

Fulfilling and Rewarding Lives

**Gloucestershire's
Adult Autism and Aspergers Syndrome Strategy
2013 – 2016**

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Executive summary incorporating purpose and aims of the strategy

Autism is a complex lifelong developmental condition. Autism is known as a spectrum condition because of the wide range of ways in which it presents itself in different individuals. However, there are common areas of difficulty experienced by all people with autism, including, difficulties with social communication, social interaction and social imagination. Although the strategy and action plan cover all adults with an autistic spectrum disorder, there are specific concerns for adults with Aspergers Syndrome. Historically the needs of this group have generally been less well addressed.

In recent years there have been a number of national developments relating to people with autism. The introduction of the Autism Act (HMSO 2009) and the publication of the national autism strategy *Fulfilling and Rewarding lives: the strategy for adults with autism in England* (Department of Health 2010) place a statutory duty on the NHS and Local Authorities to ensure that services are in place to meet the needs of people with autism. In June 2012, the National Institute for Clinical Excellence (NICE) also issued guidelines on autism in adults.

In the absence of early identification/intervention people with autism 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. Knapp 2007 (NICE 2012) estimated that the annual cost to society for each person with autism in the UK is £90,000 and with a cost to the economy of around £25.5 billion per year. Of the cost for adults, 59% is accounted for by services, 36% through lost employment and the remainder by family expenses.

Locally, the adult autism strategy is overseen by the multi-agency Autistic Spectrum Condition Partnership Board (ASCPB). Terms of reference and membership are at web link x. The Lead Commissioner for Mental Health, who is a member of ASCPB, ensures direct accountability to the Gloucestershire Health and Wellbeing Partnership Board. The Lead Commissioner for Mental Health will work closely with the Lead Commissioner for Adults with Learning Disabilities (ALD) to ensure the strategy is inclusive of all people with autism, including those with a learning disability and those who don't have a learning disability.

The current lack of comprehensive data impacts on the ability to plan effectively and deliver the services that are needed for people with autism and their carers.

A Gloucestershire Adult Autism Needs Assessment was completed between April and September 2012 (web link x). The Needs Assessment included consultation with members of Gloucestershire's Autism Network Group made up of individuals with autism and their carers.

The Needs Assessment analysed Gloucestershire in the context of evidence described in the national strategy, 'Fulfilling and rewarding lives' (2010) and the National Institute of Health and Clinical Excellence (NICE) guidelines on good practice (June 2012). It revealed some local progress in developing support for adults with autism but also gaps in services and significant unmet needs.

The Needs Assessment contained 23 recommendations from which the purpose and main aims of the strategy have been derived.

The purpose of the strategy

- To lay the basis for a planned and open approach to commissioning of services for people with autism, making use of information about unmet needs/service gaps already identified while also prompting a more comprehensive and robust collection of data about people with autism.
- To ensure that support is centred on the needs of people with autism and there is an open relationship with those who experience autism at first hand.

- To provide direction and structure for both Health and Social Care provision within Gloucestershire and for other mainstream services such as Housing, Employment, Education and Training, Criminal Justice.
- To act as a cornerstone for those agencies developing any business case or strategy relating to service provision.
- To stress the importance of preventative interventions, particularly at key transition points in the life cycle (see life cycle model at web link x developed by local carers)

The seven aims of the strategy

- Increase awareness and understanding of autism across all public services in order to increase the ability of staff to recognise autism to meet people's needs.
- Develop a clear pathway for the assessment and diagnosis of people who are on the autistic spectrum, ensuring that diagnosis leads on to improved assessment of need and support .
- Improve the transition pathway from children's to adult services.
- Help people with autism into work.
- Enable local partners to plan and develop appropriate services for people with autism meeting identified needs and priorities
- Enable people with autism to have a greater choice and control over where and how to live
- Ensure that a range of services have an understanding of autism and can be accessed by people with autism challenging the current high levels of social exclusion

In developing this strategy, the ASCPB identifies adults with autism as a group of people with specific needs as a result of a developmental disability and to challenge the traditional default positions of either subsuming people with autism into learning disability or mental health services.

This presents the dual challenge of raising awareness and understanding of the needs of people with autism whilst not creating a separate specialist service. **The intentions are thus twofold :-**

- a) **to ensure that mainstream strategies and services that impact upon people's health, accommodation, employment, social care education/training, the criminal justice system cater for people with autism,**
- b) **to ensure that local services are available to those autistic people with complex needs that require specialist, highly skilled intervention.**

Above all Gloucestershire wants to reduce the isolation and vulnerability currently experienced by people with autism and their families.

Introduction

a) What is autism?

1.1 Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. Autism is also sometimes referred to as autistic spectrum disorder or autistic spectrum condition. In this strategy the phrase 'people with autism', will be used. This includes people with Aspergers Syndrome. Some people with autism also have an accompanying learning disability, but autism itself is not a learning disability. Some people with autism may develop mental health problems - often as a result of a lack of support and because of social isolation and exclusion - but autism itself is not a mental health problem.

1.2 Autism is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Shared difficulties include.

- 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.

1.3 In addition, many people with autism may experience sensory 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.

1.4 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 as being a 'hidden disability'. Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support.

1.5 For example, people with Asperger's syndrome, a higher functioning form of autism, typically have fewer problems with speaking than others on the autistic spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are often of average or above average intelligence. They can find it harder to read the non verbal signals that most of us take for granted. This means they find it more difficult to communicate and interact with others which can lead to high levels of anxiety and confusion.

b) How many people have autism in Gloucestershire? What quantitative data exists in the county?

Total numbers

- 1.6 Across the autistic spectrum there are an estimated 535,000 children and adults living in the UK. Like most other areas, there is a lack of comprehensive data on numbers of people with autism in Gloucestershire. A study of the prevalence of ASC in adults (over 18) published in 2012 by the NHS Information Centre for health and social care estimated national prevalence to be 1.1%. The Office for National Statistics mid year estimate gives the population of Gloucestershire as 469,573. Applying this prevalence rate locally would mean 5165 people with autism in Gloucestershire.
- 1.7 People with autism often have no obvious disability. Some individuals may not wish to have their condition recognised. Many individuals have not yet received a diagnosis – in Gloucestershire the number of diagnoses rose from 1 in 2008 to 30 in 2011.
- 1.8 The Learning Disability Observatory (LDO) estimates that between 20% and 33% of adults with a learning disability also have autism. The LDO estimates that the total number of people with learning disabilities in Gloucestershire to be 11, 787. Applying the LDO estimates of the prevalence of autism to the 11,787 people with learning disabilities, the number of people in Gloucestershire with learning disabilities who also have autism would be between 2,357 (20%) and 3,890 (33%).

Education and training

- 1.9 The number of young people in Gloucestershire at year 11 with either a statement of special education need or at 'School Action Plus' (where pupils do not have a statement but receive extra support as agreed in their Individual Education Plan) with a primary or secondary need of autism increased from 22 in 2006/7 to 56 in 2011/12, an increase of 154% over a period of five years. The University of Gloucestershire's Disability advisory service has recorded an increase from 40 students in academic year 2011/12 to 70 students in 2012/13.

Employment

- 1.10 A survey by the National Autistic Society (NAS) found that only 12% of non-learning disabled adults with autism are in full-time employment (NICE 2012). Applied to the estimated 2273 non-learning disabled people with autism of working age in Gloucestershire, up to 2000 (88%) of these people may not be in full time employment.

Accommodation

- 1.11 The number of people with autism living at home on their own, or with family members – it is estimated that 79% of non-learning disabled people with autism live in private accommodation, 5% live in supported accommodation, and 16% live in residential care (Knapp 2007). Applied to the estimated 2273 non-learning disabled people with autism in Gloucestershire, 1796 may be living in private accommodation, 114 in supported accommodation and 364 in residential care.

Social care

- 1.12 Data obtained from adult social care services at Gloucestershire County Council (GCC) shows that since 2009 (which is the earliest date for which data available on the database), 327 people with autism have had an assessment for social care (either a short screening assessment – or full social care assessment).
- 1.13 The social care database records the client's identified primary need. The majority (238 people - 73%) of the 327 people on the social care database with an indication of autism had learning disability identified as their primary need and only six (1.8%) had autism identified as their primary need.

c) National context

1.14 Over the past few years, public awareness about autism has increased. Some high profile individuals with autism, media and TV programmes have raised the profile of autism whilst highlighting the difficulties that people with autism and their carers experience.

1.15 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.

There is a demand from people with autism for 'preventative services' – those services that are low level and less intensive in nature, but which can actually help prevent the development of more complex needs over time.

Failure to provide these services can have a significant impact on individuals. It can mean that they fall into crisis situations. A third of adults with autism (NAS survey) said that they had developed serious mental health problems as a result of a lack of support. 57% said that they had suffered from depression as a result of a lack of support.

In 2009, the National Audit Office carried out research looking at the cost effectiveness of services for adults with autism in England. Highlighting the importance of early identification and support for the needs of an adult with autism, the NAO stressed the costs of not providing this type of low level support. This especially applies to people with Aspergers syndrome.

1.16 The Autism Act was passed in 2009; Local Authorities and NHS bodies have a duty to follow the guidance in the Act.

1.17 The national strategy, 'Fulfilling and rewarding lives' was published in 2010.

1.18 In June 2012 the National Institute of Health and Clinical Excellence (NICE) produced clinical guidelines on the recognition, referral, diagnosis and management of people with autism. A key purpose of these guidelines was to provide evidence based recommendations to support the further implementation of the national autism strategy.

d) Local context

1.19 Gloucestershire has had an Autistic Spectrum Condition Partnership Board (ASCPB) since 2006 - The ASCPB brings together local service providers, commissioners, carers and people with autism to improve the quality and range of local services. In 2012 the ASCPB, informed by the Lead Commissioner, was tasked with the development of an integrated adult autism strategy for the county.

1.20 The ASCPB is now underpinned by an active and growing (currently about 30) Autism Network Group (ANG) made up of people with autism and their carers. Extensive consultation with ANG members has been undertaken in the preparation of this strategy.

1.21 The completion of a Department of Health (DOH) self assessment in early 2012 (web link x) confirmed that, in line with national findings:

- Commissioners need more information about Gloucestershire's 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 client group is significantly "hidden" because of under diagnosis and under referral
- People with autism who do not have a learning disability or a mental health condition are not well-supported
- Assessment and diagnosis services have no clear pathway for referral

- The workforce in both statutory and independent sectors needs further training and support to understand and meet the needs of people with autism
- There is a need to help people with autism live in appropriate accommodation and to take up employment opportunities.

2. Why we need a specific Adult Autism strategy for Gloucestershire?

(What the Gloucestershire autism needs assessment (2012) told us, what national guidelines from NICE indicate, what parents/carers and people with autism say they need and how Gloucestershire intends to respond)?

Using the **seven aims** of the strategy as a framework it is possible to identify local progress, unmet need and gaps.

A. Increasing awareness and understanding of autism

Local progress to date

- 2.01 Gloucestershire has had a programme of autism awareness training in place since 2009. The approach has been to deliver training at both generalist and specialist level.
- 2.02 Many of the key groups identified as priorities in national guidance have received training in Gloucestershire, including social workers, further education staff, police officers, disability employment advisors— 800+ to date.
- 2.03 An example of good practice is the involvement of a local service user in the planning and developing the training programmes.

Unmet needs and gaps

- 2.04 There are still major gaps in training coverage both at generalist and specialist level.
- 2.05 Although the training programme has been delivered to more than 800 people, it is not clear what percentage of staff in each target group have been trained or how new staff who require training are identified.
- 2.06 There has been no evaluation of the impact of Gloucestershire's training programme and it is therefore not clear what impact the training has had on the experiences of people with autism and their families/carers.
- 2.07 The overall weakness is that Gloucestershire has not developed a strategic approach to training and awareness.

Responding to these needs

- 2.08 Developing an integrated, workforce training framework to increase awareness and understanding of autism across all relevant agencies.
- 2.09 Commissioning training and development opportunities to enable professionals to recognise autism to communicate effectively and to adapt their behaviour and services appropriately.

B. Clear pathway from diagnosis and assessment to support

Local progress to date

- 2.10 A diagnostic and assessment service for people with autism in Gloucestershire is based on a GP referral process. Diagnostic assessments are 'spot purchased' by the PCT at two per month from the local mental health trust.
- 2.11 Current waiting times for a diagnostic assessment in Gloucestershire can be up to a year. Diagnostic assessments are not currently carried out as part of a comprehensive assessment of need as recommended by the NICE.
- 2.12 Since 2008, 87 people referred for diagnosis have been assessed in Gloucestershire. The number of referrals has increased year on year from one in 2008 to 30 in 2011.
- 2.13 People with autism and their carers are entitled to request a social care assessment, although local discussions indicate that they are often unaware of the pathway for accessing this in Gloucestershire. The route to accessing a social care assessment for adults in Gloucestershire is through the social care helpdesk.

Unmet needs and gaps

- 2.14 Gloucestershire is not currently following NICE evidence-based good practice in a number of areas relating to the identification and diagnosis of autism in adults and assessment of need for relevant services.
- 2.15 There is currently no documented referral and diagnostic pathway for autism in Gloucestershire. The current process to access a diagnostic assessment has not been widely publicised to GPs, nor have the NICE guidelines on evidence based good practice.
- 2.16 Discussions with parents/carers of adults with ASC and with the NAS suggest that people with autism without an accompanying learning disability who try to access social care are told often at the first stage that they don't meet the criteria for a full social care assessment and are not aware that they have the right to ask for one.
- 2.17 Some parents and people with autism are unaware of how to access a diagnostic assessment.

Responding to need

- 2.18 Using the diagnostic assessment service provided by the 2gether mental health trust on a case by case basis for undiagnosed adults from April 2013 at an increased contractual level of 50 per year.
- 2.19 Ensuring that all adults with a diagnosis of autism have prompt access to a community care assessment.
- 2.20 Completing a model care pathway for local commissioners to develop referral and care pathways and monitor impact.
- 2.21 Providing relevant information to adults with autism and their family or carers at the point of diagnosis.

C. Improving the transition from children's to adult services

Local progress to date

2.22 Gloucestershire's transitions protocol is currently under development as part of a review of how transition services are delivered. The County Council (GCC) has developed a transitions pathway for pupils with statements of special educational need. This pathway applies to all young people with a statement and provides information on what transition planning is, who is involved and what should happen at each stage of the transition process.

2.23 Prior to September 2011, transition reviews for children with statements were very rarely attended by a social worker. The agreement of a new protocol with adult social care has resulted in a greater adult social care presence at transition reviews since this time..

2.24 In response to problems identified with the transition process two Transition Coordinator posts were created in April 2012 with the remit of ensuring a timely and effective transition for children with disabilities who will be transitioning into adult services. The coordinators have identified a cohort of 75 children with statements who were in year 11 in September 2012 (out of a total of 240 year 11 pupils with statements) who are likely to require on-going support, either from adult social care or other sources.

2.25 GCC's transitions pathway (Gloucestershire County Council & The Key 2011) contains a flowchart detailing the transition from children's to adult mental health services in Gloucestershire. This states that the existing key worker for the young person is responsible for identifying appropriate adult services/teams and that a transition care plan should be agreed and care transferred.

Unmet needs and gaps

2.26 It is difficult to gather information on any particular issues regarding its implementation that relate specifically to young people with autism. For example it is not possible to quantify the numbers of young people with autism whose transition reviews were attended by a representative from adult social care as the transitions database held by the Youth Support Service records pupils with disabilities according to whether they have a statement, are at 'school action plus' or at 'school action' but does not contain specific details of these pupils' disabilities (such as autism).

2.27 It is not possible to quantify how many young people in receipt of child and adolescent mental health services (now called The Children and Young People's Service in Gloucestershire) have a diagnosis of autism as this is not routinely recorded.

2.28 Discussions with parents and professionals working with young people with autism indicate that the pathway protocol has not been implemented in a consistent manner in relation to adult social care attendance at transition reviews or the provision of ongoing support.

2.29 Neither Gloucestershire's transition pathway nor 2gether NHS Foundation Trust's transfer of care protocol contain any information on transition arrangements for young people who are not eligible for adult mental health services. There is no evidence that young people with autism who do not meet the referral criteria for adult mental health teams are informed about their right to a community care assessment or are signposted to other sources of support and information available.

Responding to need

2.30 Ensuring that:

- Young people with autism approaching transition are contacted by adult social care and offered an assessment and carers are offered a carer's assessment.
- Young people with autism who are not eligible for adult social care are signposted to other sources of support and information. Support and information is provided to young people with ASC who do not have a statement of SEN.

- Mental health providers (adult and children) are able to identify and report on their clients with autism.
- Young people in receipt of CAMHS who do not meet adult mental health services criteria are offered appropriate support and information.

D. Helping adults with autism into work

Local progress to date

2.31 In Gloucestershire, the Jobcentre Plus (JCP) Mental Health and Disabilities Partnership Manager is a member of the Autistic Spectrum Conditions Partnership Board with a lead on employment matters and also chairs the Learning Disability Partnership Board Employment Sub Group.

2.32 The Mental Health and Partnerships Manager from JCP has been commissioned through a secondment by Gloucestershire County Council to develop an Employment Strategy for people with learning disabilities; this will include people with autism and a learning disability.

2.33 All the Disability Employment Advisors in Gloucestershire had received autism awareness training.

2.34 People with autism in Gloucestershire and their carers have identified a range of issues they face when trying to gain employment. During focus groups in 2009 many participants talked about their experiences with interviews and the challenges this posed due to the social skills required. Participants said that having to participate in the interview process could prevent them from securing employment unless they received training and support..

Unmet needs and gaps

2.35 The ASC Partnership Board has identified developing a work programme to help people with higher functioning autism get and stay in work as one of its priorities but there has been no progress with this.

2.36 There is little local data on the numbers of adults with ASC in Gloucestershire who require employment support. Applying the NAS's figure that 15% of adults with autism are in employment to our local estimated population of 3,500 adults of working age with autism in Gloucestershire, mean that the number of adults with autism in Gloucestershire in full time employment may be as low as 525. The total estimated population includes adults across the autistic spectrum, many of whom may not be able to work. However, Gloucestershire Job Centre Plus Disability Employment Advisors (DEAs) who provide specialist support for disabled people looking for work were only able to identify 12 people with a diagnosis of autism on their caseloads.

2.37 Although there are national employment programmes which people with autism can access, disabilities are not recorded in sufficient detail to identify whether people with autism are being helped by these programmes.

2.38 Parents report a lack of employment opportunities for people with autism and have identified working with employers to highlight the benefits of employing people with autism as a priority. Parents felt that few employers seem to have an understanding of autism.

- 2.39 There are no specific employment services for people with autism in Gloucestershire. There are some employment services for people with learning disabilities, for example Forwards Job Clubs which provide specific and general employment related support for people with mental health issues and learning disabilities and which are accessible to people across the autistic spectrum.
- 2.40 Other options for people with autism available locally are existing provision such as the DWP 'Work Choice' scheme for people with disabilities. However, this has limited capacity and is currently only accessible to people with severe or complex needs.
- 2.41 The recently published NICE guidelines found that supported employment programmes for adults with autism are cost effective and provide both social and economic benefits. Gloucestershire does not have such a programme.

Responding to need

- 2.42 Joint working with the Adults with Learning Disabilities Partnership Board (ALDPB) to develop an employment strategy. The strategy will promote awareness amongst employers including the positive business benefits as well as the need to make reasonable adjustments.
- 2.43 Commissioning an individual supported employment programme for adults with autism without a learning disability, who are having difficulty obtaining or maintaining employment, reflecting NICE guidelines on evidence based good practice.
- 2.44 Develop and disseminate a resource guide for employers providing practical advice and support for employing and working with people with autism, highlighting the positive attributes that many people with autism can offer an employer.

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

Local progress to date

- 2.45 Gloucestershire's Joint Commissioner for Mental Health is the lead commissioner for adults with autism in Gloucestershire.

Adults with autism who have an accompanying learning disability are able to access learning disability services. A range of services are commissioned for people with learning disabilities in Gloucestershire.

Gloucestershire has had an Autistic Spectrum Conditions Partnership Board in place since 2006. Gloucestershire's ASC Board has representation from the groups recommended in the NICE guidelines (NICE 2012) with the exception of primary care who are not currently represented.

An enhanced diagnostic service for autism is currently under negotiation in Gloucestershire.

An Adult Autism Strategy Implementation Manager (0.4 WTE) has been appointed based at the NAS and jointly funded by NHS Gloucestershire and GCC.

Unmet needs and gaps

There is insufficient data on this population on which to effectively base service plans. Services are fragmented/non-existent, particularly for those people with autism who fall between Learning Disability and Mental Health services.

Gloucestershire has not yet developed a commissioning plan for adults with autism.

Responding to need

Ensuring the strategies of other agencies take full account of the needs of people with autism. The intention is to shape and influence the approach of other agencies, including, primary and secondary health services, assessment and care management, housing, employment and educational opportunities and those agencies forming the criminal justice system.

Agreeing a data capture strategy through the Gloucestershire JSNA, so that the data recorded by all relevant agencies is aligned with the recommendations in the national strategy.

Involving people with autism and their carers in the design and delivery of local services.

F. Enabling adults with autism to have a greater choice and control over where and how to live

Local progress to date

The number of adults with autism living at home on their own, or with family members in Gloucestershire is not known. Nationally it is estimated that 79% of non-learning disabled adults with autism live in private accommodation, 5% live in supported accommodation, and 16% live in residential care (Knapp et al 2007).

In terms of housing provision there is a distinction between adults with autism and a learning disability who are in receipt of ALD funded care and support services and adults with autism not in receipt of ALD funding.

The Housing and Communities Manager from Cheltenham Borough Council is a member of the ASC Partnership Board and the lead Commissioner in Gloucestershire for Supporting People is part of the Professional Reference Group.

Unmet needs and gaps

The ongoing lack of safe, suitable affordable housing was identified as a key priority by adults with autism and parents who are members of Gloucestershire's autism network group. Living in private shared housing was seen as stressful and unsafe for people with autism and some people reported living in housing that is more expensive than their housing allowance. Other adults remain at home with their parents, with uncertainty about what will happen when their parents can no longer support them. We do not have figures on the housing needs of adults with autism in Gloucestershire as autism is not recorded on housing databases. However, according to the National Autistic Society, over 40% of adults with autism live at home with their parents (National Autistic Society 2008).

A Housing sub group of the ALD Partnership was established in autumn 2012 and is making progress toward identifying a wider range of housing options for adults . It is not clear whether the housing needs of adults with autism including aspergers syndrome,not in receipt of learning disabilities funding, are being met.

Responding to need

There is a need to work through the ALD Housing sub group, which contains housing officers from all 6 district councils plus Registered Social Landlords to;

Actively promote 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 Aspergers and higher functioning autism in housing planning, design and allocation and strengthening community support schemes.

Work with local and national providers and with families and people with autism including Aspergers , to develop a range of housing options.

G. Ensure that a range of services have an understanding of autism and can be accessed by people with autism challenging the current high levels of social exclusion

Local progress to date

There is some evidence that wider mainstream public services have made 'reasonable adjustments' to services for people with autism in Gloucestershire. For example:

- Staff with expertise in autism from 2gether have provided several sessions to staff delivering IAPT (Improving Access to Psychological Therapies) on how to adapt their practice for people with autism
- At Gloucestershire College, each of the three campuses have a 'chill room' where people with ASC (and other students who feel distressed) can go to avoid sensory overload and remove themselves from other students.
- A review of Gloucestershire's County Council's Social Care database found that 36 people identified as having autism are in receipt of direct payments

Unmet needs and gaps

Focus groups held in Gloucestershire with people with autism and their families in 2009 identified the need for services to be in place following diagnosis. Participants felt there was a need to increase employment opportunities, access to appropriate housing, support in personal relationships and access to social opportunities.

Providing the level of support in Gloucestershire recommended by NICE guidance may require significant changes to service delivery arrangements. This may be costly but it will also save money in the long term. Where people with ASC don't qualify for social care it was felt that signposting to sources of support such as local social groups for people with autism would be helpful.

Adults with autism need support to enable them to live independently for example through some reasonable adjustments to public services. Making reasonable adjustments for people with autism requires knowledge of what adjustments can help people with autism and should be part of mainstream service delivery for services who provide services to this group.

ADULT AUTISM STRATEGY 2013 / 2016 - OUTCOMES AND ACTION PLAN

It is intended that the strategy be fully implemented by the end of 2016. It is recommended that an interim review of progress be undertaken in summer 2014.

What did the Needs Assessment Sept 2012 tell us? What do the NICE guidelines June 2012 say is good practice?	What outcomes do people with autism and their carers say they want?	Local strategy objectives to 2016	What would success look like in 2016 – performance targets?	Lead Agency(s)	Milestones
AWARENESS <p>There needs to be an evaluation of the training and awareness raising already carried out</p> <p>Staff working with people across the autistic spectrum should receive autism awareness training at the appropriate level and on an ongoing basis.</p> <p>Staff most likely to have contacts with adults with autism such as primary care staff and social care assessors should be the priority groups for training.</p> <p>Local practice development leads and/or autism awareness champions could help promote uptake of training amongst priority groups and help to ensure that the investment</p>	<p>Increased awareness and understanding of autism across all public services in Gloucestershire so that staff are better equipped to meet the needs of people with autism.</p>	<p>Develop a multi agency, multi tier integrated workforce training framework to increase awareness and understanding of autism</p>	<ol style="list-style-type: none"> 1. All public service staff will have received autism awareness training at an appropriate level and an ongoing training programme will be embedded. 2. Adults with autism, their families and carers and autism representative groups will be involved in the planning and delivery of training. 3. All GP's will have completed autism awareness training, inclusive of NICE guidance on the assessment of suspected autism. 4. All social care help desk operators will have completed level 2 autism awareness training. 	County Council and PCT	By Dec 2016 From April 2013 By Dec 2016 By Dec 2013

<p>in training and development leads to behaviour change.</p> <p>Training primary care staff, particularly GPs should be a key priority. Discussions need to take place with primary care representatives to identify the best way to achieve this, for example the Royal College of General Practitioners e-learning course for general practitioners and other primary care professionals.</p> <p>Autism awareness should be included in the existing equality and diversity training of Gloucestershire County Council and all NHS bodies and Foundation Trusts. The core aim of this training should be that staff are able to identify potential signs of ASC and understand how to make reasonable adjustments in their behaviour, communication and services for people with ASC.</p> <p>Level 2 training in autism awareness should be provided to social care helpdesk operators. This should be accompanied by the development of social care information sheets that will aid the identification of the</p>				
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specific needs of people with autism.					
<p>PATHWAY FROM DIAGNOSIS to SUPPORT</p> <p>A lead clinician should be appointed in Gloucestershire to develop diagnostic and assessment services.</p> <p>Diagnostic processes and services should be reviewed by the Lead Commissioner against the best practice published in the recent NICE guidelines on the recognition, referral, diagnosis and management of adults on the autistic spectrum.</p> <p>A clear pathway should be developed covering initial referral for suspected autism, a multi-disciplinary assessment (covering diagnosis, risks and need) through to accessing a full assessment of social care (and other) need.</p> <p>Carers have an entitlement to an assessment and good quality advice nary comprehensive assessment of need</p>	<p>A clear and easily understood pathway to diagnosis, personalised needs assessment and support</p> <p>The construction of person centred plans following positive diagnosis with the aim of wrapping services around the individual rather than the condition.</p>	<p>Develop a clear pathway following diagnosis (or transition to adult services) from health to social care and services which support independent living. The care pathways should include liaison with other agencies such as housing, further education and employment.</p> <p>Ensure that a range of services and support can be accessed by people with autism and that opportunities for employment and housing are expanded, challenging the current high levels of social exclusion.</p>	<p>5. There is a named lead clinician.</p> <p>6. Diagnostic, assessment and information based services will operate at standards in line with NICE guidelines on best practice.</p> <p>7. All relevant local organisations including primary care staff and social care teams will be aware of the pathway.</p> <p>8. Diagnostic waiting times will have reduced from nearly 12months at present to 4 weeks.</p>	<p>County Council and PCT working in partnership with 2gether mental health Trust</p>	<p>From April 2013</p> <p>By Dec 2014</p> <p>By Dec 2013</p> <p>By April 2014</p>
IMPROVED TRANSITION			<p>9. There will be clear protocols to ensure;</p> <p>a) young people with autism approaching transition are contacted by adult social care</p>	County Council and PCT	By Sept 2013

<p>with autism.</p> <p>The joint commissioner should ensure that mental health providers (adult and children) are able to identify and report on their clients with ASC.</p> <p>The joint commissioner should also ensure that young people in receipt of CAMHS who do not meet adult mental health services criteria are offered appropriate support and information</p>	<p>adult social care under local eligibility criteria.</p>	<p>commissioning services to meet future demand.</p> <p>Agree clear protocols between CYP and Adult services to ensure smooth transition for young adults with autism</p>	<p>and offered an assessment and that carers are offered a carer's assessment as well</p> <p>b) Young people with ASC who are not eligible for adult social care and/or do not have a statement are signposted to other sources of support and information</p>		
<p>HELP INTO WORK</p> <p>In line with the NICE guidelines, consideration should be given to the commissioning an individual supported employment programme for adults with autism without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment.</p> <p>Develop and disseminate a resource guide for employers providing practical advice and support for employing and working with people with ASC, highlighting the positive attributes that many people with ASC can offer an employer. An existing source of information for employers is "Untapped Talent: A guide to employing people with</p>	<p>Adults with autism in Gloucestershire are helped into work and that employers make reasonable adjustments to accommodate their needs when in employment.</p>	<p>Develop new approaches that ensure adults with autism benefit from wider employment initiatives.</p> <p>Promote awareness of autism amongst private sector employers</p>	<p>10. There will be an ASC supported employment programme which will include carefully matching adults with autism with the job and advice to employers about making reasonable adjustments to the workplace</p> <p>There will be continuing support for the person after they start work and support for the employer before and after the person starts work, including autism awareness training.</p> <p>11. There will be autism resource guides for employers.</p>	<p>Job Centre Plus</p>	<p>From April 2014</p>

Autism" a leaflet developed for employers by the Department of Work and Pensions and the National Autistic Society (DWP/NAS 2012).					
PLANNING and INFORMATION on NEED Improve the data recorded by all relevant services on Gloucestershire residents with an autistic spectrum condition. Data should be collected according to the recommendations made in <i>Implementing Rewarding and Fulfilling Lives</i> . Ensure that information collected on adults with ASC in Gloucestershire is included in the Joint Strategic Needs Assessment (JSNA) and that it is used to inform the planning and commissioning of services. The terms of reference of Gloucestershire's ASC Partnership Board should be clarified to make it clear that the board is responsible for commissioning services for all adults with ASC in Gloucestershire. The board should also review the scope of its work in line with the recommendations in the latest NICE guidelines. Develop annual commissioning plans for people with autism. This should include a	Local partners in Gloucestershire working together to plan and develop appropriate services for adults with autism to meet identified needs and priorities. Adults with autism and their carers want to be involved in the design and delivery of local services	Agree a data capture strategy. Ensure a planned, prioritised and open approach to commissioning of services for adults with autism making use of better information about the autistic population, unmet needs and gaps in support. Through ongoing consultation identify and analyse significant pinch points in the autism life	12. Gloucestershire's JSNA will include data on autism collected according to the guidelines in the national autism strategy 13. All public services will identify and code service users with an autistic spectrum condition. 14. There will be a system of annual review which will include service user and carer satisfaction with services and benchmarking information against similar local authority areas 15. There will be an Autism Partnership Board with an all spectrum remit, representation from adults with autism and their carers plus all relevant agencies. 16. The economic costs of autism are quantified and measured to be falling on a per capita basis.	County Council and PCT All agencies represented on ASCPB County Council ASCPB County Council and PCT ANG and the NAS branch supported by	By Jan 2013 By June 2015 From April 2014 From July 2013 March 2014 By Dec 2016

<p>range of services in line with NICE guidelines, including psychosocial interventions and employment support, related to key points in the autism life cycle where appropriate.</p>		<p>cycle where preventative action can reap greatest reward for the individual and in terms of cost savings to agencies (see Life Cycle model at Appendix 5).</p> <p>Agencies will work with stakeholder groups like the Autism Network Group to help develop low level support to counter social isolation.</p>	<p>17. A social inclusion framework such as self help social groups, befriending schemes, drop ins will operate in each of the 6 districts in the county.</p>	<p>wider voluntary sector</p>	
<p>CHOICE AND CONTROL OVER WHERE TO LIVE</p> <p>The ongoing lack of safe, suitable affordable housing was identified as a key priority by adults with ASC and parents who are members of Gloucestershire's autism network group. Living in private shared housing was seen as stressful and unsafe for people with ASC and some people reported living in housing that is more expensive than their housing allowance. Other adults remain at home with their parents, with uncertainty about what will happen when their parents can no longer support them. We do not have figures on the housing needs of adults with ASC in Gloucestershire. However, according to the National Autistic Society, over 40% of</p>	<p>Many adults with autism want to be less dependent on their families and to live more independently buy with support</p>	<p>Ensure the needs of adults with autism are integrated into accommodation strategies and plans for vulnerable adults</p>	<p>18 Individuals with autism will be systematically recorded on housing databases</p> <p>19 The housing needs of adults with autism will be represented at the county Advice and Inclusion group for vulnerable adults.</p> <p>20 Housing officers and registered social landlords will have completed awareness training and be aware of housing design advice in relation to the independent living needs of adults with autism</p>	<p>District Councils</p>	<p>From April 2013</p> <p>From Jan 2013</p> <p>By Dec 2014</p>

adults with autism live at home with their parents(National Autistic Society 2008).					
RANGE OF SUPPORTING SERVICES There is no evidence that adults with autism have a higher rate of offending, however the experience of adults with autism in the criminal justice system, whether as victims, witnesses, or suspects of crime can be additionally difficult compared with neuro typicals.			21 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. 22 There will be data about the number and needs of people with autism in contact with the main elements of the criminal justice system, - custody - Crown Prosecution Service - Courts - Probation and Prisons 23 High quality advice, guidance and student support for adults with autism will be available in all the FE Colleges and the University in Gloucestershire	Police Each agency in the CJ system FE and HE institutions	By Dec 2015 By Dec 2015 By Sept 2014
Further and Higher education institutions need to make reasonable adjustments to ensure adults with autism can progress in their training/education.	Additional support in the transition from home life to University life				

GLOSSARY

ADHD	Attention Deficit Hyperactivity Disorder
ALD	Adults with Learning Disabilities
ANG	Autism Network Group
ASC	Autistic Spectrum Condition
ASCPB	Autistic Spectrum Condition Partnership Board
AS	Aspergers syndrome
CSO	Customer Service Operators
DOH	Department of Health
HMSO	Her Majesty's Stationery Office
JSNA	Joint Strategic Needs Assessment
LDO	Learning Disability Observatory
NAS	The National Autistic Society
NHS	National Health Service
NICE	National Institute for Clinical Excellence
PANSI	Protecting Adult Needs and Services Information
SEN	Special Educational Needs