which promote innovative local services and projects, particularly for ‘lower level’ preventative support for people with autism who do not qualify for social care support from their local authority.
  
  - **Better data collection, and more joined up advice and information services** – this includes a new way of social care staff (such as social workers) recording autism as someone’s condition.

### 4.3 Transforming care: a national response to the Winterbourne View Hospital Review (2012)

The response outlines a programme of action introduced by the Department of Health following the documented abuse. It requires the NHS and Local Authority commissioners to complete a 3 stage process, in order to comprehensively review the care of “people in hospital with learning disabilities or autism with mental health conditions or behaviour that challenges” placed outside of their local area.

### 4.4 Closing the Gap: Priorities for essential change in mental health

The priorities challenge the health and social care community to go further and faster to transform the support and care available to people with mental health problems, for both children and adults. It also challenges the public health community, with local government in the lead, to help give mental health and wellbeing promotion and prevention the long overdue attention it needs and deserves. It identifies 25 aspects of mental health care and support where government – along with health and social care leaders, academics and a range of representative organisations – expect to see tangible changes in the next couple of years.
4.5 Care Act 2014

The Act brings care and support legislation into a single statute. It is designed to create a new principle where the overall wellbeing of the individual is at the forefront of their care and support. To promote individual wellbeing, their needs, views, feelings and wishes should be considered in all aspects of their wellbeing from physical and mental health, through dignity and respect to control over their daily needs, access to employment, education, social and domestic needs and the suitability of their accommodation. It also requires the promotion of integration of care and support with local authorities, health and housing services and other service providers to ensure the best outcomes are achieved for the individual.

4.6 NICE Guidelines

- Management of autism in children and young people - August 2013
- Autism: Recognition, referral, diagnosis and management of adults on the autism spectrum
- NICE Support for commissioning for Autism – still draft

(see Appendix 1 for NICE Clinical Guidelines)

4.7 Children and Families Act 2014

The Government is transforming the system for children and young people with special educational needs (SEN), including those who are disabled, so that services consistently support the best outcomes for them. The Bill will extend the SEN system from birth to 25, giving children, young people and their parents’ greater control and choice in decisions and ensuring needs are properly met. There will be a single, simpler assessment process for children with special educational needs or disabilities, backed by a new Education, Health and Care (EHC) plan.

5 Governance and Monitoring of the Strategy

The Somerset Autism Planning Group was established a number of years ago to bring together key organisations and representatives of people with autism and their carers. The Somerset Autism Steering Group for children and young people was established in 1995 and latterly has linked with the Autism Planning Group.

In order to take this Strategy forward a new Autism Strategy Group will be established, replacing the Planning Group and the Steering Group. The new group will be responsible for ensuring that the key priorities, identified in the Strategy are implemented through the Action Plan in Appendix 4.

We will establish a communications plan to ensure we inform key stakeholders and the general public on the progress of the implementation of the Strategy.
This Strategy Group will report to the Adult Services Partnership Board and the Somerset Children’s Trust.

There will be four subgroups created that will take forward the actions on pages 23-26. The subgroups will be:

- Living with Autism
- Workforce Development
- Identification and Diagnosis
- Education, Work, Training and Transitions

We will also work with other programmes that are concentrating on:

- Children and Adults mental health services
- Jointly commissioned services (education, health & social care)
- Learning Disability work areas
- Children and Families Bill
- Personal Budgets and Personalisation
- Crime and Disorder
- Early Help
- Transitions
- Care Act
- Better Care Fund
- Raising Participation Age

### 6 Vision for Somerset

Somerset aims to significantly improve knowledge and understanding of autism amongst the general public, statutory services, the voluntary sector and community based groups.

We aim to improve the way we all work together utilising the resources that are available to meet needs and improve outcomes for people with autism and their families/carers and give the information and support they need to remain as independent as possible.
6.1 Recommendations for action:

- Increase awareness and understanding of autism including training and development for the public, front line services (including Police, Housing etc), people with autism and their families and carers including schools and educational settings.

- Improve access to diagnostic services and post diagnostic support for children, adults and families through early help, support and advice; offering quality services that are good value for money.

- Improve the way that the Somerset Clinical Commissioning Group and Somerset County Council commission services for people with Autism. Work with providers to ensure services meet the assessed needs of people in Somerset with autism and their carers.

- Promote a ‘Person Centred’ approach to ensure that people with autism and their carers can take as much control as possible of their lives and the support they receive. Including personal budgets for those that are eligible for on-going social care funded support and for those children and young people with an Education Health Care Plan.

- Improve access to services to facilitate independent living to enable more choice and control over where people with autism live and with whom.

- Develop seamless and effective transitions throughout the child's life and into adulthood depending on individual need.

- Improve access and support for children, young people and adults with autism to access appropriate education, work and training.

- Improve the way we work with people with autism and their carers in the effective co-production of services and support.

- Ensure that people are aware of an able to access information about the different services available for autism.

7 Safeguarding

7.1 Children and Young People

Safeguarding children - the action we take to promote the welfare of children and protect them from harm - is everyone’s responsibility. Everyone who comes into contact with children and families has a role to play. The Working Together to Safeguard Children (March 2013) outlines:

- The legislative requirements and expectations on individual services to safeguard and promote the welfare of children; and

- A clear framework for Local Safeguarding Children Boards (LSCB’s) to monitor the effectiveness of local services.
7.2 Adults

Health & Social Care commissioners work in partnership with each other and the Police to protect and safeguard vulnerable adults.

As the Safeguarding lead, Somerset County Council’s Adult Social Care Service is responsible for investigating any situation where an ‘adult at risk’ may be experiencing some form of harm or exploitation.

An ‘adult at risk’ (or ‘vulnerable adult’) is a person aged 18 or over who is limited in their ability to protect themselves from harm or exploitation because they have a disability (including autism), or a mental or physical health problem, or are elderly and frail.

For further information about adults safeguarding please see:

www.somerset.gov.uk/adult-social-care/safeguarding/
1.1 Autism Quality Standards (January 2014)

This quality standard covers autism in children, young people and adults, including both health and social care services.

The quality standard for autism specifies that services should be commissioned from and coordinated across, all relevant agencies encompassing the whole autism care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to people with autism and their families and carers.

List of quality statements

- **Statement 1.** People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.

- **Statement 2.** People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

- **Statement 3.** People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.

- **Statement 4.** People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.

- **Statement 5.** People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.

- **Statement 6.** People with autism are not prescribed medication to address the core features of autism.

- **Statement 7.** People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

- **Statement 8.** People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

The full guidance can be found at: [http://guidance.nice.org.uk/QS51](http://guidance.nice.org.uk/QS51)
This clinical guideline offers best practice advice on the care of children and young people with autism.

Autism is used in the guideline to refer to autism spectrum disorder, autistic spectrum condition and Asperger syndrome.

Key priorities for implementation

- Access to health and social care services
- Knowledge and competence of health and social care professionals
- Making adjustments to the social and physical environment and processes of care
- Psychosocial interventions
- Anticipating and preventing behaviour that challenges
- Psychosocial interventions for behaviour that challenges
- Pharmacological interventions for behaviour that challenges
- Families and carers – sources of support plus formal carers assessment if appropriate
- Transition to adult services

The full guidance can be found at: [http://guidance.nice.org.uk/CG170](http://guidance.nice.org.uk/CG170)
1.3 Clinical Guidelines - Autism: recognition, referral, diagnosis and management of adults on the Autism spectrum (June 2012)

This guideline covers the care provided by primary, community, secondary, tertiary and other health and social care professionals who have direct contact with, and make decisions concerning the care of, adults with autism.

Key priorities for implementation are:

- General principles of care
- Identification and assessment
- Identifying the correct interventions and monitoring their use
- Interventions for autism
- Interventions for challenging behaviour
- Interventions for coexisting mental disorders
- Assessment and interventions for families, partners and carers
- Organisation and delivery of care

The full guidance can be found at: http://guidance.nice.org.uk/CG142
Appendix 2 Data

Figure 1: Number of people recorded with Autism spectrum conditions at Somerset GP practices by gender and age group

Figure 2: Number of people recorded with Autism spectrum conditions at GP practices per 1000 population registered at practices by gender and age group

Figure 3: Number of specific diagnoses recorded – Females
Figure 4: Number of specific diagnoses recorded – Males

Figure 5: Comparison of Observed and Expected number of people recorded with Autism spectrum conditions in GP practices – by GP Federation
This, and the following figure, are within-Somerset comparisons of diagnosis rates and is not looking at the proportion of true cases that are diagnosed: the expected numbers are calculated by applying the Somerset age/gender specific rates to the population of the Federation or deprivation quintile of practices.

Figure 6: Prevalence of autistic spectrum disorders (ASD) and speech, language and communication need (SLCN) in schools

<table>
<thead>
<tr>
<th></th>
<th>England</th>
<th>South West</th>
<th>Somerset</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary schools</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total on roll</td>
<td>4,309,580</td>
<td>380,370</td>
<td>36,018</td>
</tr>
<tr>
<td>ASD as primary need</td>
<td>25,880</td>
<td>2,050</td>
<td>124</td>
</tr>
<tr>
<td>Statement or School Action Plus (SA+)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage of all pupils</td>
<td>0.6%</td>
<td>0.5%</td>
<td>0.3%</td>
</tr>
<tr>
<td>SLCN as primary need or SA+</td>
<td>102,185</td>
<td>9,350</td>
<td>529</td>
</tr>
<tr>
<td>Percentage of all pupils</td>
<td>2.4%</td>
<td>2.5%</td>
<td>1.5%</td>
</tr>
<tr>
<td><strong>Secondary schools</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total on roll</td>
<td>3,210,120</td>
<td>317,245</td>
<td>31,002</td>
</tr>
<tr>
<td>ASD as primary need</td>
<td>24,165</td>
<td>2,405</td>
<td>168</td>
</tr>
<tr>
<td>Statement or SA+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage of all pupils</td>
<td>0.8%</td>
<td>0.8%</td>
<td>0.5%</td>
</tr>
<tr>
<td>SLCN as primary need or SA+</td>
<td>102,185</td>
<td>2,495</td>
<td>278</td>
</tr>
<tr>
<td>Percentage of all pupils</td>
<td>3.2%</td>
<td>0.8%</td>
<td>0.9%</td>
</tr>
<tr>
<td><strong>Special schools</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total on roll</td>
<td>98,595</td>
<td>7,865</td>
<td>440</td>
</tr>
<tr>
<td>ASD as primary need</td>
<td>20,735</td>
<td>1,530</td>
<td>71</td>
</tr>
<tr>
<td>Statement or SA+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage of all pupils</td>
<td>21.0%</td>
<td>19.4%</td>
<td>16.1%</td>
</tr>
<tr>
<td>SLCN as primary need or SA+</td>
<td>5,120</td>
<td>290</td>
<td>5</td>
</tr>
<tr>
<td>----------------------------</td>
<td>-------</td>
<td>-----</td>
<td>---</td>
</tr>
<tr>
<td>Percentage of all pupils</td>
<td>5.2%</td>
<td>3.7%</td>
<td>1.1%</td>
</tr>
</tbody>
</table>

Source: January 2013 School Census

Figure 7: Number of statements or School Action Plus (SA+) for which ASD is the primary need.

<table>
<thead>
<tr>
<th></th>
<th>Somerset</th>
<th>Taunton Deane</th>
<th>West Somerset</th>
<th>South Somerset</th>
<th>Mendip</th>
<th>Sedgemoor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Years Foundation Stage</td>
<td>12</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Key Stage 1</td>
<td>26</td>
<td>7</td>
<td>1</td>
<td>7</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Key Stage 2</td>
<td>119</td>
<td>18</td>
<td>3</td>
<td>22</td>
<td>38</td>
<td>38</td>
</tr>
<tr>
<td>Key Stage 3</td>
<td>93</td>
<td>24</td>
<td>4</td>
<td>25</td>
<td>26</td>
<td>14</td>
</tr>
<tr>
<td>Key Stage 4</td>
<td>91</td>
<td>18</td>
<td>7</td>
<td>23</td>
<td>32</td>
<td>11</td>
</tr>
<tr>
<td>Key Stage 5 / Post-16</td>
<td>26</td>
<td>6</td>
<td>1</td>
<td>7</td>
<td>7</td>
<td>5</td>
</tr>
</tbody>
</table>

Source: January 2013 School Census
3.1 Information and Support Networks

**Autism Somerset**

Autism Somerset (Somerset Autism Community Network) is a user-led organisation dedicated to the needs of those affected by autism.

The website provides a comprehensive directory and calendar of events as well as monthly e-bulletins which highlight national and local activity.

The network aims to connect those affected by autism and associated conditions with each other. Membership is open to all, at no cost. On signing up, members allocate themselves to, one or more of, 3 categories:-

- Individuals and their families
- Health, education and social care professionals
- Providers of support and care

The directory aspires to be indispensible to families, clinicians and professional alike and is committed to the promotion of effective cross sector and cross agency working.

**National Autistic Society**

The National Autistic Society (NAS) is the UK’s leading charity for people affected by autism. Health & social care commissioners attend South West network meetings and an NAS representative attends the county-wide Autism Planning group.

NAS are also responsible for some regional work, including the Autism Strategy Implementation peer review/stock take exercise. Somerset has been involved in the peer review process and this has usefully informed our Self-Assessment return, as well as our Autism Strategy.

Contact: 020 7833 2299 and nas@nas.org.uk

**Somerset Parent and Carer Forum (SPCF)**

SPCF is for anyone caring for children/young people aged 0-25 years with any disability and/or additional need. They aim to empower and involve parent carers to have their say in order to influence local and national decision making. On the website there is ‘Finding Your Way,’ an online handbook and Directory of Services for parents and carers.

Contact: 01278 699397 and help@somersetparentcarerforum.org.uk

**Somerset Parent Partnership**

SPP is a statutory service which provides impartial information and support for parents and carers of children with Special Educational Needs. It offers a range of services, including leaflets relating to SEN, a telephone enquiry line, individual support through trained Independent Parental Supporters and a website.
Contact: 01823 355578 and enquiries@somersetparentpartnership.org.uk

**The Choice Advice Service**

This service offers advice and support to all parents on the school admissions and appeals procedures.

Contact 01823 356903 and choiceadvice@somerset.gov.uk

**Somerset Direct**

This service provides advice and information for the general public and is a point of contact for social care referrals. Training is delivered for call handlers when communicating with people who have an autistic spectrum condition. The Emergency Duty Team (EDT) provides an out of hours contact for social care on 01458 253451.

Contact: adults 0845 345 9133 and adults@somerset.gov.uk
children 0845 345 9122 and children@somerset.gov.uk

**Village Agents**  [www.somersetrcc.org.uk/work-village-agents-project.php](http://www.somersetrcc.org.uk/work-village-agents-project.php)

Village Agents are employed on a part time basis by the Community Council for Somerset to become trusted members of their communities and a valuable resource. They network extensively with Parish Councillors, Police Community Support Officers, social group organisers, transport providers, church groups, youth workers and others within their community. They receive ‘referrals’ from agencies and members of the community about people needing information or support. Village Agents make home visits when necessary and provide high-quality information. Village Agents identify unmet needs within their community and respond by initiating and supporting new social and healthy activities.

Contact: each village agent has their mobile and email listed on the above webpage, otherwise 01823 331222 and info@somersetrcc.org.uk for general information

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### 3.2 Children


The Somerset Protocol for Autistic Spectrum Conditions assessment and diagnosis is a document written by multi-agency practitioners to ensure consistency of assessment and diagnosis across Somerset and is in line with NICE Guidelines. Parents are at the centre of the process of assessment and supported through it.

All practitioners are aware of the protocol and once yearly meetings are held to update training, to reinforce the need for multiagency collaboration and to emphasise consistency of practise as much as possible given the large rural community which clinicians serve.

**Paediatric Service**

A Paediatrician is usually involved in a diagnosis of autistic spectrum condition, although sometimes this is a Psychiatrist instead. A diagnosis follows a multi-agency assessment. Following diagnosis a Paediatrician will usually stay involved with preschool children. Follow up of older children can be by a community children’s nurse if required. Sometimes this is just to discuss the diagnosis further.
and what support is available. If there are no medical issues of significance follow up will be with the GP. Further referral to the Paediatric service can be requested if necessary. The autism service is based at Musgrove Park Hospital. Children in East Mendip or in the Yeovil areas will have their Paediatric care from Royal United Hospital, Bath and Yeovil District Hospital.

**Child and Adolescent Mental Health Service (CAMHS)**  
[www.sompar.nhs.uk/our_services/childrenandyoungpeople/camhs](www.sompar.nhs.uk/our_services/childrenandyoungpeople/camhs)

CAMHS provides specialist help with social communication difficulties for children and young people with autism and Asperger syndrome who are experiencing behavioural difficulties which are significantly affecting them, their education and/or their families.

Referral is via a GP or paediatrician.

**Integrated Therapy Service (ITS)**  
[www.sompar.nhs.uk/our_services/childrenandyoungpeople/integrated_therapy_service/](www.sompar.nhs.uk/our_services/childrenandyoungpeople/integrated_therapy_service/)

The ITS provides a service for children and young people aged 0 - 19 years who have physical, occupational and speech and language difficulties in Somerset. The service is mainly provided within community settings such as schools and children's centres, patients' own homes or in our ITS Clinics.

Where children or young people require support from more than one therapy, our vision is to provide integrated therapy, ensuring that each child's integrated package of care is tailored to their individual needs. The service comprises a number of Paediatric Physiotherapists, Paediatric Occupational Therapists, Paediatric Speech and Language Therapists, Therapy Support Practitioners and Administration teams.

Contact: 0303 033 3002 09:00 to 12:00am Monday, Wednesday, Thursday and Friday (not Bank Holidays) for any professional or parent/carer who has concerns over a child or young person's development.

**Children’s Social Care Disability Service**  

A service for children and young people aged between birth and 18 years old who have a severe disability. This includes children with an autistic spectrum condition and a severe learning disability. Following an assessment of need, when autism is identified, appropriate services are put in place to support the young person and their family.

**Children’s Autism Outreach Team (CAOT)**

CAOT work with parents and their children with Autism age 0-13 years in order to help parents / carers understand their child’s autism, to support and empower parents, to provide strategies where needed and to increase social opportunities.

CAOT provide home visits to help parents with advice and strategies within the home, new skills to support their young person and access other suitable resources.

CAOT facilitates the National Autistic Society’s Early Bird Plus training programme and the Barnardo’s Cygnet programme delivered over a six or eight week period.
CAOT provides activities for young people with autism that would otherwise be inaccessible for many families without the expert support and advice. These include clubs for children and their families across the county and a monthly coffee morning as well as activities during every school holiday.

In order to access support from the CAOT team your Paediatrician may refer your child at the point of diagnosis. If your child has a diagnosis of Autism you can self-refer via Somerset Direct.

Contact: for more information speak to Somerset Direct on 0845 345 9122 or children@somerset.gov.uk

Short Breaks

A short break is an opportunity for disabled children and young people to spend time away from their primary carers and allow parents / carers to have a break too. It helps children and young people with disabilities to do new things and have fun, for a few hours to a whole day (NB: the team do not provide overnight or residential breaks).

The Short Breaks Team provide:

- Inclusive activities every school holiday for children with a disability or additional need aged between 8-18 years. We provide group supervision on these days, not 1:1 care.
- Family days during the school holidays for any age, staff members travel to the venue with families on transport provided by the team.
- A quarterly newsletter and activity calendar to provide information on accessible short breaks across Somerset. They are open activities available to all children and young people in Somerset with disabilities and additional needs. You do not have to be referred to any service to access these – unless otherwise stated against the individual activity.

You could also gain access to some individual work with your family from a Short Breaks Coordinator if your child / young person has one or a combination of the following; a disability, requires special educational needs support, or is in receipt of Disability Living Allowance (DLA).

A Coordinator will visit you in your home and work with you to find out the short break needs for your family and offer a signposting service to opportunities to access. This is a time limited referral for up to 3 months.

Contact: a Short Breaks Referral Pack can be requested from Somerset Direct on 0845 345 9122 or children@somerset.gov.uk

Early Years

The Portage Service is a home visiting service for children aged 0 – 5 years who have special educational needs. They support a child for four terms on a weekly basis. There is an additional service provided within the Portage Service called PERSCEN which is specifically for children with language and communication needs. This is a shorter 10-week programme. Children who receive PERSCEN may then go on and have Portage if they have other significant needs.

Portage provides support for parents to help their child learn through play and will suggest activities and resources that will help the child to communicate more effectively. The service also provides emotional support for parents and support to early years settings (playgroups, nurseries). The intervention is individually tailored to meet the child’s needs. Portage Home Visitors are pro-active in
attending Family Support Plan meetings and are felt to be a real support for the family helping them through the process.

Generally referrals are made through health visitors or speech therapists via Multi Agency Identification and Support for Early Years (MAISEY).
Contact: 01749 678500 and jtoomey@somerset.gov.uk

Targeted Youth Support (TYS)

TYS work with vulnerable young people who are not in education, employment or training (NEET). This includes young offenders, looked after children, care leavers and those claiming Job Seekers Allowance.

Children’s Education - Autism and Communication Service

The service works with children, schools, families and other agencies. Support is currently provided to children at mainstream schools and those attending either a communication or ASD resource base. The team is made up of specialist teachers for Speech Language Communication and Autism, educational psychologists, teachers, teaching assistants and tutors. Access and placement at Autism and Communication resource bases is via the complex cases panel. Access to specialist teacher support is via school SENCO referral.

We are currently reviewing how support is provided to pupils identified as having high needs as part of our considerations in relation to how we implement the requirements of the Children and Families Bill.

Children’s Education – Special Educational Needs Coordinators (SENCOs)

Every preschool and nursery has access to support and guidance from an area SENCO. Every preschool and school has a SENCO who is responsible for ensuring that all aspects of a child’s needs are met. SENCOs are trained and experienced teachers who can support practitioners in practical strategies and ways of adapting the learning environment to meet the needs of children with specific or special needs. They work very closely with Speech and Language therapists and Portage workers.

Children’s Education - Special Educational Needs Support Services

Educational Psychologists and Specialist teachers can support schools to better understand, and adjust provision, to meet the needs of children with special educational needs including those with autism. They are based in area bases. The SENCO from the child’s school will have regular contact with support services and can ask them for help if this is appropriate.

3.3 Adults

Community Team for Adults with Learning Disabilities (CTALD)
www.sompar.nhs.uk/our_services/learning_disabilities/

Community Teams for Adults with Learning Disabilities (CTALD) are integrated health and social care teams which provide assessment, care management/care co-ordination, therapeutic intervention and health professional support for people with learning disabilities. Somerset Partnership Foundation NHS Trust employs the health staff who work within the teams, and the County Council employs all other team members.
CTALDs offer support to parents with mild Learning Disability and additional issues, which can include parents with Autism. Since 2010 we have had an LSCB led partnership protocol between CTALDs and Children’s Social Care which extends this. CTALDs offer extra consultations to parents-to-be and new parents who have some degree of learning difficulty and additional problems which can include Autism.

Contact: Mendip 01373 456500, Sedgemoor & West Somerset 01278 454300, South Somerset 01935 470600, Taunton 01823 257908

**Individual Funding Review Panel (IFRP)**  

Before any application is made, a patient should have had a discussion concerning their treatment options and choice of provider with their GP or Consultant. If the treatment recommended falls outside those routinely funded under the NHS, the General Practitioner or Consultant would then need to refer to the Guidance for Clinicians document (this can be found on the NHS Somerset public and staff websites) for procedures not routinely funded, before completing an application form. The completed application form, supporting evidence for treatment and the reasons why the GP or Consultant feel this patient is exceptional is forwarded to the IFRP for consideration.
Adults Diagnostic Assessment and support

If an adult has a coexisting Learning Disability, referrals for diagnosis may be made to the Psychologists/Psychiatrists within the Community Teams for Adults with Learning Disability: a range of assessments are used. The Better Health Team also offers support to access annual health checks carried out by GP’s within their practices.

If a service is requested, joint visits with social care colleagues will be made, and FACS criteria applied. Post diagnostic support can be given individually to individuals and their family or carers.

For adults without a learning disability, the Asperger Specialist Team (AST) provides pre-diagnostic screening clinics and diagnostic assessments. Post diagnostic support includes; profession specific assessments, therapeutic interventions, care co-ordination for complex individuals, and a rolling programme of “Living with Aspergers” groups. The AST also provide signposting to other support services (e.g. employment team, social support groups…), carer education, and training and consultancy to other professionals.

The team is multi-disciplinary comprising of; a team manager, team administrator, clinical psychologist, assistant psychologist, occupational therapist, community mental health nurse, and social worker.

Referrals are filtered through the Community Mental Health Teams (CMHT). If an individual wishes to be referred they should request that their GP writes a referral letter to the CMHT. If the person is already being seen by the CMHT, their care co-ordinator should follow the internal referral process.

3.4 Employment and Further Education

‘Dimensions’ scheme  www.dimensions-uk.org/support-services/supported-employment

The Dimensions Supported Employment Team helps people with a learning disability and autism find secure employment. They talk to employers and local businesses about what they need to be successful. They help employers by matching people to what employers need. They find each person a job that matches their aspirations, with an employer who needs their talents. If someone needs some more help to work out what their talents are they can organise work tasters to help them decide.

Contact: 0300 303 9001 and supportedemployment@dimensions-uk.org

Aspire  http://base-uk.org/about/members/somerset-county-council

Aspire is a specialised employment service for people with Learning Disabilities living in Somerset. It focuses on supporting people into work and aims to promote independence through employment and equality to enable people to have the opportunity to be supported into mainstream work or develop self employment opportunities whilst earning a wage.

The Aspire service offers people Individual Placement Support, so that they can consider work opportunities. The personalised approach involves one-to-one meetings, supporting choices and CV development, work experience that has the opportunity to become meaningful paid employment, and job coaching with regular reviews. Aspire also provides ongoing job maintenance support for both employer and employee to encourage a partnership which fulfils everyone’s needs and good employment retention.
Somerset Partnership Supported Employment Service for Adults (SES)
www.sompar.nhs.uk/our_services/specialist_services/employment_support_service

Based in the community mental health teams in Taunton, the Somerset Partnership Employment Support Service aims to support individuals with mental health needs to gain or retain paid employment on a full or part-time basis in their local community. The service works closely with many different employers throughout the county and other agencies, such as Jobcentre Plus, PLUSS, the Shaw Trust and MIND.

Generally referrals are made through Community Mental Health Team Care Co-ordinators or In-patient Key Worker
## 4.1 Key Priorities & Actions 2014 – 2016

### 1. Living with autism

<table>
<thead>
<tr>
<th>Key Priority</th>
<th>Planned Action (to be finalised after consultation)</th>
<th>Timescale</th>
<th>Lead</th>
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<tbody>
<tr>
<td>Increase public awareness of autism</td>
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<td>Improve housing provision for people with autism</td>
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<td>Improve the support available for carers of people with autism</td>
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<tr>
<td>Provide social and community activities for people with autism</td>
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<td>Improve the health &amp; wellbeing of people with autism including their carers and family</td>
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<td>Increase the resilience of those caring for someone with autism</td>
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<tr>
<td>Improve the way we consult and involve people with autism, their carers and family</td>
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## 2. Workforce Development

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<th>Planned Action (to be finalised after consultation)</th>
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<tr>
<td>Identify groups and services / adults mapping including parents and GPs</td>
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<td>Develop multi-tier framework – varied training according to professional role and level of involvement with people with autism.</td>
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<td>Investigate and secure additional funding (e.g. Clinical Innovation Fund)</td>
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<tr>
<td>Further develop the collaboration between children and adults services on training, including transition from children to adult services and independent living</td>
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### 3. Identification and diagnosis

**Link to the Assessment & Diagnostic sub group**

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<th>Key Priority</th>
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<tr>
<td>Improve the way we provide support for those who have had a diagnosis</td>
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<td>Review the existing pathways to diagnosis</td>
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<td>Promote awareness about pathways to diagnosis</td>
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<td>Improve the way children and adult services work together to make the transition process work better</td>
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<td>Improve signposting to other support services for people who have had a diagnosis</td>
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<td>Improve the way we share information between organisations about people who have been diagnosed</td>
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### 4. Education, work, training and transitions

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<tr>
<td>Continue to improve the education and training of children and young people aged 0-25 with autism including the implementation of Education, Health, Care (EHC) Plans through joint commissioning.</td>
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<td>Improve the education and training of young people post 16 with autism; developing a range of opportunities to ensure choice, and increasing capacity to support young people within existing educational and training provision.</td>
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<tr>
<td>Ensure effective and seamless transitions from early years through to adult services through the use of assessment and EHC plans.</td>
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<td>Increase the advice, training and support to mainstream schools and colleges to build capacity within universal education services.</td>
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<td>Encourage employment opportunities for people with autism.</td>
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<tr>
<td>Increase meaningful volunteering opportunities for people with autism</td>
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Appendix 5 Governance Structure for the Children & Adults Autism Strategy

- Adult Services Partnership Board
- Health & Wellbeing Board
- Somerset Children's Trust
- Somerset Children and Young People's Compact
- Somerset Autism Strategy Group
- SEN Transitions Steering Group
- Schools Forum/High Needs Subgroup
- Living with Autism
- Workforce Development
- Identification & Diagnosis
- Education/Work Training/Transitions
Appendix 6  Contributors

Fiona Hawker – Somerset Clinical Commissioning Group
Julie Husband – Somerset County Council (Children’s Commissioning)
Phil Lincoln – Somerset County Council (Adults & Health Commissioning)
Kay Thornley – Somerset Partnership NHS Foundation Trust
Mark Hulland – National Autistic Society (Somerset Branch)
Alison Jary – Somerset County Council (Learning & Achievement)
Claire Healey – Somerset Partnership NHS Foundation Trust
Jacq Clarkson – Somerset County Council (Public Health)
Terry Roth – Somerset Partnership NHS Foundation Trust
Hayley Johnson – Somerset Partnership NHS Foundation Trust