

# Adults with autistic spectrum conditions needs assessment

# Content

1. Executive summary .....	3
2. Summary of recommendations .....	7
3. Introduction .....	13
Policy context.....	13
Needs Assessment .....	13
Aims .....	14
Scope.....	14
Methodology.....	15
Autistic Spectrum Conditions.....	16
4. The prevalence of autistic spectrum conditions in Gloucestershire.....	18
5. Increasing awareness and understanding of autism amongst frontline professionals .....	25
6. Transition from children’s to adult services .....	33
7. Identification and diagnosis of autism in adults leading to an assessment of need for relevant services.....	42
8. Helping adults with autism get into and stay in work .....	56
9. Local planning and leadership in relation to the provision of services for adults with autism ....	61
Appendix 1 – potential local information on people with ASC and services. ....	73
Appendix 2 – Gloucestershire autism awareness training .....	74
Appendix 3 – survey of parents/carers in relation to transition.....	75
Appendix 4 – Gloucestershire Social services helpdesk enquiry form .....	77
Appendix 6 - NICE recommendations in relation to the development of care pathways .....	82
Appendix 7 - NICE recommendations in relation to psychosocial interventions for people with core symptoms of autism .....	85
References .....	87

# 1. Executive summary

Autistic Spectrum Conditions (ASC) are complex lifelong developmental conditions. The common areas of difficulty experienced by all people with ASC are often described as a 'triad of impairments'.

These are:

- Difficulty with social communication, particularly using and understanding facial expressions, gestures, tone of voice and verbal and non-verbal language.
- Difficulty with social interaction such as recognising or understanding other people's emotions and feelings, and expressing their own, making it more difficult to fit in socially.
- Difficulty with social imagination such as understanding and predicting other people's behaviour, making sense of abstract ideas, and imagining situations outside their immediate daily routine.

In recent years there have been a number of national developments relating to adults with ASC. 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 2010b) place a statutory duty on the NHS and Local Authorities to ensure that services are in place to meet the needs of people with autistic spectrum conditions. In June 2012, the National Institute for Clinical Excellence (NICE) also issued guidelines on autism in adults (National Institute for Health and Clinical Excellence 2012)

It is challenging getting an accurate figure on how many adults have an autistic spectrum condition in Gloucestershire for a number of reasons. Often information from relevant service providers contains partial/incomplete data which are also held on different systems in different formats. An estimate of numbers can be made however based on national population based studies. These suggest that there may be up to 5,165 adults with ASC in Gloucestershire (including both diagnosed and undiagnosed individuals). It is also estimated that Gloucestershire may have up to 2,892 adults with ASC and a learning disability.

This lack of comprehensive data makes it difficult to effectively plan and deliver the services that are needed for people with ASC and their carers. The current changes to the process for developing the Joint Strategic Needs Assessment (an assessment of the health needs of the local which informs

commissioning of services) provide an opportunity to address this. However, the first step is for services to collect data on people with ASC where possible.

Gloucestershire has had a programme of autism awareness training in place since 2007 and more than 800 people from a wide variety of agencies have received training. However, a more strategic and coordinated approach needs to be taken to fill the evident gaps in training coverage such as training for primary care staff, prison officers, social care helpdesk operators and social care planners. The impact of the training programme on the lives of adults with autism also needs to be evaluated.

Assessing the effectiveness of transition planning for children and young people with ASC highlighted a number of issues and challenges. There is difficulty in accurately assessing the appropriateness or adequacy of transition planning for this cohort as relevant ASC-specific information is not routinely collected or recorded across the transition process. The need to ensure that this is rectified is underscored by the evident increase in recent years in the number of young people with a statement of special educational needs for ASC in Gloucestershire. There is a transition pathway for children with such statements in place in Gloucestershire which highlights the importance of adult social care representation at transition reviews; however feedback from parents of young people with ASC and professionals involved in supporting young people through transition suggests that the transition pathway has not been implemented in a consistent manner and that representation from adult social care at transition reviews was not always a given. A key recent development is the appointment of two Transition Coordinators with the remit of ensuring a timely and effective transition to adult services for young people with disabilities. This has resulted in appreciable improvement of the transition process in relation to adult social care engagement. Where children and young people are appropriately assessed, issues include the lack of on-going support post-transition for those who do not meet the eligibility criteria for adult social care which are set at a high level of need. There is also no evidence that young people with ASC in receipt of child and adolescent mental health services who do not meet the referral criteria for adult mental health services are informed of their right to a social care assessment or signposted to other sources of support and information.

There is currently no formal commissioned diagnostic and assessment service for ASC in Gloucestershire. Diagnostic assessments are spot purchased from the local mental health trust, and some professionals and families of people with ASC are unaware of how to access a diagnostic

assessment. Current waiting times for a diagnostic assessment in Gloucestershire are up to a year. Diagnostic assessments are not currently carried out as part of a comprehensive assessment of need as recommended by the National Institute for Clinical Excellence (National Institute for Health and Clinical Excellence 2012). Furthermore, diagnosis does not result in a referral for a comprehensive assessment of social care need, with the result that many adults with diagnosed autism do not receive an assessment of their needs.

Evidence suggests that there are very few services post-diagnosis and a lack of practical support for people with autism relevant to their needs, particularly for people who fall between Learning Disability and Mental Health services. Adults with autism and their parents/carers in Gloucestershire report that there is very little support post-diagnosis. People with autism and a learning disability are able to access learning disability services; however the extent to which these services take into account ASC and support people with their specific difficulties is not clear and it should be not assumed that learning disability services automatically meet all the needs of people with autism who have an accompanying learning disability.

The vast majority of people with ASC who currently access adult social care have a learning disability. It is unlikely that people with higher functioning autism or a mild learning disability would qualify for social care according to the criteria adopted by Gloucestershire under *Fair Access to Care Services* (Department of Health 2010d) even if they were able to access a social care assessment.

There are no specific employment services for people with ASC in Gloucestershire. Nationally it is estimated that only 15% of adults with ASC are in employment. There is little local data on the numbers of adults with ASC in Gloucestershire who require employment support, and people with ASC and their families report that employment and training opportunities for people with ASC are limited. Job Centre Plus Disability Support Advisors have however received autism awareness training which is helping them provide 'reasonable adjustment' for their clients with ASC. The National Institute for Health and Clinical Excellence has provided evidence to suggest that supported employment programmes for adults with autism are cost effective and provide both social and economic benefits (National Institute for Health and Clinical Excellence 2012). Adults with ASC in Gloucestershire would benefit from the support that such a programme would provide.

There is commitment within Gloucestershire to improving the lives of people with ASC and a real desire for change. Gloucestershire has had an Autistic Spectrum Conditions Partnership Board in

place since 2006. The board was initially set up to address the needs of people with higher functioning autism as it was felt that this group lacked services and were therefore the priority. However, there are plans to extend the scope of the board to cover adults across the autistic spectrum, including those with learning disabilities.

Gloucestershire has not yet developed a formal commissioning plan for adults with ASC. Given the statutory obligation to develop commissioning plans outlined in *Implementing Fulfilling and Rewarding Lives* (Department of Health 2010c), a timeframe should be developed for drawing this up. The forthcoming Gloucestershire autism strategy should be accompanied by a commissioning plan that is informed by the recommendations of this needs assessment.

A number of recommendations have been made to improve how Gloucestershire meets the needs of adults with ASC and to ensure Gloucestershire complies with legislation and national policy. Improving the support for people with ASC will not only be of huge benefit to the individuals and their families but will also potentially provide cost savings in the long-term.

## 2. Summary of recommendations

1. 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 *Implementing Fulfilling and Rewarding Lives*. Where data is not already collected, the relevant services need to identify and code service users as having an autistic spectrum condition.

The recommended data that should be collected is

- i. Information on the need for appropriate services, including:
    - The number of adults known to have autism in Gloucestershire
    - The range of need for support to live independently
    - The age profile of people with autism including those approaching 65 and the number of children approaching adulthood to enable partners to predict how need and numbers will change over time.
  - ii. The number of adults with autism who are:
    - In employment
    - Likely to need employment support in order to work
    - Placed in the area by (and funded by) other local authorities
    - Placed out of area by local authorities
    - In hospital or living in other NHS-funded accommodation
    - Resettled from long-stay beds or NHS residential campuses to community provision
    - Living at home on their own, or with family members, and not receiving health or social care services
    - Living with older family carers
  - iii. The ethnicity, gender, religion or belief and sexual orientation of adults with autism so that local authorities and NHS bodies can understand the number of people from different backgrounds with autism.
2. Ensure that the current estimates and any further 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 future planning and commissioning of services.

3. If possible, a refresh of this needs assessment should be conducted in five years' time to update the data and assess unmet need as well as to evaluate the following:
  - Improvement in data recording and accuracy/reliability of local data
  - The proportion of people with ASC being appropriately supported by services
  - Improvement in service user and carer satisfaction with services
  - How Gloucestershire benchmarks against similar local authority areas
4. As part of a robust training needs assessment, the ASC Partnership board should carry out an evaluation of the training already carried out in terms of:
  - Coverage of key groups and whether training has been delivered at the appropriate level.
  - What gaps remain in training coverage compared to statutory guidance
  - Satisfaction with content and delivery of the training programme
  - What has changed for adults with ASC and their families as a result of the training
5. To further develop existing autism awareness training, a multi-agency workforce development strategy should be developed to ensure that all staff working with people across the autistic spectrum received autism awareness training at the appropriate level and on an ongoing basis. Adults with ASC, their families and carers and ASC representative groups should be involved in the planning and delivery of training. Those staff who are most likely to have contacts with adults with ASC (such as primary care staff and social care assessors) should be the priority groups for training.
6. The Lead Commissioner for ASC should explore appropriate ways of ensuring the ongoing development and delivery of the autism awareness training programme
7. Establish local practice development leads and/or autism awareness champions to promote uptake of training amongst priority groups and to ensure that the investment in training and development leads to behaviour change.
8. 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 through on-line dedicated computer based training such as the Royal College of



General Practitioners e-learning course for general practitioners and other primary care professionals which is aimed at improving professional standards relating to the care of people with ASC and their families.

9. 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.
10. Assess if and how Gloucestershire is meeting the transition requirements through exploration of data collection on how the transition process is working for young people with ASC, ie
  - for young people with ASC, in how many cases
    - was information passed to adult social care
    - were transition meetings attended by a representative from adult social care
    - was a social care assessment offered/carried out
    - was a carer's assessment offered/carried out.
  - What information/support was provided to young people who were eligible for adult social care
11. Develop protocols to ensure 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 ASC 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.
  - The Joint Commissioner should ensure that mental health providers (adult and children) are able to identify and report on their clients with ASC
  - 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

12. The Joint Commissioner should ensure that diagnostic and assessment services are developed in Gloucestershire.
13. The Joint Commissioner should ensure the review of Gloucestershire's diagnostic processes and services against the best practice published in the recent NICE guidelines on the recognition, referral, diagnosis and management of adults on the autistic spectrum (National Institute for Health and Clinical Excellence 2012). This should also consider the inclusion of appropriate and accessible management modalities/interventions for the core symptoms of autism.
14. As recommended by NICE, the ASC Partnership Board should ensure that all families, partners and carers are provided with verbal and written information about:
- Autistic spectrum conditions and their management
  - local support groups and services specifically for families, partners and carers
  - their right to a formal carer's assessment of their own physical and mental health needs, and how to access this.
15. A clear pathway should be developed in Gloucestershire covering initial referral for suspected autism, a multi-disciplinary comprehensive assessment of need (covering diagnosis, risks and need) through to accessing a full assessment of social care (and other) need. All relevant local organisations including primary care staff and social care teams need to be made aware of this pathway once it is developed.
16. In order to ensure that adults with ASC are able to access an assessment of their care needs, the following steps need to be part of the diagnostic pathway:
- Following a diagnosis of ASC, the attending clinician should, with the individual's consent, promptly inform Gloucestershire County Council adult services department to ensure that a community care assessment is carried out within a reasonable time (if the individual wants such an assessment). In addition, the healthcare professionals making a diagnosis should inform the adult diagnosed and their carers that they have the right to request such an assessment.

- The social care department should then contact the adults with ASC and their carers to inform them of their right to a carer's assessment
17. All Gloucestershire GPs should be made aware of NICE's recommendations on the assessment of suspected ASC (to be part of training in autism awareness)
  18. 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 specific needs of people with autism.
  19. In line with the NICE guidelines (National Institute for Health and Clinical Excellence 2012), consideration should be given to commissioning an individual supported employment programme for adults with ASC without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment. An individual supported employment programme should typically include:
    - help with writing CVs and job applications and preparing for interviews
    - training for the identified work role and work-related behaviours
    - carefully matching the person with autism with the job
    - advice to employers about making reasonable adjustments to the workplace
    - continuing support for the person after they start work
    - support for the employer before and after the person starts work, including autism awareness training
  20. 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 Autism*" a leaflet developed for employers (National Autistic Society & Department for Work and Pensions 2012).
  21. 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 (National Institute for Health and Clinical Excellence 2012).

22. Develop commissioning plans for people with ASC. This should include a range of services in line with NICE guidelines (National Institute for Health and Clinical Excellence 2012), including psychosocial interventions and employment support.

23. Develop clear pathway following diagnosis (or transition to adult services) from health to social care and services which support independent living. The care pathways should also include liaison with other agencies such as housing and employment agencies) as ASC has an impact on independent living.

### **3. Introduction**

#### ***Policy context***

In recent years there have been a number of national developments relating to adults with autistic spectrum conditions (ASC). The introduction of the Autism Act 2009 (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 2010b) place a statutory duty on the NHS and Local Authorities to ensure that services are in place to meet the needs of people with autistic spectrum conditions. The national autism strategy was accompanied by statutory guidance for health bodies and local authorities entitled *Implementing Fulfilling and Rewarding Lives* (Department of Health 2010c).

In 2009 the National Audit Office published a report *Supporting people with autism through adulthood* (National Audit Office 2009) which highlighted two key areas where the effectiveness of existing services can be improved; these were better strategy and planning based on good information and raising levels of knowledge and awareness about ASC. The Government's strategy for people with learning disabilities *Valuing People Now: a new three year strategy for people with learning disabilities* (Department of Health 2009) also highlighted that adults with ASC are some of the most excluded in society.

In June 2012, the National Institute for Health and Clinical Excellence (NICE) published *Clinical guidelines on the recognition, referral, diagnosis and management of adults on the autistic spectrum* (National Institute for Health and Clinical Excellence 2012). A key purpose of these guidelines is to provide evidence based recommendations to support the further implementation of the national autism strategy.

#### ***Needs Assessment***

This needs assessment has been undertaken at the request of Gloucestershire's Autistic Spectrum Conditions (ASC) Partnership Board. Its purpose is to inform Gloucestershire's forthcoming Autism Strategy.

Needs assessment is a systematic method of identifying the unmet needs of a population and making recommendations for changes to meet those needs. Need in health and social care is commonly defined as the capacity to benefit, i.e. if needs are identified there should be an effective intervention or service available to meet those needs.

## ***Aims***

Using the areas of focus identified in *Fulfilling and Rewarding lives: the strategy for adults with autism in England* (Department of Health 2010b), this needs assessment will inform the forthcoming Gloucestershire autism strategy by:

- Collecting information where available on the prevalence of autistic spectrum conditions in Gloucestershire
- Where possible, determining the number of people with ASC already in contact with services
- Comparing the provision of services for people with ASC in Gloucestershire against evidence and good practice described in national guidance
- Identifying gaps in services and unmet needs
- Determining priorities and making recommendations for change

## ***Scope***

This needs assessment focuses on assessing need for services in Gloucestershire for adults with autistic spectrum conditions and children in the transition from children's to adult services.

The scope of this needs assessment covers the five core areas of activity outlined in the national strategy for autism:

- Increasing awareness and understanding of autism amongst frontline professionals, delivered through the provision of training and information resources
- Developing a clear, consistent pathway for diagnosis of autism 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 get into and stay in work

- Enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities

## ***Methodology***

The needs assessment has been carried out by a Specialty Registrar in Public Health at NHS Gloucestershire. The needs assessment involved a combination of quantitative and qualitative methodologies, including epidemiological and corporate assessment of need for people in Gloucestershire with ASC

- Epidemiological needs assessment – this approach considers the prevalence of autistic spectrum conditions, how services are delivered and the evidence on what is effective
- Corporate needs assessment – this approach is based on eliciting the views of stakeholders including people with ASC, their families and carers and service providers concerning the current service provision

The assessment was done through:

- Collection and analysis of available data
- Review of relevant local documentation and other information
- Review of available services against national (and other) guidance
- Interviews with key stakeholders including service users and carers, the National Autistic Society, and representatives from health and social care (including commissioners and service providers) and other public services

Each chapter of this needs assessment also includes an analysis and discussion of the particular issues raised based on the information obtained with associated recommendations.

## ***Autistic Spectrum Conditions***

Autism is a lifelong developmental disability, sometimes referred to as Autistic Spectrum Condition (ASC). It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. For example, Asperger syndrome is a form of autism. People with Asperger syndrome typically have fewer problems with speaking than other people on the autistic spectrum but they do still experience difficulties with communication. Other people with ASC may have accompanying learning disabilities.

The autistic spectrum is very wide which means that how the 'symptoms' of ASC are presented can differ widely between individuals. However, there are areas of difficulty experienced by all people with ASC which are often described as a 'triad of impairments'. These are:

- Difficulty with social communication, particularly using and understanding facial expressions, gestures, tone of voice and verbal and non-verbal language.
- Difficulty with social interaction such as recognising or understanding other people's emotions and feelings, and expressing their own, making it more difficult to fit in socially.
- Difficulty with social imagination such as understanding and predicting other people's behaviour, making sense of abstract ideas, and imagining situations outside their immediate daily routine.

The causes of autism are still being investigated. Many experts believe that the pattern of behaviour from which autism is diagnosed may not result from a single cause. There is evidence from studies of twins and family genetics to suggest that genetic factors are responsible for some forms of autism. However, autism is likely to have multiple genes responsible rather than a single gene and the difficulty of establishing gene involvement is compounded by the interaction of genes with environmental factors (National Autistic Society 2012c).

There are a range of terms used to describe conditions on the autistic spectrum including autism, autistic spectrum disorder/conditions, high functioning autism and Asperger's or Asperger syndrome. The term 'high functioning autism' is often used to describe people with an IQ level of 70 or above, although this may be misleading as many people with ASC and an IQ of 70 or above may still experience significant difficulties with social interaction, social communication and behaviour



which may impact on their functioning. Furthermore, a small number of people with an ASC and IQ above 70 require intensive care and support, such as residential placements.

The terms Asperger syndrome and higher functioning autism are sometimes confused. People with higher functioning autism and Asperger syndrome are affected by the difficulties common to all people with autism (described above) and both groups are likely to be of average or above average intelligence. The main difference between the two is thought to be in language development: people with Asperger syndrome will typically not have had delayed language development when younger.

The forthcoming DSM-5 to be published in 2013 is expected to subsume all diagnostic categories into a single overarching diagnostic term of 'autistic spectrum disorder'. ICD (the International Classification of Diseases) version 11 which is commonly used in the UK will be published in 2015; however it is not clear whether the changes from DSM-5 will be replicated. In the UK some authors prefer to use the term 'autistic spectrum condition' because some people with autism see themselves as neurologically different but not necessarily suffering from a 'disorder'. For the purposes of this needs assessment, autism with an IQ of 70 or above (i.e. in the absence of a learning disability) will be referred to as having higher functioning autism. Autism with a learning disability will be used to describe people with autism and an IQ of below 70. The term autistic spectrum condition or ASC will be used to describe people across the autistic spectrum.

Autistic spectrum conditions have a significant economic impact due to its lifelong nature and the subsequent impact that the condition has on individuals, their families and carers. Management and support of people with ASC incurs substantial costs to families of individuals with ASC, health and social care services and to the wider public sector through provision of services and lost employment opportunities. It has been estimated that the annual cost of supporting adults with ASC amounted to £25 billion in 2005/6 prices. Of this cost, 59% is accounted for by services, 36% through lost employment and the remainder in expenses borne by the family (Knapp et al 2007 cited in (National Institute for Health and Clinical Excellence 2012). As the recently published NICE clinical guidelines state "the substantial society cost of autism in adults requires provision of effective interventions that will improve the quality of life of people with autism and their families, partners and carers and will reduce the costs borne to the health services, people with autism and their families and the wider society" (National Institute for Health and Clinical Excellence 2012).

## **4. The prevalence of autistic spectrum conditions in Gloucestershire**

The term 'prevalence' refers to the frequency of a health condition in a population at a particular point in time. It is not possible to provide an accurate figure on the current prevalence of autistic spectrum conditions (ASC) in Gloucestershire. There is no central database of adults with ASC in Gloucestershire as data is held on many different systems and most services do not routinely collect data on their clients with ASC or their carers. Furthermore, many adults with ASC, in particular those with higher functioning autism, are not receiving any specialist services or accessing support. However, there are epidemiological studies estimating the prevalence of ASC in the wider UK population and these can be applied to the local population to provide a local estimate.

A study of the prevalence of ASC in adults published in 2009 by the NHS Information Centre estimated national prevalence to be 1% (The NHS Information Centre for Health and Social Care 2009). Using this estimated prevalence figure of 1%, projections of the numbers of people age 18 – 64 in Gloucestershire estimated to have an autistic spectrum condition are available from the *Projecting Adult Needs and Service Information* (PANSI) database. These figures show that the number of people predicted to have ASC remains stable. The prevalence of ASC is far higher in males than females (Table 1 and Figure 1 below).

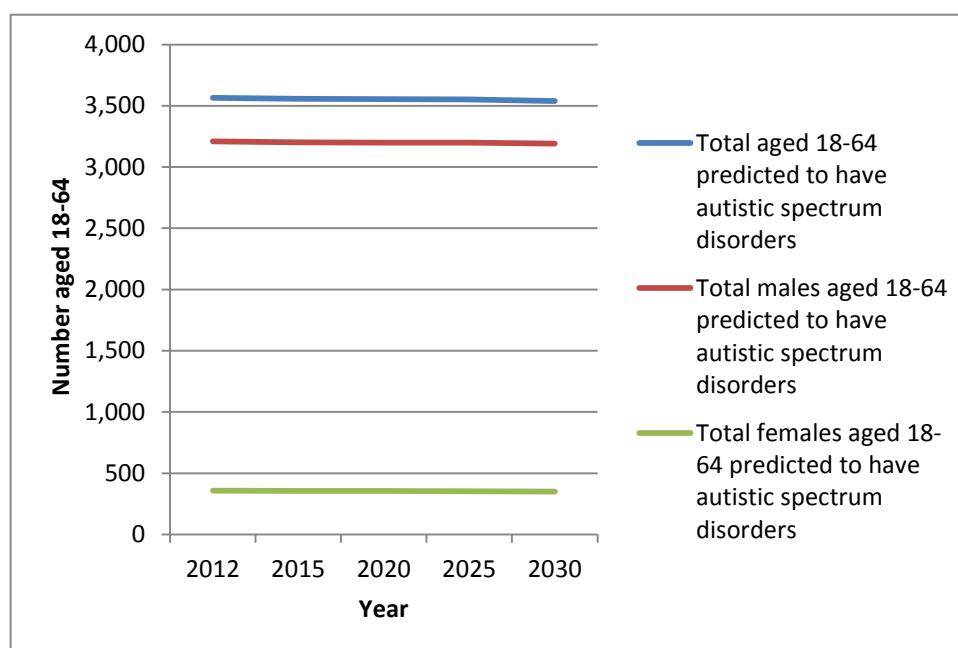
**Table 1 People in Gloucestershire aged 18-64 predicted to have autistic spectrum disorders, by age and gender, projected to 2030**

People aged 18-64 predicted to have autistic spectrum disorders, by age and gender,					
	2012	2015	2020	2025	2030
Males aged 18-24 predicted to have autistic	463	455	419	412	455
Males aged 25-34 predicted to have autistic	608	644	673	650	616
Males aged 35-44 predicted to have autistic	677	628	632	702	734
Males aged 45-54 predicted to have autistic	785	801	738	643	650
Males aged 55-64 predicted to have autistic	677	673	738	792	734
<b>Total males aged 18-64 predicted to have autistic</b>	<b>3,209</b>	<b>3,202</b>	<b>3,200</b>	<b>3,199</b>	<b>3,190</b>
Females aged 18-24 predicted to have autistic	48	47	44	44	48
Females aged 25-34 predicted to have autistic	62	65	68	66	63
Females aged 35-44 predicted to have autistic	78	73	69	74	77
Females aged 45-54 predicted to have autistic	91	94	87	76	73
Females aged 55-64 predicted to have autistic	77	78	87	94	88
<b>Total females aged 18-64 predicted to have</b>	<b>357</b>	<b>356</b>	<b>355</b>	<b>353</b>	<b>349</b>

Source: Projecting Adult Needs and Service Information System (PANSI)

<http://www.pansi.org.uk/index.php?pageNo=392&areaID=8640&loc=8640> (accessed on 24 July 2012)

**Figure 1 People in Gloucestershire aged 18-64 predicted to have autistic spectrum disorders, by age and gender, projected to 2030**



Source: Projecting Adult Needs and Service Information System (PANSI)

<http://www.pansi.org.uk/index.php?pageNo=392&areaID=8640&loc=8640> (accessed on 24 July 2012)

Since the publication of their initial report in 2009, the NHS Information Centre has published a further report with a revised estimate of the prevalence of ASC in adults of 1.1% (The NHS Information Centre for Health and Social Care 2012). The prevalence estimate was revised because the original study did not include a wide range of institutional establishments which limited the conclusions about the prevalence of ASC amongst people with learning disabilities.

The adult population (18+) in Gloucestershire is estimated to be 469,573 (ONS Mid-Year Estimates 2010). Using the revised prevalence rate of 1.1% this would mean that approximately 5,165 adults aged 18+ in Gloucestershire have ASC.

This figure includes both diagnosed and undiagnosed individuals; research suggests that for every three known cases, there are two undiagnosed individuals who might need a diagnosis at some point in their lives (Baron-Cohen et al 2009 cited in (National Institute for Health and Clinical Excellence 2012).

Further information on people with suspected ASC may also be held on GP databases. This would only reflect those cases where a GP is either aware of a diagnosis of ASC or suspects that the patient has ASC and marks this on the patient's record. Such information which would add to our current knowledge about the number of people with ASC in Gloucestershire is not currently easily accessible as it would require a separate search of all GP databases. However, it is hoped that this information can be collected from GPs in Gloucestershire later in 2012 as part of an audit of GP data on learning disabilities which will include autistic spectrum conditions.

In addition to the overall prevalence of ASC, it is useful to estimate the number of people with ASC who have an accompanying learning disability, those without a learning disability and those with other conditions. This is relevant because the needs of different groups across the autistic spectrum may differ, as will services provided. A particular issue acknowledged in *Fulfilling and Rewarding Lives* (Department of Health 2010b) is that people with higher functioning autism may be missing out with regard to accessing services because they don't tick either the learning disability or mental health 'box'.

The Learning Disability Observatory (LDO) estimates that between 20% and 33% of adults with a learning disability also have an autistic spectrum condition (Learning Disability Observatory 2010). It is not possible to get accurate figures on the total number of people in Gloucestershire with a learning disability as only a minority of people with less severe learning disabilities are known to services (Learning Disability Observatory 2012). However, using population estimates, the LDO

estimates that the total number of people with learning disabilities in Gloucestershire to be 11, 787 (Learning Disability Observatory 2012). Applying the LDO estimates of the prevalence of ASC to the 11,787 people with learning disabilities in Gloucestershire, the number of people in Gloucestershire with learning disabilities who also have ASC would be between 2,357 (20%) and 3,890 (33%). It is also estimated that 56% of people with ASC have a learning disability (Baird et al 2006 cited in (National Institute for Health and Clinical Excellence 2012). Applying this figure to the 5,165 adults estimated to have ASC in Gloucestershire would mean that approximately 2,892 adults with ASC also have a learning disability in Gloucestershire.

Evidence also suggests that people with an ASC are particularly vulnerable to mental health problems(National Autistic Society 2012b). Emotional difficulties such as social anxiety disorder or depression are common in people with ASC and are usually seen as secondary to the ASC. This is because ASC often develops first and can cause social difficulties including social isolation, which can then give rise to anxiety and depression(National Institute for Health and Clinical Excellence 2012). Mental health problems cover a wide range of conditions/diagnoses and it is difficult getting information on the prevalence of mental health problems in people with ASC. However, there is some evidence from the national charity Research Autism(Research Autism 2012) that:

- 84.1% of children with ASC met the full criteria of at least one anxiety disorder.
- 1 in 15 people with Asperger syndrome experience depression
- 8% of children with Asperger syndrome and 10% of children with high-functioning autism were diagnosed with OCD.

### **Analysis/discussion**

There are an estimated 5,165 adults with autistic spectrum conditions in Gloucestershire. Of these it is estimated that 3,539 are of working age (3,190 men and 349 women) and approximately 2,892 have an accompanying learning disability.

The current lack of comprehensive data on the numbers of people with ASC in Gloucestershire impacts on the ability to accurately plan and deliver the services that are needed for people with ASC and their carers, although prevalence estimates, which give an indication of the total number of people with ASC in the county, can be useful. *Implementing Fulfilling and Rewarding Lives* (Department of Health 2010c) included a list of the data items that local authorities and health bodies should collect – this is contained in Appendix 1 and recommendation 2 below.

A key priority for Gloucestershire's ASC Partnership Board is to enable the development of the systems to accurately capture and record the numbers of adults with ASC in the county. The Board may wish to focus on those areas where data is lacking and where a need has been identified such as:

- the range of need for support to live independently
- the number of adults with ASC who are likely to need employment support in order to work
- the number living at home on their own or with family members and not receiving health or social care services and
- the number living with older family carers.

Some of this recommended data items may already be held or can be estimated from national studies in the absence of local figures. For example:

- The number of children with ASC who have statements of special educational need (SEN) or who are at 'school action plus' is available from the Gloucestershire County Council's SEN database. There are currently 56 pupils in year 11 with ASC. Further details are contained in Chapter 6.
- The number of adults with autism who are in employment – a survey by the National Autistic Society found that only 12% of non-learning disabled adults with autism are in full-time employment (Barnard et al 2001 cited in (National Institute for Health and Clinical Excellence 2012). Applied to the estimated 2273 non-learning disabled adults with autism in Gloucestershire, up to 2000 (88%) of these adults may not be in full time employment
- The number of adults with autism living at home on their own, or with family members – it is estimated that 79% of non-learning disabled adults with ASC live in private accommodation, 5% live in supported accommodation, and 16% live in residential care (Knapp et al 2007 cited in (National Institute for Health and Clinical Excellence 2012). Applied to the estimated 2273 non-learning disabled adults with ASC in Gloucestershire, 1796 may be living in private accommodation, 114 in supported accommodation and 364 in residential care.

The statutory guidance *Implementing Fulfilling and Rewarding Lives* (Department of Health 2010c) recommends that service planning and provision locally should reflect local needs and priorities, generally identified through the Joint Strategic Needs Assessment (JSNA). The guidance recommends that local partners should include information about numbers of adults with ASC in their area in the JSNA. At the moment, there is no information on adults with ASC contained within Gloucestershire's JSNA. The current refresh of the JSNA in Gloucestershire provides an opportunity to add estimates of figures. However, accurate data can only be included in the JSNA if it is available. Addressing the lack of data on adults with ASC collected at service level is therefore a key priority.

### **Recommendations**

1. 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 *Implementing Fulfilling and Rewarding Lives (Department of Health 2010c)*. Where data is not already collected, the relevant services need to identify and code service users as having an autistic spectrum condition.

The recommended data that should be collected is

- i. Information on the need for appropriate services, including:
  - The number of adults known to have autism in Gloucestershire
  - The range of need for support to live independently
  - The age profile of people with autism including those approaching 65 and the number of children approaching adulthood to enable partners to predict how need and numbers will change over time.
- ii. The number of adults with autism who are:
  - In employment
  - Likely to need employment support in order to work
  - Placed in the area by (and funded by) other local authorities
  - Placed out of area by local authorities
  - In hospital or living in other NHS-funded accommodation
  - Resettled from long-stay beds or NHS residential campuses to community provision
  - Living at home on their own, or with family members, and not receiving health or social care services
  - Living with older family carers

- iii. The ethnicity, gender, religion or belief and sexual orientation of adults with autism so that local authorities and NHS bodies can understand the number of people from different backgrounds with autism.
2. Ensure that the current estimates and any further 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 future planning and commissioning of services.
3. If possible, a refresh of this needs assessment should be conducted in five years' time to update the data and assess unmet need as well as to evaluate the following:
  - Improvement in data recording and accuracy/reliability of local data
  - The proportion of people with ASC being appropriately supported by services
  - Improvement in service user and carer satisfaction with services
  - How Gloucestershire benchmarks against similar local authority areas



## 5. Increasing awareness and understanding of autism amongst frontline professionals

### What is the evidence/good practice?

Many of the problems that adults with ASC experience stem from poor understanding of autism amongst frontline professionals. The national autism strategy *Fulfilling and Rewarding Lives* (Department of Health 2010b) acknowledges that while most frontline professionals know something about ASC, they do not necessarily understand how ASC affects people. This can make it hard for professionals to recognise ASC, to communicate effectively and to adapt their behaviour and services appropriately.

The national autism strategy makes it clear that local authorities, NHS bodies and NHS Foundation Trusts should aim to make autism awareness training available to all staff working in health and social care. As a minimum, autism awareness training should be included within general equality and diversity training programmes across all public services. This is not just good practice – all public services have a duty under the Equality Act 2010 to make reasonable adjustments for disabled people, including adults with autism.

The core aims of autism awareness training should be to enable staff to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour, communication and services. Staff who are most likely to have contact with adults with autism should be the priority groups for training.

In addition to general autism awareness training, local areas should develop or provide specialist training for those staff in key roles that have a direct impact on access to services for adults with ASC (e.g. GPs or community care assessors) and those whose career pathways focus on working with adults with ASC (e.g. personal assistants, occupational therapists or residential care workers). The end goal should be to have some staff with clear expertise in ASC in each area.

The guidance document *Good practice in supporting adults with autism: guidance for commissioners and statutory service* (National Autistic Society 2009) identifies the key groups of professionals to whom autism awareness training should be targeted. These are:

- Health service practitioners (e.g. GPs, community psychiatric nurses, occupational therapists)
- Social care staff (e.g. social workers, managers, community teams, assessors)
- Further education staff (e.g. lecturers, learning support staff)
- Employment (e.g. disability employment advisors, Connexions staff, employers)
- The criminal justice system (e.g. police officers, prison officers)

The recently published NICE guidelines on the recognition, referral, diagnosis and management of adults on the autistic spectrum (National Institute for Health and Clinical Excellence 2012) acknowledge that the limited level of training in and knowledge of ASC amongst primary and secondary care professionals needs specific attention if the recommendations in the guidelines are to be of real benefit.

*Implementing Fulfilling and Rewarding Lives* (Department of Health 2010c) makes it clear that autism training must lead not only to improved knowledge and understanding but also to changing the behaviour and attitudes of health and social care staff and that training should reflect the actual situations that staff work in.

A number of professional organisations have issued guidance to support training in autism awareness. For example, the Department of Health has developed a handbook for professionals in the criminal justice system working with offenders with learning disabilities which includes information on autism and Asperger syndrome (Department of Health 2011). The Royal College of General Practitioners has also developed an e-learning course 'Autism in general practice' (Royal College of General Practitioners 2012).

### **What is happening in Gloucestershire?**

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. Generalist (level 1 training) consists of a half day basic autism awareness course aimed at frontline professionals likely to come into contact with people with autism. Specialist (level 2) training is a full day aimed at specialists who are most likely to have an impact on services for adults with autism. Details of level 1 and level 2 training are contained in Appendix 2.

A county-wide approach to training was agreed by the Training Subgroup of the Autistic Spectrum Conditions Partnership Board to ensure a consistent standard across different training providers. The training has been developed and delivered by Gloucestershire County Council (GCC) and 2gether NHS Foundation Trust in conjunction with the National Autistic Society. Level 1 training provided by GCC is aimed at frontline staff from social care, further education and employment support. Level 2 training is aimed at team managers, social workers, fieldwork support staff and care managers supporting individuals with ASC and undertaking assessments of need.

The level 1 training run by 2gether NHS Foundation Trust has been delivered to private care home staff who work with adults with ASC, such as staff of Brandon Trust and Home Farm Trust, in addition to front line staff within 2gether for example as part of specific unit staff induction programmes. The training is available to any care home staff who have residents accessing services from 2gether's Community Learning Disabilities Team. Level 2 training run by 2gether is aimed at clinical staff from the Trust (such as crisis teams, assertive outreach teams, and allied health professionals) to help them understand how to adapt their interventions to meet the needs of people with ASC and what strategies to use. All level 1 and level 2 training has been developed in conjunction with the National Autistic Society. Some staff have also sought individual consultations with the clinicians leading autism training regarding specific patients on their caseloads.

The Gloucestershire autism awareness training programme was initially aimed at raising awareness of higher functioning autism as this was identified as a priority and early training sessions focussed on the needs of this group. However, since the publication of the national autism strategy, training has been extended to cover people across the autistic spectrum.

Training is targeted at those groups more likely to have contact with people with ASC. It is heartening to note that on some occasions training has been delivered in response to an invitation from public services. The autism awareness training delivered to Gloucestershire Constabulary at their request (as part of their response to Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system) part fulfils the requirements to include staff of the criminal justice system in training.

To date, more than 800 people have attended autism awareness training (both levels) laid on by either Gloucestershire County Council or 2gether NHS Foundation Trust. An example of good

practice to be commended is the involvement of a local service user in the planning and developing the training programmes. Table 2 below gives a breakdown of the numbers who have attended training so far:

**Table 2 – autism awareness training delivered in Gloucestershire 2009-2012**

Level 1 training delivered		Level 2 training delivered	
Target group	Numbers	Target group	Numbers
Multi agency	158	Employment support agencies	16
Employment support agencies	16	Job Centre Plus Disability Employment Advisors	14
Gloucestershire College	30	Further and Higher Education	28
Hartpury College	3	2gether NHS Foundation Trust clinicians	250+*
Gloucestershire Police	100+*	GCC (social workers)	27
2gether NHS Foundation Trust mental health trust frontline workers	120+*	Connexions	20
Youth Offending Team and Family Support	16	Advocates (vulnerable adults)	20
<b>Total</b>	<b>443*</b>	<b>Total</b>	<b>375*</b>

\* Exact figures not available

Source: Gloucestershire County Council/2gether NHS Foundation Trust

An autism e-learning package developed by health and social care e-learning specialists KWANGO with service user involvement was also launched at the end of 2011. This package is accessible to anyone who wants to use it. The e-learning package is published through Gloucestershire County Council's e-learning brochure. To date, this has been accessed by 72 people, primarily from GCC, 2gether NHS Foundation Trust and the learning disability independent sector.

Autism awareness is not included in the equality and diversity training of NHS Gloucestershire, 2gether NHS Foundation Trust or Gloucestershire County Council. A PowerPoint presentation on autism has been developed by the training and development manager which has been shared with Gloucestershire County Councils' HR department with the view to it being incorporated into general

induction materials. However, due to stagnant recruitment at GCC, this has not yet been included in any induction sessions. Autism is not included in the corporate induction training at 2gether NHS Foundation Trust but it is included in the induction for learning disability staff.

### **Analysis of unmet needs**

Gloucestershire has made an excellent start on delivering autism awareness training and this is a key achievement of the ASC Partnership Board. 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 and Connexions staff. A county wide training programme has been developed with the involvement of a local service user and in conjunction with the National Autistic Society.

However, there are still major gaps in training coverage both at generalist and specialist level. For example there has been no autism awareness training delivered to primary care staff. This has been acknowledged as a key priority for the future by those involved in delivering training and by parents of adults with ASC as many GPs in Gloucestershire are unaware of how to recognise ASC or the pathway to diagnosis. Other gaps include prison officers, social care helpdesk operators (who undertake the initial screening for social care) and social care support planners (who work in GCC's learning disability service and support the individual planning of personalised budgets following a social care assessment).

Furthermore, 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. Uptake of level 2 training targeted at GCC social workers has proved disappointing and several courses have had to be cancelled. Discussions with staff involved in delivering autism awareness training indicate that this is due to reluctance of managers to release staff due to the difficulty of providing cover arrangements. Given the importance of social care staff understanding issues relating to ASC, it is important this is addressed.

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 ASC and their families/carers.

Discussions with staff involved in delivering Gloucestershire's autism awareness training programme indicate that the future resourcing of the programme is uncertain. Gloucestershire County Council is going through a restructure and the role of GCC's Workforce Development Manager has been altered with the postholder no longer having the capacity to lead on workforce development across different agencies, although the role will continue to support GCC's own workforce needs for autism training.

Members of Gloucestershire's ASC Partnership board recognise that the training programme needs to be further developed. A training update presented to the ASC board by GCC Workforce Development Manager in February 2011 stated that "Gloucestershire has made progress towards meeting training needs but we have patchy take up of training, no real evidence of any impact this may have had on practice and no local commissioning expectations on providers to undertake such training. This has left us in a weak position to implement a co-ordinated and prioritised training and development strategy for the country. With a strong commissioning lead and some dedicated workforce development resources, we could build on our current work....to develop and implement a multi-agency strategy for Gloucestershire".

The report also outlined recommendations for taking forward autism awareness training in Gloucestershire including:

- Developing a current approach to achieve an integrated workforce strategy for autism under the leadership of a lead professional/joint commissioner
- That funding continue to be sought from the 2011/12 GCC workforce development budget in order to provide targeted training
- Establishing local practice development leads or champions to ensure that the investment in training and development leads to behaviour change.

The issues that led to these recommendations remain and the recommendations are still relevant, although given the current pressures on public spending, it might be more relevant for the Joint Commissioner to explore pooled funding options rather than the cost of training fall on one body.

Although there is good understanding of some of the issue facing the autism awareness training programme in Gloucestershire, a more strategic approach to training is required. The ASC Partnership Board Training Sub-Committee has not met for over a year and although the training

programme continues to run, it has been subject to poor attendance and gaps remain, as already stated.

It is crucial that Gloucestershire continues to build on its impressive start with autism awareness training and that those issues already identified by members of the ASC Partnership Board are addressed. If Gloucestershire is to meet the requirements of the national autism strategy, a multi-disciplinary strategic approach to raising awareness is needed based on a robust training needs analysis and accompanied by sufficient resources. This plan needs the backing of senior managers to ensure high levels of attendance. The training programme should also be evaluated to measure its impact.

## **Recommendations**

4. As part of a robust training needs assessment, the ASC Partnership board should carry out an evaluation of the training already carried out in terms of:
  - Coverage of key groups and whether training has been delivered at the appropriate level
  - What gaps remain in training coverage compared to statutory guidance
  - Satisfaction with content and delivery of the training programme
  - What has changed for adults with ASC and their families as a result of the training
5. To further develop existing autism awareness training, a multi-agency workforce development strategy should be developed to ensure that all staff working with people across the autistic spectrum received autism awareness training at the appropriate level and on an ongoing basis. Adults with ASC, their families and carers and ASC representative groups should be involved in the planning and delivery of training. Those staff who are most likely to have contacts with adults with ASC (such as primary care staff and social care assessors) should be the priority groups for training.
6. The Lead Commissioner for ASC should explore appropriate ways of ensuring the ongoing development and delivery of the autism awareness training programme

7. Establish local practice development leads and/or autism awareness champions to promote uptake of training amongst priority groups and to ensure that the investment in training and development leads to behaviour change.
8. 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 through on-line dedicated computer based training such as the Royal College of General Practitioners' e-learning course for general practitioners and other primary care professionals which is aimed at improving professional standards relating to the care of people with ASC and their families.
9. 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.



## 6. Transition from children's to adult services

### What is the evidence/good practice?

Detection and diagnosis of childhood autism now largely occurs by early childhood (age 3 to 6 years old) (National Institute for Health and Clinical Excellence 2012). Children and young people with ASC are entitled to extra help in early years settings, school, college and university – as well as at times of transition, when they move from one education setting to another. Many children with ASC receive a statutory assessment of their special educational needs (SEN) by the local authority. This can be commenced by a local authority, or following a request from the child's parents or school. An assessment can lead to a statement of SEN which describes in writing the child's educational needs and the special help they should receive. The local authority will usually make a statement if they decide that the extra help a child needs cannot be provided from within the school's resources. Other children with ASC may be assessed as not requiring a statement but as benefitting from some extra support which can either be given at 'school action' or 'school action plus'.

The transition from children's to adult services is a time when service delivery changes and is organised in a different way. *Fulfilling and Rewarding Lives* (Department of Health 2010b) identifies ensuring that transition planning gives young people with ASC the best start in their adult life as a key priority. Local authorities must arrange assessments of needs and the provision that will be required to meet those needs for all young people with statements who are thinking of going on to further education or training. They can also arrange these assessments for other young people with SEN; these are known as section 139A assessments. The statutory guidance *Implementing Fulfilling and Rewarding Lives* (Department of Health 2010c) provides a number of key points in relation to successful transition planning:

- Professionals working with a young person with autism approaching transition should inform the parent and young person of their right to a community care assessment (an assessment carried out by a social worker to identify needs) and inform carers of the right to a carer's assessment. They should also inform social services that this individual is approaching adulthood and may need a community care assessment. The social services department should then formally contact the young person with autism, and their family, before the young person reaches adulthood, to invite them to receive a community care assessment.

- Transition should not be seen as a single point of switch-over. The most effective transitions are carefully planned and managed over a number of years.
- Young people with autism – and their families and carers – should always be involved in transition planning. This is in line with the principle set out in *Equity and Excellence: Liberating the NHS* (Department of Health 2010a) of “no decision about me without me.” Where appropriate, young people could be offered the assistance of an advocate to speak on their behalf and ensure their views are heard.
- For transition to be effective, it is essential that information is passed on between children’s and adult services. This is not just in terms of information about individuals at the point of transition, but also reflects the need to share information about the needs and numbers of children with ASC in a local area to help with longer-term service planning.
- Local authorities, NHS bodies and NHS Foundation Trusts should ensure that all professionals involved in transition for young people with ASC have received appropriate training about autism so that they may adjust their behaviour to reflect the needs of the young person concerned.
- NHS bodies and NHS Foundation Trusts should ensure that protocols are in place for the transition of clinical mental health care for children with autism in receipt of child and adolescent mental health services (CAMHS). Where individuals do not meet the referral criteria for adult mental health teams, good practice is for local authorities and NHS bodies to signpost on to other sources of support and information available locally and nationally.

Further guidance contained in *Good practice in supporting adults with autism: guidance for commissioners and statutory services* (National Autistic Society 2009) emphasises that ASC impacts across a range of agencies and therefore effective multi-agency working is central to the smooth transition of young people with the condition. Local authorities need to develop clear protocols identifying the responsibilities of each agency in the transition process. Effective transition planning should include career preparation up to age 16 and plans for education, employment, training, transport, housing and leisure from 16 to 19 and beyond. Crucially, transition plans should be individually tailored to the needs and wishes of the individual young person and reviewed and

updated each year. This guidance also states that local authorities need to know how many young people with ASC are leaving school over the next five years and the type of support they are likely to need in order to plan and commission accordingly. This information should be included in the Joint Strategic Needs Assessment (JSNA).

The recently published NICE guidelines on the recognition, referral and diagnosis of children and young people on the autism spectrum (National Institute for Health and Clinical Excellence 2012) also emphasises that the care of young people in transition between paediatric and adult healthcare services should be planned and managed according to the best practice guidance described in *'Transition: getting it right for young People'* (Department of Health 2006). Adult and paediatric healthcare teams should work jointly to provide assessment and services to young people with autism in transition.

### **What is happening in Gloucestershire?**

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 ASC increased from 22 in 2006/7 to 56 in 2011/12 (Table 3 below), an increase of 154% over a period of five years. Whilst the number of pupils with ASC at school action plus remained steady during this period, the increase was particularly marked for pupils with a statement of SEN for ASC which showed an increase from 15 to 50 statements representing a 230% increase. This is in contrast to a 0.9% increase in the total number of statements in Gloucestershire during the same period (from 2166 to 2186). Discussions with staff working with young people with ASC indicate that this is due to an increase in diagnosis of ASC and a greater awareness amongst schools.

**Table 3 - Gloucestershire students with ASD as a primary or secondary need in year 11.**

Academic Year	Statement		Total State-ments	School Action Plus		Total School Action Plus	Total ASD for Academic Year
	Primary need	Secondary need		Primary need	Secondary need		
<b>2006-07</b>	14	1	15	7	0	7	<b>22</b>
<b>2007-08</b>	23	6	29	5	0	5	<b>34</b>
<b>2008-09</b>	19	2	21	3	2	5	<b>26</b>
<b>2009-10</b>	16	4	20	4	1	5	<b>25</b>
<b>2010-11</b>	23	6	29	5	0	5	<b>34</b>
<b>2011-12</b>	34	16	50	6	0	6	<b>56</b>

Source: Gloucestershire Schools Census Jan 2007, 2008, 2009, 2010, 2011 and 2012

Gloucestershire's transitions protocol is currently under development as part of a review of how transition services are delivered. Gloucestershire County Council has developed a transitions pathway for pupils with statements of special educational need entitled *Transitions: a Step in the Right Direction* (Gloucestershire County Council & The Key 2011). 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. For each stage of transition, the pathway details what the law/government guidance says, what will happen in Gloucestershire, which agency will do this and when. The transition pathway also provides information for young people and their families on what they can expect during the transition process relating to employment, housing, leisure, transport and health and useful contacts for these areas.

The transition pathway states that at school years 10 – 14 (ages 15 – 19), information should be added to the Council's adult social care database for those young people who are likely to be eligible for adult social care services and that information from the young person's transition plan should be

used to inform adult services of their likely future needs. An adult team social worker should attend the transition review for young people likely to be eligible for social care services.

Gloucestershire's transition pathway applies to all young people with statements of SEN and it is difficult to gather information on any particular issues regarding its implementation that relate specifically to young people with ASC. For example it is not possible to quantify the numbers of young people with ASC 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 ASC).

Gloucestershire's transition protocol is currently being re-drafted as part of the review of transition that is taking place across the county. Discussions with parents and professionals working with young people with ASC 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. Prior to September 2011, transition reviews for children with statements were very rarely attended by a social worker. However, this is currently being addressed; 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. For example during 2011/12, an adult social care worker was present at approximately 60 out of 220 reviews for children with statements. However, it is not possible to identify how many of these related to young people with ASC.

A survey on the experience of transition for parents of children with ASC was e-mailed to all contacts on the database of Carer's Gloucestershire (approximately 700 people) in May 2012 as part of this needs assessment. A copy of the survey is contained in Appendix 3. Three responses were received. Whilst this only represents a small sample, the responses reveal that the transition protocol for Gloucestershire may not be meeting the needs of some young people with ASC and their families. For example one parent commented that "We are still going through the transition to adult social care services, but it can seem stressful and complicated at times with a lot of procedures and 'hoops' to jump through". In relation to social care involvement in the process, another parent commented "(we had) no input from social care, no input from Connexions and I was left to try to manage it myself".

In response to problems identified with the transition process in Gloucestershire, two Transition Coordinator posts were also 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 and to other appropriate alternate services. The Transition Coordinators are employed by the Youth Support Service (previously Connexions) until March 2013. Their role includes identifying the cohort of children with disabilities who may require adult services. For example 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. The Transition Coordinators will attend the annual reviews for these young people and act as the social care representative. They also meet regularly with adult social care teams and where a young person is considered likely to be eligible for services, this is passed on to adult social care.

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 ASC as this is not routinely recorded. Gloucestershire County Council'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.

Gloucestershire's mental health service provider (2gether NHS Foundation Trust) has a protocol for transition of care which outlines the principles that apply when service users are transferred within services provided by 2gether. However, young people with ASC will only be picked up by adult mental health services if they have a diagnosed mental health condition and 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 ASC 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.

The extent to which transition is planned and managed over a number of years varies in Gloucestershire. Once a child has left school and entered further education, transition planning continues to take place on an annual basis for pupils at Ruskin Mill and Farleigh College (which provides education for young people with ASC). However, there is no automatic transition annual

review for pupils who go to mainstream colleges such as the Gloucestershire College campuses or Hartpury College. In a paper presented to the ASC Partnership Board in July 2011, Gloucestershire County Council's former Transitions Coordinator identified the fact that many of Gloucestershire's special schools do not have a 6<sup>th</sup> form as an issue and mainstream Further Education Colleges cannot always provide for the complex needs of young people with ASC. This was reiterated in our survey by a parent of a child who attends a mainstream college who commented "Now he is attending..... College, I feel I have been left alone to fight his battles without even the protection of a statement, no one to offer advice on what he will do next year and no help for the days when he is not in college. It is all very depressing and none of the services are prepared to help".

In the same paper to the ASC Board, the Council's former Transitions Coordinator also raised the issue of the difference in eligibility between support for young people under 18 and support for young adults over 18. She concluded that "For young people who are not eligible for a personal budget when they are 18, there seems to be a lack of options, facilities and support to transition to". This reflects the issue – discussed further later in this document – of a lack of ongoing support for adults with ASC.

### **Analysis of unmet needs**

The number of pupils identified as having ASC in Gloucestershire is increasing and it is important they are supported during the transition to adulthood. However, planning for young people with ASC coming through transition is difficult as ASC is not recorded on the databases where details of transition are held. This is something that should be addressed so that the local implementation of the statutory guidance contained in *Implementing Fulfilling and Rewarding Lives* (Department of Health 2010c) can be monitored.

A current review of transition is underway, looking at different models of service delivery in Gloucestershire. This review and the introduction of the new Transition Coordinators provide an opportunity to ensure that young people with ASC receive the support they need during transition such as adult social care representation at transition reviews.

Where adult social care are involved in transition, discussions with professionals working with young people have identified that accessing an assessment for adult social care can still be problematic. Young people with ASC are not automatically contacted by adult social care and offered an

assessment – the young person or their carer needs to request this. There is also no mechanism to ensure that information about the right to request a carer's assessment is passed on to carers in a consistent way. This needs to be addressed through the further development of transition protocols.

Where an assessment is offered/requested, waiting times for social care assessments are long. When a full assessment for adult social care is carried out, young people with ASC often don't meet the criteria for accessing social care according to the Fair Access to Care Services criteria (Department of Health 2010d) which are discussed in more detail in a later chapter. At the moment, there is very little support and information about services available for young people who are not eligible for adult social care which has been identified as a key area of need by professionals working with young people during the transition process. A further planned role of the Transition Coordinators is to understand the availability of support to which it may be appropriate to signpost children with disabilities and their families if they are not eligible for continuing adult services. The workers will also identify available support and services and develop a database that can be used to signpost young people. It is important that young people with ASC are provided with support and information throughout the transition period for example on supported education, employment opportunities and social support.

If a child doesn't have a statement (for example children at school action plus) they are not covered by Gloucestershire's transition pathway and are outside the remit of the Transition Coordinators. These pupils are likely to be on the school's own SEN register but there is no automatic mechanism for them to access social care. Careers education and guidance for these pupils has passed to schools who now have the responsibility for helping their students on school action plus to make effective transition, including buying in careers advice and informing any future placement of the students' needs. Schools are also able to buy in learning disability advice from the Youth Support Service if they have identified this as a need for pupils at school action plus. The numbers of pupils with identified ASC at school action plus is low but it is important that the needs of this group are also met.



## Recommendations

10. Assess if and how Gloucestershire is meeting the transition requirements through exploration of data collection on how the transition process is working for young people with ASC, i.e.

- For young people with ASC, in how many cases
  - was information passed to adult social care
  - were transition meetings attended by a representative from adult social care
  - was a social care assessment offered/carried out
  - was a carer's assessment offered/carried out.
- What information/support was provided to young people who were eligible for adult social care

11. Develop protocols to ensure 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 ASC 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.
- The Joint Commissioner should ensure that mental health providers (adult and children) are able to identify and report on their clients with ASC
- 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

## **7. Identification and diagnosis of autism in adults leading to an assessment of need for relevant services**

### **What is the evidence/good practice?**

*Fulfilling and Rewarding Lives* (Department of Health 2010b) acknowledges that for many adults, receiving a clinical diagnosis of autism is an important first step towards living a fulfilling life. For many adults with ASC, obtaining a diagnosis also gives them something they can refer to when seeking to access services. Diagnosis is particularly important for adults who have not previously had their condition recognised. The National Audit Office report *Supporting people with autism through adulthood* (National Audit Office 2009) found that many people with ASC reported that a diagnosis helped them make sense of difficulties they had experienced in their lives, for example in forming friendships. This is the case even for those who are already receiving learning disability or mental health services – a diagnosis of ASC can change the way they are treated and supported (Department of Health 2010b).

*Fulfilling and Rewarding Lives* (Department of Health 2010b) also makes it clear that identification of possible autism is the first step to accessing effective support, even before a formal diagnosis. Frontline staff play a key role in this and the strategy acknowledges that the biggest barrier to identification of autism is a lack of awareness amongst frontline staff.

Diagnosis of childhood autism now largely occurs by early childhood; however higher functioning autism is often not diagnosed until adulthood and can be misdiagnosed as depression or a personality disorder. Studies have also shown that four out of five adults find obtaining a diagnosis in adulthood difficult or not possible (Taylor and Marrable 2011 cited in (National Institute for Health and Clinical Excellence 2012). As the recently published guidelines by the National Institute for Health and Clinical Excellence (NICE) on the recognition, referral, diagnosis and management of adults on the autistic spectrum (National Institute for Health and Clinical Excellence 2012) recognise “inadequate identification and assessment of adults with autism not only leads to a lack of adequate provision of care and support for the problems associated with autism, but can also lead to inadequate recognition and assessment of coexisting mental and physical health problems”. Whilst NICE acknowledged that many people with ASC have rewarding and successful lives (National Institute for Health and Clinical Excellence 2012) and may not require any interventions or even wish

for a formal diagnosis, under recognition can result in subsequent sub-optimal care (or lack of care) for adults with ASC which can lead to huge emotional costs both for individuals with ASC and their families and carers as well as increased health and social care costs. For example Knapp et al 2007 (National Institute for Health and Clinical Excellence 2012) estimated that the annual cost to society for each adult with ASC 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.

*Fulfilling and Rewarding Lives* (Department of Health 2010b) states that there should be a cost effective referral pathway for autism available in every area which GPs, mental health practitioners and the voluntary sector are aware of and can follow. Local areas should appoint a lead professional to develop diagnostic and assessment services. The national strategy makes it clear that “by 2013, when this strategy will be reviewed, we expect there to be a clear pathway to diagnosis in every area”.

The NICE guidelines (National Institute for Health and Clinical Excellence 2012) make recommendations on the signs and symptoms that should prompt an initial assessment of autism in adults. Once an individual has been assessed for possible autism, case identification tools can be used to identify those likely to have autism who should then be referred for a full diagnostic assessment.

An assessment of suspected autism in adults requires a broad range of skills and knowledge. The recent NICE guidelines recommend that any assessment should be team based and involve a range of professionals with the requisite skills to contribute to a comprehensive assessment. The comprehensive assessment should cover diagnosis, needs and risks (including self-harm, rapid escalation of problems, harm to others, self-neglect, breakdown of family or residential support or exploitation or abuse by others). A care plan should be developed for each adult based on the comprehensive assessment, incorporating a risk management plan and including any particular needs (such as adaptations to the social or physical environment), and also taking into account the needs of the family, partner or carer(s).

The guidelines also state that “it is important that autism is seen not only as a medical diagnosis for which the NHS has responsibilities, but also as a social care responsibility (in the areas of education, housing and employment) because people with autism often fall through the gaps between health

and social care, especially if they do not present with an accompanying mental health problem or learning disability". *Fulfilling and Rewarding Lives* (Department of Health 2010b) also makes it clear that diagnosis is not a goal in itself and once a diagnosis of autism has been confirmed, this should lead to an assessment of social care needs. A diagnosis of autism should be part of an integrated process which should lead to adults being able to access the services and support they need. Adults with suspected ASC should not need to wait for diagnosis to request and receive a community care assessment – they or their carers are already entitled to request one if they believe they require support.

*Implementing Fulfilling and Rewarding Lives* (Department of Health 2010c) outlines the pathway that should follow a diagnosis of autism. When an adult is diagnosed with autism, the body providing healthcare services to the adult should contact the relevant local authority adult services department promptly so that that a community care assessment can be carried out if the individual wants it. In addition, healthcare professionals who make a diagnosis of autism should inform the adult diagnosed, and/or their carers, that they also have the right to request such an assessment - this will help ensure that if adults diagnosed with ASC are not offered an assessment by the local authority following diagnosis, they can still access one. Assessment of eligible needs for services should not be influenced by availability of services; for example, if the assessing professional identifies that the adult with ASC would benefit from an advocate; the report should reflect that, regardless of whether advocacy services are actually available.

*Implementing Fulfilling and Rewarding Lives* (Department of Health 2010c) also makes it clear that:

- diagnosis of autism is not a guarantee of support or services. It is a reason for assessment of needs and an important piece of information to be stored on an individual's health record to support future care. Access to publicly funded care services is based on meeting the FACS criteria
- Diagnosis is not compulsory: not all adults who exhibit the characteristics of autistic spectrum conditions will want to be referred for formal diagnosis. Therefore, adults who may not have a formal diagnosis of autism are still entitled to an assessment of their needs
- Diagnosis of autism can be a life-changing moment for both the individual and their family. Therefore, it is important that adults diagnosed with autism are given access to information about autism and about sources of support – even if they do not qualify for publicly funded care services following an assessment of needs. These should include:

- Contact details for local autism support services and voluntary groups
  - Contact details for national autism representative groups
  - Signposting to the “Living with Autism” section of the NHS Choices website (NHS Choices 2012)
- An individual’s needs may change during their lives: an adult with autism who has been assessed as not needing care services when first diagnosed may later require services. This is particularly the case for older adults with autism living with family carers: while the family carers are able to support them, they may not require additional social care. However, when those family carers are no longer able to support them, adults with autism may need to be reassessed.

*Fulfilling and Rewarding Lives* (Department of Health 2010b) also makes it clear that staff undertaking social care assessments should be sufficiently skilled in understanding the needs of adults with ASC and the guidance therefore recommends that assessment of needs be carried out by a professional who has a good knowledge of autism, and reasonable adjustments made to the assessment process to enable the adult with autism to take part fully (National Audit Office 2009).

### **What is happening in Gloucestershire?**

There is currently no commissioned diagnostic and assessment service for ASC in Gloucestershire. The current referral process is that GPs who suspects a patient may have ASC should contact NHS Gloucestershire who send them a screening questionnaire, the standard Autism Spectrum Quotient (AQ), a 50 question case identification tool published in 2001 by the Autism Research Centre in Cambridge (Baron-Cohen 2001). If the patient scores more than 32 on the questionnaire, they are referred for a full diagnostic assessment at 2gether NHS Foundation Trust, otherwise an assessment is refused.

When a referral is made, a diagnostic assessment is spot-purchased from 2gether NHS Foundation Trust. Diagnoses of autism are made through a structured diagnostic interview, carried out by one of a team of Learning Disability Consultants. Parents/carers are invited to attend the diagnostic interview. However, diagnostic assessments in Gloucestershire are not carried out as part of a multi-disciplinary comprehensive assessment as this level of service is not commissioned.

Since 2008, 87 people referred for diagnosis have been assessed in Gloucestershire. The number of referrals has increased year on year (Table 4)

**Table 4 - diagnostic assessments carried out in Gloucestershire 2008-2012**

<b>Year</b>	<b>Number of diagnostic assessments carried out</b>
2008	1
2009	10
2010	25
2011	30
2102 (up to 12 July)	21

Source: 2gether NHS Foundation Trust

It is not possible to get accurate figures on the number of diagnostic assessments which have resulted in a diagnosis of ASC as this is not recorded on a central database. However, it is estimated by the Learning Disability Consultants who undertake the diagnostic assessments that 75% of assessments result in a diagnosis.

There are currently 17 people on the waiting list for a diagnostic assessment, with current waiting times of up to a year. Focus groups held in 2009 with people with higher functioning autism in Gloucestershire indicated that getting a timely diagnosis of autism is difficult for many people and discussions with professionals and parents of adults with ASC indicate that this remains the case. Parents and professionals report a low level of awareness amongst GPs of how to get a diagnostic assessment in Gloucestershire. Whilst some GPs are aware of the pathway, others are unsure what action to take when they suspect a patient has ASC. One parent of an adult with ASC reported that the family paid themselves for a private diagnosis as they were unable to access a diagnostic assessment via the NHS.

Following the diagnostic assessment, a letter is sent by 2gether NHS Foundation Trust to the patient and their GP confirming the diagnosis; however, no further information is provided on how to access a social care assessment.

Adults with autism and their carers are entitled to request a social care assessment, although 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. When an enquiry is received, Helpdesk Customer Service Operators (CSOs) collect background information and make a brief initial assessment using the national Fair Access to Care Services criteria (Department of Health 2010d) for accessing services before deciding what further action to take. If the customer doesn't meet the Fair Access to Care Services eligibility criteria, no further action is taken but advice/information is provided (such as details of local voluntary organisations).

Helpdesk CSOs use a generic form to respond to all initial enquiries (a copy is included in Appendix 4). The key questions asked on the form relate to current difficulties and concerns and recent events/changes in life. The form also collects optional information on day-to-day activities, personal care, mobility, home and living situation, physical health and wellbeing (including 'disabilities, impairments or health conditions'). The CSO team have a range of guidance to aid the decision on whether to refer for a social care assessment, including use a number of different prompt sheets. However, they have no access to specific materials on autism and have not received any training in autism awareness. Discussions with Helpdesk staff indicate that they would use a prompt sheet designed to identify learning difficulties when dealing with calls regarding ASC.

Discussions with parents/carers of adults with ASC and with the National Autistic Society suggest that adults with ASC 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. However, it is not possible to quantify this and there are no figures available on the numbers of people with ASC who call the Helpdesk but do not receive any further support as this is not recorded on the social care database.

If the customer is judged to meet the FACS criteria, further action may include putting in place some short-term preventative measures or referral to the relevant adult social care team for a full assessment. Adults with learning disabilities will be assessed by the adult learning disability social care team. Adults without a learning disability will be assessed by the relevant locality adult social care team. Some training in autism awareness has been provided to social care staff who carry out full social care assessments, but there are still gaps amongst this groups and some training aimed at social care staff who carry out assessments has been cancelled. Social care services will only be provided if the adult with ASC meets the FACS criteria.

The national guidance on FACS sets out four different categories of risk to independence (critical, substantial, moderate or low) (Department of Health 2010d). Local authorities have the freedom to

decide on where to set the threshold for accessing services although once the threshold is set, it must be applied across all services (i.e. threshold decisions cannot be made on an individual case basis). Gloucestershire has set the threshold for accessing social care services at critical or substantial – further details are contained in Table 5



**Table 5 - Criteria for assessing Fair Access to Care Services**

Need is deemed **critical** when

- life is, or will be, threatened; and/or
- significant health problems have developed or will develop; and/or
- there is, or will be, little or no choice and control over vital aspects of the immediate environment; and/or
- serious abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out vital personal care or domestic routines; and/or
- vital involvement in work, education or learning cannot or will not be sustained; and/or
- vital social support systems and relationships cannot or will not be sustained; and/or
- vital family and other social roles and responsibilities cannot or will not be undertaken.

Need is deemed **substantial** when

- there is, or will be, only partial choice and control over the immediate environment; and/or
- abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out the majority of personal care or domestic routines; and/or
- involvement in many aspects of work, education or learning cannot or will not be sustained; and/or
- the majority of social support systems and relationships cannot or will not be sustained; and/or
- the majority of family and other social roles and responsibilities cannot or will not be undertaken.

Source: (Department of Health 2010d)

Data obtained from adult social care services at Gloucestershire County Council shows that since 2009 (which is the earliest date for which data available on the database), 327 adults with an autistic spectrum condition have had an assessment for social care (either a short screening assessment or full social care assessment). This includes re-assessments for people whose initial assessment was before 2009 (all people receiving social care services are regularly re-assessed).

The data on the 327 people identified with ASC indicates that:

- 232 had received a full social care assessment and are receiving services
- 18 had received a full assessment but hadn't received a social care service (i.e. were deemed to be ineligible)
- 46 hadn't received a full assessment but were receiving a service (which can happen as some short-term services such as meals on wheels can be accessed on the basis of a screening assessment rather than a full assessment)
- 31 people had not received either a full assessment or services

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 ASC had learning disability identified as their primary need and only six (1.8%) had autistic spectrum condition identified as their primary need (Table 6)

**Table 6 - Primary need of people with ASC on Gloucestershire County Council social care database**

Primary need identified on social services database	Number	% of total
ASC	6	1.8
Learning Disability	238	72.8
Mental Health	31	9.5
Physical disability	50	15.3
Carer	1	0.3
Other	1	0.3
<b>Total</b>	<b>327</b>	<b>100</b>

Source: Gloucestershire County Council Social Care Database

All of the above figures must be interpreted with some caution. They refer to people entered on the Gloucestershire County Council social care database with ASC indicated but this doesn't necessarily indicate a clinical diagnosis of ASC. They also do not include people with a primary diagnosis of a mental health condition as their social care needs would be met by 2gether NHS Foundation Trust.

However, these figures do at least give some indication of the number of people with ASC in Gloucestershire who are receiving social care services. This data covers only a very small percentage of the estimated 5,000 adults in Gloucestershire with ASC and shows that the vast majority of people with ASC are not receiving either a social care assessment or social care services. This is particularly the case for people with ASC who do not have an accompanying severe/moderate learning disability, mental health problem or physical disability.

### **Analysis of unmet need/recommendations**

Gloucestershire is not currently following evidence-based good practice in a number of areas relating to the identification and diagnosis of ASC in adults and assessment of need for relevant services. The process for accessing diagnosis and assessment in Gloucestershire is unclear to many people with ASC, their families and professionals. Diagnostic capacity is limited and post-diagnosis there is no linked route to an assessment of need.

There is currently no documented referral and diagnostic pathway for ASC in Gloucestershire. There is no evidence that training or guidance has been provided to GPs in general on the signs and symptoms that should prompt an assessment of ASC in adults or that the current process to access a diagnostic assessment has been widely publicised to GPs. Discussions with professionals and parents/carers of adults with ASC suggest that many GPs are unaware of the process.

In the recently publicised NICE guidelines (National Institute for Health and Clinical Excellence 2012), the AQ screening questionnaire, which is currently used in Gloucestershire, was found to be based on sound evidence of effectiveness for assessment of possible autism in people with higher functioning autism/Asperger's syndrome, although the NICE guideline development group concluded that the AQ-10 (British) would be the most appropriate version for use in primary care and other non-specialist settings to support the decision to refer for a specialist assessment in people without a learning disability.

NICE guidelines on the identification and initial assessment of possible ASC are contained in Figure 2. GPs in Gloucestershire need to be made aware of this and of the pathway to make a referral for a diagnostic assessment when ASC is suspected.

**Figure 2 NICE guidelines on the identification and initial assessment of possible autism**

NICE recommends consideration of assessment for possible autism when a person has one or more of the following:

- persistent difficulties in social interaction
- persistent difficulties in social communication
- stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, **and**

one or more of the following:

- problems in obtaining or sustaining employment or education
- difficulties in initiating or sustaining social relationships
- previous or current contact with mental health or learning disability services
- a history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder)

Source: (National Institute for Health and Clinical Excellence 2012)

Where GPs are aware of the referral pathway, there is limited capacity to carry out diagnostic assessments and a long waiting list. When people do receive a diagnosis, the diagnostic assessment is not carried out as part of a wider multi-disciplinary comprehensive assessment of need.

Furthermore, once a diagnosis of autism has been confirmed there is no evidence that further information is given on the right to access a social care assessment and there is no automatic route to receiving a comprehensive assessment of social care need in Gloucestershire.

When people with autism or their carers or referring professionals contact the adult social care helpdesk to request an assessment, they may well be screened out at the first stage and do not receive a full assessment. This is particularly likely to be the case for people with higher functioning autism or with mild learning disabilities. The social care helpdesk deals with a very wide range of

enquiries from a diverse population. However, the standard form used by the Helpdesk may be too generic to identify the specific needs of people ASC and it is of concern that Helpdesk operators haven't received any specific training on ASC nor do they have access to any autism specific materials to help aid their decision on next steps.

Gloucestershire County Council, like all local authorities, has a statutory duty to assess social care needs under section 47 (1) of the NHS and Community Care Act and the criteria for accessing an assessment are set out in Fair Access to Care Services (Department of Health 2010d). The national autism strategy also makes it clear that a diagnosis of ASC is a sufficient ground for offering an assessment for social care. The courts have stated that local authorities should set a low threshold for access to assessment and that they should not take account of resource when setting that threshold and that it is irrelevant that a person is ultimately unlikely to qualify for services since assessment is a benefit and a duty in its own right (Michael Mandelstam 2008).

The majority of people with ASC who receive a social care assessment, have a learning disability. Very few people with ASC without an accompanying condition are accessing a social care assessment. In order to determine the unmet needs of people with an ASC, the initial screening assessment should be accompanied by guidance that is tailored to the needs of people with ASC. If following the initial assessment, an individual is found not to be eligible for a service they should still be signposted to appropriate services that will maximise their independence and enhance their quality of life.

There have been plans in the past to develop a diagnostic service and a new diagnostic and assessment pathway is currently being developed. Given the current waiting times for a diagnosis and the lack of information/advice for people with ASC post-diagnosis, developing a clear and evidence-based pathway that covers a full comprehensive assessment covering diagnosis and need followed by an assessment of social care need is a priority, in line with NICE guidelines (National Institute for Health and Clinical Excellence 2012) and the statutory guidance contained in *Implementing Fulfilling and Rewarding Lives* (Department of Health 2010b).

## **Recommendations**

In order to comply with the statutory guidance outlined in *Implementing Fulfilling and Rewarding Lives* (Department of Health 2010c) and to follow evidence-based practice outlined in the recent NICE guidelines (National Institute for Health and Clinical Excellence 2012), the following recommendations are made:

12. The Joint Commissioner should ensure that diagnostic and assessment services are developed in Gloucestershire.
13. The Joint Commissioner should ensure the review of Gloucestershire's diagnostic processes and services against the best practice published in the recent NICE guidelines on the recognition, referral, diagnosis and management of adults on the autistic spectrum (National Institute for Health and Clinical Excellence 2012). This should also consider the inclusion of appropriate and accessible management modalities/interventions for the core symptoms of autism.
14. As recommended by NICE, the ASC Partnership Board should ensure that all families, partners and carers are provided with verbal and written information about:
  - Autistic spectrum conditions and their management
  - local support groups and services specifically for families, partners and carers
  - their right to a formal carer's assessment of their own physical and mental health needs, and how to access this.
15. A clear pathway should be developed in Gloucestershire covering initial referral for suspected autism, a multi-disciplinary comprehensive assessment of need (covering diagnosis, risks and need) through to accessing a full assessment of social care (and other) need. All relevant local organisations including primary care staff and social care teams need to be made aware of this pathway once it is developed.
16. In order to ensure that adults with ASC are able to access an assessment of their care needs, the following steps need to be part of the diagnostic pathway:
  - Following a diagnosis of ASC, the attending clinician should, with the individual's consent, promptly inform Gloucestershire County Council adult services department to ensure that a community care assessment is carried out within a reasonable time (if the individual wants such an assessment). In addition, the healthcare professionals making a diagnosis should inform the adult diagnosed and their carers that they have the right to request such an assessment.
  - The social care department should then contact the adults with ASC and their carers to inform them of their right to a carer's assessment

A diagram illustrating the best practice pathway for referral, diagnosis and assessment of autism is contained in Appendix 5

17. All Gloucestershire GPs should be made aware of NICE's recommendations on the assessment of suspected ASC (to be part of training in autism awareness)
18. 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 specific needs of people with autism.

## **8. Helping adults with autism get into and stay in work**

### **What is the evidence/best practice?**

Much of the work being done to support adults with ASC into work are national initiatives by the Department of Work and Pensions (DWP) such as Work Choice which provides specialist support to people with disabilities whose needs cannot be met through other work programmes; or the Work Programme which is a generic programme for people looking for work. The DWP current approach to supported employment for people with disabilities is 'pan disability' rather than disability specific and there are no DWP initiatives that are designed specifically to meet the needs of people with ASC. However, there is much that can be done locally to help adults with autism get into and stay in work. For example the need for increased awareness among employment and benefits advisors has been identified as a key priority by adults with autism themselves.

People with ASC can make a valuable contribution in the workplace. Many people with ASC are highly competent at logical tasks including data entry and IT support and many may have special interests that can easily be developed into transferrable skills. However, research by the National Autistic Society has shown that only 15% of people with ASC have full-time paid employment (National Autistic Society 2012a). This compares with around 31% for all disabled people in full-time employment and 57% for non-disabled people of working age in full time employment (National Autistic Society & Department for Work and Pensions 2012). The under-representation of people with ASC in the labour market not only has financial consequences for adults with ASC and their families, but also means that adults with ASC are excluded from the social benefits that come from work such as increased self-esteem and social inclusion.

The National Autistic Society 2012 survey of adults with ASC also found that only 10% of adults with ASC currently receive employment support but 53% said they would like this support (National Autistic Society 2012d). Of those surveyed, a third of those aged 16-24 with ASC are not in education, employment or training. This is more than double the number among the general population. In addition, 37% of adults had never been in paid employment after the age of 16, with 41% of people over 55 spending more than ten years without a paid job. Among those who aren't currently employed, 59% said they don't believe or don't know if they will ever get a job.



Evidence cited in the latest NICE guidelines shows that people with ASC often have difficulty getting jobs as they may not be able to convey their skills in interviews due to communication difficulties and difficulties in responding quickly to questions (Berney 2004 and Romoser 2000 cited in (National Institute for Health and Clinical Excellence 2012)). Furthermore evidence shows that amongst adults with ASC who are in employment, the majority are in unskilled and poorly paid work. Adults with ASC who work are also more likely to switch jobs frequently, have difficulty adjusting to new job settings and earn lower wages than peers without ASC (Howlin 2000 cited in (National Institute for Health and Clinical Excellence 2012)).

The report *Supporting people with autism through adulthood* (National Audit Office 2009) recommends specialised supported employment schemes which involve working with adults with ASC to prepare them for employment, finding them appropriate work experience and employing a job coach to work alongside them in the workplace. Evidence suggests that such schemes can result in significantly higher rates of employment and higher employer satisfaction when compared to generic disability employment services. Furthermore although the additional costs of such support schemes are high, these can usually be recovered in up to seven years.

This recommendation is reiterated in the recently published NICE guidelines which recommends that commissioning an individual supported employment programme should be considered for adults with autism without a learning disability or with a mild learning disability who are having difficulty obtaining or maintaining employment. NICE found that the effects of these programmes on increasing the number of job placements are consistently positive. Furthermore, the positive effects of supported employment programmes appear to extend beyond the direct impacts on employment, with additional improvements observed for autistic behaviours and quality of life. NICE's economic modelling suggested that supported employment is likely to be a cost-effective intervention for adults with ASC. They concluded that where they are delivered should be individualised but include common core elements of prior and on-the-job training, advocacy, and long-term support to ensure job retention.

## **What is happening in Gloucestershire?**

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.

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 ASC are in employment to our local estimated population of 3,500 adults of working age with ASC in Gloucestershire, mean that the number of adults with ASC 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 ASC on their caseloads. These figures were collected by going through case notes and the very small number of people with ASC who are receiving support from DEAs may well be because they are not identified as having ASC on the Job Centre Plus DEA database. It is also the case that ASC will only be picked up if people disclose it or if it is suspected at the initial stage of registering with Job Centre Plus, when the initial claim is processed by telephone which is followed by an interview with a Personal Advisor.

All the DEAs in Gloucestershire had received autism awareness provided through the training programme developed by Gloucestershire's ASC partnership board. Discussions with parent members of the ASC Board suggests that DEAs do have good awareness of ASC, but the employment and training opportunities for people with ASC are limited. Parents also felt that it was critical to provide training to employers about how to communicate and treat people with ASC in the work place. As one parent commented "the workplace can be very hostile for people with ASC and they can be vulnerable to bullying". Parents also identified working with employers to highlight the benefits of employing people with ASC as a priority.

There are no specific employment services for people with ASC 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.

Other options for people with ASC 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.

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. The strategy looks at redesigning the council's existing services to provide help specifically in getting people with learning disabilities into work. There are plans for the Mental Health and Partnerships Manager to develop an employment strategy for people with ASC but at the moment no specific details are available on when this will be done, what it would include or what impact it would have for people with ASC. 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.

### **Analysis of unmet needs**

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

People with ASC in Gloucestershire and their parents have identified a range of issues they face when trying to gain employment. During focus groups held with people with ASC and their carers 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. They felt they would benefit hugely from some work experience, access to employment support and support with interviews.

Parents also report a lack of employment opportunities for people with ASC and have identified working with employers to highlight the benefits of employing people with ASC as a priority. Parents felt that few employers seem to have an understanding of ASC. One parent whose adult son with ASC has part time work at a supermarket commented "at the moment, prospects for more

permanent full-time work seem bleak; only a degree of positive discrimination or at least a better understanding of autism and employment may be the only way forward” .

The recently published NICE guidelines found that supported employment programmes for adults with autism are cost effective and provide both social and economic benefits. Adults with ASC in Gloucestershire would benefit from the support that such a programme would provide.

### **Recommendations**

19. In line with the NICE guidelines (National Institute for Health and Clinical Excellence 2012), consideration should be given to commissioning an individual supported employment programme for adults with ASC without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment. An individual supported employment programme should typically include:

- help with writing CVs and job applications and preparing for interviews
- training for the identified work role and work-related behaviours
- carefully matching the person with autism with the job
- advice to employers about making reasonable adjustments to the workplace
- continuing support for the person after they start work
- support for the employer before and after the person starts work, including autism awareness training.

20. 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 Autism*” a leaflet developed for employers (National Autistic Society & Department for Work and Pensions 2012).

## 9. Local planning and leadership in relation to the provision of services for adults with autism

### What is the evidence/good practice?

*Fulfilling and Rewarding Lives* (Department of Health 2010b) recognises that effective local leadership is essential to ensuring the needs of adults with ASC are met in local areas. The statutory guidance *Implementing Fulfilling and Rewarding Lives* (Department of Health 2010c) outlines what this means in practice for health bodies and local authorities:

- Local authorities should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of community care services for adults with ASC in the area. This named commissioner should participate in relevant local and regional strategic planning groups and partnership boards to ensure that the needs of adults with ASC are being addressed.
- Local authorities, NHS bodies and NHS foundation trusts should develop local commissioning plans for services for adults with ASC that reflect the output of the JSNA and all other relevant data around prevalence. Commissioning plans should be reviewed annually.
- To develop such plans, a wide range of local information on adults with ASC is needed including the number of adults known to have ASC in the local area, the range of need for support to live independently and the age profile of people with ASC in the area to enable local partners to predict how need and numbers will change over time.
- The most important tool in putting the needs of adults with ASC on the map in every area is the Joint Strategic Needs Assessment (JSNA) which requires all local partners to come together and identify priorities for services.

- Local authorities, NHS Bodies and NHS Foundation Trusts and organisations with whom they have contracted to provide services are expected to take account of the views of adults with ASC and their families and carers in developing and commissioning services for adults with ASC.
- In developing these plans, consideration should be given to the role of family carers and the support they need. Consideration should also be given to The Big Society, in particular local community and volunteer groups in delivering services to meet the needs of adults with ASC, their families and carers.

To support the work of the local commissioner/manager, *Fulfilling and Rewarding Lives* (Department of Health 2010b) suggests that local partners may also want to consider establishing a local autism partnership board that brings together different organisations, services and stakeholders locally and sets a clear direction for improved services.

The recently published NICE guidelines (National Institute for Health and Clinical Excellence 2012) reiterate this by recommending that each area establishes a multi-agency strategy group with representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector. There should be meaningful representation from people with ASC and their families, partners and carers.

The national autism strategy *Fulfilling and Rewarding Lives* (Department of Health 2010b) also highlighted best practice approaches to support service planning. It suggested that “where outcomes for adults with ASC have improved, this has been as a result of the development of local teams dedicated to supporting adults with autism from diagnosis through to health management and help with day to day living”. These approaches have also been shown to cost-effective. The National Audit Office report *Supporting People with Autism in Adulthood* (National Audit Office 2009) also found that providing specialised support for adults with high functioning autism can improve outcomes for this group.

The NICE guidelines (National Institute for Health and Clinical Excellence 2012) also recommend that in each area a specialist community-based multidisciplinary team for adults with autism (the

specialist autism team) should be established. The membership should include clinical psychologists, nurses, occupational therapists, psychiatrists, social workers, speech and language therapists and support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills). The specialist autism team should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services
- specialist care and interventions
- advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team)
- support in accessing, and maintaining contact with, housing, educational and employment services
- support to families, partners and carers where appropriate
- care and interventions for adults with autism living in specialist residential accommodation
- training, support and consultation for staff who care for adults with autism in residential and community settings.

NICE also emphasises that the NHS needs to work closely with social care and education services since ASC does not just affect health but has an impact on independent living (such as education, housing, employment, social networks, leisure, shopping and travel). The National Audit Office (National Audit Office 2009) suggests that good practice is for local health and social care organisations and Job Centre Plus to work together in developing services, for example through pooled health and social care budgets and joint commissioning arrangements. In its recently published guidelines NICE recommends that care pathways should be developed to promote implementation of key principles of good care (National Institute for Health and Clinical Excellence 2012). Care pathways should therefore include liaison with these other agencies and with disability resource centres in colleges or with human resources departments in the workplace. NICE makes a number of recommendations in relation to the development of care pathways - full details of these are contained in Appendix 6.

NICE also evaluated the evidence for psychosocial interventions for adults with a diagnosis of autism, including interventions for the core symptoms of autism and interventions focused on life skills. The NICE guideline development group felt that social learning interventions for social interaction

could improve the problems of isolation felt by people with autism. Based on evidence, they also decided that adaptive skills training based on behavioural principles could be beneficial for adults with autism who need help developing daily living skills. Full details of NICE's recommendations in relation to psychosocial interventions that could be commissioned for adults with autism are contained in Appendix 7.

NICE guidelines (National Institute for Health and Clinical Excellence 2012) recommend that autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the development of the local autism care pathway. The aims of the strategy group should include:

- developing clear policy and protocols for the operation of the pathway
- ensuring the provision of multi-agency training about signs and symptoms of autism, and
- training and support on the operation of the pathway
- making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services
- supporting the integrated delivery of services across all care settings
- supporting the smooth transition to adult services for young people going through the pathway
- auditing and reviewing the performance of the pathway.

NICE guidelines (National Institute for Health and Clinical Excellence 2012) also identified serious limitations in the services available for families, partners and carers to facilitate and support their active involvement in the care of their child with ASC. This led NICE to identify a number of issues for where local action is recommended. These include the involvement of families, partners and carers in the care of their family member or friend; the assessment of the needs of families, partners and carers; information about and help in accessing care and support for their family member; and a range of family and carer support groups.

*Fulfilling and Rewarding Lives* (Department of Health 2010b) also acknowledges that currently, adults with ASC are often not able to access the services or support they need. For many, mainstream public services can be inaccessible. Some of this may be due to a lack of understanding amongst staff but there are also a number of other factors that prevent adults with ASC from accessing services, such as the fact that many people with ASC are hypersensitive to light and noise,



can struggle with language and instructions of standard letters and have difficulty in communication. The result is often that when people with ASC try to access mainstream public services such as health care, education and employment advice, they can find it difficult to cope with the way those services are offered.

*Fulfilling and Rewarding Lives* (Department of Health 2010b) aims to ensure that adults with ASC are able to benefit fully from mainstream public services by:

- Reiterating the requirement of the Disability Discrimination Act (now superseded by the Equalities Act 2010) for all organisations that provide a service to the public to make reasonable adjustments to those services to ensure they are accessible for disabled people, including people with ASC. Adults with ASC should be able to access personal budgets and direct payments in line with the assessment of their needs.
- Enabling adults with ASC to benefit from the personalisation of social care

The strategy emphasises the importance of enabling adults with ASC and their families to have greater choice and control over where and how they live. This means that the needs of adults with ASC should be taken into account in local housing planning, design and allocation, in line with local priorities. Support should be available for adults with ASC who want to, or have to, live independently – both on an ongoing basis and during the transition period into a new home, and adults with ASC and their carers should be given help to understand the options available to them, including the financial help they may be entitled to.

Some guidance on housing design for adults with autism is contained in guidance on non-mainstream housing design (Homes and Communities Agency 2012). This suggests that supported accommodation should reflect the trend away from large, institutional care facilities towards environments with a more domestic scale and feel which are integrated into the community rather than removed from it.

### **What is happening in Gloucestershire?**

Gloucestershire's Joint Commissioner for Mental Health is the lead commissioner for health and social care services for all adults with ASC in Gloucestershire.

There is currently no specialist autism team in Gloucestershire who are commissioned to support adults with ASC. 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. These include a range of residential care such as Hollybrook Learning Disability Hospital run by 2gether NHS Foundation Trust which provides inpatient services for up to eight patients with a learning disability some of whom will have autism and Matson House a 13-bed care home run by Selwyn Care, a private provider specialising in care for adults with ASC. Adults with autism and an accompanying mental health diagnosis are able to access adult mental health services although it is not clear how much provision these make for their ASC. However, there are currently appears to be no appropriate services in Gloucestershire for people with autism who are not able to access either learning disability or mental health services.

Gloucestershire has not yet developed a commissioning plan for adults with ASC. This was identified as a priority in a progress report on the implementation of *Fulfilling and Rewarding Lives* (Department of Health 2010b) which was presented to Gloucestershire County Council's Departmental Management Team in August 2011. However, there has been no progress with developing a commissioning plan since then. Discussions with members of the ASC Partnership Board, indicate that commissioning plans will be developed following the development of a local autism strategy. Given the statutory obligation to develop these plans outlined in *Implementing Fulfilling and Rewarding Lives (Department of Health 2010c)*, a timeframe should be developed for drawing up a commissioning plan for adults with ASC.

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 (National Institute for Health and Clinical Excellence 2012) with the exception of primary care who are not currently represented. There is also under-representation from clinicians from the mental health provider.

Gloucestershire's ASC Partnership Board was established prior to the Autism Act and the publication of *Fulfilling and Rewarding Lives* (Department of Health 2010b) and was initially set up to address the need of people with higher functioning autism, as it was felt that this group lacked services and were therefore the priority. However, there are plans to extend the scope of the Board to cover adults across the autistic spectrum including those with learning disabilities. The current terms of reference for the Board state that "it is proposed that, subject to discussions with the Learning

Disabilities Partnership Board, the ASC Partnership Board remit be extended to all adults with autism.” Gloucestershire’s plan for people with a learning disability also states that “the whole approach to work with people with Autistic Spectrum Disorder is one that is taking a specific path with a separate Autistic Spectrum Disorder Strategy Group commissioning work to address all ASD needs in Gloucestershire” (Gloucestershire County Council 2010). However, discussions with members of the board indicate that the board is still seen as primarily about the needs of adults with higher functioning autism. The extension of the ASC Board’s remit needs to be agreed and documented so that the board can ensure it is addressing the needs of adults in Gloucestershire across the autistic spectrum.

The terms of reference for this board include identifying commissioning priorities and mapping local needs and resources and identifying gaps in order to inform service development. The recent publication of the NICE guidelines (National Institute for Health and Clinical Excellence 2012) provide the opportunity to review the terms of reference and membership of the ASC Partnership Board to ensure that Gloucestershire is adhering to the latest evidence based practice.

In addition to the ASC partnership board, an autism network group and a professional reference group have been established as sub groups. The autism network group’s terms of reference are to promote engagement with the adult autism strategy development process from a wider network of adults with autism, parents/carers and family members, to supply information relevant to the content of the autism strategy for Gloucestershire, to offer commentary at all main stages of strategy development and to provide case study examples of living with autism. The group has only recently met and its membership consists of parents and carers of adults with autism, adults with autism and wider members from families containing an adult with autism. However, there is currently under-representation from parents of adults with autism and learning disabilities. Given that the national autism strategy applies to all adults with autism - of whom it is estimated that more than half have a learning disability - it is important that the voices of adults with autism and a learning disability and their parents, carers and families are heard. Wider representation (including from minority ethnic groups) from parents/carers of adults with autism with a learning disability on the Gloucestershire autism groups should therefore be considered. The professional reference group will have representation from a range of professionals from commissioning and service provision.

An enhanced diagnostic service for ASC is currently under development in Gloucestershire. An Adult Autism Strategy Implementation Manager (0.4 WTE) has been appointed based at the National Autistic Society and jointly funded by NHS Gloucestershire and Gloucestershire County Council. These developments provide the opportunity to consider implementing the recommendations contained in the recent NICE guidelines in relation to the development of a specialist autism team and the development of local care pathways.

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

- Local Job Centre Plus Disability Employment Advisors can make reasonable adjustments such as having private interview rooms which will minimise the effects of external noise and rooms having blinds so that DEAs can make adjustments to accommodate sensitivity to light.
- Staff with expertise in ASC from 2gether have provided several sessions to staff delivering IAPT (Improving Access to Psychological Therapies) on how to adapt their practice for people with ASC.
- 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. Other adjustments are tailored to students' individual needs, for example one student with ASC is able to access 1:1 study much of the time and wear his hood up (normally not allowed according to college rules) when he is in a class with other students.
- Travel training is provided for adults with learning disabilities (including those with ASC) through drop in centres which offer travel training as part of their enablement services and through Gloucestershire Voices (a campaign group for people with learning disabilities) who have recently been commissioned to provide a 'bus buddy' programme which matches people up for travel training and to facilitate transport

Support for people in receipt of social care is reviewed on an annual basis to explore whether it is currently meeting the service user's need. Commissioners agree that the annual review process may provide scope to increase the benefits of personalisation for people with ASC in receipt of learning disability services. A review of Gloucestershire's County Council's Social Care database found that 36 people identified as having ASC are in receipt of direct payments.

The main way for people with autism to access housing in Gloucestershire is through the Housing Options service provided by each district council which helps people to find a suitable home for their needs and/or prevents them from losing their current home. If a specific need was identified, the person would be referred to the Supporting People service who provide short-term housing support to vulnerable groups. If longer term needs were identified, the person would be referred for a social care assessment.

### **Analysis of unmet needs**

There is commitment within Gloucestershire to improving the lives of people with ASC and a real desire for change. However, there is insufficient data on this population on which to effectively base service plans. Services are fragmented/non-existent, particularly for those people with ASC who fall between Learning Disability and Mental Health services and have few other services they can access for support.

The current lack of comprehensive data impacts on the ability to effectively plan and deliver the services that are needed for people with ASC and their carers. The current changes to the JSNA process provide an opportunity to address this. However, the first step is for services to collect data on people with ASC.

Gloucestershire's Joint Commissioner for Mental Health is responsible for commissioning community care services for adults with autism. However, current services do not fully meet the needs of people with ASC. There are plans to develop a strategy for adults with ASC in Gloucestershire following this needs assessment.

Currently, there is mixed evidence that adults with ASC in Gloucestershire are given access to the services and support they need to live independently that are directly relevant to their needs. People with autism and a learning disability are able to access learning disability services. However, the extent to which learning disability services take into account ASC and support people with the specific difficulties faced by people with an ASC is not clear. It should be not assumed that learning disability services automatically meet all the needs of people with autism and a learning disability. This is something that Gloucestershire's ASC Partnership Board should seek assurance of.

Adults with autism and their parents/carers in Gloucestershire report that there is very little support post-diagnosis and feel abandoned. One parent commented “it was very dispiriting to learn.....that there were no specific services made available to adults with ASC in Gloucestershire. At present unless you are already known to the system, care and the organisation of it is left to the family – for a lifetime it seems.” Another parent of an adult diagnosed with Asperger’s felt they were ‘getting by’ but feared that his son will be a ‘costly’ disaster’ for the state when his parents die. This family paid for a private diagnosis and are continuing to pay for psychological support for their son as they have found accessing support locally impossible. This parent concluded that “if we have made any progress, we have done it ourselves on every front, almost despite - not because of - existing services”.

Another parent commented “there is an urgent need to improve services to people with ASC in Gloucestershire that address the whole range of need they have, e.g. social, physical, psychological, language, mental, health, work, educational, housing”.

An adult with autism and a mild learning disability commented “My Mum is the only support I have with my daily living. I call or email her when I don’t understand what I’m supposed to do or what things mean. I need that support because my ASD means I don’t always see things the way they actually are”. This same adult commented “social services need to have a different assessment for the autistic. They weren’t interested that I was isolated, without transport and that I needed help going to appointments”. In regard to trying to access support from a housing association, the same person added “..... Housing told me that didn’t have any suitable accommodation for me as I was a vulnerable adult with ASD”.

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 so that they can feel safe and live on their own. 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 as ASC 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). 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 has recently joined the ASC Professional Reference Group. However, there are no specific housing plans or service provision for people with autism and it is not clear whether the housing needs of this group are being met.

Focus groups held in Gloucestershire with people with Asperger's syndrome and their families in 2009 also 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 (National Institute for Health and Clinical Excellence 2012) may require significant changes to service delivery arrangements. This may be costly but it will also save money in the long term. Parents of adults with ASC in Gloucestershire felt they would benefit from an 'ASC Coordinator' who could act as an intermediary between newly diagnosed adults and services by familiarising people with ASC with the services they are entitled to, supporting adults and families in accessing and securing those services. 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 ASC would be helpful.

There is some evidence that adults with ASC in Gloucestershire are given some support to enable them to live independently for example through some reasonable adjustments to public services. However, this is not yet embedded across all areas of mainstream service delivery. Making reasonable adjustments for people with ASC requires specialist knowledge of what adjustments can help people with ASC and should be part of mainstream service delivery for services who provide services to this group. It should also be linked to training in autism awareness which provides a key opportunity to discuss with service providers how they can make reasonable adjustments. Extending autism awareness training to key group such as primary care staff has already been identified as a priority in a previous section of this report. Providing autism awareness training learning social care support planners, as has been previously mentioned, may help to improve the options available to people with ASC, although these options may be more limited for long-term service users in residential care.

Gloucestershire needs to develop a commissioning plan for adults with ASC which bring together a range of support services. A clear care pathway therefore needs to be developed in Gloucestershire

covering the pathway from diagnosis (or transition to adult services) to health to social care services and other services which support independent living such as housing and employment agencies.

The forthcoming Gloucestershire autism strategy (which should be signed off by Gloucestershire's Health and Wellbeing Board in April 2013) should be accompanied by a commissioning plan that is informed by the recommendations in this needs assessment.

## **Recommendations**

21. 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 (National Institute for Health and Clinical Excellence 2012).
22. Develop commissioning plans for people with ASC. This should include a range of services in line with NICE guidelines (National Institute for Health and Clinical Excellence 2012), including psychosocial interventions and employment support
23. Develop clear pathway following diagnosis (or transition to adult services) from health to social care and services which support independent living. The care pathways should also include liaison with other agencies such as housing and employment agencies) as ASC has an impact on independent living.



## **Appendix 1 – potential local information on people with ASC and services.**

The statutory guidance for local authorities and NHS organisations issued following the Autism Act *Implementing ‘Fulfilling and rewarding lives’* (Department of Health 2010c) outlines the following as information that should be collected in order to plan and commission services for people with ASC:

I. Information on the need for appropriate services, including:

- The number of adults known to have autism in Gloucestershire
- The range of need for support to live independently
- The age profile of people with autism including those approaching 65 and the number of children approaching adulthood to enable partners to predict how need and numbers will change over time.

II. The number of adults with autism who are:

- In employment
- Likely to need employment support in order to work
- Placed in the area by (and funded by) other local authorities
- Placed out of area by local authorities
- In hospital or living in other NHS-funded accommodation
- Resettled from long-stay beds or NHS residential campuses to community provision
- Living at home on their own, or with family members, and not receiving health or social care services
- Living with older family carers

III. The ethnicity, gender, religion or belief and sexual orientation of adults with autism so that local authorities and NHS bodies can understand the number of people from different backgrounds with autism.

## Appendix 2 – Gloucestershire autism awareness training

### Level 1 Autistic Spectrum Disorder Awareness course

**Aim of the course:**

To give participants the opportunity to gain a greater understanding of the difficulties and experiences faced by people with Autistic Spectrum Disorder, (with particular reference to Asperger syndrome), and how to improve outcomes.

**Objectives:**

By the end of this session, each participant will have:

- A greater awareness of Autistic Spectrum Disorder including identification, environmental difficulties and sensory issues
- Fulfilled the requirements of the Disability Discrimination Act
- Discussed examples of good practice and how to improve outcomes

### Level 2 “Supporting Adults with autism and undertaking assessments”

**Aim:** To equip practitioners with the knowledge to support adults with Autism and undertake effective assessments

**Content:**

- Understanding communication strategies
- Placing the individual at the centre of thinking about autism and matching support to the person's needs
- An overview of key laws and policies relating to supporting an adult with ASC and what they mean in practice
- Sources of information/advice to aid supporting an individual with ASC

**Course outline:**

- Quick recap – what is autism?
- Preparing for assessments
- Effective communication using SPELL\*
- Undertaking assessments within SPELL framework
- Partnerships with parents/carers
- Person-centred planning for people with autism
- Service planning and delivery

## **Appendix 3 – survey of parents/carers in relation to transition**

### **People with autism spectrum conditions - parents/carers' views on the transition process.**

NHS Gloucestershire is conducting a needs assessment for adults with autistic spectrum conditions.

As part of this, we are very interested in hearing about the experiences of parents/carers of people with autistic spectrum conditions during the transition from children's to adults services. If you have experience of the transition process, we would very much like to hear your views so that we can include them in the needs assessment.

If you could take a few minutes to answer the following questions, we would be very grateful. The information you provide to us will only be used for the purpose of informing the needs assessment. No personal identifiable information or information about individual will be included and your views will be used to draw out broad themes about the transition process.

-----

1. Does your child have a statement of special educational needs YES/NO (please delete as appropriate)
2. Does your child have:
  - autism with a learning disability YES/NO
  - Asperger's syndrome/higher functioning autism YES/NO
3. Approximately how long ago was your child's transition review meeting (*this information will only be used to identify whether any issues raised are recent or may refer to meetings that took place some time ago*)
  - Within the last year
  - 1-2 years ago
  - 2-3 years ago
  - More than 3 years ago

4. Was a representative from adult social care services present at the year transition review meeting?

YES/NO

COMMENTS

5. Were you informed during the transition process that you were entitled to an assessment of your child's adult social care needs?

YES/NO

COMMENTS

6. Were you informed that you were entitled to a carer's assessment?

YES/NO

COMMENTS

7. Has your child received an assessment of their adult social care needs?

YES/NO

COMMENTS

8. Did you feel you were sufficiently involved in the transition process?  
YES/NO

COMMENTS

9. Do you have any other comments about the transition process?

10. Do you have any other comments you'd like to pass on regarding services for people with autistic spectrum conditions?

## Appendix 4 – Gloucestershire Social services helpdesk enquiry form

Your name:		Main ID:		Completed by:	
<b>FACE Background Information Form v.8</b> <span style="float: right;">Confidential</span>					
<i>Background information &amp; referral details can be collected directly from the person or from someone else on their behalf</i>					
Family name		Given name		Title	
Preferred name		Date of birth		Age	
NHS Number		Social care ID			
Gender		Preferred language			
Ethnicity		Marital status			
Religion		Employment status			
Current address		Current phone number			
Postcode:		Mobile phone number			
Permanent address (if different)		Email address			
Postcode:		Accommodation type			
Lives with		Accommodation tenure			
Contact and visit details					
<b>Alerts</b>					
Known risks to self		Special dietary needs			
Known risks to others		Communication support			
Allergies		Advocate required			
Recent/risk of infection		Mental capacity needs			
Risk of falls		Advance decision made			
<b>Referral details</b> <i>(if self-referral address will be assumed to be as above. If in hospital identify person's ward)</i>					
Referral date		Referral time		Location at referral	
Referral method			Referral type		
Referrer name			Referrer role		
Referrer address (e.g. hospital)	Postcode:		Referrer email		
		Referrer telephone no			
Reason for referral (Identify reason type right then detail)					
Details:					
Is the client aware of the referral? If no why not? <span style="float: right;">Yes <input type="checkbox"/> No <input type="checkbox"/></span>					
Details:					
Date of first contact (with trained staff member)		Time of first contact			
Next of kin		Main carer		Other	
Relationship		Relationship	Age	Relationship	
Tel no		Tel no		Tel no	
Address		Address		Address	
GP		Consultant		Key worker	
Practice		Title		Role	
Tel no		Tel no		Tel no	
Dependents		Partner	<input type="checkbox"/>	Children	<input type="checkbox"/>
		Other adults	<input type="checkbox"/>	Pets	<input type="checkbox"/>
Details:					

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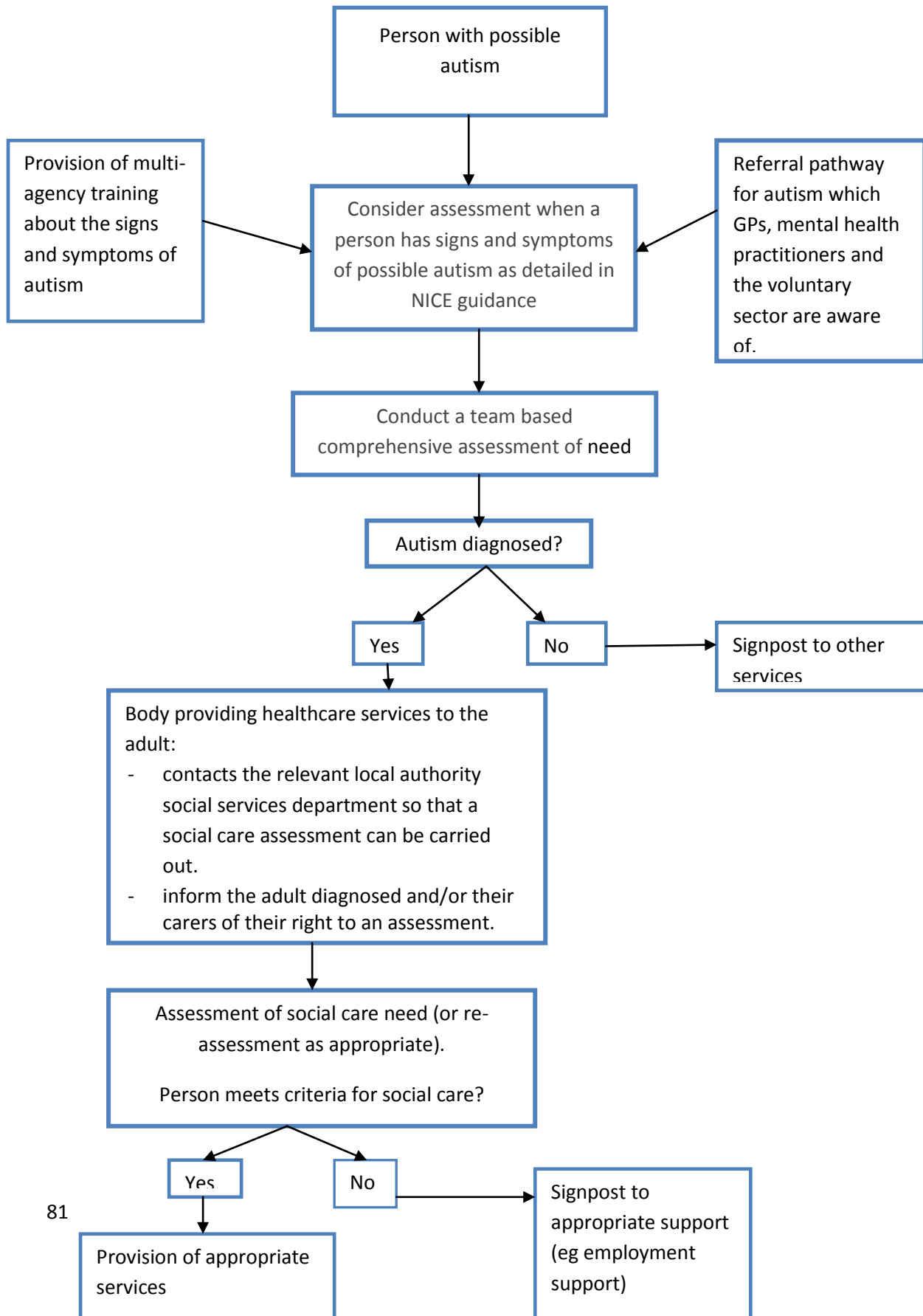
Your name:		Main ID:		Completed by:	
<b>FACE Contact assessment v.8</b>					<b>Confidential</b>
<i>To be completed with the person and/or advocate on person's behalf</i>					
Your main current difficulties and concerns (including perceived impact on life and relevant personal history)					
Details:					
Have there been any important recent events or changes in your life?					Yes <input type="checkbox"/> No <input type="checkbox"/>
Details:					
How you would like your situation to improve					
Details:					
Your family or carer(s) or advocate's views of your situation and what would improve it					
Details:					
Do you have any other difficulties or concerns? (complete other domains as indicated)					Yes <input type="checkbox"/> No <input type="checkbox"/>
<i>If straightforward enquiry, need for aids/equipment only and/or no indication of requirement for holistic assessment go to Next steps and actions on p.4</i>					
Your day-to-day activities (e.g. shopping, laundry, cleaning) (optional)					Problem/need reported <input type="checkbox"/>
Details:					
Your personal care (e.g. dressing, washing, toileting) (optional)					Problem/need reported <input type="checkbox"/>
How often do you need help with your personal care? (per week)					
Details:					
Your mobility (e.g. getting out and about, falls, transfers) (optional)					Problem/need reported <input type="checkbox"/>
Details:					
Your home and living situation (optional)					Problem/need reported <input type="checkbox"/>
Details:					
Your physical health and well-being (optional)					Problem/need reported <input type="checkbox"/>
Details:					
Disabilities, impairments or health conditions (note relevant medical history)					
					Details:

Your name:		Main ID:		Completed by:	
<b>Relevant medical history</b>					
Details:					
Findings of recent observations, screening, tests or investigations				Yes	<input type="checkbox"/>
Details:				None	<input type="checkbox"/>
<b>Medication</b> (relating to physical or mental health problems) (optional)				Problem/need reported	<input type="checkbox"/>
Details:					
<b>Your finances</b> (optional)				Problem/need reported	<input type="checkbox"/>
Details:					
<b>Your relationships and social activities</b> (optional)				Problem/need reported	<input type="checkbox"/>
Details:					
<b>Involvement in work, education or training</b> (optional)				Problem/need reported	<input type="checkbox"/>
Details:					
<b>Your emotional well-being and mental health</b> (optional)				Problem/need reported	<input type="checkbox"/>
Details:					
<b>Safety and risk</b> (consider any safeguarding adults issues)				Problem/need reported	<input type="checkbox"/>
Details:					
<b>Current support</b> (support received at time of referral)					
Do you receive support from family, friends or other local people?				Yes	<input type="checkbox"/>
Details:				No	<input type="checkbox"/>
Do you receive support from social care or health care services?				Yes	<input type="checkbox"/>
Details:				No	<input type="checkbox"/>
Have you specific care or support preferences? (Consider cultural & spiritual preferences)				Yes	<input type="checkbox"/>
Details:				No	<input type="checkbox"/>
About how much additional support do you need at present?					
Details:					
Is your need for support likely to be temporary? (e.g. brief illness, carer absent)				Yes	<input type="checkbox"/>
Details:				No	<input type="checkbox"/>

Your name:		Main ID:		Completed by:	
<b>Summary of Your Needs and the Outcomes You Wish to Achieve</b>					
Domain	Your needs		Outcomes you wish to achieve		
Highest level of need/risk (FACS) None <input type="checkbox"/> Low <input type="checkbox"/> Moderate <input type="checkbox"/> Substantial <input type="checkbox"/> Critical <input type="checkbox"/>					
Does eligibility for NHS continuing care require consideration? (if so use checklist) Yes <input type="checkbox"/> No <input type="checkbox"/>					
<b>Next steps</b> (note actions already undertaken)					
Information & advice					
Referral(s)					
Tests/investigations					
Equipment/adaptations					
Telecare/telehealth					
Re-ablement/rehab					
Crisis support					
Further assessment					
Other actions					
Primary client category (social services only)					
Does mental capacity or deprivation of liberty need further consideration? Yes <input type="checkbox"/> No <input type="checkbox"/>					
Details:					
<b>I agree that this assessment may be shared as needed to support my care:</b>					
Yes <input type="checkbox"/>	Yes, but with limitations <input type="checkbox"/>	No <input type="checkbox"/>	Unable to consent <input type="checkbox"/>		
Details of any limitations:					
Your signature	Date	Signature of your advocate or proxy and printed name	Date		
Assessor's signature and printed name	Date	Proxy telephone number			
Authorised by signature and printed name	Date	Source of proxy authorisation			
Completed by		Contact details (tel)			
Role/profession		Care/support team			



## Appendix 5 – good practice pathway for referral, diagnosis and assessment of autism



## **Appendix 6 - NICE recommendations in relation to the development of care pathways**

1. Local care pathways should be developed to promote implementation of key principles of good care. Pathways should be:
  - negotiable, workable and understandable for adults with autism, their families, partners and carers, and professionals
  - accessible and acceptable to all people in need of the services served by the pathway
  - responsive to the needs of adults with autism and their families, partners and carers
  - integrated so that there are no barriers to movement between different levels of the pathway
  - outcome focused (including measures of quality, service user experience and harm)
2. Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:
  - developing clear policy and protocols for the operation of the pathway
  - ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway
  - making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services
  - supporting the integrated delivery of services across all care settings
  - supporting the smooth transition to adult services for young people going through the pathway
  - auditing and reviewing the performance of the pathway[

The autism strategy group should develop local care pathways that promote

- access to services for all adults with autism, including:
- people with coexisting physical and mental disorders (including substance misuse)

- women
- people with learning disabilities
- older people
- people from black and minority ethnic groups
- transgender people
- homeless people
- people from the traveller community
- people in the criminal justice system
- parents with autism.

When providing information about local care pathways to adults with autism and their families, partners and carers, all professionals should:

- take into account the person's knowledge and understanding of autism and its care and management
- ensure that such information is appropriate to the communities using the pathway

The autism strategy group should design local care pathways that promote a range of evidence-based interventions at each step in the pathway and support adults with autism in their choice of interventions

The autism strategy group should design local care pathways that respond promptly and effectively to the changing needs of all populations served by the pathways. Pathways should have in place:

- clear and agreed goals for the services offered to adults with autism
- robust and effective means for measuring and evaluating the outcomes associated with the agreed goals
- clear and agreed mechanisms for responding promptly to identified changes to people's needs

The autism strategy group should design local care pathways that provide an integrated programme of care across all care settings. Pathways should:

- minimise the need for transition between different services or providers
- allow services to be built around the pathway and not the pathway around the services

- establish clear links (including access and entry points) to other care pathways (including those for physical healthcare needs)
- have designated staff who are responsible for the coordination of people's
- engagement with the pathway

## **Appendix 7 - NICE recommendations in relation to psychosocial interventions for people with core symptoms of autism**

For adults with autism without a learning disability or with a mild to moderate learning disability, who have identified problems with social interaction, consider:

- a group-based social learning programme focused on improving social interaction
- an individually delivered social learning programme for people who find group based activities difficult.

Social learning programmes to improve social interaction should typically include:

- modelling
  - peer feedback (for group-based programmes) or individual feedback (for individually delivered programmes)
  - discussion and decision-making
  - explicit rules
  - suggested strategies for dealing with socially difficult situations.
- 
- Do not provide 'facilitated communication' for adults with autism.

For adults with autism of all ranges of intellectual ability, who need help with activities of daily living, consider a structured and predictable training programme based on behavioural principles.

For adults with autism without a learning disability or with a mild to moderate learning disability, who are socially isolated or have restricted social contact, consider:

- a group-based structured leisure activity programme
- an individually delivered structured leisure activity programme for people who find group-based activities difficult.

A structured leisure activity programme should typically include:

- a focus on the interests and abilities of the participant(s)
- regular meetings for a valued leisure activity

- for group-based programmes, a facilitator with a broad understanding of autism to
- help integrate the participants
- the provision of structure and support.

For adults with autism without a learning disability or with a mild to moderate learning disability, who have problems with anger and aggression, offer an anger management intervention, adjusted to the needs of adults with autism. Anger management interventions should typically include:

- functional analysis of anger and anger-provoking situations
- coping-skills training and behaviour rehearsal
- relaxation training
- development of problem-solving skills.

For adults with autism without a learning disability or with a mild learning disability, who are at risk of victimisation, consider anti-victimisation interventions based on teaching decision-making and problem-solving skills.

Anti-victimisation interventions should typically include:

- identifying and, where possible, modifying and developing decision-making skills in
- situations associated with abuse
- developing personal safety skills.

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