

**Bath and North East Somerset
Fulfilling and Rewarding Lives
Autism Strategy
2012 - 2016**

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Executive summary

In Bath and North East Somerset, the adult autism strategy is overseen by a multi-agency 'Autism Strategy Group'. The two lead commissioners for mental health and learning disabilities will jointly ensure direct accountability to the B&NES Health and Wellbeing Partnership Board. **To promote alignment across localities we have also ensured that our strategy is closely aligned to that of Wiltshire Council and NHS Services and would like to thank them for their work in structuring this strategy for adoption in B&NES.**

All work in B&NES will be built upon the Government's Autism Act (2009) and the national strategy "Fulfilling and Rewarding Lives" (March 2010). In practice this means that we will strive within local resources to ensure that the national vision is realised locally i.e.

"All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access the support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents."

The strategy identifies clear areas for action:

- Increase awareness and understanding of autism across all public services in order to increase the recognition of autism and enable staff to be better equipped to meet people's needs.
- Develop a clear pathway for the assessment and diagnosis of people who are on the autism spectrum. It is then important to ensure that diagnosis leads on to improved assessment of need and support for an adult who has been diagnosed with autism.
- Ensure that a range of services and support can be accessed by people with autism and that most importantly; opportunities for employment and housing are expanded, challenging the current high levels of social exclusion.
- Helping adults with autism into work
- Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

In drawing up this strategy, B&NES wishes to identify people with autism as a group of people with specific needs as a result of developmental disability and to challenge the traditional default positions of either subsuming adults with autism into learning disability or mental health services – neither of which have necessarily best met people's needs – or leaving them with little support if they are not eligible for either of these services. We want to improve the experience of adults with autism and their families so that they feel less isolated and vulnerable.

This presents the dual challenge of raising awareness and specific understanding of the needs of people on the autism spectrum whilst not creating a separate "specialism" of services. Our aim therefore, is to ensure that mainstream strategies and services that impact upon people's health, accommodation, employment, social care etc includes adults with autism, whilst ensuring that local services are available to those people with autism who have complex needs that require specialist, highly skilled and experienced intervention.

The aims of this Autism Strategy are:-

- To ensure a planned and open approach to commissioning of services for people with autism spectrum condition, making use of information about demand, unmet needs/service gaps and resources
- To ensure that services are centred on service users' needs
- To ensure a transparent relationship with Stakeholders (eg users, family carers, providers, etc), in the commissioning and provision of services.
- To provide direction and structure for both Health and Social Care provision within Bath and North East Somerset and for other mainstream services such as Housing, Leisure, Education and Training
- To link with (or where appropriate develop) local and national target performance indicators
- To continue to review service requirements identified through the Joint Strategic Needs Assessment with due regard to available resources and to use this information to inform the Primary Care Trust's financial planning process and the Council's Strategic Financial Planning of service pressures and requirements
- To act as a cornerstone in the development of any Business Cases or Specific Strategies developed in relation to agreed or proposed changes in service provision .
- To promote the civil rights and equality of opportunity for people with Autism in line with the Disability Discrimination Act 2005

This document will be supported by an implementation plan setting out how the intentions and aspirations in this document will be delivered.

1. What is autism?

- 1.1 Autism Spectrum Condition is also sometimes referred to as autism spectrum disorder, autism spectrum difference and neuro-diversity.
- 1.2 Autism Spectrum Condition (ASC) is a lifelong condition that affects how a person communicates with and relates to other people. It also affects how a person makes sense of the world around them. Autism is known as a spectrum condition both because of the range of difficulties that affect adults with autism and the way that these present in different people. This means that while some people can lead relatively independent lives, others will require significant support. We therefore use the term 'autism' in this document to include people with Asperger's syndrome.
- 1.3 People with autism have a wide spectrum of needs and, therefore, no two people are the same, although three areas of difficulty known as the 'triad of impairments' are common in people with autism. They are:
 - social communication, for example problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice
 - social interaction, for example difficulties with recognising and understanding other people's feelings and managing their own
 - social imagination, for example problems in understanding and predicting other people's intentions and behaviour and coping with new or unfamiliar situations.
- 1.4 In addition, many people with autism may experience sensory sensitivity or under-sensitivity, for example, to certain sounds, tastes, smells, colours or touch. Many people can also have other conditions such as Attention Deficit Hyperactivity Disorder (ADHD), a learning disability, dyspraxia, dysphasia and difficulties understanding the spoken word.
- 1.5 Although some people with autism can have an accompanying learning disability, the needs of people with autism are often very different to those with a learning disability or mental health condition and people often refer to an autism spectrum condition as being a 'hidden disability'. For example, people with Asperger's syndrome typically have fewer problems with speaking than others on the autism spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence.
- 1.6 Autism therefore presents a real challenge to commissioners and strategic planners as it is a spectrum condition presenting a wide range of needs.

2. How many people have autism?

- 2.1 Across the autism spectrum there are an estimated 535,000 children and adults living in the UK. There is no means of accurately estimating how many of those are at the higher functioning end of the spectrum.

- 2.2 People with an ASC often have no obvious disability and many adults find that they are often misunderstood. Some individuals may also not wish to have their condition recognised although the need for support may be great. It can therefore be difficult to create awareness of ASC.
- 2.3 The existing estimates of the prevalence rates for ASC vary dependent upon how it is diagnosed and defined. Prevalence is estimated to be around 116 per 10,000 of population.
- 2.5 Within Bath and North East Somerset in March 2012 we are aware of:
- 40 people are adults with learning disabilities who also have autism and are known to the county's learning disability services.
 - 14 adults with autism being care co-ordinated by the specialist mental health services and are in receipt of health and care services funding for specialist placements.
 - 12 adults with autism are known to the generic adult care services.
 - 76 young people between the ages of 14 and 19 years have been identified within B&NES children's and education services.
 - xx people with autism live out of county.

3. Why do we need a specific strategy for B&NES?

National context

- 3.1 Over the past few years, public awareness about autism has increased. Public concern about links between the 'triple vaccine' and autism, alongside the increasing diagnosis of children and young people in the school system, has both raised the profile of autism whilst highlighting the difficulties that people with autism and their carers experience when seeking support.
- 3.2 In 2006, the Department of Health published 'Better services for people with an autistic spectrum disorder' which aimed to clarify existing government policy in relation to adults with autism and identified the need for the development of local action plans by health and social care providers.

3.3 The document made the following key points:

- Some people with autism fall through gaps in local services, particularly between mental health and learning disabilities services.
- There is need for individualised assessments, based on person centred approaches.
- Services should be provided by trained staff with the right skills to meet individual needs.
- Services should focus on supporting inclusion of the individual, rather than focusing on diagnosis.
- People with autism should have access to services on the same basis as all other people.

3.4 The document did not have sufficient impact to generate the changes that the government hoped for. Research continues to demonstrate that the needs of people with autism are not being efficiently met and that this has financial repercussions. People with autism are eventually accessing very expensive acute services, whereas if they had received the right support earlier in their lives that would have produced both better outcomes for the individuals and less of a financial impact upon the economy.

3.5 Increasing political support plus strong lobbying from organisations such as the National Autistic Society led to the following publications:

- April 2009 A better future - Government consultation.
- October 2009 National Audit Office Report.
- November 2009 Autism Act 2009.
- March 2010 Strategy for adults with autism in England.
- April 2010 Towards 'Fulfilling and rewarding lives'

The government strategy reaffirms the issues identified in 2006 and sets out its new agenda for change.

Local context.

3.6 For many years in B&NES an Autism Providers Group has been running, bringing together local service providers and carers to improve the quality and range of local services. In 2010 the B&NES Autism Strategy group, led by commissioners, was formed to inform the development of an integrated strategy. The learning from both groups and the completion of a self assessment has confirmed that, in line with national findings:

- commissioners need more information about our population with autism. Overall numbers and needs are not known and therefore it is difficult to plan the right services and support for the future
- the numbers of people with autism who are on the caseload of the specialist mental health teams is known and the associated spend on services is quantifiable –

however as the client group is “hidden” in mental health services we do not use this information properly to improve planning.

- some, but not all, people with learning disabilities or mental health conditions, who also have autism, receive a service but those services are sometimes not ideal
- people on the autism spectrum who do not have a learning disability or a mental health condition are even less well-supported
- assessment and diagnosis services have no clear pathway for referral
- B&NES does not understand the full range of autism/Asperger specific services or non-specific services with the experience and expertise to support people with autism well
- The workforce in both statutory and independent sectors needs further training and support to understand and meet the needs of people with autism
- We need to continue to strive to help people with autism live in appropriate accommodation and to take up employment opportunities.

4 The aims of this Autism Strategy are:-

- To ensure a planned and open approach to commissioning of services for people with autism spectrum condition, making use of information about demand, unmet needs/service gaps and resources
- To ensure that services are centred on service users’ needs
- To ensure a transparent relationship with Stakeholders (eg users, family carers, providers, etc), in the commissioning and provision of services.
- To provide direction and structure for both Health and Social Care provision within Bath and North East Somerset and for other mainstream services such as Housing, Leisure, Education and Training
- To link with (or where appropriate develop) local and national target performance indicators
- To continue to review service requirements identified through the Joint Strategic Needs Assessment with due regard to available resources and to use this information to inform the Primary Care Trust’s financial planning process and the Council’s Strategic Financial Planning of service pressures and requirements
- To act as a cornerstone in the development of any Business Cases or Specific Strategies developed in relation to agreed or proposed changes in service provision .

5. Commissioning intentions.

The following commissioning intentions have been identified themed around the 5 key themes within Fulfilling Lives

5.1 Improve information about the population of people with autism in B&NES

5.1.1 Children and young people under 18 who have been diagnosed with an autism spectrum condition are currently identified in the existing department of children and education records. However, as these children become adults, they have traditionally not been easy to identify as adult care departments have not classified people by diagnosis. This has contributed to many people with autism falling through the gap between learning disability and mental health services.

B&NES will:

- identify and count adults with autism to support the future commissioning of appropriate services, ensuring that the number and needs of adults with autism is accurately recorded
- identify children with autism who have complex needs (including behaviour that may challenge services) and are likely to need support from adult care in the future
- ensure all young people have person-centred, holistic transition plans that take into account their future needs.

5.2 Increasing awareness and understanding

5.2.1 Many of the difficulties that adults with autism experience are the result of a poor understanding of autism and its impact in the wider community and amongst community professionals working in a range of agencies:

- Health service practitioners such as GPs, community nurses, occupational therapist
- Social care workers such as social workers, customer advisors, managers

- Further education professionals such as lecturers and learning support staff and professionals who support people into work such as disability employment advisors, Connexions and Job Centre Plus
- Housing professionals
- The criminal justice system such as police officers and prison officers.

B&NES will:

- Develop opportunities for training professionals that will be appropriate and proportionate dependent on their level of responsibility. The following principles will underpin all training:
 - Training will be developed and delivered in partnership with adults with autism and carers and/or informed by their experience.
 - It will be a person-centred, strength-based approach whereby focus is on future outcomes and individual strengths to address and overcome challenges.
 - Training will give staff insight into how autism affects people, rather than the theory of autism.
 - Training will take into account and make use of any national, online resources and guidance.
- Raise awareness amongst employers and employment agencies such as Jobcentre plus
- Develop public awareness of autism
- Ensure that employers make reasonable adjustments for people with autism

5.3 Develop a clear, consistent pathway for diagnosis across Bath and North East Somerset

- 5.3.1 It is important that people with autism have access to a diagnostic pathway as this access has been very limited for adults who have not been diagnosed in childhood. In the past this need has been met – where it has been met at all – via funding from Interventions Not Normally Funded route, via interested professionals or through contact with mental health or learning disability services. If assessment services have not been available then, consequently, access to information, advice and support has also been limited.

B&NES will:

- Use the diagnostic assessment service provided by the Avon and Wiltshire Partnership Trust on a case by case basis for undiagnosed adults during 2011-12. This service will be for adults over 18 years and will provide person centred assessment, diagnosis and information/support plans, linking with other professionals where appropriate and including advice to support significant others to understand autism.
- Ensure that all adults with a diagnosis of autism have prompt access to a community care assessment
- Develop and/or adopt a model care pathway for local commissioners to develop referral and care pathways and monitor impact of same
- Establish protocols for the provision of relevant information to adults with autism and their family or carers at the point of diagnosis
- Identify ways to map current services against best practice

5.4 Improving access for adults with autism to the services and support they need to live independently within the community.

- 5.4.1 Improving access to services and support is a longer term goal as it will require a cultural change within public services and in the community that will be linked to the training and awareness raising programme referred to above.
- 5.4.2 Our key aim is, therefore, to embed understanding of autism to enhance mainstream services instead of creating separate services for people based solely upon the criteria that they have a diagnostic label of autism. However, it is recognised that this ethos should be underpinned by specialist knowledge and support when needed. An example is 'reasonable adjustment' which requires an additional focus to ensure that the most marginalised people really do have equal opportunity.
- 5.4.3 Initially, to a large extent, this will be delivered by ensuring that other current and emerging strategies take full account of the specific needs of people with autism, promoting inclusive provision within B&NES. This will help to shape and influence the approach of other people, processes and services, including:
- primary and secondary health services
 - assessment and care management
 - person-centred planning
 - self directed support
 - housing and support options

- employment opportunities

B&NES will:

- actively promote and support alternatives to residential care ensuring that everyone who has the potential to live more independently is given the chance to do so
- Ensure partnership arrangements with Registered Social Landlords include the needs of adults with autism in housing planning, design and allocation
- Explore strengthening community support schemes
- Continue to review people's care (often for complex needs and/or requiring a secure facility) in out of county residential placements with a view to understanding whether more local services can be (jointly) commissioned to meet their needs
- Provide flexible support services to keep people at home or as near to home as possible that include shared service interventions from mainstream adult services.
- Work with local and national providers, and with families and people with autism, to develop a range of housing options
- Ensure that adults with autism who live at home are still eligible for a Community Care Assessment. Their carers will also still be eligible for a carers' assessment when they are providing, or intend to provide, regular and substantial amounts of care.
- Support people to develop individual support plans funded through use of personal budgets, ensuring that the Resource Allocation system reflects the needs of people with autism
- Work within the legal framework of the Mental Capacity Act for those people who may lack capacity to make a decision, considering best interests decision making and appointment of an Independent Mental Capacity Advocate (IMCA)
- Ensure that adults with autism are able to access personal budgets in line with their assessment of need

5.4 The training programme referred to above will also play a key role in achieving this aim.

5.5 Having greater choice and control over where and how to live

5.5.1 It is recognised that many adults with autism live and are dependent on their families well into adulthood, whereby the majority of support is provided by unpaid people and an ageing population. Many of these people with autism may be unable to access the support they need to continue to live with their family if they wish, or to live independently.

5.5.2 A small number of people, primarily with complex needs including behaviour that may challenge services, are placed 'out of area' in expensive specialist units or in generic learning disability or mental health accommodation. This accommodation may not be fit for purpose, while the support given may not provide the skills necessary to enable a person with autism to learn independent living skills and reach their full potential.

5.6 Helping adults with autism into work

5.6.1 It is the aspiration of many people with autism, like most people, to have and keep a paid job. However, the National Autistic Society suggests that people with autism are underrepresented in the labour market with an employment rate as low as 15%. This can lead to adults with autism missing out on the social inclusion and personal fulfilment that comes through work. Many people with autism are at risk of falling into the category of 'NEET – not in Employment, Education or Training'.

5.6.2 Improving access to employment opportunities and support is, therefore, key to supporting people to fulfil their job ambitions, social inclusion and independence.

5.6.3 It is important to consider the role of Valuing Employment Now (VEN) which also refers to people with autism. VEN aims to increase the employment of people with a learning disability and, according to the Department of Health (DoH), 50% of people with autism also have a learning disability and so VEN will also be of benefit to many adults with autism.

B&NES will:

- ensure that any B&NES employment support is equal, fair and accessible for people with autism
- Ensure that the needs of people with Autism are recognised within the wider strategy to support people into Employment, Education and Training and avoid becoming 'NEET'.
- collect local data that indicates how many people with autism are, or would like to be, in paid or voluntary work
- look at ways to recruit adults with autism proactively into any available jobs within the council
- promote work experience to increase skills and experience. This could be through voluntary opportunities or education
- ensure that Connexions attend all Year 9 reviews, making sure employment is on the agenda as a first choice option when planning for the future
- work with employers throughout B&NES and the surrounding counties to promote the value of employing people with autism. This will be done through local relationship building and structured channels such as chambers of commerce and other employer representative groups
- ensure job coaches have up-to-date training to tackle blockages that may stop people from working, such as benefits, or housing. It is also important that common barriers to work are recognised and unpicked at a strategic level
- train job coaches in the use of personal budgets to enable people to have more choice and take control in achieving and sustaining employment
- promote and explore wider government initiatives such as 'Work Choice' and the 'Mindful Employer'
- work in partnership with Jobcentre plus to:
 - ensure all local disability employment advisors receive autism training
 - ensure all work focused interviews are accessible for people with autism. This will be complemented by DEA's awareness training
 - explore the 'what's employability' DWP pilot scheme which challenges and changes employee attitudes, promoting the skills' set of people with autism
 - promote the benefit for people with autism of sharing the fact that they have a diagnosis of autism (with a disability employment advisor). This is so that they can be supported in the best way possible
 - work with people with autism to promote and unpick barriers to employment.

5.7 Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

- 5.7.1 It is crucial that adults with autism are able to access mainstream public services and to be fully included in society. It should, however, be recognised that specific services and support dedicated to adults with autism can play a pivotal role in enabling them to use mainstream services effectively.
- 5.7.2 B&NES therefore intends to use the Joint Strategic Needs Assessment (JSNA) to identify priorities for services which will inform the direction of single agency or joint commissioning for people with autism. This will enable commissioners to plan, within the scope of existing resources and budgets, where and how services are commissioned for people with autism. This could result in the reallocation of resources from, for example, inappropriate placements of adults with autism from full time psychiatric care to provide day-to-day support, enabling greater independence, with the additional advantage of being more cost effective.
- 5.7.3 The priorities and challenges of this will be discussed and co-ordinated through the B&NES Autism Strategy group. However, the wider views of people with autism and carers across B&NES will be sought through an identified group of social, parent and therapeutic groups and the B&NES Autism Provider Forum.

B&NES will:

- Ensure that the Joint Strategic Needs Assessment (JSNA) includes data on the needs of people with autism
- Ensure that the local housing strategy addresses the long and short term needs of people with autism
- Raise awareness of the needs of people with autism with the community, voluntary and independent sector.

6 Supporting Strategies

This sections provides supplementary information to the 5 themes above and outlines the additional commissioning intentions for Bath and North East Somerset

6.1 Specialist Services

- 6.1.1 A few adults with autism will have a range of needs that will require a residential care home placement or very specialist, possibly secure accommodation. This is in order to

B&NES will:

- work with providers to ensure there is an appropriate balance of residential placements for people with autism available locally
- explore whether local authorities can jointly commission very specialist, possibly secure accommodation within the region..

ensure their safety in an environment with staff that have experience and expertise in working with people with autism and complex needs, or have access to those skills.

6.2 Advocacy

- 6.2.1 Government policy makes it clear that people who need support in their lives should have good access to information and advocacy to help them navigate the system and get the support they may need. This includes people with autism.

B&NES intends to work with advocacy organisations to:

- a) promote awareness and training amongst their workers so that adults with autism are supported by people with specific skills
- b) explore different forms of advocacy and how this can be improved for adults with autism.
- c) Ensure there is good information and access available for adults with autism to inform their decision making. This includes recognition of statutory duties.

6.3 Criminal Justice system

- 6.3.1 There is no evidence of a higher rate of offending amongst people with autism; however, the social difficulties of people with autism may make them both vulnerable to becoming victims of crime and, sometimes, perpetrators.
- 6.3.2 Economies of scale would mean that it is not practical to put in place local resources. However, the potential needs of this group of people could be met through a regional network of highly specialised professionals with particular skill sets.

B&NES will:

- Ensure adults with autism have access to an 'appropriate adult' to facilitate communication and understanding between the person with autism and police. This will protect the rights, welfare and safeguarding of the person with autism who may be vulnerable
- Invite representation from the criminal justice system on to the Autism Partnership group
- Explore and Identify opportunities to engage in a regional network of appropriately qualified professionals
- Seek ways to collect data about the number and needs of people with autism in contact with the criminal justice system
- Operate within the regional framework of the Specialised Services Commissioning group for people who need specialised (Tier 40 services)

6.4 Health and wellbeing

- 6.4.1 In the absence of specialist autism spectrum conditions provision, the expectation is that the majority of the needs of people with autism spectrum conditions will be met by mainstream services, however services are often inaccessible to people with autism spectrum conditions, and/or unlikely to be able to support the person in an effective manner.
- 6.4.2 People with Asperger's Syndrome in particular are often excluded from accessing appropriate mainstream mental healthcare services, as they are unlikely to meet the eligibility criteria for entry into secondary mental health services. General Practitioners are often unable to refer people who may have Asperger's syndrome for assessment or intervention, and consequently the majority of this group tend to be held at primary care level with no access to assessment or appropriate support.
- 6.4.3 A similar issue exists in terms of entry into social care services through Fair Access to Care assessments. Due to a lack of specialist training and expertise amongst front-line staff around how to work with people with autism spectrum conditions, Fair Access to Care assessments are unlikely to reflect an accurate representation of a person's difficulties.
- 6.4.4 Following this even if a person with autism spectrum conditions is accessed as being eligible for social care services, it is likely that they will need a certain amount of support to enable them to develop a personalised package of care that meets their needs. At present however it is unlikely that social workers in generic social care teams will have the necessary skills and experience to provide this support.
- 6.4.5 Without appropriate support and access to preventative interventions, when people with Asperger Syndrome experience difficulties, typically they either become frequent presenters at primary care, or they are occasionally supported by secondary mental

health services – both of which struggle to provide a service to them. Similarly, adults with Asperger Syndrome form a significant, chronic presence on generic inpatient wards, and specialist tertiary services such as drug, alcohol and eating disorders, where they tend not to respond well to conventional treatment packages, and thus take up a disproportionate amount of resources.

- 6.4.6 In the absence of early identification/intervention therefore, people with autism spectrum conditions are likely to experience unnecessary exacerbation of their mental health problems, and will only receive services at points of crisis via acute admission and/or crisis intervention. This is both costly and avoidable.
- 6.4.7 Similarly they are unlikely to be able to access an appropriate range of social care services or benefit from personalised care. It is recommended that a small specialist service for Adults with autism spectrum conditions is commissioned to help with the above issues.
- 6.4.8 It is also important to recognise that the complex nature and characteristics of autism can contribute to increased behaviour and mental health problems that can challenge services. As a result we can lose people to specialist out of area placements and fail to develop local skills and support services.
- 6.4.9 B&NES Council and NHS, through our joint commissioning partnership arrangements, exercise a joint responsibility to commission services that reduce health inequalities for vulnerable groups in the community. This includes people with autism.

B&NES will:

- ensure health professionals have a better awareness of people with autism
- promote person-centred planning approaches. This includes the need for participation and planning ahead for health related decision making (Mental Capacity Act, 2005)
- ensure reasonable adjustments are made to improve patient experience in primary and secondary care settings
- ensure adults with autism can access both primary care health services such as Improving Access to Psychological Therapies (IAPT) and secondary mental health teams.
- aim to identify people with autism with ongoing high support needs so that, as far as possible, potential emergencies can be identified, preventative approaches can be developed, effective contingency plans are available and service responses are quick.
- develop and expand the capacity of local services to understand and respond to challenging behaviour
- Ensure that any restrictions or restraints are compliant with the Mental Capacity Act and if these amount to a Deprivation of a person's liberty, then consideration of DOLS (Deprivation of Liberty Safeguards) authorisation needs to be evidenced.
- provide specialist responses locally which can support good mainstream practice as well as potentially directly work with a small number of people with the most challenging needs within existing services
- explore independent advocacy and co ordination to ensure that every person whose behaviour presents serious challenges to services has a person-centred plan for services to work with.
- further strengthen commissioning knowledge by continuing to establish how many people with autism are within current services – especially where these people are experiencing complex challenges. This will include:
 - young people in transition
 - People within learning disability services
 - People within mental health services
 - People within mainstream adult community services
 - People with additional physical or sensory impairments
 - People placed out of area
 - Potential numbers of people living at home not receiving services

6.5 Personalisation and self-directed support

6.5.1 B&NES's long term goal is to deliver personalised services that give each individual the right support to live a more fulfilling life. This requires planning and support services to be creative, purposeful and tailored to individual specific requirements, thus promoting individual outcomes.

- 6.5.2 The life opportunities of people with autism should be determined by their personal choices and needs, taking account of the individual characteristics of their autism, rather than by any diagnostic label.
- 6.5.3 It is, therefore, the intention of the strategy to ensure that factors likely to be particularly emphasised by people on the autism spectrum are fully understood and taken into account throughout person-centred planning, assessment, care management, service delivery and the review process.
- 6.5.4 This way of working enables an empowering, flexible and creative approach, placing focus on individual outcomes instead of a process driven, risk averse culture. The Mental Capacity Act is intrinsically tied within this, as it gives a legal way of both empowering and protecting a person who may not understand the risks and consequences of making certain decisions. Capacity assessments, best interest decisions, risk assessments and consideration of any other Mental Capacity or Mental Health law is upheld within the whole person centered planning process and therefore should take place whether a person has capacity to make decisions or not.

B&NES will:

- explore how the provision of a brokerage service can better include brokerage, information and guidance for adults with an Autism Spectrum Condition (ASC) who manage their own support. This could include information and advice about recruiting personal assistants, staffing issues and employment law as well as a 'brokers' toolkit' which will tell people about the range of support services that are available locally, in an accessible way. This will support people with autism to make informed choices
- Ensure any safeguarding issues are considered when planning support for people with autism. The Mental Capacity Act (2005) and Mental Health Act (2007) code of practice, policy and procedures are paramount to this.
- ensure person-centred planning is at the heart of all services, when individual strengths, hopes and dreams are recognised to participate successfully in meaningful activities and relationships
- ensure every person with autism has person-centred plans, prioritising young people in transition and people with complex needs. This intention includes the need to develop 'emergency and contingency plans' when appropriate. This may include people with complex needs or people living at home with carers prioritising those over 65 years old
- continue to work with children's services so that person-centred planning starts when the person is a child and is built upon through transition and into adulthood. This intention includes the need to continue to develop protocols, systems or better joined up working between children and adult services to ensure that workers in adults' teams can access appropriate records from previous assessments

6.6 Physical and sensory issues

- 6.6.1 Large numbers of people with autism experience some form of sensory difference to sounds, touch, taste, smells, lights, temperature or colours. These sensitivities combined with anxieties over social interactions can lead to real and major difficulties on a daily basis, both in the home environment and accessing the community. The Disability Rights Commission report published in 2007 notes the difficulties that people with autism might have in a doctor's surgery and the impact this could have on subsequent treatment and placement.
- 6.6.2 To help people with autism spectrum conditions access some public spaces reasonable adjustments need to be made to some environments.

6.6.3 Some public spaces can be inaccessible for adults with autism, largely due to sensory issues, but also as a result of lack of support to help adults with autism navigate new places.

B&NES will:

- work with Council colleagues in environmental planning to raise awareness of needs of people with autism to improve access to public spaces
- work with voluntary and third sector groups to establish alternative options for support
- ensure local transport plans include the needs of adults with autism
- ensure travel training is made available for people with autism.
- Raise awareness of physical and sensory issues for people with autism through the training highlighted above

6.7 Relationships

6.7.1 As part of the characteristics of autism, people on the autism spectrum often find it difficult to relate to and form relationships with others. These difficulties, for example, can be due to idiosyncratic behavior, precise language, unusual interests, and an impaired ability to perceive and respond in socially expected ways. This does not mean that people with autism do not want to form relationships; they simply find it much more difficult.

B&NES will:

- work with people with autism and carers to explore ideas to overcome barriers and address ways to promote and support relationships. Discussions could be focused on support to build social skills; develop practical strategies and understanding; or tools to enable and give people the opportunity to meet and form relationships with others.

6.8 Support for carers

6.8.1 Many people with autism continue to live and/ or rely on their parents into adulthood, often due to difficulty in finding appropriate supported living or residential care. The practical and emotional cost of this should not be under estimated.

B&NES will:

- ensure carers are aware of their entitlement to have a carer's assessment of their needs
- ensure that a carer is assessed in their own right and in context of not only the person they care for, but their immediate family and possible additional pressures which may have an impact on the carer. An emphasis on a 'family-centred' approach, as well as a 'person-centred' approach, is important to support the family unit, building on strengths and preventing breakdown. This should require multi-agency working
- ensure carers have easy access to sources of high quality information
- ensure that carers are treated as expert partners and are, therefore, involved and informed, when appropriate, about any support, assistance and planning for the person with autism
- develop ways of seeking feedback from carers, including information collected from the Social Care Survey

6.9 Transitions

- 6.9.1 It is important that young people with autism are supported to think about, prepare, understand and plan what and where they want to be in the future. This is particularly important as people with autism can find change difficult so careful consideration and good interagency practice across services is important to support young people in the best way.

B&NES will:

- Map all young people with SEN and autism and identify those at risk of not meeting eligibility criteria within adult social care
- Develop protocols to ensure that young people with autism can be appropriately signposted to other sources of support as an adult, if they will not be eligible for social services
- ensure people with any autism spectrum condition are included in the multi-agency protocol that supports the transition process for young people.. This will ensure better person-centred support planning for young people with autism and their families, while enabling the council to develop a commissioning and financial impact plan.
- actively encourage and promote young people with autism in mainstream schools to create person-centred plans, identifying future needs in all areas including employment, education, social care, health and housing
- promote the importance of effective co-ordination and transition planning in various life changes that people with autism may experience. This could include a change of residence, family break-ups or bereavements. Such a life transition can be as difficult as the transition into adulthood and should be planned in the same way.

6.10 Involvement of people with autism and carers

6.10.1 In accordance with one of the key principles for effective commissioning, the involvement of people with autism and carers will be integral to this commissioning strategy. The B&NES Autism Strategy Group will lead on this strategy and how it is delivered and be responsible for liaising with other identified support groups, including parental and therapeutic, to consult, seek advice and monitor B&NES's strategic direction.

6.11 Equality Impact Assessment

6.11.1 An Equality Impact Assessment (EIA) is a systematic approach to ensuring that policies, functions or services do not discriminate against any individuals or groups. This is part of a statutory duty for all public authorities.

6.11.2 An Equality Impact Assessment relating to the commissioning of services for people with autism is attached as Appendix X to this document.

6.12 Workforce strategy

6.12.1 A workforce strategy is a plan to achieve 'the right workforce in the right place with the right skills' [ADASS /CSIP 2007]. We will include the need to develop the skills and knowledge to work with people with autism within existing workforce strategies and plans.

7 Next steps

- 7.1 An implementation plan will be developed to support the intended commissioning intentions/outcomes set out in this document. This plan will be updated to reflect progress and the setting of new proposals.
- 7.2 An easy-read version of this report will be produced.

8 Outcomes

- 8.1 Fulfilling and Rewarding Lives- the strategy for adults with autism in England has a long term vision with the first three years focused on:
- increasing awareness and understanding of autism among frontline professionals;
 - developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment;
 - improving access for adults with autism to the services and support they need to live independently within the community;
 - helping adults with autism into work;
 - enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

8.2 This section suggests a number of outcomes and indicators that might be adopted for measuring the success of this strategy and the benefits gained for people with autism, their families and carers, support staff and public services

Table 2 – Outcome Measures (from the South West Commissioning Guidance.

Activity	Indicators
OUTCOME 1: Increased awareness and understanding of autism	
1.1 GPs, staff in health and social care, criminal justice sector, Disability Employment advisors receive awareness raising training on ASC	<ul style="list-style-type: none"> • Increased awareness, knowledge and competencies around ASC
1.2 A Specialist ASC Team provides supervision, training and liaison for health and social care staff, housing providers, employment and education providers	<ul style="list-style-type: none"> • Front-line staff feel more confident and skilled in working with people with ASC
OUTCOME 2: Local partners plan and develop appropriate services for adults with autism to meet identified needs and priorities	
2.1 A Specialist ASC service is established in every local authority area through joint funding	<ul style="list-style-type: none"> • Joint commissioning plan • Capacity plan • Sustained funding
2.2 Health and Wellbeing Boards ensure the needs of people with ASC within their area are reflected in local strategic plans and commissioning priorities	<ul style="list-style-type: none"> • JSNA data • Local ASC strategy
2.3 People with ASC and their carers are involved in the design and delivery of local services (Section 242 (1B) of NHS Act 2006 – Duty to Involve	<ul style="list-style-type: none"> • Local Involvement Network /Healthwatch reports • Evidence of involvement of, and consultation with people with ASC/carers via local planning and commissioning mechanisms
OUTCOME 3: A clear, consistent pathway for diagnosis in every area which is followed by the offer of a personalised needs assessment	

<p>3.1 Primary Care, Secondary/tertiary healthcare, A&E Liaison, Criminal Justice system, NHS Direct and Social Services have greater awareness and make appropriate referrals /diagnosis to achieve earlier intervention and diagnosis</p>	<ul style="list-style-type: none"> • Increase in people given ASC diagnosis • Improved service user/carer satisfaction • Increase in numbers of assessments • Rate of ASC diagnosis as a percentage of estimated local prevalence • Improved service user/carer satisfaction • Staff satisfaction survey • Improved waiting times • Reduction in number of out of area placements • Reduction in complex care packages
<p>3.2 People with a possible diagnosis of ASC are offered an assessment of needs, and personalised support plan of</p>	<ul style="list-style-type: none"> • Increased number of people receiving personal budgets
<p>3.3 Case Management is planned and maintained</p>	<ul style="list-style-type: none"> • % people given an ASC diagnosis in receipt of services have a case manager/care co-ordinator from referring agency • % people with ASC in receipt of services have a support plan/ Wellness Recovery Action Plan
<p>3.4 Improved access for carers: access to information, assessment and care plans.</p>	<ul style="list-style-type: none"> • Number of carer assessments offered and number undertaken per annum • Number of carers with a care plan • Increased carer satisfaction
<p>OUTCOME 4: Improved access for adults with autism to the services and support they need to live independently within the community</p>	
<p>4.1 Support, treatment and signposting from ASC services team</p>	<ul style="list-style-type: none"> • Reduction in incidence of mental health problems of people with ASC in receipt of services • Reduced relapse or re-entry to specialist mental health services • Reduction in GP appointments • Increase numbers of people with ASC returning to employment or gaining employment

	<ul style="list-style-type: none"> • Increased numbers of people with ASC living independently • Increase in numbers of people with ASC in settled accommodation • Improved person-reported outcomes – (measures may include recovery outcome measures, wheel of life, • Reduction in the number of out of area placements • Avoidance of out of area placements
4.2 Establishment of peer support groups	<ul style="list-style-type: none"> • People with ASC feel empowered and supported independent of statutory services (person-reported outcome measures, surveys)
4.3 Careful planning around transitions for people leaving children and young people's services	<ul style="list-style-type: none"> • Increased number of young people with AS receiving a Section 139a Assessment
4.4 Improved support for people within criminal justice system or prison with a ASC	<ul style="list-style-type: none"> • Increase in the number of referrals from Police and courts direct to services (court diversion) • Increase in number of people with ASC in prison receiving screening, assessment, care plans
OUTCOME 5: Adults with autism helped into work	
5.1 Careful planning and support for young people in transition from education or home study	<ul style="list-style-type: none"> • Increase in young people with AS accessing further education and /or vocational training • Improved retention rates of young people with AS in local Further Education provision • Increased success rates (recognised qualifications) of young people with AS in local Further Education • Increased numbers of people with AS in progressing from further education to employment
5.2 Improved support for people with ASC to be able to work and maintain a job	<ul style="list-style-type: none"> • Increased awareness and confidence reported by employment support staff

- Increase in numbers of people with ASC in employment 16+ hours per week
- Greater awareness reported by employers of needs of people with ASC
- Evidence of more reasonable adjustments made to support people with ASC at work (eg individual placement support schemes; coaching; mentoring)
- Improved retention rates of people with ASC within work

8.3 In addition, the following Outcome measures (from Devon), might be adopted for use with people with Autism as a measure of quality of life for individuals

Do you definitely agree, slightly agree, slightly disagree, or definitely disagree with the following statements?

1. I like the house where I live
2. I have no fear about the area I live in
3. I like to be around other people
4. Other people like to be around me
5. I can manage my life on my own
6. Other people respect decisions about my own life
7. There are people around me that I can trust
8. There are people around me that I can ask for help
9. I have at least one close friend
10. I can have time to myself if I want to
11. I achieve things that other people respect me for
12. I make use of my abilities
13. I am equal to others in society
14. I have a direction in life
15. I am confident about the future
16. Is there anything else you would like to say about your life?

Appendix 1 – Bath and North East Somerset Autism Strategy Services Values and Principles

Values

- People with autism have the same human value and statutory rights as everyone else.
- People with autism should be able to use general health and social services wherever possible, and have access to specialist services when necessary.
- Service users should be empowered and supported to assume as much responsibility for their own lives as possible.
- People with autism have the right to express their views independently of their carers.
- People with autism and their carers should be fully involved in decisions, which affect their lives.
- Services will be based on equal opportunities principles (which respect differences in race, culture, religion, gender, etc).
- Services will be commissioned and provided which demonstrate best value and are delivered to the highest possible standards.
- There should be equity of access to services across Bath and North East Somerset.

Principles

- The process will be a learning one aimed at empowering people with autism to have a voice in the service provision and to take as much responsibility for their own lives as possible.
- We will be proactive in seeking continuous involvement of people with autism throughout the process.
- We will actively involve people with complex needs and high support needs.
- We will ensure consultation with people from Black and ethnic minorities.
- We will be flexible and responsive to changing needs and we will respect people's individual views.

Appendix 2 – Key Objectives of the Bath and North East Somerset Autism Strategy Group

- Review and consider current guidance and policy at national and local level relating to autism
- Develop local understanding of prevalence of autism and demand for services
- To ensure a planned and open approach to commissioning of services for people with autism spectrum condition, making use of information about demand, unmet needs/service gaps and resources, and identifying commissioning priorities
- Oversee the development of a multi-tier training framework to increase awareness and understanding of autism
- Oversee the development of a clear pathway to diagnosis and assessment, followed by the offer of a personalised needs assessment. Ensure that autism is recognised as a reason for assessment under the Community Care Act
- To enable adults with autism to benefit from personalisation of social care and access personal budgets in line with assessment of need
- To ensure that adults with autism have fair access to a range of health services, and the reasonable adjustments are made to accommodate their needs where necessary
- To ensure that adults with autism have access to a range of services, including appropriate housing, and can access help to make choices about their support
- Develop a range of preventative services to reduce the number of people with autism who develop mental health and other crises.
- To ensure that schools and children's services have mechanisms in place to share information to aid planning and commissioning services to meet future demand
- Develop a transitions pathway for young adults with autism including those not eligible for adult social services under local eligibility criteria
- To develop new approaches that ensure that adults with autism benefit from wider employment initiatives

- To promote and monitor the effectiveness of multi-agency working, in relation to the policies, procedures and protocols and to resolve issues and problems where identified.
- To ensure provision of clear and accessible information for people with autism and their family carers including information about services available within Bath and North East Somerset, referral routes and access to support, national advice and guidance services,
- To establish any groups/action groups and board believes will be required to sustain and promote the autism strategy. The terms of reference of these groups will be determined by the board.
- To champion work on autism across all services.
- To establish mechanisms to ensure that adults with autism and their families have a voice and that their views are communicated appropriately.
- To ensure that services meet the whole needs of each person taking into account ethnic origin, culture, religion, sexuality, gender and language, as well as social and emotional needs.
- Oversee the development of a long term strategy to improve local support services for adults with autism – based on 5 key themes of Fulfilling and rewarding lives
- Develop an action plan to deliver the strategy