



"Working together for people living with autism in Somerset"

2015 - 2018

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1 Introduction

This Strategy has been produced by the Somerset Autism Strategy Group (previously known as 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) and Somerset Parent Carer Forum. Representation from people with autism and people who care for someone with autism has also happened through the Group, a range of surveys and a formal consultation for the draft strategy which ran from June to October 2014. This consultation saw over 250 responses from people with autism, their families and carers and also professionals. These responses have been used to inform this document and the action plan in Appendix 4. Somerset County Council and NHS Somerset Clinical Commissioning Group give their thanks to everyone who has contributed to the development of this strategy. More details can be found in Appendix 6.

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 existing available resources, within the statutory agencies.

The multi-agency group has also been guided by 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 changes needed to deliver this strategy.

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 co-existing 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 was not 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. In 2014, the population of Somerset was approximately 540,000, so it is estimated that approximately 5,400 people may have autism.

Around four times more men than women have diagnosed autism, although this may be due to under recognition in women. This is shown in more detail in Appendix 2.

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 condition, and 40% meet diagnostic criteria for at least 2 conditions, 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 is 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 2014 there were 2,096 people diagnosed with a condition in the autistic spectrum and recorded on Somerset GP clinical systems. This figure is about 40% of that suggested above and may reflect low recognition of the condition, especially in the older population. Rates of diagnosed ASD (Autism Spectrum Disorder) 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. Since the end of 2012 the number of people with a diagnosis has increased by 26% from 1,659, which could reflect more intensive efforts to identify and record the condition.

There is variation in the recorded prevalence in different parts of the county, and this has changed in the last two years, perhaps reflecting more intense efforts to identify and record the condition in some areas. In 2012 there was a particularly high concentration in the North Sedgemoor Federation area and a particularly low concentration in Bridgwater Bay Health Federation area. In 2014 the areas of high concentration are Central Mendip and South Somerset Healthcare and the rates are lower in West Somerset, Taunton Deane and West Mendip.

In 2014 there is a suggestion that the rates of diagnosed ASD increase as deprivation decreases: The most deprived fifth of practices has the lowest rate and the least deprived fifth has a high rate, but the highest rate is for the middle fifth deprived practices. In 2012 there had been no significant difference between rates across the deprivation groups.

A comparison of the numbers with ASD in 2012 and 2014 shows that the increase is mainly occurring in the three least deprived quintiles of the population.

These observations could be because the proportion of people with ASD who are diagnosed is different in different areas (which might be related to the socioeconomic conditions of the areas) as well as the possibility of a true difference in the proportion of people with ASD.

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

- Autism Quality Standards. January 2014
- 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 January 2014

(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 has been recently 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. This plan will be a working document and updated regularly to reflect progress and local developments.

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 Joint Commissioning Board and the Somerset Children's Trust.

There will be four subgroups created that will take forward the actions in Appendix 4. The subgroups will be:

- Living with Autism
- Workforce Development
- Identification and Diagnosis
- Children and Young People

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 Act
- 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.

90% of respondents to the strategy consultation agreed with the vision.

6.1 Experiences of people living with autism in Somerset

In developing this strategy people with autism and their carers and families have shared their experiences in Somerset. Whilst it is important to note that every person will have different experiences of living with autism, in implementing this strategy we need to ensure that we take into consideration the key messages that people have shared with us. Some of these messages relate to specific parts of the strategy and so have been included in the action plan in Appendix 4. However, others relate to all elements of the strategy and these include:

- Services and support need to be provided as early as possible to make the greatest difference to people's lives.
- Whilst a diagnosis is important, it needs to be followed by good quality and timely information and support and this must accessible throughout a person's life.
- The wide range of the autistic spectrum means that a 'one size fits all approach' to services will not meet everyone's needs and phrases such as 'independent living' will look different to different people.
- There needs to be more awareness of autism within Somerset and all public services should make reasonable adjustments to support people with autism to access them.
- Work is required to improve people's experiences of accessing services –
 Services need to improve how they actively involve people in the planning and
 delivery of services and listen to their experiences, concerns and wishes. This
 does not always happen which leaves people feeling unsupported.
- Consideration needs to be given to the support available for people at all levels of the autistic spectrum as many people who are not entitled to statutory services report feeling isolated and unsupported.

- There needs to be better information, in one place, about support and services and it must be easily accessible to everyone – people with autism, their carers and families and professionals.
- There needs to be greater consistency in services across Somerset, with everyone having the same shared understanding about who can access them and what they provide.
- There must be easy access to timely and good quality support for carers, including a range of break opportunities.
- Organisations and services must improve the way that they work together if people with autism and their carers/families are to receive high quality, coordinated and timely support.

6.2 Recommendations for action:

91% of respondents to the strategy consultation agreed with the recommendations for action outlined below.

Respondents were also asked to rank in level of importance the key priorities within each of the four areas of the Action Plan (Appendix 4). The plan has been updated to reflect people's responses.

- 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. This includes the use of personal budgets for those that are eligible for ongoing 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 able to access information about the different services available for autism.
- Ensure that when services are working with people, they look at them as a 'whole' person taking into consideration their whole life and identity.
- Ensure that all people with autism and their families and carers have equal opportunity to access services and support. This may require further work particularly in relation to people from the following groups:
 - Female population
 - Older people (over 65 years old)
 - Black and minority ethnic communities
 - Limited transport / rural location
 - People with complex needs and other health conditions
 - People on low incomes
 - People without a diagnosis
 - Carers

82% of consultation respondents felt that the proposals within the strategy were unlikely to have an adverse impact on groups with protected characteristics. The list above includes some of the areas where people thought that there could be an impact on certain groups of people.

Consultation discussions highlighted that autism is not discriminatory, but can affect anyone. However we must remember that autism is not one characteristic, but many and can manifest itself in many ways across the spectrum.

Everyone needs to be treated as an individual.

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.

For further information about children's safeguarding please see:

www.somerset.gov.uk/childrens-services/safeguarding-children/

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/

Appendix 1 NICE Clinical Guidelines

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 personcentred, 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

1.2 Clinical Guidelines: management of autism in children and young people (August 2013)

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

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.

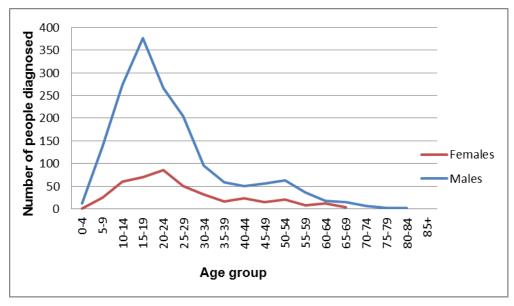
Key priorities for implementation are:

- 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

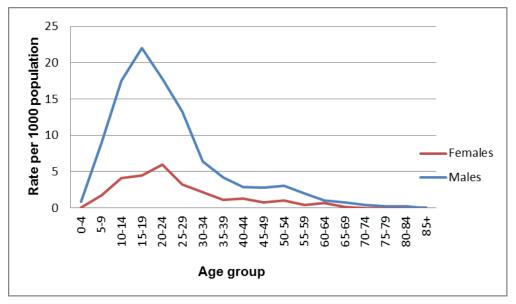
Appendix 2 Data

Figure 1: Number of people recorded with Autism spectrum conditions at Somerset GP practices by gender and age group at the end of December 2014



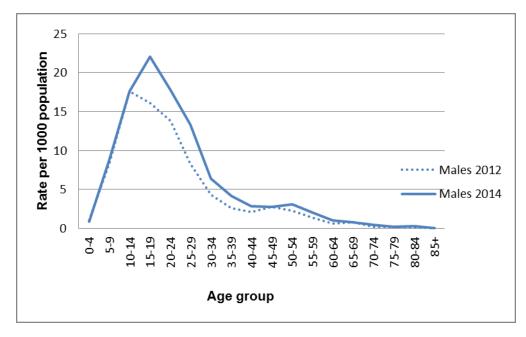
Source: MIQUEST queries on GP clinical systems

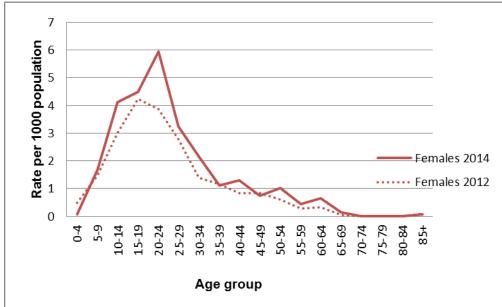
Figure 2: Number of people recorded with Autism spectrum conditions at GP practices per 1,000 population registered at practices by gender and age group at the end of December 2014



Source: MIQUEST queries on GP clinical systems and Primary Care Information System GP registered populations

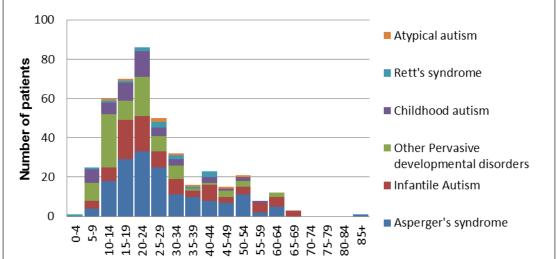
Figure 2a: Number of people recorded with Autism spectrum conditions at GP practices per 1,000 population registered at practices by gender and age group at the end of December 2014 compared to at the end of December 2012, separately for males and females





Source: MIQUEST queries on GP clinical systems and Primary Care Information System GP registered populations

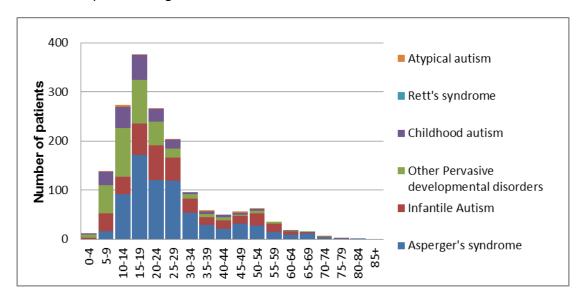
100 Atypical autism 80



Source: MIQUEST queries on GP clinical systems

Figure 4: Number of specific diagnoses recorded - Males

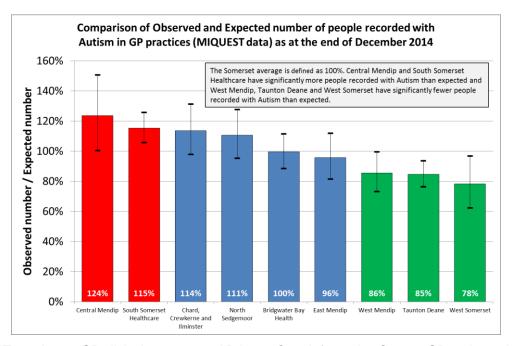
Figure 3: Number of specific diagnoses recorded – Females



Source: MIQUEST queries on GP clinical systems

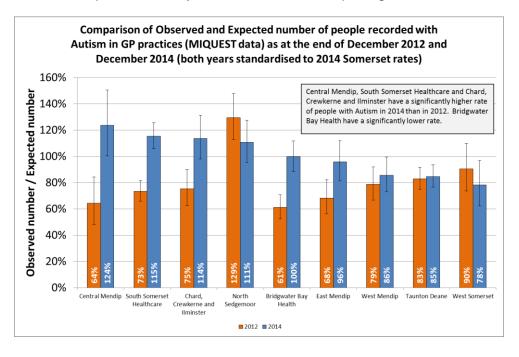
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Figure 5: Comparison of Observed and Expected number of people recorded with Autism spectrum conditions in GP practices – by GP Federation at the end of December 2014



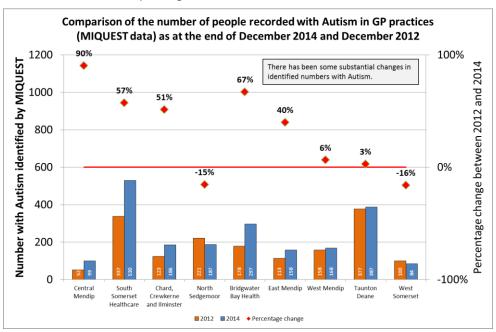
Source: MIQUEST queries on GP clinical systems and Primary Care Information System GP registered populations

Figure 5a: Comparison of Observed and Expected number of people recorded with Autism spectrum conditions in GP practices – by GP Federation, comparing rates in 2012 and 2014



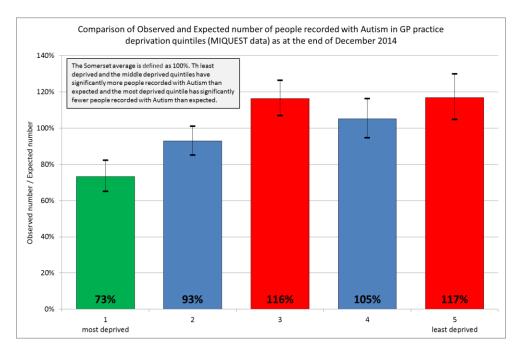
Source: MIQUEST queries on GP clinical systems and Primary Care Information System GP registered populations

Figure 5b: Comparison of the number of people recorded with Autism spectrum conditions in GP practices – by GP Federation, comparing numbers in 2012 and 2014



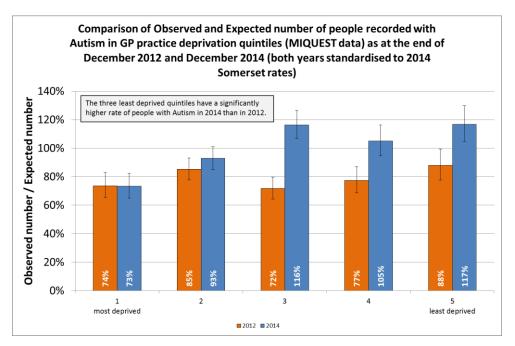
Source: MIQUEST queries on GP clinical systems

Figure 6: Comparison of Observed and Expected number of people recorded with Autism spectrum conditions in GP practices – by deprivation quintile of practices within Somerset at the end of December 2014



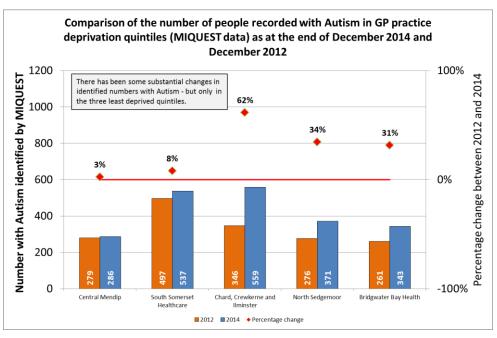
Source: MIQUEST queries on GP clinical systems and Primary Care Information System GP registered populations

Figure 6a: Comparison of Observed and Expected number of people recorded with Autism spectrum conditions in GP practices – by deprivation quintile of practices within Somerset, comparing rates in 2012 and 2014



Source: MIQUEST queries on GP clinical systems and Primary Care Information System GP registered populations

Figure 6b: Comparison of the number of people recorded with Autism spectrum conditions in GP practices – by deprivation quintile of practices within Somerset, comparing numbers in 2012 and 2014



Source: MIQUEST queries on GP clinical systems

Figure 7: Prevalence of autistic spectrum disorders (ASD) and speech, language and communication need (SLCN) in schools

		England	South West	Somerset
	Total on roll	4,309,580	380,370	36,018
	ASD as primary need	25,880	2,050	124
	Statement or School Action			
<u>s</u>	Plus (SA+)			
ا کر	Percentage of all pupils	0.6%	0.5%	0.3%
sck	SLCN as primary need or	102,185	9,350	529
<u> </u>	SA+			
Primary schools	Percentage of all pupils	2.4%	2.5%	1.5%
Pri	. Groomago or am papilo	2,0	2.070	11070
	Total on roll	3,210,120	317,245	31,002
	ASD as primary need	24,165	2,405	168
	Statement or SA+			
	Percentage of all pupils	0.8%	0.8%	0.5%
	SLCN as primary need or	102,185	2,495	278
	SA+			
	Percentage of all pupils	3.2%	0.8%	0.9%
8	Total on roll	98,595	7,865	440
oh:	ASD as primary need	20,735	1,530	71
) S .	Statement or SA+			
ary scl	Percentage of all pupils	21.0%	19.4%	16.1%
Secondary schools Special schools	SLCN as primary need or	5,120	290	5
၂ ၁	SA+			
Sp	Percentage of all pupils	5.2%	3.7%	1.1%

Source: January 2013 School Census

Figure 8: Number of statements or School Action Plus (SA+) for which ASD is the primary need.

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

Source: January 2013 School Census

Appendix 3 Access to Support Services and Information

3.1 Information and Support Networks

Autism Somerset

www.autismsomerset.org.uk

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

The network aims to connect those affected by autism and associated conditions with each other. Membership is open to all, at no cost. Autism Somerset provides monthly e-bulletins which highlight national and local activity.

Autism Wessex

http://autismwessex.org.uk/

Founded in 1968 by parents of children with autism, Autism Wessex is the regional charity providing information and advice for people affected by autism and associated difficulties across the counties of Dorset, Somerset, Hampshire and Wiltshire.

Contact: 01305 213135 and advice@autismwessex.org.uk

National Autistic Society

www.autism.org.uk

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 Choices

www.somersetchoices.org.uk

Somerset Choices is a website that gives people access to information and advice on adult social care and health and on a wide range of services and support groups from the private, public, community and voluntary sectors within Somerset. There are specific pages on the website on autism, as well as a directory of local services and support.

Somerset Local Offer

https://somerset.local-offer.org/

The Local Offer website provides information about services relating to special educational needs, disabilities, education and more.

Somerset Parent and Carer Forum (SPCF)

www.somersetpcf.org.uk

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 SENDIAS

www.somersetsend.org.uk

Somerset SENDIAS 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 info@somersetsend.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 0300 123 2327

Contact: Adults - 0300 123 2224 and adults@somerset.gov.uk Children's - 0300 123 2224 and childrens@somerset.gov.uk

Village Agents

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.

3.2 Children

Assessment and Diagnosis for children and young people

www.somersetintelligence.org.uk/files/Somerset%20Protocol%20for%20ASD%20Assessment.pdf

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

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/

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

www.somerset.gov.uk/organisation/departments/disabled-children-and-young-peoples-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.

Contact: 0300 123 2224 or childrens@somerset.gov.uk

Children's Autism Outreach Team (CAOT)

The service offers a range of support and activities aimed at children and parents, groups, and 1:1 support. A referral (needs a diagnosis of autism to accompany it), can come from families, teachers, social workers, paediatricians and GPs. If a child does not have a diagnosis but displays similar characteristics then the CAOT will seek advice from a paediatrician. The Team works with children from the age of 5 - 13 years.

The Early Bird programme of training (accredited by the National Autistic Society) for parents and carers of children aged 5yrs to 9yrs is run regularly across the county by the CAOT team and specialist Autism and Communication advisory teachers. Those aged 0-5 years old are referred straight to "Portage" (a programme for parents to help their child with autism, put in at pre-school age) but will return back to CAOT after this. The "Cygnets" Group is for parents with children aged 8 – 19 years old and is also delivered by CAOT and the specialist Autism and Communication advisory teachers.

Contact: 01458 241460

Short Breaks

This is a service available to children who are in receipt of the middle rate of Disability Living Allowance. Short Breaks are able to be more flexible to children with lower level needs, including children with autism. It is a service that offers day trips and activities, mainly in school holidays and some family days.

There are 5 short breaks co-ordinators carrying a case load of 25 children, with a 3 month short term intervention for those who don't meet the CAOT criteria.

Contact: 01823 358117 and ljwhite@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 PERSCEY which is specifically for children with language and communication needs. This is a shorter 10-week programme. Children who receive PERSCEY 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 itoomey@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 Requests (IFR)

www.somersetccg.nhs.uk/about-us/how-we-do-things/individual-funding-requests/

If you are a patient who wishes to access a specific treatment which is not routinely funded, please discuss this with your doctor or consultant and, if appropriate, an IFR application form can be put forward for review and consideration. You can also put forward with the application correspondence on how your condition affects you and how the treatment will benefit you.

In order to guide the panel in their decision making, the CCG has developed a number of policies which set out the criteria which allow patients to access the treatment they wish to have.

It may also be necessary to gather additional information from any doctors or healthcare professionals involved in your care.

Adults Diagnostic Assessment and support

If an adult has a co existing 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 national social care eligibility 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.

Contact: 01278 447721 and sfpayne@somerset.gov.uk

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 Inpatient Key Worker

Appendix 4 Somerset Autism Strategy Action Plan (The plan is a working document and will be updated on an ongoing basis to reflect progress and local developments.)

4.1 Key Priorities & Actions 2015 – 2017

The following action plan is structured around four key areas of work. Within each area, the priorities have been listed according to the ranking of importance that respondents to the consultation gave them, with 1 being the most important, 2 being the second most important etc.

1. Living with autism						
Consultation ranking	Key Priority	Planned Action	Timescale	Lead		
1	Improve the health & wellbeing of people with autism including their carers and family	Undertake a full needs assessment to identify the needs of the population with autism living in Somerset, including work to understand the population with autism who have other protected characteristics.	Dec 2015	SCC Public Health / Commissioners / CCG		
		Undertake work to ensure that people with autism who are over 40 are offered appropriate age health checks. Link with relevant commissioners to consider how health and wellbeing services (smoking cessation,	Spring 2016 Summer 2016	SCC Public Health / CCG SCC Public Health / CCG		
		weight management and health trainers) can be made autism friendly. Link with relevant commissioners to consider how social interventions and peer support provided by GP	Summer 2016	SCC Public Health / CCG		

		Federations can be made autism friendly. Review the provision of community care assessments in line with the Care Act in order to increase understanding of and access to them by people with autism.	Spring 2016	SCC commissioners
2	Improve the support available for carers of people with autism	Promote carers rights to an assessment under the Care Act	Ongoing	SCC Adults and Health Commissioning
5	Increase the resilience of those caring for someone with autism	Map existing support and pathways available to carers and ensure that information is made available on Somerset Choices / Somerset Offer Promote information sources to all.	Autumn 2015	SCC Adults and Health Commissioning / SCC Children's Commissioning
		Participate in the development of a new Somerset Carers Strategy and ensure that it encompasses the needs of carers of people with autism.	Spring 2016	SCC Adults and Health Commissioning / SCC Children's Commissioning
3	Improve the way we consult and involve people with autism, their carers and family	Develop and implement a model for consulting and involving people with autism, their carers and family. To be undertaken in partnership with the Somerset Parent Carers Forum and the National Autistic Society.	Dec 2015	SCC Adults and Health / SCC Children's Commissioning
4	Provide social and community activities for	In line with the prevention workstream of the Care Act,	Spring 2016	SCC Adults and

	people with autism and carers	undertake a review of social and community activities for people with autism and also for carers, which will include Map existing provision Identify gaps Develop an action plan to address gaps with a focus on promoting existing autism activities to all, encouraging activities that are available to the general public to become autism friendly and where possible support the development of new activities (within existing financial resources).		Health / SCC Public Health
		Ensure Safe Places Scheme is accessible to people with autism and that individuals are aware of the scheme.	Winter 2015	TBC
6	Improve housing provision for people with autism	Revisit and update previous work on housing issues for people with autism. This may include work to: • Map provision • Identify housing issues for people with autism Link with the Somerset Strategic Housing Officers Group to explore opportunities to address issues raised through their strategic workstreams and the work already undertaken in making reasonable adjustments in Choice Based Lettings for people with	Spring 2016	District council housing rep / SCC Adults & Health commissioning

		learning disabilities.		
7	Increase public awareness of autism	Use the Autism Capital Grant to develop autism library collections which will be accessible to the general public	Autumn 2015	SCC Adults and Health / SCC Public Health
		Celebrate Autism Awareness Week Explore opportunities to link up with national awareness campaign and develop local awareness materials	April 2016 / 2017	SCC Public Health / Adult & Health Commissioning / Communications
N/A	Encourage employment opportunities for people with autism.	Raising awareness of Autism with employers Up skill of advisors in Partners and Providers (including Schools Advisors and Careers Advisors) Make contact with FSB and Chamber of Commerce to conduct presentations at their monthly meetings Link in with the Disability Confident Campaign (engaging with employers) Make contact with the Fossway School – Alison Revey – to gain experience of what they are doing.	Ongoing Dec 2015 Nov 2015 Autumn 2015 Autumn 2015	SCC Aspire DWP SCC Aspire Somerset Parent Carer Forum

N/A	Increase meaningful volunteering opportunities for people with autism	Make contact with 'You Can Do' to explore opportunities	Autumn 2015	DWP

2. Workforce Development					
Consultation ranking	Key Priority	Planned Action	Timescale	Lead	
1	Further develop the collaboration between children and adults services on training, including transition from children to adult services and independent living	Initial engagement through Children's Social Care Learning and Development.	Current and on-going	SCC Learning & Development – Children's & Adults	
2	Develop multi-tier framework – varied training according to professional role and level of involvement with people with autism.	A tiered approach involving a number of targeted courses and e-learning dependent upon the level of contact/interaction. Sub Group members will develop proposals for different training approaches.	Spring to Autumn 2015	Somerset Partnership	
3	Investigate and secure additional funding (e.g. Clinical Innovation Fund)	A charging policy needs to be developed to protect budgets. To be developed further through discussions with partner organisations.	Current and on-going	SCC ASC Learning & Development	
4	Identify groups and services / adults mapping including parents and GPs	Workstreams will be split into the following headings based on professions identified in the consultation to the strategy. Other professions will also be included (e.g. Library and Housing staff and care workers in the private, voluntary and independent sector):			

Health GPs Health Visitors Engagement through CCG and	Autumn 2015 other groups.	CCG / Somerset Partnership
Education Teachers Lunchtime Supervisors Early Years Providers School Nurses Engagement through headteact (SASH, SAPHTO etc). Potential to deliver through INS		SCC Learning & Development
Social Care PFSAs Social Workers Engagement through Learning teams in Adults' and Children's General course to be commissineeds of Social Care staff which appropriate for other staff in other	Social Care. oned to cater for the h may also be	SCC ASC Learning & Development
Support Services Transport (Bus Drivers e Police Engagement through larger tranthrough Police contacts. Potential to deliver through Trancurrent training programme.	nsport employers and 2015	SCC ASC Learning & Development / Police

Private, Voluntary and Independent Sec • Research needs and gaps • Assess ability to attend training of other groups	On-going	Care Focus
Assess charging expectations		

3. Identification and diagnosis (Link to the Assessment & Diagnostic sub group) Consultation **Key Priority Planned Action Timescale** Lead ranking Improve the way we provide support for 1 Provide post-diagnostic information Spring 2016 Autism those who have had a diagnosis about Autism and how it may affect the Teams individual. within Somerset Ensure the provision of psychosocial Partnership support for core areas of Autism, taking into account of the impact of mental health, physical health and learning disability. Promote consultation between services in health, mental health, social care and education. Maintain links to other sub-groups within the Somerset Autism Strategy. 2 Review the existing pathways to Adopt clear triage and screening Autumn 2015 Autism diagnosis **Teams** protocols in response to concerns about possible autism within Somerset Complete comprehensive diagnostic Partnership (diagnostic, needs and risks) assessments in line with NICE

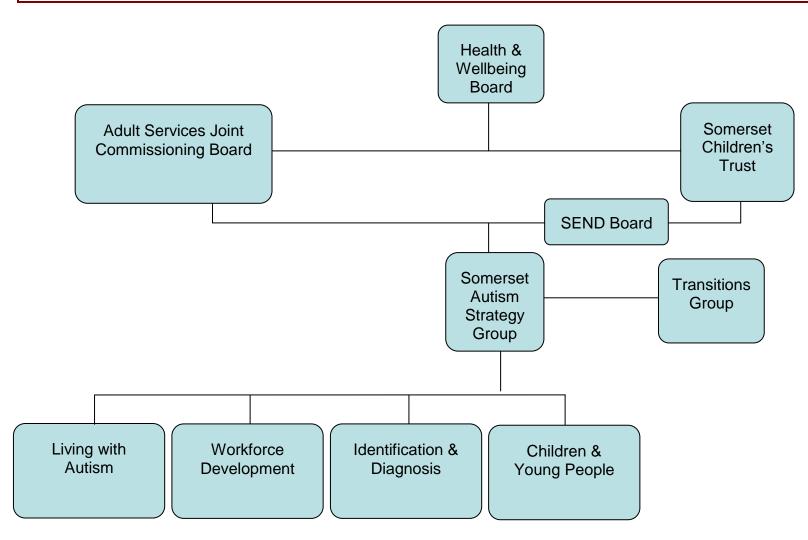
		guidelines. Review autism specific diagnostic tools used in assessments. Reflect on the diagnostic changes in DSM-V and forthcoming ICD-11		
3	Improve the way children and adult services work together to make the transition process work better	Promote the reassessment of needs in childhood and adolescence with a view to transitioning to adult services. Provide information about adult services when transitioning from children and young people's services. Maintain close links with a current service provision change which will extend age-range of children and young people's service to 25yrs. This will provide unique opportunities for more integrated child and adult working and a smoother transition process.	Spring 2016	Autism Teams within Somerset Partnership
4	Improve signposting to other support services for people who have had a diagnosis	Develop an information pack of services appropriate for people with Autism (Social care, Education, Local and National Support Groups). Ensure information is passed onto individuals and families.	Spring 2016	Autism Teams within Somerset Partnership

5	Promote awareness about pathways to diagnosis	Establish clearly written pathways to diagnosis for children and adults (as agreed). Write up pathways in a format that is accessible (Service leaflets and Information on Internet) Ensure information about pathways is shared with public, health, social care, education.	Autumn 2015	Autism Teams within Somerset Partnership
6	Improve the way we share information between organisations about people who have been diagnosed	Map the provision of services typically involved in a person's care (health, social care, education). Ensure information about a person's needs is written and shared between organisations, where appropriate.	Spring 2016	Autism Teams within Somerset Partnership

	4. Children and Young People's Group						
Consultation ranking	Key Priority	Planned Action (to be finalised after consultation)	Timescale	Lead			
1	Continue to improve the transitions of children and young people with autism.	Transition planning in education check for gaps in existing process.	Dec 2015	Ali Jary			
		Develop transition processes into post 16 provision and activity.	July 2016	To be allocated with the group			
2	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.	Investigate joint commissioning for adults between 16-25 age range – link with Roz Pither Raise awareness of support available for Parents and Young People for the EHC process	July 2015 Nov 2015	SCC Children's Commissioning (RP) Parent & Young People's Partnership Service			
3	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.	Consider and raise the profile for Internships, Traineeships, Apprenticeships and Work Experience Investigate putting together job clubs for post 16's with Autism (colleges, schools, sixth forms)	Dec 2015	Tim Porter, SCC			

4	Provide a model for advice, training and support to be available for all schools and colleges to build capacity within universal education services.	Support development of SLA's between services and commissioners from SCC and Colleges	April 2016	To be allocated

Appendix 5 Governance Structure for the Children & Adults Autism Strategy



Appendix 6 Contributors

The following individuals were involved in developing this strategy:

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

Somerset County Council and NHS Somerset Clinical Commissioning Group would like to thank the following groups and organisations who participated in the consultation on the draft strategy between June and October 2014. Their responses and feedback has been incorporated in to this document:

- West Somerset Health Forum (Minehead)
- Bridgwater Parent Support Group
- Coping with Autism Through Support (CATS) (Bridgwater)
- Disability Somerset Exhibition (Bridgwater)
- Wells Parent Support Group
- Mendip Autism Support Group (Shepton Mallet)
- National Autistic Society Local Branch Meeting (Frome)
- National Autistic Society Local Branch Carers Forum (Yeovil)
- Yeovil Aspergers Support Group
- Yeovil Parent Support Group
- South Somerset Health Forum (Yeovil)
- Chard, Ilminster and Crewkerne Health Forum
- Children with Autism Outreach Team (CAOT) coffee morning (Langport)
- Short Breaks Family Fun Day (Langport)
- National Autistic Society Local Branch Meeting (Taunton)
- Selworthy School Parents (Taunton)
- Taunton Autism Support Group
- Patient Participation Group Chairs Network

The following groups were contacted and offered a session but declined; some opting to contribute individually:

- Minehead Support and Social Group
- Frome Autistic Support Team
- Yeovil Aspergers Social Group
- Crewkerne Autism Support Group
- Taunton Aspergers Group/Aspie Pirates
- Self-Advocacy 'Speak Up Groups' (12 towns across the County)

Organisations that responded to the consultation:

- Advocacy in Somerset
- Autism Somerset
- Creech St Michael Patient Participation Group
- Family Focus (Developing Health & Independence)
- Healthwatch Somerset
- Knightstone Housing
- Life After Stroke Services, The Stroke Association
- NHS Musgrove Park Children's Services, GP and Primary Care
- Pluss
- Police
- Rethink Mental Illness
- Sandwell
- Sedgemoor District Council; Housing Advice Team
- Schools Bishops Hull Pre School, Halcon Community Primary School, Holy Trinity CEVA Primary School and Selworthy School
- Somerset County Council Adult Social Care, Children's Social Care and Leaving Care Service
- Somerset Partnership NHS Trust Integrated Therapy Service and Learning Disability Psychiatry
- Taunton & District Citizens Advice Bureau
- Wellington Medical Centre