

Needs Assessment: Autistic Adults and Children

South Gloucestershire

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1. Summary and Recommendations

1.1. Summary

The South Gloucestershire autism needs assessment considers both autistic adults and children. Autism is a lifelong developmental disorder that affects how people perceive the world and interact with others – it is not an illness or disease and cannot be cured. Nationally autism affects approximately 1 in 100 people. Estimates for South Gloucestershire indicate that 2,776 local people are autistic, of whom 577 are under the age of 18. Due to population increases, this could rise to 3,225 in 2035, including 669 children. Whilst most diagnoses occur during childhood, there are believed to be many adults and older people remaining undiagnosed, particularly women and girls.

This assessment has identified a number of needs for autistic people which are currently not being fully met. Whilst work is already underway to meet some of these, others are addressed in the report's recommendations. Particular areas of need were found in the coordination and communication between services, organisations and service users. Proposals have been put forward to ensure appropriate and comprehensive support for all autistic children and adults. Specifically there is scope for improving support at the time of diagnosis and ensuring that waiting times for assessments are reduced. Underlying all the recommendations is the prerequisite to ensure that the needs of autistic people are understood.

1.2. Summary of findings and gaps

The autism needs assessment has identified a series of findings that have provided the basis for developing a set of recommendations for future work and the next steps to be taken locally to improve the provision of services and support for autistic people in South Gloucestershire.

1. Prevalence of autism

- There is a high level of professional concern regarding an increased incidence and prevalence of autism locally.
- Collecting comprehensive data on numbers of autistic people is difficult.
- Statutory services are only able to identify a small proportion of the estimated population of autistic people.
- Data collection processes do not currently record information on ethnicity, sexuality or religion.
- The number of children on the autism spectrum in South Gloucestershire appears to be slightly higher than predicted by using a 1% population prevalence rate.
- The numbers of people currently accessing services and population growth figures could be used together to estimate future level of service demand. This is not currently standard practice.
- There are no reliable figures for the number of autistic adults in South Gloucestershire.
- There is scope to carry out further investigations into the high prevalence of autism in South Gloucestershire.

2. The process of diagnosis

- The journey to diagnosis is long, complicated and can involve unsupported waiting periods between appointments.

- Multi-disciplinary autism diagnosis assessments are not always achieved. A child might need to attend a series of separate appointments with different professionals.
- Waiting times for initial assessment can be up to two years for children.
- Electronic recording systems are not currently robust enough to provide all data on assessment and waiting times.
- Appropriate support after diagnosis is critical. In education settings, dedicated autism support would help address this current gap.

3. Health and social care needs of autistic people

- Recording of autism across all ages in GP practices is variable as there are no centrally agreed recording guidelines or register.
- There is a range of support available in South Gloucestershire for both autistic children and adults, however there may be an emphasis and reliance on support offered by peers.
- There is an increasing demand for support for children and young people who develop mental health needs.
- There needs to be upfront information and clarity about the services that are available.
- Eligibility criteria for social care services may currently exclude autistic adults.
- There is scope for improvement in continuity, clarity and openness in communication about service provision to autistic people.

4. Transition from primary to secondary school and child to adult services

- There is scope for improving the transition support and provision on offer for young people.
- There is a gap in transition provision for those children who do not have an EHC plan.
- More internships, apprenticeships and meaningful work experience for young people would enhance prospects for autistic people.

5. Work and employment for autistic people

- Positive changes are being recognised in improved access to services, for example through the Job Coach Provider List, but further work is required
- More employers need a better understanding of autism and the skills of people with autism spectrum condition

1.3. Summary of recommendations

In order to meet the needs of autistic children and adults in South Gloucestershire, there must be a shared understanding of what we aim to achieve and how we will work collaboratively to achieve it. The overarching recommendation from the needs assessment is for South Gloucestershire to establish this shared understanding, as a foundation for future work.

Recommendations

Five key themes emerged from the assessment of needs and the review of good practice and guidance:

1. Improve collection of data on people with a diagnosis of autism

- Ensure collected data helps with an understanding of local need.
- Collect comprehensive data on the diagnostic assessment including waiting times for different services on the diagnostic pathway.

- Ensure that outcomes are measured to determine quality and improvement of services, including behaviour and education outcomes.
- Improve clarity of data collection in education settings so that all diagnoses are recorded.
- Develop systems to ensure the collection of reliable figures for autistic adults.
- Further investigate the reported high levels of autism in South Gloucestershire.

2. Increase coordination and the strategic overview of services

- Ensure that the local autism multi-agency groups have a clear scope and mandate.
- Improve communication between professionals and develop proactive links between organisations.
- Improve communication between professionals and autistic people and their families.
- Ensure that the Local Offer clearly outlines the services and support available for children and young people on the autism spectrum.
- Ensure that the level of support available for autistic people is commensurate with the demand for services.
- Encourage collaborative working and oversight of the whole system, including transition.
- Ensure that professionals in both specialist and mainstream services are supported through an ongoing programme of autism training, encompassing social communication, social interaction, restricted and repetitive patterns of behaviours and sensory processing.
- Engage with mental health services to ensure timely and appropriate access to services for autistic people, recognising that autism is not a mental health problem and that the people delivering this training will need specialist knowledge.
- Ensure that South Gloucestershire website (Local Offer) delivers current information in an accessible format and that it signposts to other relevant information.
- Commission a review of good practice evidence and guidance.

3. Improve access to diagnostic services

- Develop clear diagnostic pathways for children, young people and adults.
- Ensure that multi-disciplinary assessment is available, where appropriate.
- Ensure that pre and post-diagnosis support is explicitly included within the pathways.
- Clearly sign post clients to sources of information and support.
- Improve early recognition of autism through raising awareness of signs and symptoms and increased training, particularly in schools and early years' settings.
- Ensure that diagnosis recognises all potential characteristics of autism including persistent problems with social communication, social interaction, restricted and repetitive patterns of behaviours and sensory processing.
- Ensure resources within Community Paediatrics are able to meet the demand for assessment.

4. Support engagement and collaboration with service users and their families

- Increase collaborative work with service users and their families.
- Consider establishing a fixed term project group focusing on improving client engagement and community support.
- Improve understanding of the needs of autistic adults particularly the older generation.
- Ensure the children and young people who develop mental health needs are supported in accessing appropriate services.

5. Increase autism awareness within the wider community and mainstream services

- Improve awareness of autism amongst local authority and NHS staff.
- Ensure that the training offered to local authority and NHS staff is effective and appropriate.
- Review the support available in accessing employment and housing for autistic people, ensuring clarity of advice and signposting.
- Review the Autism Friendly scheme, increasing the number of local organisations and businesses achieving accreditation.
- Ensure that mainstream services maximise their accessibility to autistic people.

2. Background and context

2.1. Definition of Autism

Autism is a lifelong developmental disorder that affects how people perceive the world and interact with others.

Autistic people see, hear and feel the world differently to other people. If you are autistic, you are autistic for life – autism is not an illness or disease and cannot be cured.

Autism is a spectrum condition, both because of the range of difficulties that affect autistic people and the way that these present in different people. All autistic people share certain difficulties, but being autistic will affect them in different ways.

Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support. All people on the autism spectrum can learn and develop and with the right support be helped to live a fulfilling life of their own choosing.

The characteristics of autism vary from one person to another, but in order for a diagnosis to be made, a person will usually be assessed as having had persistent difficulties with:

- Social communication
- Social interaction
- Restricted and repetitive patterns of behaviours, activities or interests since early childhood, to the extent that these limit and impair everyday functioning
- Sensory processing

In this needs assessment, the term *autism* is used to refer to all parts of the spectrum.

2.2. Scope of this Needs Assessment

This assessment considers the needs of autistic people in South Gloucestershire:

- Children, adults and older people.
- Across the autistic spectrum, including those without a learning disability.
- The needs of people who may not have a diagnosis or currently be accessing any services.

A wide range of needs are considered, and gaps in service provision to meet these needs identified. These needs are:

1. Diagnosis
2. Therapeutic needs
3. Health needs
4. Education
5. Transitions
6. Social care
7. Training and employment
8. Housing

9. Mainstream services
10. Social support
11. Criminal justice
12. Involvement in service planning and provision
13. The needs of carers
14. Coordination

2.3. Policy context

The [Autism Act](#) (2009)¹ established the requirement for the Government to produce a strategy for meeting the needs of adults in England with autism spectrum conditions by improving the provision of relevant services by local authorities, NHS bodies and NHS foundation trusts.

The first autism strategy *Fulfilling and Rewarding Lives* was produced in 2010².

This was updated in 2014 and published as *Think Autism*³.

There are duties on local authorities and NHS bodies to act under the statutory guidance produced by the Government to accompany each strategy⁴.

The NICE guidelines on autism recommend the development of services to meet the needs of autistic people. The quality standard⁵ provides a tool to inform the commissioning of autism services for children, young people and adults and improve the quality of existing services.

2.4. Summary of duties under the statutory guidance

Local authorities

- Must ensure that any person carrying out a needs assessment under the [Care Act](#) (2014)⁶ has the skills, knowledge and competence to carry out the assessment.
- Must ensure that the duties under the [Children and Families Act](#) (2014)⁷ are applied where relevant to children and young people on the autism spectrum and their families.
- Must identify and develop resources that will prevent or delay the development of care and support needs of autistic adults and their carers ([Care Act](#) 2014)
- Must identify the local care and support needs of autistic people and gaps in service provision ([Care Act](#) 2014)

¹ Autism Act 2009 www.legislation.gov.uk/ukpga/2009/15/section/1

² Fulfilling and rewarding lives

http://webarchive.nationalarchives.gov.uk/20130104203954/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

³ Think Autism www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf

⁴ Statutory Guidance www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf

⁵ NICE guidance <https://www.nice.org.uk/guidance/qs51>

⁶ Care Act 2014 <http://www.legislation.gov.uk/ukpga/2014/23/contents>

⁷ Children and Families Act 2014 <http://www.legislation.gov.uk/ukpga/2014/6/contents>

- Should ensure that there is a meaningful local autism partnership arrangement that brings together different stakeholders locally, including the CCG, and autistic people.
- Should allocate responsibility to a named joint commissioner or senior manager for commissioning services (autism lead).
- Should bring partners together, for example through Health and Wellbeing Boards, to ensure information sharing protocols are in place and that all necessary information for service planning is available.
- Must identify the local care and support needs of autistic people and gaps in service provision ([Care Act 2014](#))
- Must provide access to specialist advocacy provision where the person would have a significant difficulty in understanding the assessment and care management process ([Care Act 2014](#))
- Must ensure that the assessment and care planning process for adult needs for care and support considers participation in employment as a key outcome, if appropriate.

NHS bodies

- Should ensure they are involved in the development of local workforce planning, and GPs and all primary care staff are engaged in the training agenda in relation to autism.
- Should provide access to an autism diagnostic and treatment pathway including those who do not have a learning disability.
- Should designate a health lead responsible for developing, maintaining and promoting a diagnostic and treatment pathway.
- Should ensure that Liaison and Diversion services have in place a clear process to communicate the needs of an autistic offender to the relevant prison or probation provider.

LAs and NHS bodies jointly

- Should ensure the existence of a clear trigger from diagnostic to local authority adult services to notify individuals of their entitlement to an assessment of needs.
- Should work together to put in place a locally agreed joint plan to ensure high-quality care and support services for all people with behaviour that challenges, including autism.
- Should work in partnership so there is a substantial reduction in reliance on inpatient care for autistic people.
- Should ensure that in commissioning health services for persons in prison and other forms of detention prisoners are able to access autism diagnosis in a timely way and ensure that there is appropriate education provision.

3. Prevalence

3.1. National picture – prevalence

Gathering data on the numbers of autistic people is challenging as historically services have not collected comprehensive data about this population. Autism is a relatively ‘modern’ diagnosis, with the term ‘autism’ only coming into common clinical use in the 1960s.

Autism is believed to affect approximately 1 in 100 people in the UK

- Leo Kanner’s original conception of the condition in the 1940s emphasised its rarity, and it was estimated to affect only 2-4 per 10,000 of the population⁸
- Since then, our understanding of autism has developed, with changes to diagnostic criteria and the incorporation of other parts of the spectrum, including that described by Hans Asperger in the 1940s.
- The definition of autism has broadened and diagnosis rates have increased significantly, with some estimates of population prevalence as high as 1.5%.⁹
- There is disagreement about the cause of this increase. It could be explained solely through changes to diagnostic criteria and improved awareness and detection, although some have suggested that actual prevalence may also have increased in this period.

Whilst most diagnoses now occur during childhood, many adults remain undiagnosed. There may be many older people with autistic spectrum conditions who were never diagnosed.

It is estimated that autism is between 4 and 9 times more common in men than women¹⁰. However, there is increasing recognition that women are often misdiagnosed or missed due to different presentation and stereotypes about autism¹¹.

Autism affects all ethnic and socio-economic groups. Diagnosis rates are believed to be particularly low for some population groups, including older people and people from Black and Minority Ethnic groups.

It is estimated that around half of the total number of autistic people have a learning disability (IQ below 70). A review undertaken in 2010 found substantial differences in estimates between different studies. It settled on a lower estimate of 40% and a higher estimate of 67% for its modelling¹².

The most common co-morbidities for autistic people are mental health conditions; although different studies have calculated different figures, up to 70% of autistic people also meet the diagnostic criteria for at least one other psychiatric, mental or behavioural disorder¹³.

⁸Wing, L., Potter, D (2002) The Epidemiology of autistic spectrum disorders: is the prevalence rising? *Developmental Disorders Research Reviews* 8:3 pp51–161

⁹ Baron-Cohen et al. (2009) Prevalence of autism-spectrum conditions: UK school-based population study. *British Journal of Psychiatry*, 194 (6) pp 500-509

¹⁰ NICE Guidance www.nice.org.uk/guidance/qs51/resources/support-for-commissioning-for-autism-253717885

¹¹ Statutory Guidance to support the implementation of the adult autism strategy -

www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autismguidance.pdf

¹² Emerson, E., Baines, S (2010) The estimated prevalence of autism among adults with learning disabilities in England. *Improving Health and Lives* www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf

¹³ www.nice.org.uk/guidance/cg128/ Autism spectrum disorder in under 19s: recognition, referral and diagnosis

3.2. Local picture – estimated prevalence

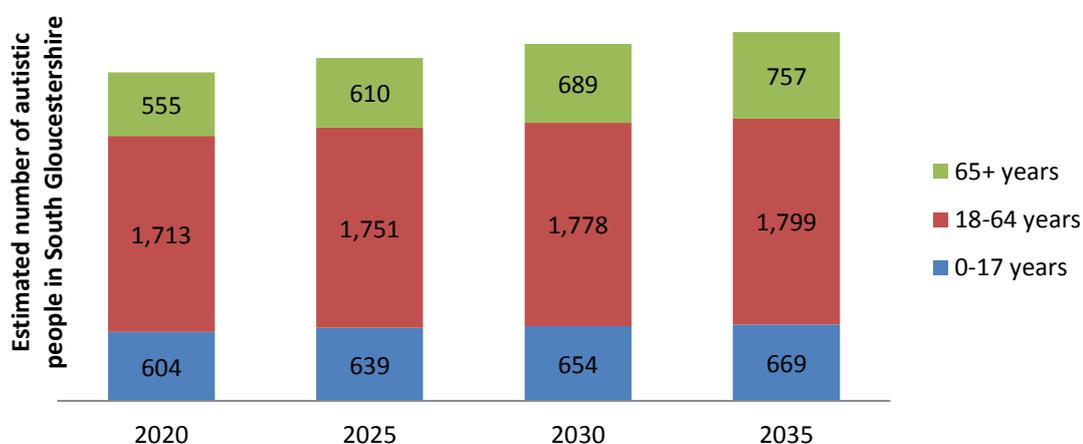
These estimates were calculated by applying a 1% autism prevalence level to Office for National Statistics population projections for South Gloucestershire. The actual numbers could be higher or lower than these. While not accurate, they give an indication of the likely size of the autistic population. These estimates assume that prevalence is stable over time (i.e. that the rate of autism in the population has not been increasing in recent years).

Table 1- Estimated prevalence of autistic people in South Gloucestershire

Year	2017	2020	2025	2030	2035
Age range					
0-17 years	577	604	639	654	669
18-64 years	1,685	1,713	1,751	1,778	1,799
65+ years	514	555	610	689	757
Total	2,776	2,872	3,000	3,121	3,225

Source: Population Projections - Office for National Statistics, 2014 Subnational Population Projections, Local Authorities in England. Release date June 2016

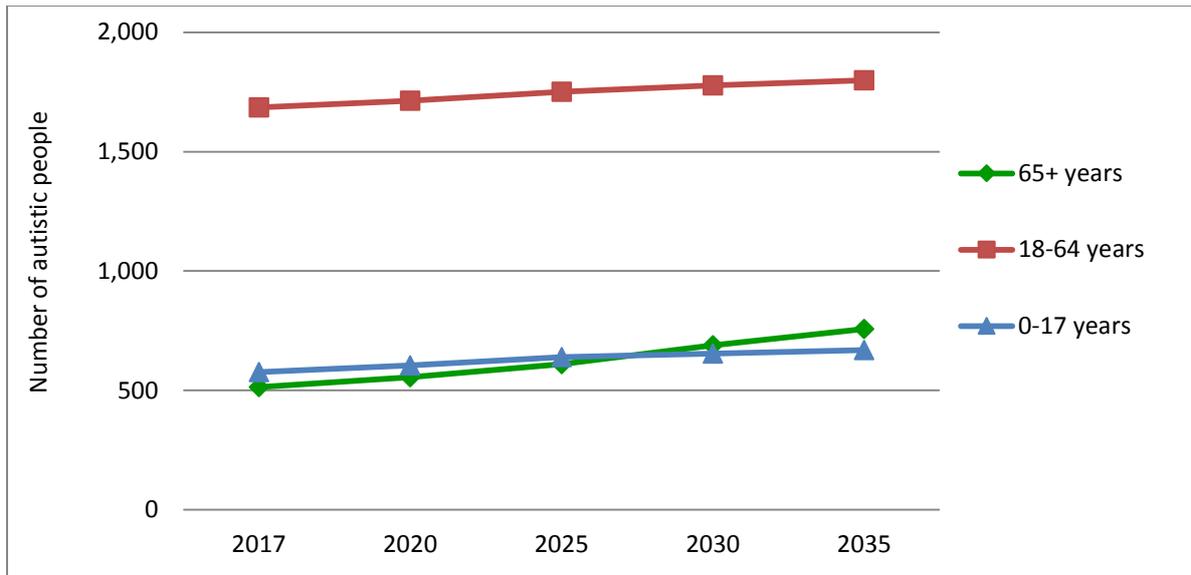
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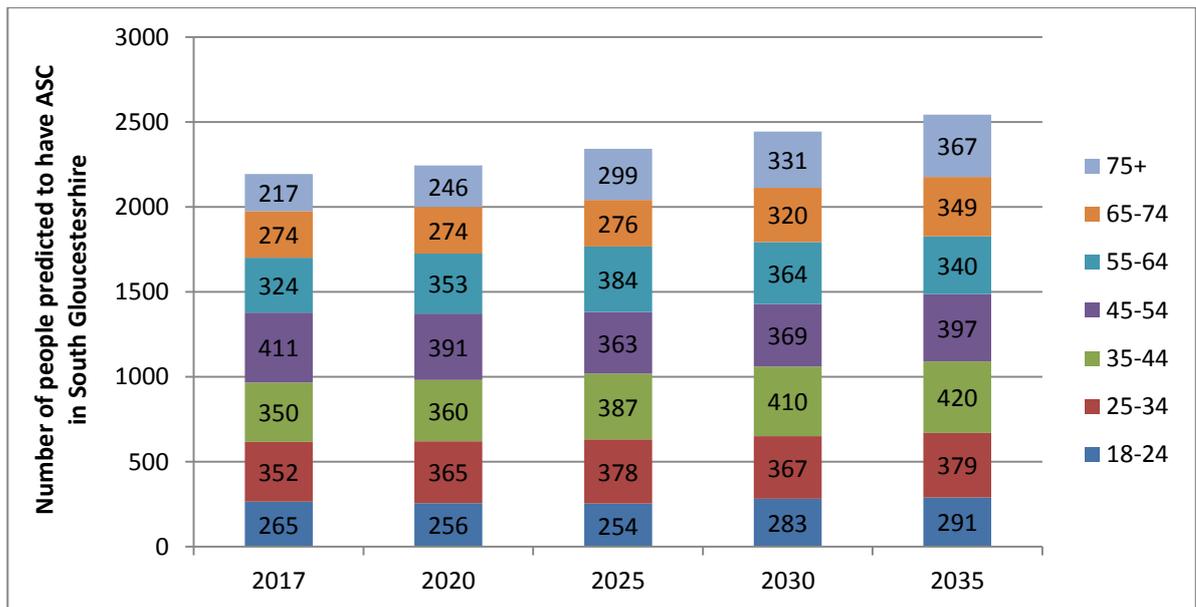
Although the prevalence of autism is not expected to change, as the number of people living in South Gloucestershire increases, so too will the number of autistic adults. Applying a 1% autism prevalence level to local ONS population projections, the estimated number of autistic adults aged over 18 is predicted to rise from 2,199 in 2017 to 2,467 in 2030.

Figure 2- Estimated autism prevalence in South Gloucestershire by age group



Similar estimates of future prevalence have been calculated based on figures published by the Health and Social Care Information Centre (September 2009) and ONS population projections, using Projecting Adult Need and Service Information (PANSI). The projected number of adults aged between 18 and 64 with autism is predicted to rise from 1,703 in 2017 to 1,827 in 2035.

Figure 3 - People aged 18 and over predicted to have ASC projected to 2035



Source: Projecting Adult Need and Service Information (PANSI) www.pansi.org.uk

3.3. Local picture – people known to services

Estimated number of autistic people in South Gloucestershire (1% prevalence estimate)

Estimated number of children on the autism spectrum in South Gloucestershire (1% prevalence estimate)

= **2,776**¹⁴

= **577**¹⁵

*Children on the autism spectrum
known to SEND*
= **453**¹⁶

Total number of adults receiving
local authority funded
social care services¹⁷
= **3,911**

Adults eligible for
NHS continuing care ¹⁸
= **212**

In South Gloucestershire, a wide range of professionals across many agencies hold a concern that using the national prevalence estimate for autism is not an appropriate metric for the South Gloucestershire population. There are long held concerns that there is a particularly high prevalence of ASC locally. The 1% estimate for the number of autistic people should therefore be considered alongside an estimate produced by collating case records and data from services working with autistic people.

The statutory services in South Gloucestershire report a higher number of autism cases than might be expected for an area with the same population size. Locally, 70% of people seen by CAMHS (child and adolescent mental health services) have a diagnosis of autism and community paediatrics also experience a very high proportion of ASC related work.

It should also be noted however that statutory services are only able to identify a small proportion of the estimated population of autistic people in South Gloucestershire. The rest may be:

- Undiagnosed.
- Diagnosed and accessing services, but their diagnosis not known by the service.
- Known to services (including their diagnosis) but not recorded in a way which can be reported.
- Diagnosed but not accessing services.

¹⁴ Population projections – ONS, 2014 Subnational Population Projections, LAs in England 2016

¹⁵ Population projections – ONS, 2014 Subnational Population Projections, LAs in England 2016

¹⁶ Data extracted from Capita One, 13th Feb 2018 and is based on stated Primary Need of children and young people (Year R to Year 13) with current EHC Plan or SEN Statement

¹⁷ Determining eligibility is not an accurate measure, instead data is based on those receiving an Adult Social Care service (excluding equipment and adaptations, telecare, piper lifeline, meals) as at 28th Feb 2018

¹⁸ People eligible for NHS Continuing Healthcare (CHC) as at 31st Dec 2017. Data Source: NHS Continuing Healthcare Quarterly Figures, NHS England, <https://www.england.nhs.uk/statistics/statistical-work-areas/nhs-chc-fnc/2017-18>

In addition, given the spectrum nature of autism, the needs of this group will vary considerably. It is not possible to identify how many of those not known to services might benefit from them.

This information shows that there is potentially a significant number of autistic adults that are not known to services or currently receiving support. However, it is not known what percentage of this group may actually be eligible to receive support.

There is limited data collected on the characteristics of autistic people such as ethnicity. However, age and gender are noted.

3.4. Local picture – estimates of future need

The current number of children on the autism spectrum in schools¹⁹ (453) is slightly higher than predicted by a 1% prevalence rate (415) – approximately 11 in 1,000 instead of 10 in 1,000. However, the comparison of figures does indicate that the predicted number of children on the autism spectrum is potentially a fairly close estimate of the number of autistic children known to SEND.

Table 2- Estimated and recorded autism prevalence in children in South Gloucestershire

	2016/17
1% prevalence estimate (5-17years)	415
Total population (5-17 years)	41,480 ²⁰
Current SEND population (school years Yr R – Yr 13) with ASC	453 ²¹
Current SEND population (school years Yr 1 – Yr 13)	1,535 ²²

A caveat to this comparison should be noted. The figures used to record the number of children on the autism spectrum known to SEND are only based of the number of children with a diagnosis and do not include those without a diagnosis but receiving SEN support.

As many children are likely to be diagnosed at different points during their time in education settings, it is likely that actual prevalence is higher than the recorded level. This figure is lower than the 15.7 per 1,000 children aged between 5 and 9 years found by Baron-Cohen et al (2009)²³.

It should also be noted that some children are diagnosed before the age of five and these children are not captured within these summaries.

Data from schools and South Gloucestershire’s SEND database gives an indication of the number of children on the autism spectrum likely to begin the transition process (Year 9) towards adult services in coming years. Numbers are small, and therefore subject to variation year on year, but existing figures do suggest

¹⁹ Based on South Gloucestershire SEND database 2017 school years 0 to 13

²⁰ ONS 2016 Mid Year Pop Estimates, children aged 5 to 17

²¹ Data extracted from Capita One, 13th Feb 2018 and is based on stated Primary Need of children and young people (Year R to Year 13) with current EHC Plan or SEN Statement

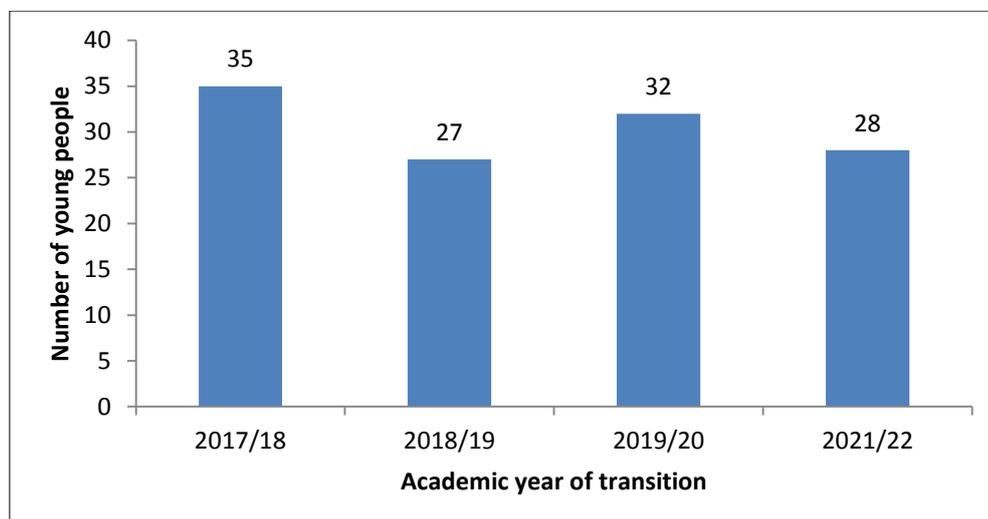
²² Data extracted from Capita One, 13th Feb 2018 and is based on National Curriculum Year (Year R to Year 13) of children and young people with current EHC Plan or SEN Statement

²³ Baron-Cohen et al (2009) Prevalence of autism-spectrum conditions: UK school-based population study. British Journal of Psychiatry, 194 (6) pp 500-509

that there is a need to plan for approximately 30 young people with autism entering adulthood each year in South Gloucestershire.

However, beyond the PANSI estimates based on 1% population prevalence, the information about the numbers and characteristics of those who are already adults is limited and therefore little is known about the potential future needs of this group.

Figure 4 – Children on the autism spectrum likely to transition into adult services from 2017/18 to 2021/22



It would be useful to produce a simple projection based on current numbers of users of statutory services (adult social care services, mental health services and children’s SEND) and using population growth estimates to give an indication of future level of demand for services. These figures would be based on current levels of service use so may be an underestimate of true demand or need, due to the difficulties in obtaining diagnosis or accessing existing services.

3.5. Local picture – gaps in the data

There are a number of significant gaps in the data which make it impossible to present a comprehensive picture of the autistic population in South Gloucestershire and their needs. These gaps are similar to gaps recognised nationally and in other areas, and include:

- Reliable figures for the number of autistic adults in South Gloucestershire.
- Specific data for South Gloucestershire on the number of people with varying needs across the spectrum, including those learning disabilities and/or behaviour that challenges. Specific data for South Gloucestershire in a number of areas of need, including housing, employment.
- No figures are available for the number of children with an autism diagnosis who are receiving SEN support rather than having an EHC.
- A full understanding of the quality, effectiveness and cost of services available for autistic people in South Gloucestershire

Reasons for these gaps can include:

- Some autistic people, especially adults, are undiagnosed and are therefore not identifiable as being autistic.

- Some adults, even those with a diagnosis, may not be eligible for using any statutory services.
- Statutory services, including local authority and NHS services, often do not keep records of which people using their services are autistic.
- There have been issues in accessing data held in different parts of the system.
- The data available is not always up to date or complete.
- Some autistic people may be represented more than once in the data sets, therefore providing an overestimate of the total number.

The lack of robust data on the numbers of autistic people in South Gloucestershire is of major public health concern. Without a precise understanding of the scale of the issue, it is difficult to assess the correct response and level of provision.

However, given the increasing level of alarm amongst professionals working with autistic children and adults, it is clear that this is a priority area for immediate action.

4. The health needs of local people

4.1. The needs of autistic people – national assessment

The National Autistic Society's research report *I Exist* (2008)²⁴ found that autistic adults are often isolated, unable to access support and are dependent on their families. The report states that:

- 63% of autistic adults do not have enough support to meet their needs.
- 92% of parents are either very worried or quite worried about their son or daughter's future when they are no longer able to support them.
- 60% of parents say that a lack of support has resulted in their son or daughter having higher support needs in the longer term.
- 61% of autistic adults rely on their parents financially.
- 40% live with their parents.
- 33% have experienced severe mental health difficulties because of a lack of support.
- Only 16% are in full time employment.
- 66% are not working at all (including voluntary employment).
- 67% of Local Authorities do not know how many autistic adults are in their area.

4.2. Summary of organisations and services

NHS	Local Authority	National Government	Voluntary / Private Sector
Adult Diagnostic Service (AWP)	Education	Disability Benefits	Support for carers
Community Paediatrics (CCHP / Sirona)	Social Care – short breaks for children 0-18, residential care, community based support and day services	Employment Support	Social and peer support
Mental Health (CCHP / AWP)		Prison Support	Additional or top up provision of therapies, support and respite
Speech and Language Therapy (CCHP / BCH)	Housing		
Occupational Therapy (CCHP / BCH)			
Continuing Care (CCG)			
Physiotherapy (CCHP / BCH)			

²⁴ | Exist (2008) National Autistic Society

The Community Children’s Health Partnership (CCHP) is a partnership led by Sirona care & health CIC working with partners Avon and Wiltshire Mental Health Partnership NHS Trust (AWP), Bristol Community Health CIC (BCH), University Hospital Bristol NHS Foundation Trust (UHB), Barnardo’s and Off The Record. Together CCHP provide all of the community child health and child and adolescent mental health services for Bristol and South Gloucestershire.

4.3. Needs assessment

The results of the needs assessment will cover general information at a national or international level about the needs of autistic people and a summary of the services in place locally to meet those needs.

The needs covered are:

- 4.3.1 Diagnosis
- 4.3.2 Therapeutic needs
- 4.3.3 Health needs
- 4.3.4 Education
- 4.3.5 Transitions
- 4.3.6 Social care
- 4.3.7 Training and employment
- 4.3.8 Housing
- 4.3.9 Mainstream services
- 4.3.10 Social support
- 4.3.11 Criminal justice
- 4.3.12 Involvement in service planning and provision
- 4.3.13 The needs of carers
- 4.3.14 Co-ordination

4.3.1. Diagnosis

Rates of diagnosis are increasing, as is a general awareness of autism. The increase might be due in part to an element of diagnostic substitution where people previously given diagnoses of learning disabilities are now being recognised as having autism.

Despite this increase, there are still significant numbers of autistic people who have not been diagnosed. Diagnosis rates are believed to be particularly low for some population groups, including women, older people and people from Black and Minority Ethnic groups. However, very little information about ethnicity, sexuality, faith or any of the protected characteristics is routinely collected or easily available.

Diagnosis is important for a number of reasons:

- It may facilitate access to benefits, specialist services, or adapted mainstream services and provide access to appropriate parenting courses.
- For those diagnosed in later life, it can be a relief and provide an explanation for challenges and difficulties that have been faced. It will also provide a future framework for understanding triggers which can help inform adjustments that might make every day living more comfortable.
- Diagnosis delays mean people are experiencing avoidable mental health problems including anxiety, depression and prolonged stress due to a lack of explanation for symptoms, and their behaviour not being understood by others.

The NICE Quality Standard on autism²⁵ calls for waiting times between referral and initial appointment for assessment to be no longer than three months. However, recent reports indicate that there are long waits to receive an autism diagnosis.

- In a recent report²⁶, over two thirds (69%) of parents said that they had waited more than a year to get a diagnosis for their child following the initial expression of concern and one in six (16%) had waited more than three years
- In 2015 the National Autistic Society²⁷ reported average waits of two years for adults

Diagnostic pathways in South Gloucestershire

Statutory guidance based on the Autism Act states that CCGs should commission a local diagnostic pathway, and should work closely with the local authority to provide post-diagnostic support. In South Gloucestershire there are a number of different diagnostic pathways for autism.

CHILDREN

Following the recognition of symptoms that might indicate ASC, the child will be referred to the most appropriate service within CCHP²⁸ in recognition of the presenting symptoms:

- SLT – primary problem with language
- Community Paediatric service – concerns about social communication and interaction
- CAMHS – concerns about mental health as the main presenting feature
- Specialist service for children with Learning Disabilities – moderate to severe learning disability with complex emotional, behavioural or mental health difficulties

The assessment will involve a series of steps:

A1 – Initial appointment with the lead professional to review information and agree next steps:

- Not ASC
- Watchful waiting
- Autism Diagnostic Assessment

A2 – Decision to undertake an Autism Diagnostic Assessment

The decision is made jointly with the family and young person, where appropriate.

A3 – Autism Diagnostic Assessment

Diagnostic assessments should gather as much information as needed and involve at least two different professionals from the autism team. The assessments may be carried out by community paediatricians with locality speech therapists or educational psychologists; CAMHS; the learning disability team; or by a multi-disciplinary assessment team (Autism Spectrum Assessment Team ASAT).

²⁵ NICE Quality Standard [QS51] on autism (2014) www.nice.org.uk/guidance/qs51

²⁶ School Report (2016) National Autistic Society www.autism.org.uk/get-involved/media-centre/news/2016-09-02-school-report-2016.aspx

²⁷ www.autism.org.uk/~media/nas/documents/get-involved/autism%20diagnosis%20campaign%20briefing.ashx

²⁸ CCHP autism diagnostic assessment <http://cchp.nhs.uk/cchp/clinicians/autistic-spectrum-condition-referral>

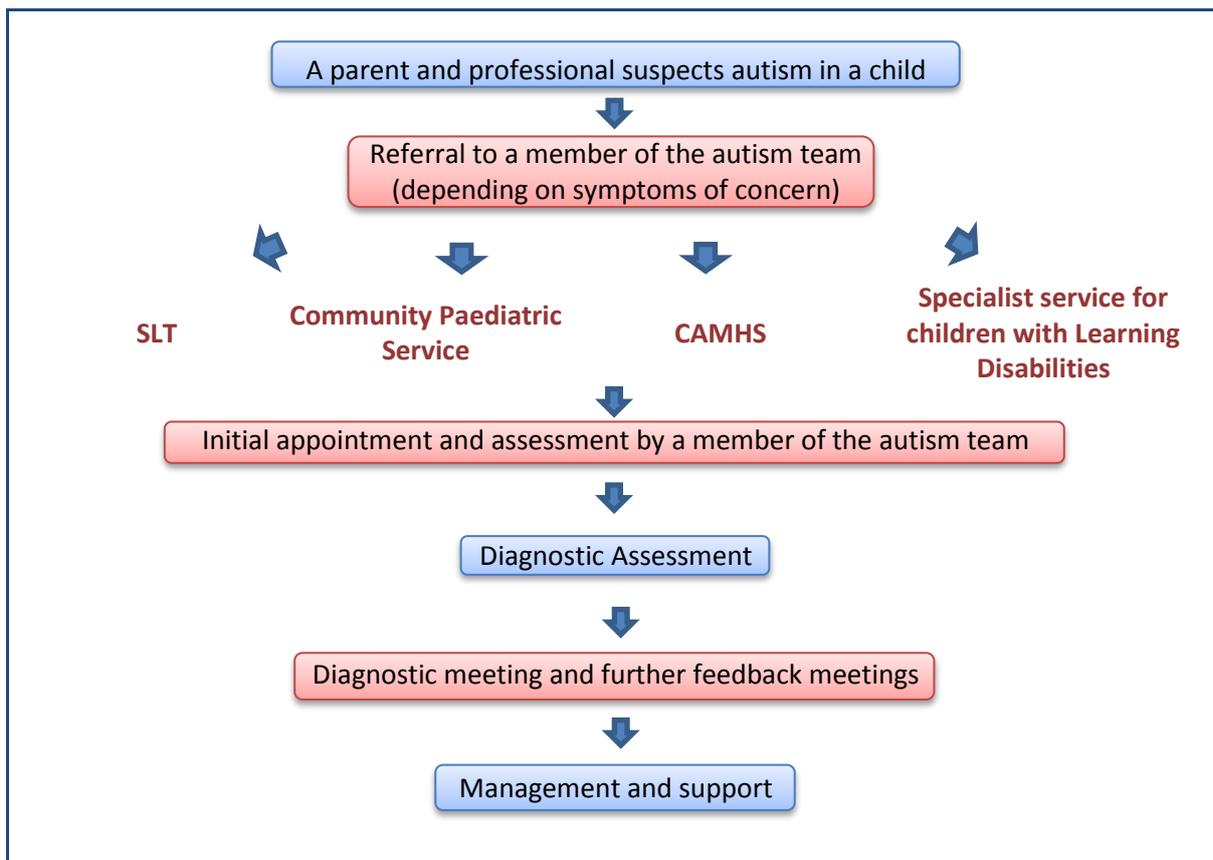
A4 – Diagnostic meeting and further feedback meetings

The diagnostic meeting will include all professionals involved to review the information gathered during the diagnostic assessment. This will be followed by a feedback meeting with parents and the young person, if appropriate; to share the outcome and agree if a diagnosis would be helpful at this time. An action plan will also be agreed with the parents.

A5 – Management and support

A post-diagnosis appointment will be held with a member of the diagnostic team. Follow-up and support will be agreed with families on an individual basis. Interventions from other health services will be tailored to the child’s needs

Figure 5 - Diagnostic pathway for children aged 0 - 18 years in South Gloucestershire



The referrals for community paediatric intervention during 2016/17 reached a total of 219 for ASC. This represents over a third (36%) of the paediatric referral caseload.

The number of young people referred for ASC assessments by CAMHS reached a total of 41 between January 2017 and March 2018. Over this period 39 people were seen and assessed, resulting in 31 diagnosed with ASC. Young people can only be referred to the CAMHS ASC specialist assessment clinic by a CAMHS clinician who will have already seen the young person for a mental health concern. It is possible that the young person may have also been seen by a community paediatrician and therefore been on the paediatrics waiting list.

CAMHS assessments are carried out as a single session rather than through multiple appointment slots. The young person receives the assessment outcome on the day. This is a new model which has been receiving positive feedback from young people and their families. It is also effectively reducing waits for ASC assessment.

The multi-disciplinary autism diagnostic assessment should ideally include a wide range of professionals including SLT, community paediatrician, consultant nurse and psychologist. However, there is insufficient capacity in all professional groups to ensure full participation. Children are currently waiting up to two years to be assessed. There are some children who will have social communication needs but will not meet the criteria for a diagnosis of autism. These children will usually benefit from the types of support provided for children with a diagnosis.

A crude report of the number of ASC assessments completed over the course of one year (2015/16) across the Community Children’s Health Partnership (CCHP) in South Gloucestershire includes the following detail:

Table 3 - Assessments completed by CCHP during 2015/16 for South Gloucestershire

Assessments completed	Multi-disciplinary assessments completed	Number of people on waiting list at year end	Number of people on multi-disciplinary assessment waiting list at year end
179	82	249	195

ADULTS

In South Gloucestershire the Bristol Autism Spectrum Service (BASS) coordinate the diagnostic service for adults, which is accessible via GP and secondary care referral. The rate of referrals to BASS is increasing steadily. The assessments, diagnostic rates and number of people remaining on the waiting list are detailed below:

Table 4 -South Gloucestershire Referral and Diagnostic Rates for BASS

Year	Referrals received	Average referrals per month	Diagnostic assessments undertaken	Number of people on waiting list at year end	Positive diagnosis	Negative diagnosis
2014/15	50	4.2	64	20	N/A	N/A
2015/16	72	6	64	29	29	35
2016/17	61	5.9	60	31	28	32
2017/18 (to end of Q3)	71	7.9	43	43	16	27

The longest wait for an assessment in South Gloucestershire at the end of the third quarter in 2017/18 was seven months.

There are a number of concerns about current diagnostic arrangements:

- **Delays in diagnosis** – Families are only able to access support services once their child has received a diagnosis. Delay in receiving a confirmed diagnosis is resulting in a lack of access to support
- **Coordination issues** - Families of children receiving a diagnosis are signposted to a range of different support groups, alongside statutory provision including education and therapies. However, this offer is not felt to be well co-ordinated and occasionally is started, but not completed

- **Communication** - The interface between educational psychologists, health and schools is not always effective. This might be improved if an educational psychologist was included in the diagnosis process
- **Inefficiency** - Currently, the assessment process for a child in South Gloucestershire is inefficient. It is usual for a child to attend a series of appointments with different professionals. Ideally the child would attend a single multi-professional appointment with a paediatrician, CAMHS, an occupational therapist and speech and language therapist
- **Information** – the electronic patient record systems are currently not robust enough to provide accurate data on assessment and waiting times. Funding for IT improvement has been requested from NHS England

“Now diagnosed there has been more support available to us, however the road to diagnosis is very long and there is no help or support during the wait for assessment” Parent/carer on behalf of a child on the autism spectrum

4.3.2. Therapeutic needs

Some of the everyday difficulties experienced by autistic people can be alleviated through the use of therapies. For children, early provision of suitable therapies is believed to make a big difference in their ability to communicate, learn and ultimately to be independent. In England, the NHS provides two therapies to children – Occupational Therapy (OT) and Speech and Language Therapy (SLT). Other interventions may also be offered by different agencies including schools, therapists, voluntary sector organisations and private sector providers. These might include vision therapy and classes in social skill development.

NICE guidelines emphasise that all children on the autism spectrum are individuals and their care should be individually tailored²⁹. A US survey of parents of children on the autism spectrum³⁰ found that the therapies that were reported as working best were:

- Speech and language therapy (27%)
- Occupational therapy (39%)

Therapeutic needs in South Gloucestershire

Locally, when a child is diagnosed as autistic they are generally offered:

- Speech and language therapy
- Occupational therapy

Speech and language therapy - For autistic children with social communication needs, the Children’s Speech and Language Therapy Service within Bristol Community Health CIC offer universal access to drop-in clinics and parent training sessions for early years children. This is supplemented with a specialist diagnosis group, multi-disciplinary assessment (EDAC), individual SLT assessment and treatment, where appropriate.

School age children have access to a Link Speech and Language Therapist through their school. The therapist will offer drop-in sessions and liaison visits in school to provide advice and sign-posting. They are able to discuss possible next steps for children who may require further assessment or intervention for ASC. When required, the therapist and SLT training team will provide a range of training courses for both

²⁹ www.nice.org.uk/guidance/cg170

³⁰ www.autismspeaks.org/blog/2012/09/25/top-8-autism-therapies-%E2%80%93-reported-parents

teaching staff and parents. However, it should be noted that in South Gloucestershire there is insufficient capacity in the SLT training team to run sufficient courses to meet demand.

Where the child meets specific core criteria, they are offered individual blocks of therapy. In South Gloucestershire this is only available up to the end of Key Stage 1 due to capacity within the SLT team. However Key Stage 2 is often when social communication difficulties emerge as social interactions become more complex.

Occupational therapy provision - Children's Occupational Therapy is provided by CCHP for children on the autism spectrum in South Gloucestershire. Access to support for sensory needs is often difficult with long waits for children offered this therapy. Access to occupational therapy for motor skills is more easily accessed.

Voluntary sector – Advice and signposting are offered by the NAS, NAS branches, the NAS Autism Helpline, NAS Transition Support Service, Bristol Autism Support, SG Parents and Carers and Supportive Parents.

4.3.3. Health needs

The health needs of autistic people are the same as for other people in the population. However, they have a higher risk for some conditions and often require additional support to enable them to access health services.

Physical health – Autistic people have higher rates of many physical health conditions than the general population, including epilepsy, diabetes, stroke, respiratory conditions and heart disease. Autistic adults die on average 16 years earlier than the average for the whole population, and 30 years earlier for those who are both autistic and have a learning disability³¹.

Mental health – Up to 70% of autistic people also meet the diagnostic criteria for at least one other mental or behavioural disorder - with as many as 40% meeting the diagnostic criteria for two or more. In addition, for many individuals these disorders are often unrecognised. The most commonly experienced conditions are anxiety, attention deficit hyperactivity disorder (ADHD) and oppositional defiant disorder (ODD)³². Other studies have found high rates of anxiety and depression, especially during late adolescence and early adulthood³³ and suicide³⁴.

Severe anxiety is a major health problem alongside escalating issues with violence in middle to late teenage years. This occurs as the autistic young person responds to increasing social stress, an increased physical presence and their wish to exert their independence. It can lead to major distress and high levels of unmet need. Families and young people require timely support during this period, as these issues arise.

NICE recommends that for autistic adults and a mental health condition, the NICE guidelines for treating the mental health condition be followed, with modifications to make them more effective and accessible to autistic people.

³¹ Cusak, J et al (2015) Personal Tragedies, public crisis: the urgent need for a national response to early death in autism. London: Autistica www.autistica.org.uk/wp-content/uploads/2016/03/Personal-tragedies-public-crisis.pdf

³² Simonoff E, et al (2008) Psychiatric disorders in children with autism spectrum disorders: prevalence, co-morbidity and associated factors. Journal of the American Academy of Child and Adolescent Psychiatry 47: 921–9

³³ Tantum, D., Prestwood, S (1999) A mind of one's own: a guide to the special difficulties and needs of the more able person with autism

³⁴ Cusak, J et al (2015) Personal Tragedies, public crisis: the urgent need for a national response to early death in autism. London: Autistica www.autistica.org.uk/wp-content/uploads/2016/03/Personal-tragedies-public-crisis.pdf

Accessing health services - Autistic people may struggle to access health services for reasons that might include:

- Limited communication or difficulties explaining health needs
- Not being taken seriously or having symptoms dismissed as 'autistic behaviours'
- Discomfort in attending health care settings, due to sensory overload

Some of these problems may be alleviated by ensuring health professionals received autism awareness training, the invitation to annual health checks and ensuring routine recording of autism by GPs.

Co-ordination of health services – Autistic people often have multiple health professionals involved in their care. It would be preferable for each autistic person to have a single care co-ordinator or case manager to co-ordinate care across different professions.

Health needs in South Gloucestershire

PRIMARY CARE:

The recording of autism by GP practices is variable. There is no central information on how autism diagnoses are recorded in primary care. Currently there is no specialist GP register for autistic people, so individuals rely on informal networks and recommendations to identify GPs who are knowledgeable and supportive of autistic people.

SPECIALIST AND SECONDARY CARE:

Children on the autism spectrum – There are a number of specialist health services available to children and young people on the autism spectrum post-diagnosis in South Gloucestershire:

- **CAMHS** - child and adolescent mental health service (CAMHS) are provided across Bristol and South Gloucestershire through community teams that help children and young people with emotional, behavioural and mental health difficulties as part of the CCHP
- **Counselling service** – Off the Record (OTR) provides mental health support and information to young people aged 11 to 25 across Bristol and South Gloucestershire. Their service is generic and the staff may not necessarily be trained to address the specific needs of young people on the autism spectrum
- **Therapeutic services** – The services currently provided by the NHS (SLT and OT) are well adapted to the needs of children on the autism spectrum. Intensive positive behavioural support (IPBS) for children with learning disabilities are not currently offered to children on the autism spectrum, but these are being developed as part of a pilot project

Problems and delays can arise due to a lack of co-ordination between different health services. There is no single professional responsible for overseeing the progress a child is making or ensuring that the services they receive continue to be appropriate.

In South Gloucestershire, CAMHS do not currently have sufficient resources to meet the needs of the increasing number of children requiring their support.

The required level of multi-agency support for the ongoing health needs of autistic children and young people is not currently being met. The mismatch between demand or need and supply is of major concern.

Autistic adults - Access to health services for autistic adults in South Gloucestershire is variable:

- BASS Autism Services for Adults provide a service to autistic adults and professionals and carers who support them
- For those with a learning disability there are a range of services available via the Bristol Learning Disabilities service, including mental health services (psychology and psychiatry), Occupational Therapy, Physiotherapy and Speech and Language Therapy
- As with children, there is a lack of co-ordination across health services for adults without learning disabilities
- For both adults and children there is a need for understanding of autism in hospitals by all levels of staff
- There is a potential need for specialist support within the hospitals, particularly for inpatients

“It’s an impossible maze to get the help my son needs” Parent/carer on behalf of a child on the autism spectrum

4.3.4. Education

The spectrum nature of autism means that the educational needs of children on the autism spectrum vary widely. Approximately half of children on the autism spectrum do not have a low IQ (under 70), yet many will still require additional educational support due to sensory, social or attention difficulties.

Educational settings – Nationally, the majority (70%) of autistic children attend mainstream schools. Others may attend resource bases attached to mainstream schools, specialist autism schools or schools for children with a range of disabilities, colleges and Universities.

Challenges - Children on the autism spectrum face a number of challenges in education:

- 27% of autistic children have been formally excluded from school, compared with 4% of children without autism, most commonly this is due to physical assault against a pupil or teacher³⁵
- One third of children on the autism spectrum have been ‘informally’ excluded from school or asked not to attend, on at least one occasion³⁶
- There is also some evidence that autistic young people attending university are at higher risk of dropping out if they are not accessing specialist support³⁷
- Nationally, three quarters (74%) of parents of autistic children report that it is not easy to get the educational support their children need. The areas where support is most likely to be missing are: SLT, OT, mental health, leisure opportunities, befriending, short breaks and daily living skills³⁸

Education in South Gloucestershire

South Gloucestershire has a higher number of children with an Educational Health Care plan (EHC plan) placed in mainstream schools and academies than other local authorities in the south west and nationally. In contrast, the number of placements at special schools is lower in comparison with national data.

Over a quarter (26.6%, 436) of children with an EHC plan have a primary need of autism. Approximately 45% (774) have a primary need identified as speech, language and communication needs or autism.

³⁵ Bancroft K, Batten A, Lambert S, Madders T (2013) The way we are: autism in 2012 National Autistic Society, London

³⁶ School Report (2016) NAS www.autism.org.uk/get-involved/media-centre/news/2016-09-02-school-report-2016.aspx

³⁷ <http://network.autism.org.uk/good-practice/evidence-base/widening-access-higher-education-autistic-students>

³⁸ School Report (2016) NAS www.autism.org.uk/get-involved/media-centre/news/2016-09-02-school-report-2016.aspx

Specialist provision in South Gloucestershire includes three special schools and five specialist resource bases or access centres located within mainstream schools. The total number of specialist places in South Gloucestershire for children with special educational needs including autism is 596.

Children on the autism spectrum may attend:

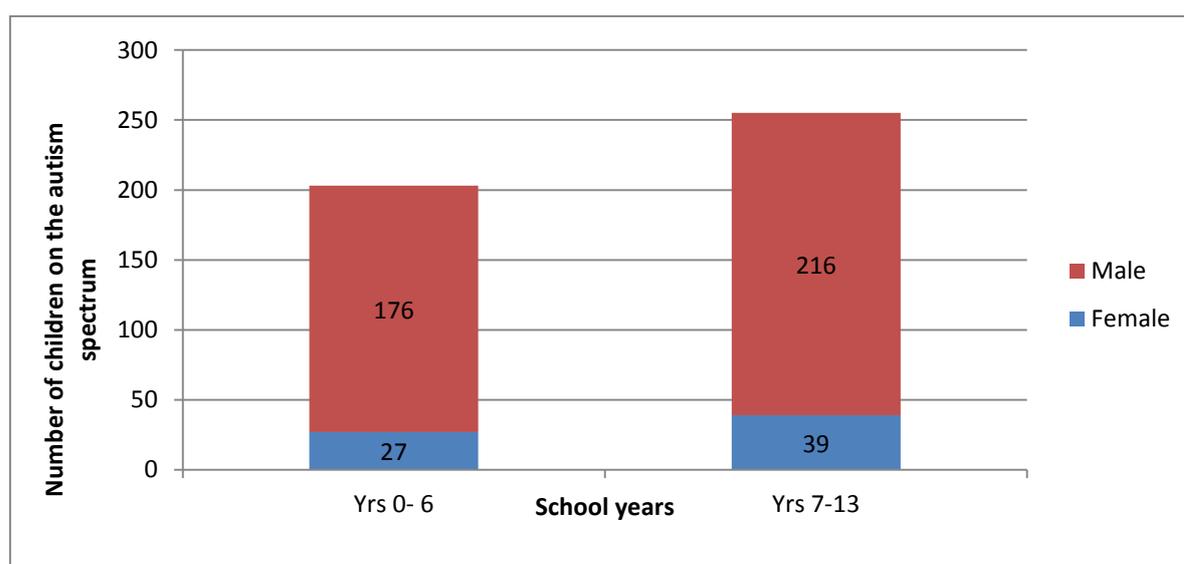
- Special Schools:
 - Warmley Park (age 2-19)
 - New Siblands (age 2-18)
 - Pegasus School (age 4-19) - currently only taking cognitively able pupils

- Specialist Resource Bases and Access Centres:
 - Blackhorse Primary - Social Communication (age 4-11)
 - Abbeywood – Language and Communication (age 11-18)
 - Hanham Woods – Language and Communication (age 11-18)
 - Lyde Green Access Centre – ASC (age 4-17) – no integration with mainstream at the moment
 - Chipping Sodbury Access Centre – ASC (age 11-18) – limited integration with mainstream

There is an expectation that children attending Blackhorse, Abbeywood and Hanham Woods Resource Bases are included in mainstream school for the majority of the curriculum. Lyde Green and Chipping Sodbury are Access Centres, where children receive their curriculum on site rather than attending the mainstream school.

Of the 610 SEN children attending mainstream provision, 22.8% (139) are children on the autism spectrum. Similarly, out of the 411 SEN children attending special schools, 22.4% (92) are children on the autism spectrum. In contrast, a higher proportion of the 122 SEN children attending specialist resource bases, 45.9% (56) are children on the autism spectrum. Of the children on role with a SEN need, more children are autistic than any other SEN need (26.6%).

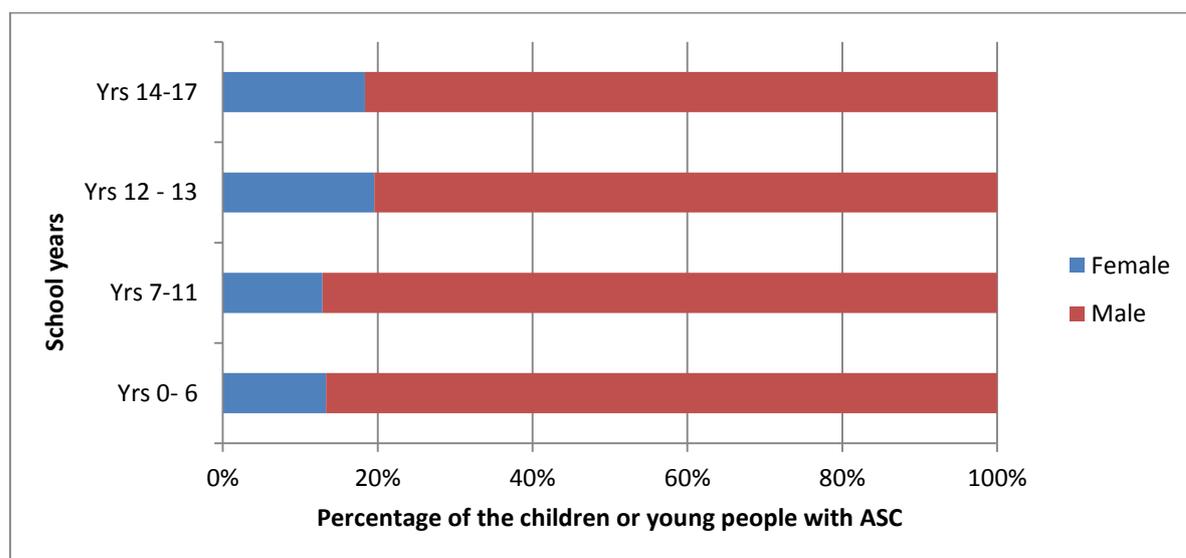
Figure 6 - Number of children on the autism spectrum in South Gloucestershire by school year



The distribution of autism by school stage and by gender shows an increase in number over time, although the denominator figure is likely to be different, so totals are not exactly comparable. There is only a minor

change in the proportion of boys to girls diagnosed with ASC, with a slight rise in the percentage of girls on the autism spectrum in the later stages of school and college.

Figure 7 - Gender distribution of autistic children and young people by school year in South Gloucestershire



Two thirds (66%) of children on the autism spectrum in South Gloucestershire attend mainstream schools (with or without specialist units). This compares to a national average of 70%. Most other children attend one of the special schools either in South Gloucestershire or a neighbouring local authority. A small number of children are educated at home, attend independent schools or attend Further Education College.

Currently there are a number of children accessing education outside South Gloucestershire. In total 10 children are attending either mainstream or special school out of area.

Table 5 - Education provision for autistic children and young people in South Gloucestershire

ASC	Number	% of SEN
South Gloucestershire mainstream	139	22.8
Other LA mainstream	7	21.9
Pre-school	5	17.2
Further education college	56	28.7
Independent school	4	16.7
Resource Base	56	45.9
Pupil referral unit	0	0
Elective home education	8	36.4
Alternative provision	7	41.2
Other	4	21.1
South Gloucestershire special school	92	22.4
Other LA special school	5	14.7
Independent special school	38	50.0
Independent specialist college	15	32.6
Secure units	0	0
Total	436	26.6

The autism data submitted to the Department of Education by schools uses statutory SEN codes and therefore does not include information on pupils who are either waiting for an assessment or those who have autistic traits but have not received a diagnosis of autism. The figures only represent the children who have received an autism diagnosis. In order to capture a clearer picture of the number of children in schools who may have social communication needs or autism, a local survey of schools was carried out in May 2017.

With a response rate of 86% (98 out of 114 schools), the Integra survey³⁹ reported that there were a total of 402 children diagnosed as being on the autism spectrum in South Gloucestershire schools. However, it also found that there were a further 620 pupils with possible autism. These children were identified as having either social, emotional and mental health needs; speech, language or communication needs; moderate learning difficulties; specific learning difficulties or other impairments.

This data has been based on the report and opinion of education professionals including SENCOs and head teachers, so does not represent actual diagnosis figures. However, it does demonstrate that there are over 1,000 children on the autism spectrum or exhibiting autistic traits in South Gloucestershire. In addition, it should be noted that there are possible further children who have yet to be uncovered within the education system.

Support for autistic pupils following diagnosis is currently limited as there is no dedicated Autism Team to provide specific support to schools. In addition, at the time of diagnosis, parents often report that they feel that they are not given enough support.

In South Gloucestershire it has been recognised that there are increasing numbers of autistic pupils who have avoidant profiles. As a result of their need for control and high anxiety levels, these children will avoid everyday demands and exhibit escalated and challenging behaviours such as risk taking. These pupils are very vulnerable and require a specific and different approach, which has implications for provision.

By using Census projected growth figures and the 2016 numbers on roll, assuming a 100% transfer rate between cohorts, the numbers of autistic pupils can be estimated for the next ten years, as shown in Table 6. By 2026 it can therefore be estimated that there will be a growth in numbers by 22%, from 436 to 531.

Table 6- Projected growth in numbers of autistic pupils from 2016 to 2026

	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025	2026
Number	436	455	467	477	484	492	501	509	513	521	531
Growth	-	19	12	10	7	8	9	8	4	8	10

³⁹ Integra - Autism Data Report (May 2017)

4.3.5. Transition

The process of transition has been developed in recent years. This follows earlier problems experienced by children moving from the very supportive world of education to the very different environment of adult services. At whatever stage, transition should ensure a continuity of the services received by the individual, as well as co-ordination between a young person's health, education and care needs. All areas should be considered during the transition planning phases. The term transition is primarily used to describe the move from education into the world of work or further education and adult life. However, there are also critical periods of transition and change that need to be considered, including the move from Early Years to primary education and the move from primary to secondary education.

Planning for transition from education – There needs to be a multi-agency process that takes into consideration the young person's benefits, further education, higher education, employment, health issues, transport, housing, leisure opportunities, social care services, direct payments and individual budgets.

It should be noted that not every autistic child is automatically eligible for a transition plan. However, their care needs should be assessed by the local authority if there is a chance they will meet the national eligibility criteria for care:

- Their needs arise from or are related to a physical or mental impairment or illness AND
- This makes them unable to achieve two or more specified outcomes (including maintaining personal hygiene, managing toileting, maintaining relationships to prevent loneliness, accessing and maintaining employment, keeping the home clean and safe) AND
- As a result of being unable to meet these outcomes, there is likely to be a significant impact on the adult's wellbeing

Even if an autistic young person is not eligible for a formal transition plan, they are likely to benefit from planning the key aspects of life as an adult, including:

- Help with facing and planning for adult life.
- Specialist and ongoing employment support.
- Peer support and opportunities to spend time with others with the same diagnosis.
- Voluntary work placements in settings where autism is understood and accommodated.

Transitions in South Gloucestershire

In South Gloucestershire, educational psychologists work with pre-school children, their parents and professionals from health and education through the transition from Early Years to primary school. The focus of the work is to ensure that individual children's needs are identified and appropriately supported during transition.

All children who have an EHC plan receive a person centred transition support plan as part of their annual review when they reach the end of primary school, the end of secondary school and at the Post 19 stage. All South Gloucestershire maintained schools, both mainstream and specialist, hold Whole School Consultation meetings in the autumn term where SENCOs and educational psychologists are able to discuss plans and support strategies for children transitioning into the school.

For the transition when a young person leaves education, the 0-25 Transition Team in South Gloucestershire is able to support young people, families, partners, providers and communities to enable the young person to continue living at home or independently. The team works across four pathways:

- Gain skills and prepare for **further education, employment, training** or volunteer work
- Help being part of the **local community and to build relationships**
- Guide and support young people to access and maintain **housing**
- Guide young people in staying safe, **healthy** and connected to health services, where appropriate

In all four pathways there is a focus on maintaining life skills or learning new skills, plus achieving and sustaining greater personal independence.

The 0-25 Transition Team has identified potential future work that would improve the transition support and provision on offer:

- Improve the preparing for adulthood section of the Local Offer.
- Develop more internship and apprenticeship opportunities.
- Develop meaningful work experience for young people.
- Support special schools in providing work experience with a job coach.
- Introduce a hospital or health passport at transition stage.
- Introduce a health checklist as part of the EHC plan review to ensure timely referrals.

There is a gap in transition provision for those children who do not have an EHC plan.

'It would be useful to work with colleges and groups of young people with ASC to gather views about the transition to adult services' Voluntary organisation worker

4.3.6. Social care

Social care for adults can be subdivided into four areas:

- Physical disabilities.
- Learning disabilities.
- Mental health.
- Older people.

There is a gap in service provision for those autistic adults who do not fall into one of these groups. However, the National Autism Strategy (2015) states that local authorities should not refuse a care assessment for autistic adults due to their IQ, so do not have a learning disability.

The Care Act (2015)⁴⁰ introduced a single law to replace existing complex legislation around adult social care, new duties for local authorities and partners, and new rights for service users and carers. These include new rules on who qualifies for publicly funded care and support and new responsibilities on councils around prevention and wellbeing.

Care assessments should be carried out by assessors who have been trained in autism, who have specialist knowledge and skills, and appropriate communication skills, including:

⁴⁰ www.gov.uk/government/publications/care-act-2014-part-1-factsheets

- how autism may present across the lifespan and levels of ability, and are defined and diagnosed, and the relevant pathways and screening tools
- the common difficulties faced by autistic individuals and their families or carers, including social and economic hardship
- the impact of autism on personal, social, educational and occupational functioning, and interaction with the social and physical environment
- current good practice guidelines including the NICE Quality Standard 11 and local diagnostic and care pathways
- current good practice guidance with respect to an autistic individual's capacity to assess risk

For those who do not meet eligibility thresholds, there should be advice and signposting to other sources of support and guidance

Social care in South Gloucestershire

In South Gloucestershire the Community Children's Health Partnership (CCHP) provides all of the community child health and child and adolescent mental health services for Bristol and South Gloucestershire. The Local Offer sets out information about the provision available across education, health and social care for children and young people who have special education needs or are disabled, including those on the autism spectrum and those who do not have an EHC plan.

Locally, council social care services and funding are only provided for adults with care needs that meet learning disability, physical disability or mental health eligibility criteria. Many autistic adults are therefore omitted from access to services.

A range of therapeutic interventions to support people's differing emotional needs are also available across South Gloucestershire. The NHS talking therapy services within South Gloucestershire provide access to a range of therapeutic interventions in line with people's differing emotional needs, from psycho-educational courses to one-to-one intervention.

'There needs to be better support for autistic adults who aren't considered 'eligible' for care' NAS branch volunteer

4.3.7. Training and employment

Depending on the needs and abilities of individuals, a wide range of training could be appropriate; this could range from the development of life skills to support independence (as recommended by NICE) to supported apprenticeships or higher education. Training opportunities should be matched to meet both the needs and the existing strengths of the individual in order to ensure increased independence and successful employment.

Tailoring opportunities to meet individual needs may require additional investment, for example setting up work experience placements in settings in which the autistic person is comfortable rather than with existing partners. However, this approach is likely to be more effective in the long term.

Autistic people are substantially disadvantaged in the employment market:

- Only one in six (16%) of autistic adults are in full time paid employment, 16% are in part time work⁴¹
- Over three quarters (77%) of unemployed autistic people want to work and 40% of those who work part time want to increase their hours
- One quarter (26%) of autistic people who have graduated from university are unemployed, the highest percentage for any disability group
- Autistic people face a number of barriers to employment, including:
 - Lack of understanding of autism by employers and lack of knowledge to make reasonable adjustments
 - Difficulties handling sensory and social aspects of the work environment
 - Workplace bullying and discrimination
 - Difficulties managing change in the workplace and the need for additional support⁴²

NICE guidelines recommend supported employment programmes for those without significant learning disabilities who are struggling to obtain or maintain employment.

- Work Choice and Access to Work are national services to help disabled people to work.
- A number of methodologies, including Individual Placement Support, Prospects and ProjectSEARCH have been evaluated and found to be effective and cost effective for autistic people⁴³
- A specialist agency, Specialisterne, has been successful placing people with Asperger's in technology companies

Training and employment in South Gloucestershire

The Bristol Autism Advice Service (BASS) runs a weekly South Gloucestershire advice service in Yate. Autistic young adults can access workshops and advice on friendships, relationships, wellbeing, budgeting and independent living. In addition, outside agencies are invited to the sessions to talk about the support that they are able to offer and service users can book appointments with a specialist vocational advisor from the Avon and Wiltshire Mental Health Partnership (AWP). Social workers in BASS are also able to offer specific support in discussing reasonable adjustments with employers, where appropriate.

South Gloucestershire Council is committed to improving outcomes for people with disabilities through their 0-25 Service and through their dedicated Employment Support Commissioning Officer. Work continues with local employers to improve opportunities for autistic people and increasing their understanding of autism and the skills of autistic people. Although there is still development work to be done, positive changes are already being recognised through improved access to services through allocation of Personal Budgets for eligible people and through the establishment of a Job Coach Provider List.

Job Coaches are able to offer support for people facing barriers to employment. This includes help with finding a job, support when starting work, help with training and learning new tasks and helping colleagues understand the individual's needs.

South Gloucestershire and Stroud (SGS) College has established the Chase, a new project working in partnership with the Council to develop opportunities for independent living and employment in a variety

⁴¹ National Autistic Society (2016) Too much information: the autism employment gap www.autism.org.uk/get-involved/tmi/advice.aspx

⁴² www.gov.uk/government/uploads/system/uploads/attachment_data/file/210683/rrep846

⁴³ Mavranzouli, I et al (2014) The cost-effectiveness of supported employment for adults with autism in the United Kingdom. *Autism*, 18(8), 975–984

of industries, including catering and hospitality. It will allow South Gloucestershire learners to gain qualifications and life skills in addition to benefiting from local work placements.

Supported internships offer a programme of study that is specifically aimed at young people aged 16 to 24 who have an EHC plan, who want to move into employment and need extra support to do so. Locally, SGS College and the National Star College both offer supported internships.

‘Autistic adults, even those who have support from parents or carers, need better access to assistance with Personal Independence Payment (PIP) and Employment and Support Allowance (ESA), both with completing the forms and the whole process’ NAS branch volunteer

‘More employers need to have a better understanding of autism, the skills of autistic people, and person-centred reasonable adjustments’ NAS branch volunteer

4.3.8. Housing

Accessing suitable housing can be a challenge for people from across all parts of the autism spectrum:

- **Complex needs** - Residential or supported accommodation may be designed to meet the needs of those with severe learning disabilities or physical health problems, but rarely specifically for autistic people
- **Intermediate needs** - Those with an intermediate level of need may not qualify for sufficient funding to make independent living possible - family carers may end up with a significant burden of care
- **Less significant needs** – For those with less significant needs, the general shortage of affordable housing can create barrier to independence and leaving the family home, even where the person has the skills and confidence to do so

In 2012, one in three (38%) of autistic adults lived with their parents. Of these, half wanted to live in their own home⁴⁴. Many parents and other family members may be happy to provide care within the family home on a long term basis, but there is often significant concern about what will happen when they are no longer able to do so.

Housing and associated support can be paid for in a number of ways:

- Housing benefit can cover the cost of rent, often from a social landlord. However, Supported Living accommodation is currently exempt from the Local Housing Allowance caps.
- Adult Social Care can pay for the care and support needed to function in a residential setting - a family home, an independent tenancy or a residential care home.
- Housing Related Support funding can provide extra support to enable people to maintain an independent tenancy.
- For those with the most complex needs, accommodation and care costs are met from Continuing Health Care funds - in a family home or care home.

Housing in South Gloucestershire

⁴⁴ Bancroft K, Batten A, Lambert S, Madders T (2013) The way we are: autism in 2012. The National Autistic Society, London

There is a lack of information about the housing situation of autistic adults in South Gloucestershire. It is likely that a significant number of the autistic adults in South Gloucestershire are social housing tenants, but no data is collected on autism diagnoses by social landlords.

‘There needs to be better understanding of autism and the needs of autistic people’ when looking at housing provision - NAS branch volunteer

4.3.9. Mainstream service

Although specialist services are important, autistic people are likely to be accessing mainstream services most of the time. There is scope for making these services more accessible and autism friendly. The mainstream services accessed by autistic people include:

- NHS health services.
- Council services.
- A range of services offered by the private sector including leisure and shopping.

For statutory services, the National Autism Strategy⁴⁵ requires that all staff in health or care roles should have autism awareness training and should know how to make reasonable adjustments. For non-statutory services, there are no requirements to ensure staff are trained. However, autism awareness training is available from a number of providers and could be incorporated into standard equalities and diversity training.

The National Autistic Society has developed an ‘Autism friendly’ award for mainstream services⁴⁶. To gain accreditation, actions should be taken in the following areas:

- customer information
- staff and volunteer understanding
- physical environment
- customer experience
- promoting understanding

One of the fundamental needs of autistic people is to be understood. This is reflected in the NAS ‘Too Much Information’ campaign and the NAS strapline ‘Until everyone understands’. Ensuring improved awareness of autism in the wider community as well as amongst council and NHS staff needs to be a priority.

Mainstream services in South Gloucestershire

In South Gloucestershire the council offers autism training to staff delivered by the NAS, although this contract is up for tender at the end of July 2018. The current multi-agency programme of autism training from NAS offers eight different courses, with a total of 15 courses running over the course of a year.

Courses include:

- Understanding Autistic Spectrum Conditions (Level 1)
- Understanding Behaviour (Level 2)
- Supporting Adults with Autism (Level 2)

⁴⁵ National Strategy Good Practice Guides –Training - NAS www.autism.org.uk/autismstrategyguide

⁴⁶ Autism Friendly Guidelines - <http://www.autism.org.uk/professionals/autism-friendly-award.aspx>

- Autism and Maturity (Level 2)
- Relationships, Boundaries and Sexuality (Level 2)
- Sensory Considerations (Level 2)
- Introduction to Criminal Justice Issues (Level 2)

The courses are available to every relevant employing organisation in South Gloucestershire – for council and non-council employers. Courses are mainly accessed by social care and health staff, but some are attended by the police, general customer services staff and those working with children and young people. Over the last three years, annual attendance has ranged from 116 to 201 staff.

Employers have been offered free access to the NAS Understanding Autism e-module, although demand has been low. The NAS training team also provides bespoke training to any organisation requesting it.

There are no official ‘Autism friendly’ venues in South Gloucestershire, but there are some in neighbouring local authority areas. Details of locations that hold the award can be accessed via NAS⁴⁷.

4.3.10. Social support

Autistic people can benefit from a range of social support services. In the NICE guidance for autistic adults⁴⁸, the only interventions recommended for treating the core symptoms of autism in adults are psychosocial interventions, for example:

- A social learning programme focused on improving social interaction – individual or group sessions.
- Anger-management interventions adjusted to the needs of autistic adults.
- Anti-victimisation interventions based on teaching decision-making and problem-solving skills.
- Employment support programmes.
- A structured leisure activity programme.

The NICE guidance also suggests that where there are gaps in the availability of psychosocial support, CCGs might need to work with the local authority to commission additional interventions.

In 2008, the National Autistic Society’s survey⁴⁹ found that type of support most people wanted, yet not always provided, was social support. It was identified that this support could be offered through befriending, social programmes, training in social skills and life skills sessions. The majority of respondents (82%) said that they would feel less isolated if they received more support.

Social support in South Gloucestershire

In South Gloucestershire autistic young people can attend the NAS out of schools club, organised by members of the NAS staff. The NAS voluntary branch also offers a range of activities for children and young people including a science club and youth club.

South Gloucestershire Council offer short breaks for children and young people, usually away from home, enabling them to have fun and time with their peers, while at the same time giving a break to parents from

⁴⁷ www.autism.org.uk/professionals/autism-friendly-award/people/holders.aspx

⁴⁸ www.nice.org.uk/Guidance/CG142

⁴⁹ I Exist (2008) National Autistic Society

their caring role. Breaks can also be arranged for the whole family together and range from a few hours' activities to a longer break.

There are a number of existing social groups for autistic adults; these include a monthly walking group and a film group that meets twice per month. Carriages at the Avon Valley Railway provide a weekly meeting place and arts and craft sessions for adults with additional needs and their carers.

The Carers Support Service runs workshops and events for carers and the NAS branch coordinates support groups for parents and carers that meet regularly.

4.3.11. The criminal justice system

Although the available evidence is limited, existing information suggests that autistic people are overrepresented within the criminal justice system in the UK. Estimates of the numbers of autistic people having contact with the Criminal Justice System vary, but a recent study has found that autistic people may represent up to 4.4% of the prison population. It has also been suggested that 2% of people in secure psychiatric establishments have autism. If this figure is accurate, this represents twice the estimated national prevalence.

The National Autistic Society has produced guidance for police, those working in the Court system and barristers on how to interact with autistic people⁵⁰. They also manage the Autism and Intellectual Disability in Criminal Justice Network for those with an interest in autistic people who come into contact with the Criminal Justice system or secure services⁵¹

Under the Care Act, local authorities have a responsibility to assess the needs of all their residents, including those in prison. This will include ensuring that sufficient support mechanisms are in place for them.

Birmingham City Council has carried out a review of interventions that are most important for improving the experience of autistic people in the criminal justice system. These include:

- Early diagnosis which enables access to support services.
- Training of frontline police officers in autism awareness.
- Offering fixed activity routines, such as paid employment, that fill the autistic adult's day, which they will feel safe doing, thus minimising the risk of other people exploiting their vulnerabilities.
- Ensuring ease in access to advice and support services when needed, particularly during transitional periods.
- Developing a social care advice, guidance and coaching pathway to which courts can divert autistic offenders as an alternative to criminal conviction.

The criminal justice system in South Gloucestershire

There is a clear social care pathway within the three prisons in South Gloucestershire. There is an open social care referral process, which includes self-referrals from prisoners.

⁵⁰ Guide for criminal justice professionals www.autism.org.uk/products/core-nas-publications/autism-a-guide-for-criminal-justice-professionals

⁵¹ Autism and Intellectual Disability in Criminal Justice Network www.autism.org.uk/professionals/others/criminal-justice/signup.aspx

Assessments are completed by the senior social worker employed by South Gloucestershire Council. The threshold for eligibility for social care services is the same as in the community.

The social worker completes a care and support plan, which details the social care needs that a prisoner requires to be met, including any needs associated with, or as a result of, ASC. The care and support plan is sent to the care provider, Agincare, who are commissioned to provide the social care in the three prisons and care commences within 48 hours.

The local authority has made their training programmes available to staff from the prisons and working in the prisons. Training includes a number of courses that detail good practice in working with autistic people.

4.3.12. Involvement in service planning and provision

The national strategy *Think Autism* stresses the importance of actively involving autistic people in the design and development of services. In many areas of the country, this has been implemented effectively, as highlighted in the Good Practice summary (section 6).

Involvement in service planning and provision in South Gloucestershire

In South Gloucestershire there are currently no structures for involving autistic people in the development of strategy, action plans or service development. However, the views of children, young people and parents are routinely sought through the South Gloucestershire Parents and Carers forum and NAS South Gloucestershire representatives.

4.3.13. The needs of carers

The majority of care for both autistic children and adults is provided by family carers⁵². Family carers often receive little or no support for their caring responsibilities:

- Three quarters (76%) of carers do not receive any support from their Local Authority.⁵³
- Two thirds (68%) report that they have not even received a carers' assessment.
- The benefits received by family carers has been calculated as insufficient to cover the costs incurred in caring for a child with significant needs due to autism.⁵⁴

The vast majority (92%) of parents have stated that they are either very worried or quite worried about their child's future when they are no longer able to support them.

Under the Care Act, carers have a statutory right to receive an assessment of their needs. Carers are eligible for an assessment where there is seen to be a significant impact on their wellbeing as a result of caring for another person. The results of the assessment may result in the award of a financial allowance or may facilitate access to a range of support including:

- Access to respite - either day support or overnight.
- Support to help maintain good health and wellbeing.
- Training, advice and support to improve confidence in providing care.

⁵² Barnard, J, Harvey, V, Potter, D and Prior, A (2001) Ignored or Ineligible? The Reality for Adults with Autistic Spectrum Disorder. NAS, London

⁵³ IExist (2008) National Autistic Society

⁵⁴ The Impact of Autism (2001) All Party Parliamentary Group on Autism

www.appga.org.uk/sitecore/content/Microsites/APPGA/Home/Resources/Past-Reports.aspx

- Access to home adaptations, equipment or IT to aid caring.
- Support to remain in work if that is what the carer wants.

There is evidence to suggest that caring for an autistic person places strain on families⁵⁵ and can increase the likelihood of family breakdown. It is estimated that one in three families with a child on the autism spectrum are headed by a single parent. This compared to a proportion of one in four for the whole population.

The needs of carers in South Gloucestershire

A range of courses for parents or carers whose children have been diagnosed with ASC including Asperger syndrome are offered by South Gloucestershire Council. These courses have been designed by the NAS and Barnardo's and are based on the age of the child:

- Ages 2 up to 4 years – Early Bird NAS
- Ages 5 up to 18 years – Cygnets Barnardo's

The courses are very much in demand and there is currently approximately 100 families on the waiting list to attend.

The NAS South Gloucestershire Branch offers support to parents and carers of children who have an autism spectrum disorder, including Asperger syndrome or a demand avoidant profile. The branch has two support groups that meet monthly, one during the day and one in the evening. Bristol Autism Support also offers a range of support that can be accessed by South Gloucestershire residents, including a very active Facebook group.

Parent and Carers Views South Gloucestershire Parents and Carers is a group of parents and carers in South Gloucestershire all with children and young people who have a disability or additional needs. The group helps to improve the services and support available for families by working in partnership with the local authority, NHS and any other groups in South Gloucestershire. It also runs a monthly informal coffee morning where parents can drop in chat with other parents or be signposted to further areas of support.

In addition, there are other parent groups that provide support as well as planned activities for children. These include Jigsaw and Little Treasures Incredible kids and safe space.

The NAS Avon Branch offers support and information for parents and carers of adults who may be autistic including Asperger syndrome. Branch meetings, workshops and information events are organised periodically to discuss topics of interest. These are an opportunity to exchange experiences and information, usually with an outside speaker. The main areas of concern covered are diagnosis, assessment, training, employment, housing and support. The branch officer and committee members attend meetings and events to raise awareness of autism spectrum conditions and the needs of individuals and can provide information on the areas of concern and where to go to get help if it is needed.

4.3.14. Coordination

The effective coordination of care for autistic people is essential, as there are a large number of services involved in provision. NICE guidance⁵⁶ recommends the following local structures are put in place:

⁵⁵ www.ncbi.nlm.nih.gov/pmc/articles/PMC4230960/ Defining crisis in families of individuals with ASD

⁵⁶ www.nice.org.uk/guidance/cg170/chapter/1-Recommendations#general-principles-of-care

- **Autism strategy group** - Responsible for developing, managing and evaluating local care pathways, including appointing a lead professional for the local autism care pathways for adults and children, supporting the integrated delivery of services across all care settings
- **Autism team for children** – To provide a single point of referral for diagnosis and post-diagnostic support and to include at a minimum:
 - A care coordinator for every child or young person with a diagnosis.
 - A paediatrician and /or child and adolescent psychiatrist.
 - Speech and language therapists.
 - Clinical and / or educational psychologists.
- **Autism team for adults** – To include:
 - A care coordinator for every adult with a diagnosis.
 - Clinical psychologists.
 - Nurses.
 - Occupational Therapists.
 - Psychiatrists.
 - Social workers.
 - Speech and language therapists.
 - Support staff for specific issues including housing, education, employment and financial advice.

Coordination in South Gloucestershire

In South Gloucestershire there are two multi-agency groups providing an overview for autism services and planning.

- **ADULTS**

The South Gloucestershire autism planning group (APG) is a multi- professional group with carer and user representation with the aim of reviewing and considering national and local guidance and policy relating to autistic adults.

The group also oversees the development of a long term strategy to improve local support for autistic people. The group supports the development of services for autistic people and works with other providers to ensure that non-specialist services are accessible for autistic people.

- **CHILDREN**

The South Gloucestershire Local Autism Group – children and young people (LAG) includes representation from CAMHS, education, social care, parents and carers, the voluntary sector and commissioning. The group aims to coordinate services and interventions for children and young people on the autism spectrum, to identify and make recommendations to address unmet needs.

5. Service user and provider views

5.1. Methodology

During March 2018 an autism survey was distributed via providers, voluntary sector and commissioners to collate views and gain an understanding of people's opinions on the autism services in South Gloucestershire. The survey also included questions aimed at staff and providers to gather information on the services delivered across South Gloucestershire.

The survey was open from 6th to 21st March 2018 and received 160 responses. Of these:

- 95 were completing on a child's behalf.
- 33 were a relative or carer of an autistic person.
- 23 were providers of services for autistic people.
- 3 were autistic adults.
- 1 was a child or young person on the autism spectrum.
- 5 were 'other' (teacher, voluntary sector, awaiting assessment, nurses)

5.2. Views from those completing on a child's behalf

The majority of respondents (55%) did not feel adequately supported, with less than a third (30%) feeling supported. Generally, people did not feel that they had adequate information about autism and the services available (50% disagreed or strongly disagreed). Especially they did not feel that they had enough support to meet their or their child's needs (63% disagreed or strongly disagreed).

Comments were varied in response to these questions, but generally highlighted:

- a lack of clarity about what was available.
- a lack of information about how to access services.
- the difficulty in knowing what support was available whilst awaiting diagnosis.
- the length of time waiting to get a diagnosis.

"Children are being denied support when they need it most"

"Waiting times are completely unacceptable"

There were positive comments about the support offered by schools and the standard of the formal services, once they had been accessed.

The range of services that were reported as having been used for support included educational settings (71%), community paediatrics (56%) and GP (55%). Other services were based in the voluntary sector, CAMHS, social care, and the family and young people service. Again comments were varied with different people finding different services useful. Generally, people found out about these services as a result of word-of-mouth from friends and family (46%), through a health or social care professional (45%) or their own search on the internet (39%).

There were lots of aspects mentioned that the respondent felt had helped or had worked well in offering autism support. These included:

- Support groups including Bristol Autism Support, South Gloucestershire Parents and Carers.
- School.
- Assessment by multiple professionals.
- Specific courses including Early Bird courses and Cygnet.
- Support of friends, family and the community.

13% of those with an autistic child had experienced the transition process when their child had moved between children and adults services. Of these, over half (56%) did not feel supported through the process and only 13% strongly agreed that they had felt been supported.

Comments suggested that improvements in the transition process might be achieved by:

- more coordination and joining-up of services
- starting the process earlier
- clarity about future support

5.3. Views from carers

Three quarters of the carers responding (77%) did not feel that they had been able to access respite when needed.

5.4. Views from autistic adults

There were only a small number of autistic adults who completed the survey, so the results may not be representative. Generally, the people who replied did not feel they received effective help with gaining employment, housing or primary care access.

5.5. Views about possible improvements

Key suggestions for improvements that emerged from the comments received were:

- Facilitated pathway.
- Reduction in waiting times and wait for funding.
- Clarity about what is available and the process and timescales for accessing.
- A central source for information with sources of support and training. All professionals should know how the system works and where to signpost for support and advice.
- Communication and listening - both with individuals and between organisations.
- Multi-disciplinary assessment on one day.
- More support for schools.
- Improved partnership working including at transition.
- Continuity of care.
- Improved access to services, with reference to travel distances and time of appointments.

“Centralized info - one stop shop style. More communication and info shared among professionals from different sectors”

“Continuity of staff involved, clarity, communication and openness about how long the EHCP process is in reality”

“State clearly any support available and not have to wait until things fall apart to or you demand the support”

“Stop having to have to fight for everything! Everyone should be given information on what services are available and what support/entitlement you should have”

5.6. Equality

133 people responded either on behalf of a child’s, as a relative or carer of an autistic person, an autistic adult or a child or young person on the autism spectrum. Of these, 17% were male and 79% were female. The majority (86%) were aged between 25 and 64 years; 93% were white and 70% did not consider themselves disabled. There did not seem to be any difference in feeling that they had enough support by gender, age, ethnicity or disability. However, the ethnic numbers are small and therefore difficult to assess for differences.

5.7. Views from providers

Half (50%) of those who responded provided information about adults services, 41% about services for children and young people, 5% about the transition process whilst 5% of the services supported children, young people and adults. Most providers (87%) felt that they, their staff or volunteers had the knowledge and skills to provide a quality autism service. There were many reports of examples of good practice and areas that were going well. Most of the services also identified a number of ways in which they had ensured their service is autism friendly. All the services offered a wide range of training to staff (48% in-house, 22% council provided and 30% other provider).

Many of the comments received from providers highlighted the key issues of increasing numbers of referrals and the lack of resources available to meet this need.

“There is insufficient volume in Community Paediatrics – hence the waiting list of 200 plus cases for assessment with an expectation that it will take over two years to get to the top of that list’

There needs to be “increased capacity in the Community Paediatrics team”

“The paediatric and diagnostic services are extremely under supported”

“The waiting times for children to be assessed for ASC in South Gloucestershire are currently too long. It is so important that the needs of these young people are quickly assessed and diagnosed in order for their needs to be quickly met. Autistic children whose needs are not being met can quickly disengage from education, withdraw socially and can experience extremely high levels of anxiety which in turn has a huge negative impact on not only the child but their family unit and support network”

5.8. Summary

In summary, the views from this survey show that there is a strong feeling of being abandoned at the point between initially raising concerns about potential autism and being seen by a specific autism service or professional. During this early stage there appears to be little information provided about either the support to be offered or the process. The waiting times are also highlighted as being very long - a delay of over two years before assessment is a major public health concern. Once the individual has been seen by a service, the experience is generally reported to be good. However, there are still concerns about waiting times between appointments and follow-up. In addition, people felt that there was a lack of communication

between organisations. Concerns were also raised about ensuring that support was received and accessing funding after an assessment or diagnosis.

Finally, wider support for job, housing, access to health care and respite were often felt to be lacking.

Some suggestions for improvements were:

- Clear pathways, both for individuals and professionals, showing what support is available at different points in a person's life.
- Better signposting to support.
- Improved communication between organisations.
- Reducing waiting times.
- Increased resources for Community Paediatrics.

6. Good practice

6.1. Good practice examples

6.1.1. Cumbria County Council – mapping exercise

In 2006 Cumbria County Council conducted a mapping exercise after concerns about the increasing numbers of people being diagnosed as autistic in the county. The mapping exercise identified a 43% increase in the number of autistic adults recorded in Cumbria, compared with an exercise carried out in 2003. Following the mapping exercise, Cumbria developed a new electronic social care record system which includes people who have a diagnosis of autism, allowing the authority to know more about the numbers of autistic people accessing social care services and negating the need to carry out more mapping exercises.

6.1.2. Royal Borough of Windsor and Maidenhead – data collection

The Royal Borough of Windsor and Maidenhead (RBWM) commissioned Berkshire Autistic Society to work on a data collection and needs analysis project. An Asperger specialist post was created to do this, and a comprehensive report written and recommendations made. As a result RBWM has established an adult ASD team. The team monitors existing services for autistic people, works with the transition team, and develops new services.

RBWM is one of a small number of local authorities that has detailed data on autistic adults in their area. They are also in the minority of local authorities who are following Government guidance by having a named individual or team with responsibility for autism. Other local authorities have referred to RBWM as being an example of good practice in this area.

6.1.3. Northamptonshire – transition

In Northamptonshire the emphasis is on identifying autistic people who are making the move into adulthood and on support after diagnosis. Transition support is normally offered to young people during their last year in school. Northamptonshire has a transition and liaison team that provides a diagnosis service and short-term post-diagnosis support to adults over the age of 18, with no upper age limit.

Support services are available to adults who already have a diagnosis and who are experiencing difficulties. These services might include learning about new ways to cope with difficulties; issues with friendship and relationships; helping the person and their family to understand their needs; and helping the person to access college or employment. People are referred by their GP, a health professional or a care manager. Local authority commissioners have also been working closely with the NAS to find out how many people have to go out of county to get support.

6.1.4. Glasgow – supporting autistic adults

In 2004 Glasgow opened the Autism Resource Centre (ARC), the focal point for the development of autism-friendly services in the area. It works with other services and people affected by autism to develop best practice, and design, deliver and evaluate new services.

The ARC's services include:

- information base – advice and information for autistic people, including the services available to them; a library of books, articles and service information; computer access; access to specialist support and advice
- training – the ARC works to improve understanding of autism among professionals, especially in the field of social care and health. It offers a range of training from one-day autism awareness training to high-level diagnostic training. Training is currently free and available on an outreach basis
- adult autism service – diagnosis and assessment, via weekly clinics; individual and group interventions; drop-in facility; user-led interest groups
- development team – planning for autism services; partnership working with mainstream services and care groups; ensuring standards of service delivery for all autistic people

Developments include the initiation of post-diagnosis courses for autistic people, autism alert cards, a prison screening project, a housing needs assessment, and a good practice guidance for housing staff who work with autistic people and their families.

6.2. Summary of NICE guidance

The NICE autism quality standard⁵⁷ covers autism in children, young people and adults, including both health and social care services. It includes assessment and diagnosis of autism spectrum disorders, and care and support for people diagnosed with an autism spectrum disorder. It describes high-quality care in priority areas for improvement.

Statement 1 - People who may be autistic 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 – Autistic people 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 – Autistic people are offered a named key worker to coordinate the care and support detailed in their personalised plan.

Statement 5 – Autistic people have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address their own individual challenges.

Statement 6 – Autistic people are not prescribed medication to address the core features of autism.

Statement 7 – Autistic people who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

Statement 8 – Autistic people who can demonstrate 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.

⁵⁷ NICE guidance <https://www.nice.org.uk/guidance/qs51>

7. Recommendations

7.1. Summary of findings and gaps

The autism needs assessment has identified a series of findings that have provided the basis for developing a set of recommendations for future work and the next steps to be taken locally to improve the provision of services and support for autistic people in South Gloucestershire.

1. Prevalence of autism

- There is a high level of professional concern regarding an increased incidence and prevalence of autism locally.
- Collecting comprehensive data on numbers of autistic people is difficult.
- Statutory services are only able to identify a small proportion of the estimated population of autistic people.
- Data collection processes do not currently record information on ethnicity, sexuality or religion.
- The number of children on the autism spectrum in South Gloucestershire appears to be slightly higher than predicted by using a 1% population prevalence rate.
- The numbers of people currently accessing services and population growth figures could be used together to estimate future level of service demand. This is not currently standard practice.
- There are no reliable figures for the number of autistic adults in South Gloucestershire.
- There is scope to carry out further investigations into the high prevalence of autism in South Gloucestershire.

2. The process of diagnosis

- The journey to diagnosis is long, complicated and can involve unsupported waiting periods between appointments.
- Multi-disciplinary autism diagnosis assessments are not always achieved. A child might need to attend a series of separate appointments with different professionals.
- Waiting times for initial assessment can be up to two years for children.
- Electronic recording systems are not currently robust enough to provide all data on assessment and waiting times.
- Appropriate support after diagnosis is critical. In education settings, dedicated autism support would help address this current gap.

3. Health and social care needs of autistic people

- Recording of autism across all ages in GP practices is variable as there are no centrally agreed recording guidelines or register.
- There is a range of support available in South Gloucestershire for both autistic children and adults, however there may be an emphasis and reliance on support offered by peers.
- There is an increasing demand for support for children and young people who develop mental health needs.
- There needs to be upfront information and clarity about the services that are available.

- Eligibility criteria for social care services may currently exclude autistic adults.
- There is scope for improvement in continuity, clarity and openness in communication about service provision to autistic people.

4. Transition from primary to secondary school and child to adult services

- There is scope for improving the transition support and provision on offer for young people.
- There is a gap in transition provision for those children who do not have an EHC plan.
- More internships, apprenticeships and meaningful work experience for young people would enhance prospects for autistic people.

5. Work and employment for autistic people

- Positive changes are being recognised in improved access to services, for example through the Job Coach Provider List, but further work is required
- More employers need a better understanding of autism and the skills of people with autism spectrum condition

7.2. Summary of recommendations

In order to meet the needs of autistic children and adults in South Gloucestershire, there must be a shared understanding of what we aim to achieve and how we will work collaboratively to achieve it. The overarching recommendation from the needs assessment is for South Gloucestershire to establish this shared understanding, as a foundation for future work.

Recommendations

Five key themes emerged from the assessment of needs and the review of good practice and guidance:

1. Improve collection of data on people with a diagnosis of autism

- Ensure collected data helps with an understanding of local need.
- Collect comprehensive data on the diagnostic assessment including waiting times for different services on the diagnostic pathway.
- Ensure that outcomes are measured to determine quality and improvement of services, including behaviour and education outcomes.
- Improve clarity of data collection in education settings so that all diagnoses are recorded.
- Develop systems to ensure the collection of reliable figures for autistic adults.
- Further investigate the reported high levels of autism in South Gloucestershire.

2. Increase coordination and the strategic overview of services

- Ensure that the local autism multi-agency groups have a clear scope and mandate.
- Improve communication between professionals and develop proactive links between organisations.
- Improve communication between professionals and autistic people and their families.
- Ensure that the Local Offer clearly outlines the services and support available for children and young people on the autism spectrum.
- Ensure that the level of support available for autistic people is commensurate with the demand for services.
- Encourage collaborative working and oversight of the whole system, including transition.

- Ensure that professionals in both specialist and mainstream services are supported through an ongoing programme of autism training, encompassing social communication, social interaction, restricted and repetitive patterns of behaviours and sensory processing.
- Engage with mental health services to ensure timely and appropriate access to services for autistic people, recognising that autism is not a mental health problem and that the people delivering this training will need specialist knowledge.
- Ensure that South Gloucestershire website (Local Offer) delivers current information in an accessible format and that it signposts to other relevant information.
- Commission a review of good practice evidence and guidance.

3. Improve access to diagnostic services

- Develop clear diagnostic pathways for children, young people and adults.
- Ensure that multi-disciplinary assessment is available, where appropriate.
- Ensure that pre and post-diagnosis support is explicitly included within the pathways.
- Clearly sign post clients to sources of information and support.
- Improve early recognition of autism through raising awareness of signs and symptoms and increased training, particularly in schools and early years' settings.
- Ensure that diagnosis recognises all potential characteristics of autism including persistent problems with social communication, social interaction, restricted and repetitive patterns of behaviours and sensory processing.
- Ensure resources within Community Paediatrics are able to meet the demand for assessment.

4. Support engagement and collaboration with service users and their families

- Increase collaborative work with service users and their families.
- Consider establishing a fixed term project group focusing on improving client engagement and community support.
- Improve understanding of the needs of autistic adults particularly the older generation.
- Ensure the children and young people who develop mental health needs are supported in accessing appropriate services.

5. Increase autism awareness within the wider community and mainstream services

- Improve awareness of autism amongst local authority and NHS staff.
- Ensure that the training offered to local authority and NHS staff is effective and appropriate.
- Review the support available in accessing employment and housing for autistic people, ensuring clarity of advice and signposting.
- Review the Autism Friendly scheme, increasing the number of local organisations and businesses achieving accreditation.
- Ensure that mainstream services maximise their accessibility to autistic people.

8. Appendices

8.1. Appendix 1 – National evidence on service costs

- Ariane V. S. Buescher, MSc; Zuleyha Cidav, PhD; Martin Knapp, PhD; et al (2014) Costs of Autism Spectrum Disorders in the United Kingdom and the United States. *JAMA Pediatr.* 2014; 168(8):721-728. doi:10.1001/jamapediatrics.2014.210
<https://jamanetwork.com/journals/jamapediatrics/fullarticle/1879723>

Using the prevalence of autism in children and in adults of 1.1%, Buescher and colleagues' (2014) study estimated an annual cost of supporting children on the autism spectrum of £3.1-£3.4 billion. For adults, this cost amounted to £29-£31 billion (in 2010/11 prices). These cost estimates excluded benefits but included lost employment for individuals and hence lost productivity to society. The largest cost components for children were special education services and parental productivity loss. During adulthood, residential care or supportive living accommodation and individual productivity loss contributed the highest costs. Medical costs were much higher for adults than for children. In the United Kingdom, 56% of the total cost for autistic individuals is accounted for by services, 42% by lost employment for the autistic individual, and the remaining 2% by caregiver time costs.

- Knapp et al (2009) The Economic Cost of Autism in the UK *Autism*13, 317-36
<https://www.ncbi.nlm.nih.gov/pubmed/19369391>

This study estimated the economic costs of autism spectrum disorders (ASDs) in the UK. Data on prevalence, level of intellectual disability and place of residence were combined with average annual costs of services and support, together with the opportunity costs of lost productivity. The costs of supporting children on the autism spectrum were estimated to be 2.7 billion pounds each year. For adults, these costs amount to 25 billion pounds each year. The lifetime cost, after discounting, for an autistic person and intellectual disability is estimated at approximately 1.23 million pounds, and for an autistic person without intellectual disability is approximately 0.80 million pounds.