

GLOUCESTERSHIRE COUNTY COUNCIL

# **AUTISM IN GLOUCESTERSHIRE**

---

## **WHAT WE KNOW SO FAR?**

Sola Aruna

9/10/2014

## Contents

Executive Summary.....	2
Background .....	5
Primary Care Audit.....	6
Adult Social Care Data.....	6
Results.....	7
How many people have an autistic spectrum condition in Gloucestershire, where are they and how old are they? .....	7
Age, Gender and Ethnicity Profile of People with Autism in Gloucestershire .....	10
Support Needs of People with Autism .....	12
What carer support is available to people with Autism? .....	15
Living Arrangements of people with Autism .....	15
How many people with Autism are in Employment? .....	17
Mental Health Issues in People with Autism .....	18
People with Autism and Learning Disabilities.....	19
Conclusion.....	19
APPENDIX 1: PRIMARY CARE AUDIT QUERIES .....	21

## Executive Summary

The needs assessment for adults with autistic spectrum conditions which was carried out late 2012 showed there was a relative lack of accurate data on people with Autism in Gloucestershire. It proposed a number of recommendations around data collection including the specific types of data to be collected. The county's Autism Strategy Outcomes and Action Plan subsequently developed specific objectives around data capture and use of better information in the planning and commissioning of services for Gloucestershire's autistic population.

In order to address this data challenge, an audit of autism-related data held in primary care was conducted. This was supplemented by data and information obtained from Gloucestershire County Council's Strategic Needs and Analysis Team that were related to Autism.

The data results of this exercise are as follows:

- Number of people/adults known to have Autism in Gloucestershire
  - The GP audit found that 1,267 people were recorded as diagnosed with Autism with 50 people with suspected Autism but not diagnosed making a total of 1317 people with Autism or suspected Autism. 1,882 people were recorded with Autism, suspected Autism or Asperger's. These numbers are however much lower than the number expected for the county in 2014 (i.e. 4757). **There were 544 adults aged 20 years and above diagnosed with Autism**
  - Gloucester, Stroud and Cheltenham GP Localities currently have the highest **numbers** of potential clients, while Forest, Stroud and Berkeley Vale and Gloucester GP Localities have a greater **proportion** of their practice population having Autism, compared with the county average. Gloucester, Stroud and Forest of Dean districts have the highest numbers receiving social care services.
  - The highest referrals to the enhanced diagnostic service since inception have been from Cheltenham followed by Gloucester GP Locality. However, Stroud and Berkeley Vale Locality has the highest number of people suspected of having Autism but not diagnosed (15), followed by Forest Locality (12).
  - The male to female ration of those diagnosed with Autism is 3.5:1. This compares with a national ratio of 5:1.
- The age profile of people with Autism
  - More than half of those diagnosed with Autism are children and young people aged up to 19 years, while 41% are of working age (20-64 years) with 2.1% being aged 65 years and over. **236 are aged 10-14 years, (i.e. approaching adulthood**, and for whom transition planning should have started); while **13 were found to be aged 60-64 years** (i.e., the upper end of working age). The expected number of older people with Autism will continue to increase in Gloucestershire with the number of older people aged 75+ set to exceed those aged 65-74 years by 2015.
  - There are three times as many children and young with special educational needs (SEN) due to an underlying autistic spectrum disorder who had statements compared with those at School Action Plus in 2012/13. There has been an increasing trend in numbers in both categories over recent years.
- Ethnicity

- The recording of ethnicity at GP practice level was very poor. About a third of people with Autism or suspected Autism had their ethnicity as unknown with a further 6.2% recorded as 'not stated/not recorded/refused'. The greatest majority (21.2%) was recorded as 'White British', while 1.37% was recorded as 'White other'.
- Need for support to live independently
  - The recording of carer status was found to be very poor in the GP audit with almost none existent carer details
  - There have been a total of 77 FACE assessments for people with Autism as a primary disability since December 2012. 5% were in older people (65+ years), while the rest (95%) were in people aged 16 to 64 years of age.
  - The greatest number of people using adult social care services care is in the 16-24 age band with and 11 % aged 65+ years.
  - Amongst adults with Autism who are social care service users, the highest proportions of those of working age were from Gloucester and Stroud districts, while the highest proportion of older people was from Cheltenham district. The GP audit showed a higher rate of service use by people with Autism in Forest, North Cotswold and Gloucester Localities compared with the county average
  - 16 service users live outside the county
- Living arrangements
  - The recording of living arrangements was also very poor in the GP audit. Among the 252 with records, 11% were living in a residential home, 2.4% in a care home, about 2% living with relatives and 0.46% living alone with help available. North Cotswold GP locality had the highest proportion living alone. These figures are however likely to be gross underestimations as residential status of 81% is unknown.
  - Amongst the 430 adults with Autism using social care services with records, 69% (298) are recorded as living at a private address, 27% (114) in residential care for personal care, and 2% (10) in residential care for nursing care.
- Placements
  - Of the 430 adults with Autism using social care services, 1.9% (8) are in adult placement
  - Gloucestershire County Council does not hold information on service users placed in the county by other local authorities
- Employment
  - The recording of employment status was very poor in the GP audit. Of those with records, 7.7% were recorded as ever being employed, with lowest rates in North Cotswold and South Cotswold GP localities. 1.6% were recorded as not ever been in employment. This compares with a national figure of 15% in full-time paid employment.
- Other health conditions
  - 8.7% of people with Autism/suspected Autism/Asperger's are also diagnosed with Depression, while 15.2% are also diagnosed with Anxiety.
  - 72% of those recorded with Autism or suspected Autism were also diagnosed with a learning disability. This is higher than the expected rate of about 56%.

- 58.78% of people with Autism and learning disabilities were found to have had a health check. This compares with a level of 69.95% (in 2012/13) among people with Learning Disabilities in Gloucestershire

## Conclusion

The primary care audit and data from social services have greatly improved our knowledge of the autistic population in Gloucestershire. There are however still a number of gaps that need to be filled. No information was found about adults with Autism who are:

- Likely to need employment support
- Placed in the area by (and funded by) other local authorities
- In hospital or living in other NH-funded accommodation
- Resettled from long-stay beds or NHS residential campuses to community provision

The Joint Commissioner and other partners on the ASC Board may be able to help fill these gaps.

The recording in primary care of ethnicity, employment status, carer details and living arrangements need to be greatly improved. PCCAG is providing feedback to GP practices. A re-audit in future following advice from PCCAG, will help assess improvements in these areas.

The identification and ascertainment of adults with Autism still needs some work. Awareness raising/training of GPs (especially in the Forest and Stroud and Berkeley Vale Localities) and other health professionals needs to continue.

The ASC Network Group may wish to extend its reach to areas with high numbers of people with Autism e.g. Gloucester, Stroud, and Forest of Dean.

The great majority of people diagnosed with Autism and those current using social care services are of working age. This makes the provision of appropriate employment support very important. Work related initiatives may need to be targeted e.g. to areas like North Cotswold, South Cotswold and Forest localities which have low levels of employment in people with Autism.

The ASC Board should review and re-assure itself that there is a working process in place which ensures that every adult with Autism gets a social care assessment.

Alternative support needs (outside of health and social care) may be of importance for adults in Forest, North Cotswold (especially for those living alone) and Gloucester Localities.

The mental health needs of adults with Autism need to be addressed to the same level as the needs of those without Autism.

Health checks carried out in adults with both Autism and Learning Disabilities needs to be monitored and improved.

This report can complement the existing needs assessment to inform the Joint Strategic Needs Assessment on Autism.

## Background

A needs assessment for adults with autistic spectrum conditions was carried out late 2012 which helped inform the development of the county's autism strategy. The relative lack of accurate data on people with Autism led to this assessment having a number of recommendations around the need for relevant services in the county to improve their collection of data on people with an autistic spectrum condition.

There was also a recommendation on the type of information to be collected, in line with relevant parts of the statutory guidance *Implementing 'Fulfilling and Rewarding Lives'*<sup>1</sup>. These are:

- 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.
- 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
- 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.

The resultant Gloucestershire Autism Strategy Outcomes and Action Plan has specific objectives around data capture and use of better information about Gloucestershire's autistic population in the planning and commissioning of services. Furthermore, it is envisaged that all agencies represented on the Autistic Spectrum Condition Partnership Board (ASCPB) would be identifying and coding services users with an autistic spectrum condition, and that the county's Joint Strategic Needs Assessment (JSNA) will include relevant data on autism.

---

<sup>1</sup> Department of Health (2010). *Implementing 'Fulfilling and Rewarding Lives'*. Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy

## Primary Care Audit

Given the challenges identified in terms of collecting accurate information on people with Autism, it was recognised that primary care would be a logical place to start with this, given that this was a service that everyone (including people with Autism) was likely to use.

An audit process was subsequently developed to help ascertain what information was available in primary care. It was also envisaged that the audit would support GPs' work by:

- Providing information on the health of the Autism registered population – particularly information on those also with Learning Disabilities (LD) or Asperger's Syndrome having a health check, and identification of depression and anxiety.
- Reviewing the Autism register and identifying additional people who might need to be included.
- Informing GP Locality Groups and CCG commissioners of pertinent information on Autism as they develop their commissioning strategies and consider specific support required for patients.
- Improving patient pathways from primary through to secondary care, and to support good practice in making reasonable adjustments that ensure equity of health outcome.
- Improving the recording of information on: carers, employment, living arrangements and referrals/seen by other services.

The audit which ran in December 2013 had a 100% response to it with all 85 Practices in the county taking part. All Practices are affiliated to one of seven localities<sup>2</sup> namely:

1. Cheltenham – 17 Practices
2. North Cotswold – 5 Practices
3. South Cotswold – 8 Practices
4. Forest – 11 Practices
5. Gloucester – 19 Practices
6. Stroud and Berkeley Vale – 20 Practices
7. Tewkesbury, Newent and Staunton – 5 Practices

The audit queries/questions are detailed in Appendix 1

## Adult Social Care Data

The Strategic Needs and Analysis Team at Gloucestershire County Council provided Autism-related data from data they hold on adults using social care services

---

<sup>2</sup> Note that localities do not map well to local authority boundaries in a number of cases. Stroud & Berkeley Vale Locality is coterminous with Stroud District Council, North and South Cotswold Localities are coterminous with Cotswold District Council, and Cheltenham Locality is largely coterminous with Cheltenham Borough Council, except for Winchcombe Medical Practice. Gloucester Locality is largely coterminous with Gloucester City Council, except for Churchdown and Brockworth Surgeries. Tewkesbury Locality includes Newent and Staunton Surgeries.

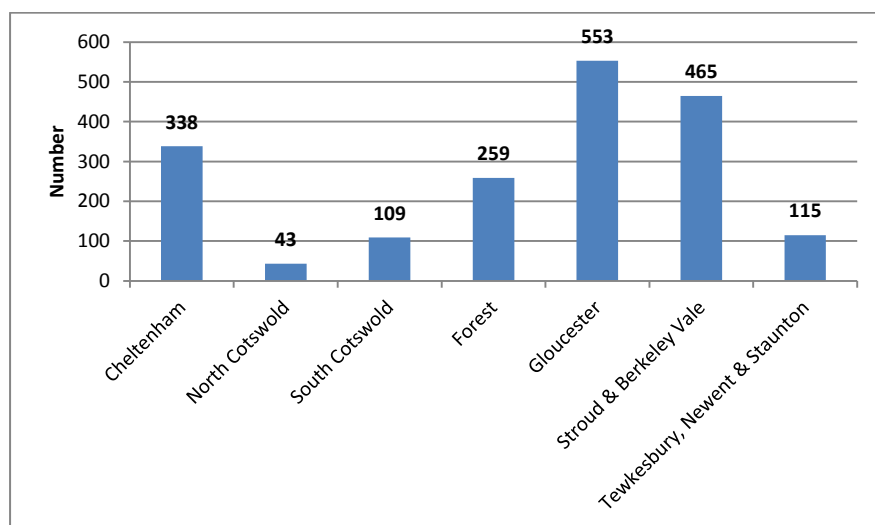
## Results

### How many people have an autistic spectrum condition in Gloucestershire, where are they and how old are they?

The GP audit found that a total of **1,267 people were recorded as diagnosed with Autism**. There were also 50 people with suspected Autism but not diagnosed making a total of **1317 people with Autism or suspected Autism**. In order to capture as many people as possible, given the fact that not everyone meeting relevant criteria would have had a formal diagnosis, the audit found a total of **1,882 people recorded with Autism, suspected Autism or Asperger's, (variable across the GP localities)** which is equivalent to 0.3% of the total GP registered population of 625,830<sup>3</sup> or **0.1% of the GP adult (20+ years) population of 485,376**. What this suggests is that we may still have some way to go in terms of accurately identifying/ascertaining everyone with autism, especially as national estimates<sup>4</sup> suggest that there may be about to 1.1% (ranging from 0.3% to 1.9%) of the adult population having Autism. The POPPI and PANSI databases<sup>5</sup> show that a total of 4757 adults (18+years) are predicted to have Autism in Gloucestershire in 2014, i.e. almost nine times the number of adults identified in this audit.

The audit shows that Gloucester, Stroud and Cheltenham GP Localities currently have the highest numbers of potential clients (Figure 1).

Figure 1: Number of People with Autism, suspected Autism or Asperger's in Gloucestershire by GP Locality



Source: Gloucestershire Primary and Community Care Audit Group (PCCAG)

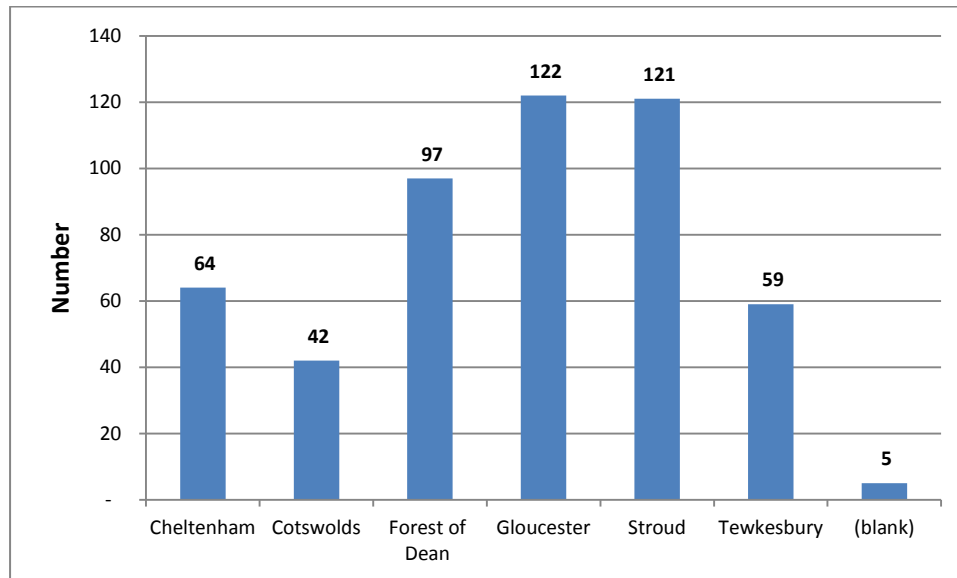
<sup>3</sup> As at Q3 2013/14

<sup>4</sup> NHS Information Centre (2012). Estimating the prevalence of Autistic Spectrum Conditions in Adults: extending the 2007 Adult Psychiatric Morbidity Survey. <http://www.hscic.gov.uk/catalogue/PUB05061/esti-prev-auti-ext-07-psyc-morb-surv-rep.pdf>

<sup>5</sup> POPPI (Projecting Older People Population Information System) <http://www.poppi.org.uk/index.php?pageNo=428&PHPSESSID=fcrq7shnm168jm84bbs7pbk3u0&sc=1&loc=8260&np=1> . PANSI (Projecting Adult Needs and Service Information System) <http://www.pansi.org.uk/index.php?pageNo=392&PHPSESSID=fcrq7shnm168jm84bbs7pbk3u0&sc=1&loc=8260&np=1>

Data held by Gloucestershire County Council on all adult social care service users receiving any services since April 1<sup>st</sup> 2011, showed that 510 adults (out of 53,216) were recorded as having Autism. Figure 2 shows that the districts with the highest numbers are Gloucester and Stroud districts, followed by Forest of Dean.

Figure 2: Adults (18 years+) Recorded by Gloucestershire County Council as having Autism by Local Authority

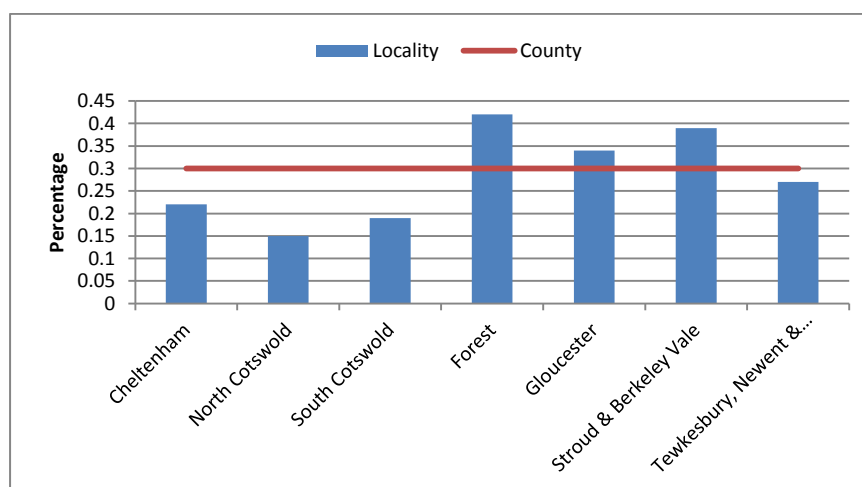


Source: GCC Strategic Needs and Analysis Team

The distribution in Figure 1 and Figure 2 is important in terms of helping to determine the shape of any service response across the county. In terms of self help and support and with their strong presence in Cheltenham, the Autism Network Group may therefore want to extend its reaches to Gloucester, Stroud and Forest of Dean where numbers are relatively high.

In terms of relative need however, Figure 3 however suggests that Forest, Stroud and Berkeley Vale and Gloucester GP Localities have a greater **proportion** of their practice population having Autism, compared with the county average, which represent higher needs in these areas.

Figure 3: Proportion of GP Locality Practice Population with Autism, suspected Autism or Asperger's



Source: Gloucestershire Primary and Community Care Audit Group (PCCAG)

In terms of awareness raising and training, the ASC Board may need to review the publicity and uptake of its training programme to check that GP practices and their staff in these localities are benefitting as appropriate from the various training and supportive activities that are available.

Information was received from the Autism Enhanced Diagnosis Service in relation to the number of referrals received from GPs since the inception of the service in April 2013. The highest referrals have been from Cheltenham followed by Gloucester GP Locality (Table 1).

**Table 1: Referrals to Enhanced Diagnostic Service by GP Locality May 2014**

<b>GP Locality</b>	<b>No. of Referrals for Diagnosis</b>
Cheltenham	25
North Cotswold	*
South Cotswold	6
Forest	11
Gloucester	19
Stroud & Berkeley Vale	11
Tewkesbury, Newent & Staunton	5
Total	79

Source: Zgether NHS Foundation Trust ASC Enhanced Diagnostic Service

It is reassuring to note from the audit that only 0.01% (50 out of 1317) of people suspected of having Autism have not been diagnosed. This is assuming however that GPs have a sufficiently high level of awareness of the current process and criteria for accessing the diagnostic service. There may however be a need to ensure that all GPs are aware of this and perhaps target specific practices with relatively high numbers of undiagnosed people. Table 2 shows that within the GP localities, Stroud and Berkeley Vale Locality has the highest number of people suspected of having Autism but not diagnosed (15), followed by Forest Locality (12). Table 1 above however shows that the highest referrals to the diagnostic service have not been from these two localities.

**Table 2: Diagnosis in People suspected of having Autism by GP Locality**

<b>GP Locality</b>	<b>No. of people suspected but not diagnosed</b>
Cheltenham	6
North Cotswold	0
South Cotswold	6
Forest	12
Gloucester	9
Stroud & Berkeley Vale	15
Tewkesbury, Newent & Staunton	*

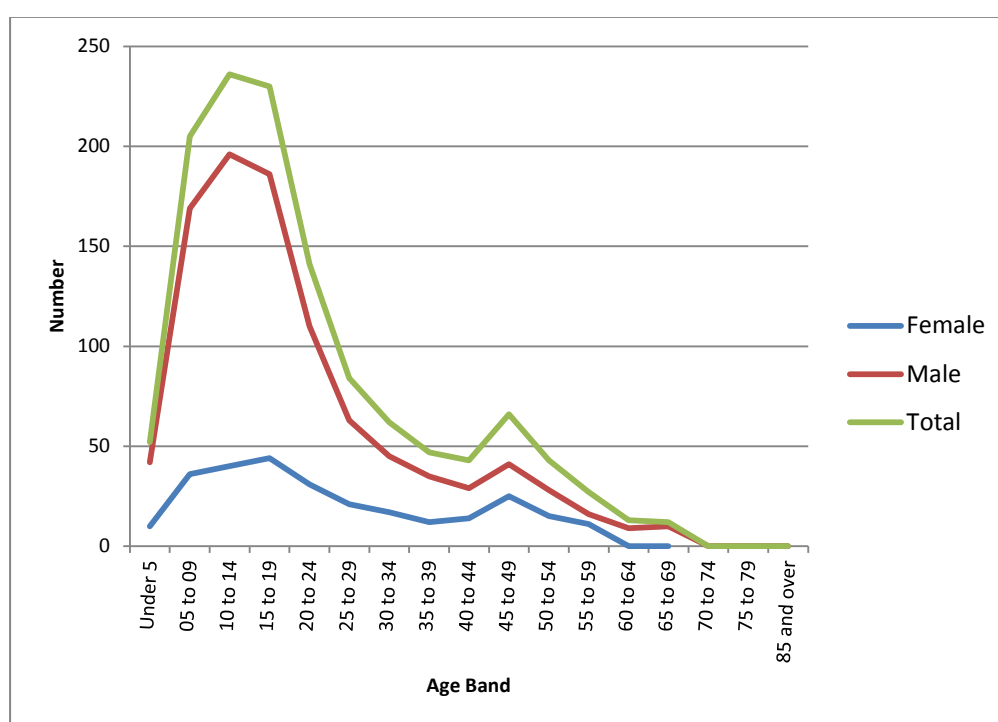
Source: Zgether NHS Foundation Trust ASC Enhanced Diagnostic Service

## Age, Gender and Ethnicity Profile of People with Autism in Gloucestershire

Of the 1,276 people found to be diagnosed with Autism in the GP audit, 984 were males and 283 were females, a **ratio of 3.5:1**. The National Autistic Society estimates there are five times as many males with Autism as there are females<sup>6</sup>.

Figure 4 which shows the age and gender distribution from the GP audit indicates that more than half (723) of those diagnosed with Autism are children and young people aged up to 19 years, while 41% are of working age (20-64 years) with only 2.1% of people diagnosed with Autism being aged 65 years and over. 236 (18.5%) of those diagnosed with Autism are aged 10-14 years, and so can be **regarded as approaching adulthood**, and for whom transition planning should have started; while 13 were found to be aged 60-64 years, the upper end of working age.

Figure 4 : People with Autism known to GPs in Gloucestershire by Gender and Age Band

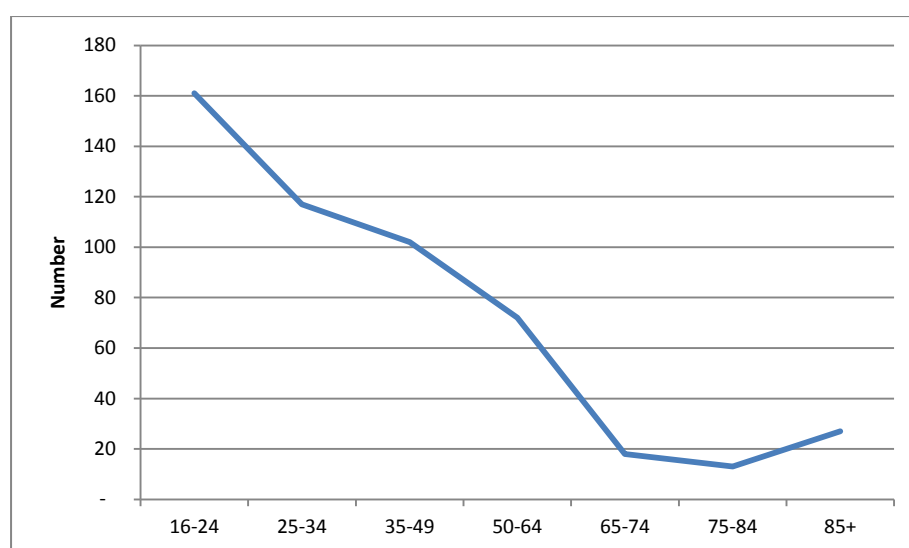


Source: Gloucestershire Primary and Community Care Audit Group (PCCAG)

GCC data on 510 adults using social services with Autism shows that the greatest numbers are in the 16-24 age band with numbers also falling with age (Figure 5) and 11 % (58) aged 65+ years.

<sup>6</sup> <http://www.autism.org.uk/About-autism/Myths-facts-and-statistics/Statistics-how-many-people-have-autism-spectrum-disorders.aspx>

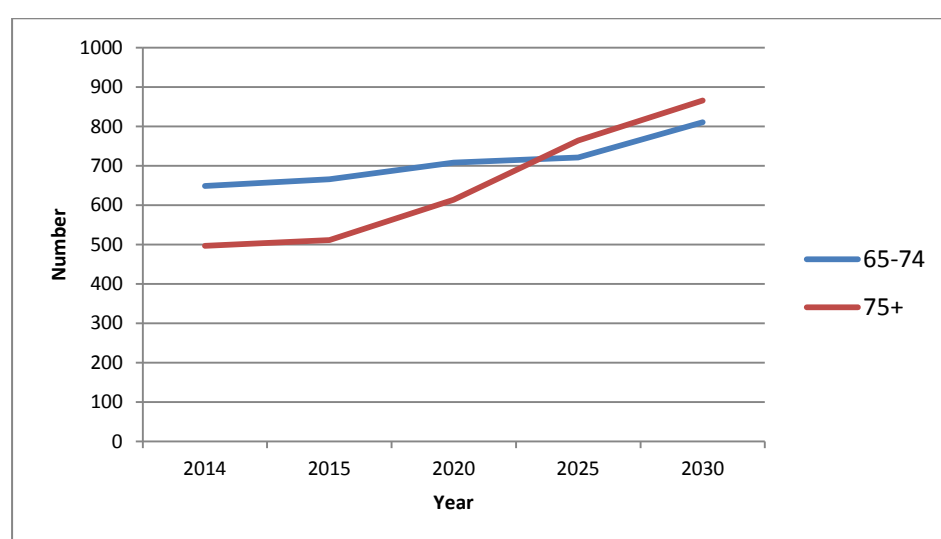
Figure 5: Adult Social Care Services Users with Autism in Gloucestershire by Age Band



Source: GCC Strategic Needs and Analysis Team

Despite there being a relatively small number of older people with Autism currently, the POPPI data<sup>7</sup> on predicted numbers of people with Autism in Gloucestershire, indicates that expected numbers of older people will continue to increase. Figure 6 shows that the number of older people aged 75+ with Autism is set to exceed those aged 65 – 74 years by 2025.

Figure 6: Projected Trend of Older People with Autism in Gloucestershire, 2014 - 2030



Source: POPPI/PANSI

Available GCC data on children and young people (CYP) with special educational needs (SEN) shows that a total of 377 who had Statements<sup>8</sup> or were assessed as needing support at School Action Plus<sup>9</sup>

<sup>7</sup>

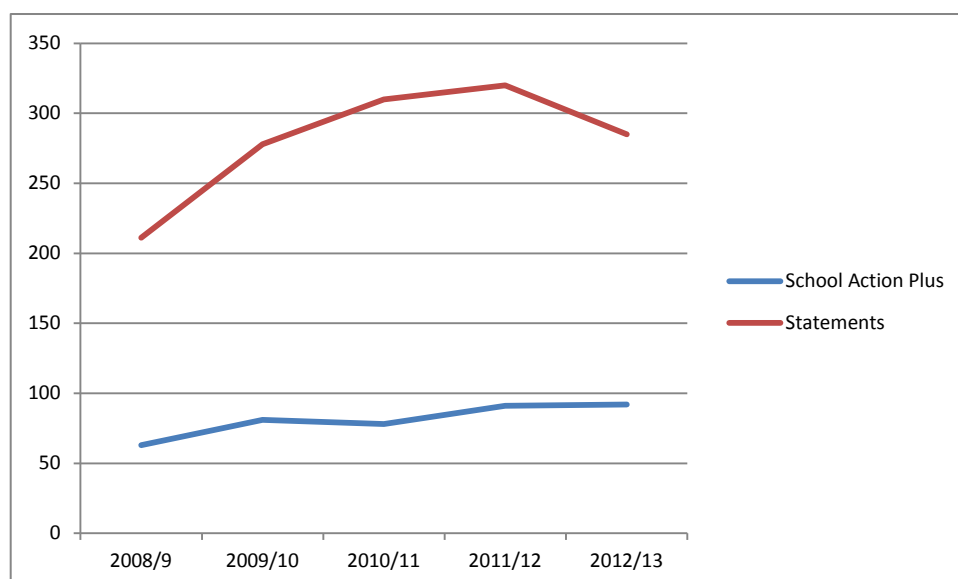
<http://www.poppi.org.uk/index.php?pageNo=428&PHPSESSID=isf4m3ac7ard8ou41jhucvi9b7&sc=1&loc=8260&np=1>

<sup>8</sup> Those in need of the most intensive support for their additional learning needs are given a Statement of Special Educational Needs

<sup>9</sup> Staff working with such children should receive advice or support from outside specialists

in the 2012/13 academic year had Autistic Spectrum Disorder (ASD) as their recorded underlying SEN need. This represented 7.8% of all who had statements or were at School Action Plus. There were **three times as many CYP with ASD who had statements compared with those at School Action Plus**. Figure 7 also shows that there has been an **increasing trend in numbers in both categories over recent years**.

**Figure 7 : Children and Young People with Special Educational Needs as a result of Autistic Spectrum Disorder, 2008/9 to 2012/13**



Source: GCC Strategic Needs and Analysis Team

**Ethnicity – the recording of this at GP practice level was very poor.** About a third (32.1%) of 1,317 people with Autism or suspected Autism had their ethnicity as unknown in the GP audit, with a further 6.2% recorded as ‘not stated/not recorded/refused’. 21.2% had their ethnicity recorded as ‘White British’, while 1.37% was recorded as ‘White other’.

## Support Needs of People with Autism

Nationally, 61% of adults surveyed in 2012 said their local authority had never assessed their needs as an adult<sup>10</sup>. Though we do not have an estimate of this locally, we however explored the data held by Gloucestershire County Council on adult social care assessments. Table 3 shows that there are currently huge gaps in the data, and that **since December 2012, there have been a total of 77 assessment for people with Autism as a primary disability**. This compares with a total of 666 for people with a learning disability over the same time period. Of the 77 assessments for Autism, 5% were in older people, while the rest (95%) were in people aged 16 to 64 years of age.

<sup>10</sup> <http://www.autism.org.uk/about-autism/myths-facts-and-statistics/myths-and-facts.aspx>

**Table 3: All FACE Table Primary Disabilities for FACE Assessments in Gloucestershire since December 2012**

<b>FACE table primary disability</b>	<b>16-24</b>	<b>25-34</b>	<b>35-49</b>	<b>50-64</b>	<b>65-74</b>
Null	41	42	122	265	302
Dementia(including Alzheimer's)			4	18	94
Arthritis	2	2	32	85	120
Learning disability	139	138	191	158	40
Neurological condition	11	27	63	104	100
Cardiac condition	1	3	4	16	44
Physical impairment	19	25	42	48	51
Stroke	1		14	41	58
Other physical illness	8	13	23	42	44
Cancer	1		4	44	63
Diabetes		2	9	36	46
Sensory impairment	5	10	15	22	16
Physical injury	1	7	19	17	19
Respiratory condition	2	1	7	15	27
COPD			2	13	24
Depression/anxiety	1	2	7	18	17
Other mental health problem	5	6	10	12	16
Autism/autistic spectrum	26	23	17	7	4
Sensory impairment (dual)		1	3	3	6
Head injury (including Acquired Brain Injury)	2	9	14	22	7
Epilepsy	4	8	8	10	5
Severe mental illness		1	3	5	11
Not known	2	1	2		3
Substance misuse			3	6	4
None known			1	3	
Serious infection (viral or bacterial)			1	2	
Severe sensory impairment				1	
Fracture				1	
Not applicable			1		
<b>Total</b>	<b>271</b>	<b>321</b>	<b>621</b>	<b>1014</b>	<b>1121</b>

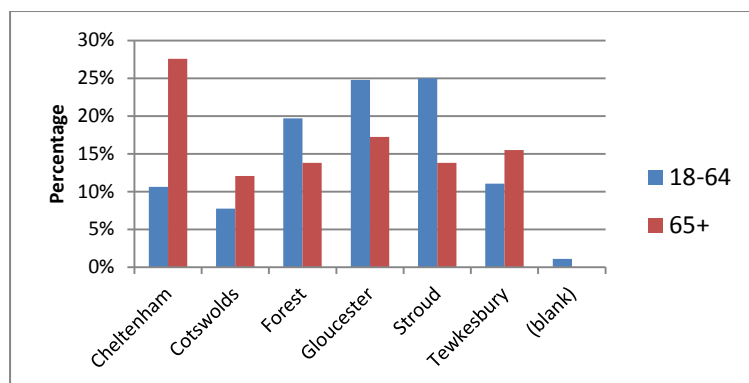
Source: GCC Strategic Needs and Analysis Team

We would need to reassure ourselves that we have processes in place that ensure everyone diagnosed with Autism gets a social care assessment as laid down in guidance.

[GCC data on the 510 people with Autism recorded as using adult social services gives an indication of how they are of how they are spread across the district councils.](#)

Figure 8 shows that Gloucester and Stroud districts have the highest proportion of people of working age with Autism as social care service users. This may have implications for the appropriate provision of employment support across the county. Cheltenham district has the highest proportion of older people with Autism using adult social care services in the county.

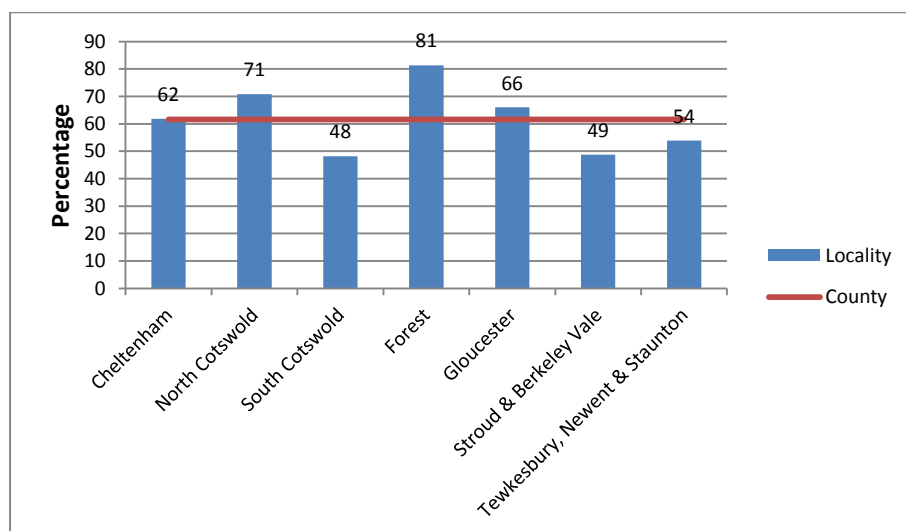
**Figure 8: Adult Social Care Service Users with Autism by Age Band and Local Authority**



Source: GCC Strategic Needs and Analysis Team

The GP audit was unable to identify specific support needs of people with Autism as the codes used within GP systems (Read Codes<sup>11</sup>) do not include codes for these. There are however codes for people seen by 'services' (health or social care), and these were applied in the audit as a proxy for meeting identified need. Figure 9 shows that there is a higher rate of service use by people with Autism in Forest, North Cotswold and Gloucester Localities compared with the county average. It is instructive to see that North Cotswold locality which has the lowest proportion of its practice population with Autism (Figure 9); however seems to have the second highest proportion with identified need after Forest Locality. The relatively higher use of services by people with Autism in Forest, North Cotswold and Gloucester localities may point to a higher level of health and social care need or a relative lack of alternative support systems available to them.

**Figure 9: Proportion of People with Autism or Suspected Autism who have been seen by Services by GP Locality**

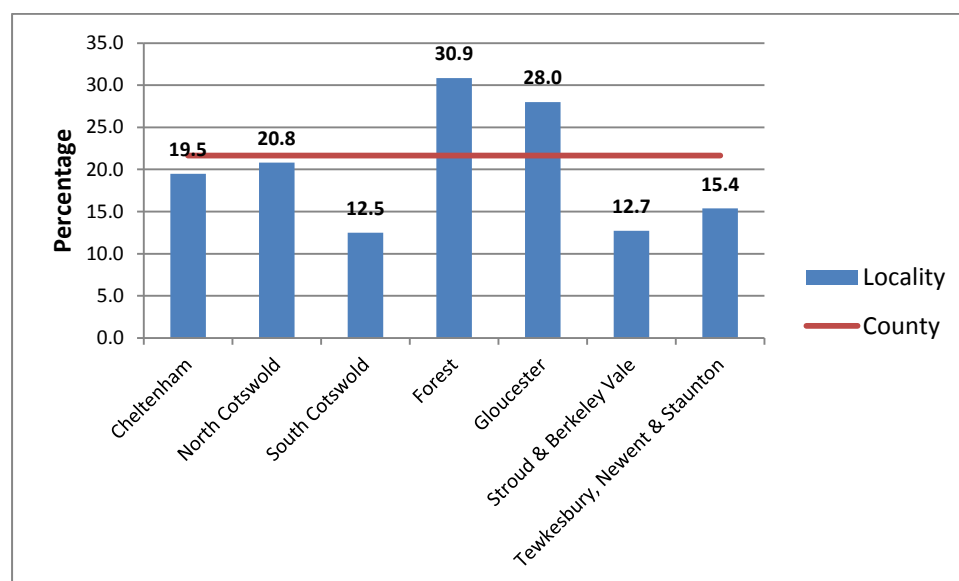


<sup>11</sup> The standard clinical terminology system used in General Practice in the United Kingdom. It supports detailed clinical encoding of multiple patient phenomena including: occupation; social circumstances; ethnicity and religion; clinical signs, symptoms and observations; laboratory tests and results; diagnoses; diagnostic, therapeutic or surgical procedures performed; and a variety of administrative items

## What carer support is available to people with Autism?

People with Autism can have available to them family or paid carer support. It was difficult to understand through the GP audit, what carer support (if any) was available to people with Autism as **only 285 patients (22% out of 1317 diagnosed or suspected Autism) had a record of whether or not they had a carer – two were recorded as not having a carer.** Figure 10 shows that only Forest and Gloucester GP Localities had their recordings higher than county average.

Figure 10: Proportion of People with Autism or Suspected Autism with their Carer Status Recorded by GP Locality



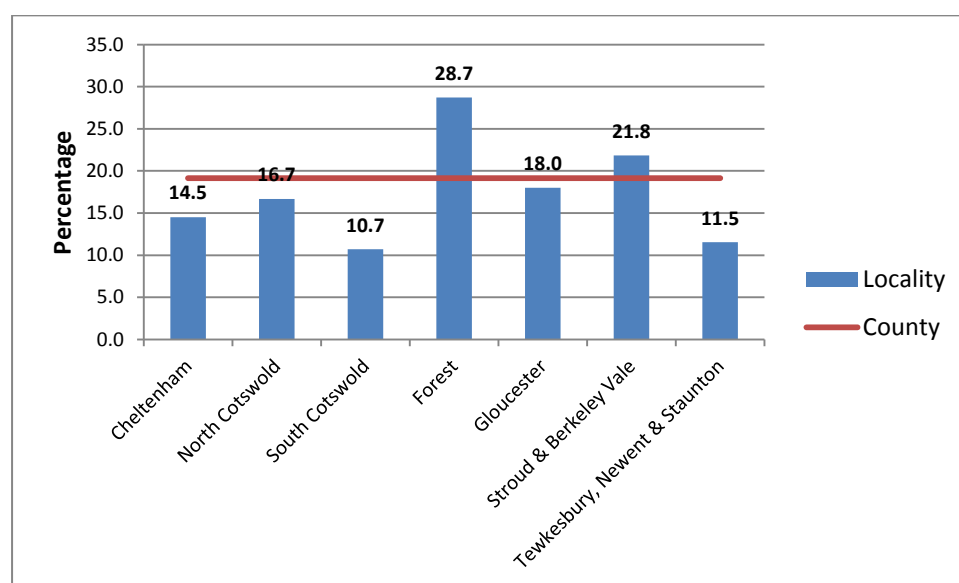
Source: Gloucestershire Primary and Community Care Audit Group (PCCAG)

For the 285 patients with a recorded status, only two GP localities had any details of their carers recorded – Stroud and Berkeley Vale with 0.3% of its patients and Tewkesbury, Newent and Staunton with 1.28% of their patients. South Cotswold was the only GP Locality with a record of those without a carer. This is obviously an area that requires significant improvement in recording and this has been reflected in the individual feedback that has gone back to Practices. Improvement would include the recording of the gender, age and ethnicity of carers who are not paid carers. A re-audit in the future will show any subsequent improvement in this.

## Living Arrangements of people with Autism

The GP audit showed that the recording of this was also poor with just 252 (19%) of people with Autism/suspected Autism having a record of their living arrangements. Figure 11 shows that apart from Forest and Stroud and Berkeley Vale Localities, the other five GP localities recording rates are lower than the county average.

**Figure 11: Proportion of People with Autism or Suspected Autism with their Living Arrangements Status Recorded by GP Locality**



Source: Gloucestershire Primary and Community Care Audit Group (PCCAG)

Table 4 details the residential status of most of those with a record with **11% living in a residential home, 2.4% in a care home and about 2% living with relatives**. These figures are however likely to be gross underestimations as residential status of 81% is unknown.

**Table 4: Residential Status of People with Autism or Suspected Autism**

Residential Status	% with Autism or Suspected Autism
UNKNOWN	80.87%
Lives in a residential home	11.09%
Lives in care home	2.43%
Lives with relatives	1.90%
Resident in sheltered accommodation	0.68%
Residential institution	0.53%
Institutional place of residence	0.53%
Lives alone help available	0.46%

Source: Gloucestershire Primary and Community Care Audit Group (PCCAG)

The GP locality with the highest proportion of people with Autism/suspected Autism living alone is North Cotswold, which has the lowest number/proportion.

With a national survey in 2012 shows that 28% of adults with Autism still lived with their parents<sup>12</sup>, it may therefore still be the case that a substantial proportion of those with unknown status may in fact be living at home with family members.

GCC data provided showed that of the 430 adult social care service users with Autism recorded in an assessment (though this may not be the reason for which they are receiving support), **69% live at a private address**. Table 5 gives more details of this.

<sup>12</sup> <http://www.autism.org.uk/about-autism/myths-facts-and-statistics/myths-and-facts.aspx>

**Table 5: Living Arrangements of GCC Adult Social Care Service Users with Autism Recorded in an Assessment**

Address Type	Service Users
Private Address	298
Residential – Personal Care	114
Residential – Nursing Care	10
Residential – Adult Placement	8
<b>Total</b>	<b>430</b>

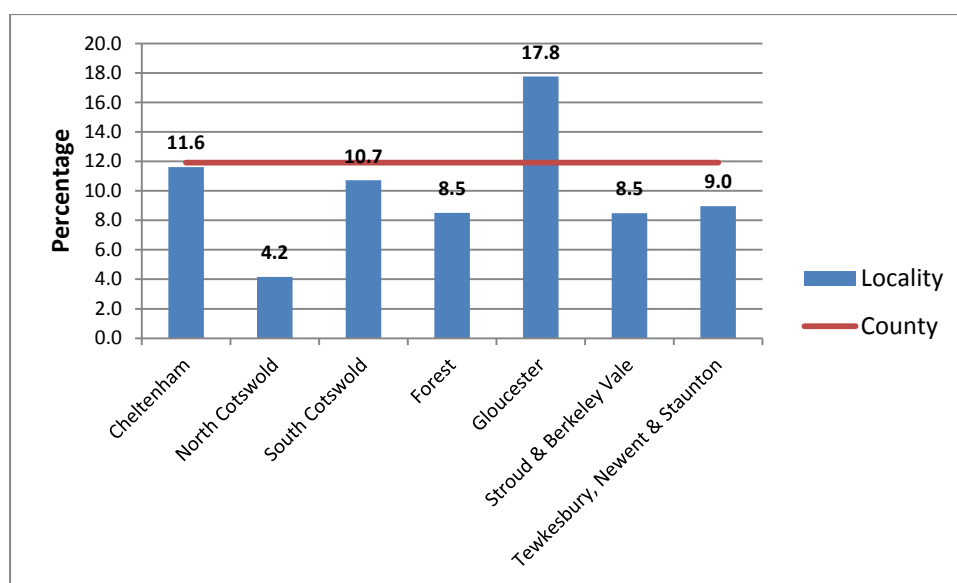
Source: GCC Strategic Needs and Analysis Team

**16 of the service users live outside Gloucestershire** while GCC holds no information on service users placed in Gloucestershire from other local authorities.

### How many people with Autism are in Employment?

The recording of this was very poor in the GP Audit with only 157 people having a record of their employment status out of a total of 1,317 people with Autism or suspected Autism (i.e. 12%). Gloucester GP Locality has the highest rate of recording.

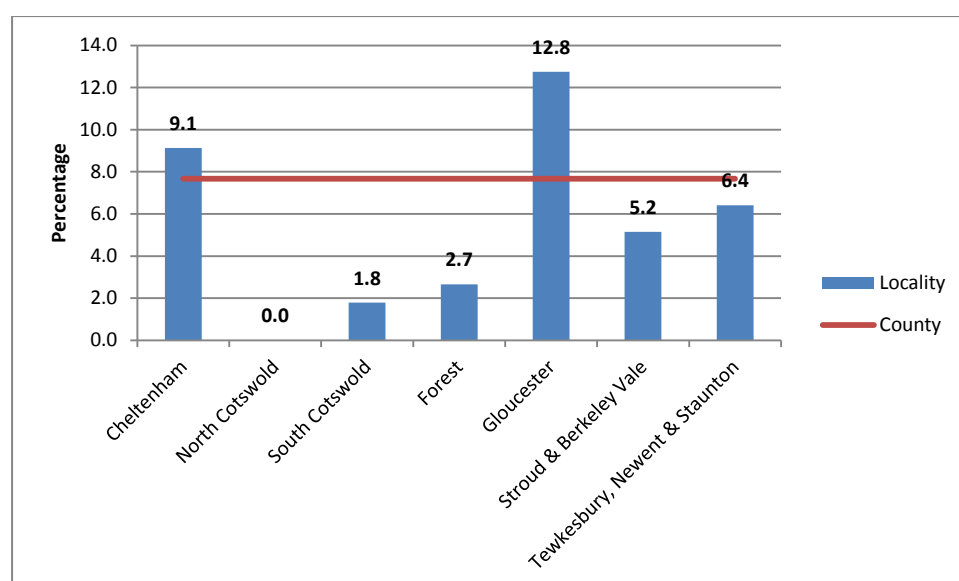
**Figure 12: Proportion of People with Autism or Suspected Autism with their Employment Status Recorded by GP Locality**



Source: Gloucestershire Primary and Community Care Audit Group (PCCAG)

This poor state of recording may be because GPs are more likely to record employment status for people who are in employment. 101 (7.7%) were recorded as ever being employed, while 21 (1.6%) were recorded as not ever been in employment. Nationally, only 15% of adults with autism in the UK are estimated to be in full-time paid employment, with about half having spent time without jobs nor access to benefits, 1 in 10 of who have been in this situation for at least a decade. This is despite the fact that the great majority of those unemployed or on benefits would like to be in work. Figure 13 shows that Cheltenham and Gloucester Localities currently have higher than average rates (Gloucester highest) while North Cotswold has no one recorded as being in work. This may help target work-related initiatives to areas of more need (e.g. North and South Cotswold and Forest Localities)

**Figure 13: Proportion of People with Autism or Suspected Autism Recorded as being in Work by GP Locality**

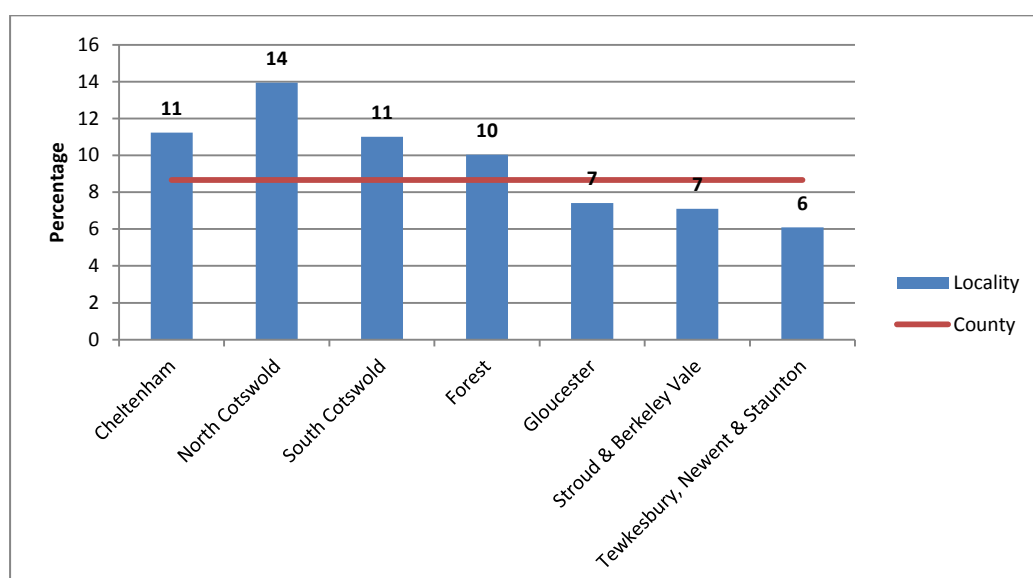


Source: Gloucestershire Primary and Community Care Audit Group (PCCAG)

## Mental Health Issues in People with Autism

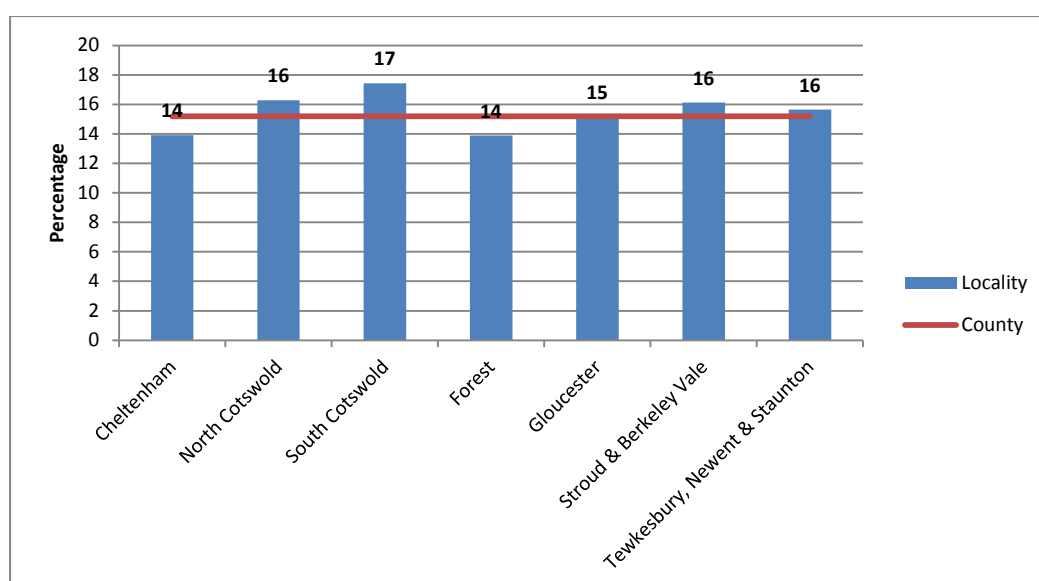
People with Autism or Asperger syndrome are known to be particularly vulnerable to mental health problems such as anxiety and depression, especially in late adolescence and early adult life. In the county as a whole, 8.7% of 1882 people with Autism/suspected Autism/Asperger's are also diagnosed with Depression, with a higher proportion (15.2%) diagnosed with Anxiety. The picture varies across the localities as shown in Figure 14 and Figure 15

**Figure 14: Proportion of People with Autism/suspected Autism/Asperger's also diagnosed with Depression by Locality**



Source: Gloucestershire Primary and Community Care Audit Group (PCCAG)

Figure 15: Proportion of People with Autism/suspected Autism/Asperger's also diagnosed with Anxiety by GP Locality



Source: Gloucestershire Primary and Community Care Audit Group (PCCAG)

## People with Autism and Learning Disabilities

The Learning Disability Observatory (Improving Health and Lives)<sup>13</sup> estimates that between 20% and 33% of adults with a learning disability also have an autistic spectrum condition. It is also estimated that 56% of people with ASC have a learning disability<sup>14</sup>. The GP audit found that there were 951 people with recorded Autism who were also diagnosed as having with Learning Disability representing 72% of those recorded with Autism or suspected Autism. 58.78% of people with Autism and learning disabilities were found to have had a health check. This compares with a level of 69.95% for 2012/13 among people with Learning Disabilities in Gloucestershire.<sup>15</sup>

## Conclusion

The primary care audit and data from social services have greatly improved our knowledge of the autistic population in Gloucestershire. There are however still a number of gaps that need to be filled. No information was found about adults with Autism who are:

- Likely to need employment support
- Placed in the area by (and funded by) other local authorities
- In hospital or living in other NH-funded accommodation
- Resettled from long-stay beds or NHS residential campuses to community provision

The Joint Commissioner and other partners on the ASC Board may be able to help fill these gaps.

<sup>13</sup> <http://www.improvinghealthandlives.org.uk/>

<sup>14</sup> National Institute for Health and Clinical Excellence. Recognition, referral, diagnosis and management of adults on the autism spectrum. National Clinical Guideline Number 142. <http://guidance.nice.org.uk/CG142> 2012.

<sup>15</sup> <http://www.improvinghealthandlives.org.uk/numbers/healthcheck2013>

The recording in primary care of ethnicity, employment status, carer details and living arrangements need to be greatly improved. PCCAG is providing feedback to GP practices. A re-audit in future following advice from PCCAG will help assess improvements in these areas.

The identification and ascertainment of adults with Autism still needs some work. Awareness raising/training of GPs (especially in the Forest and Stroud and Berkeley Vale Localities) and other health professionals needs to continue.

The ASC Network Group may wish to extend its reach to areas with high numbers of people with Autism e.g. Gloucester, Stroud, and Forest of Dean.

The great majority of people diagnosed with Autism and those current using social care services are of working age. This makes the provision of appropriate employment support very important. Work related initiatives may need to be targeted e.g. to areas like North Cotswold, South Cotswold and Forest localities which have low levels of employment in people with Autism.

The ASC Board should review and re-assure itself that there is a working process in place which ensures that every adult with Autism gets a social care assessment.

Alternative support needs (outside of health and social care) may be of importance for adults in Forest, North Cotswold (especially for those living alone) and Gloucester Localities.

The mental health needs of adults with Autism need to be addressed to the same level as the needs of those without Autism.

Health checks carried out in adults with both Autism and Learning Disabilities needs to be monitored and improved.

This report can complement the existing needs assessment to inform the Joint Strategic Needs Assessment on Autism.

## **APPENDIX 1: PRIMARY CARE AUDIT QUERIES**

Q1: No of people diagnosed with Autism (out of total practice population as at end Q3 2013/14)

Q2: No of people with suspected autism with no autism diagnosis (out of total practice population as at end Q3 2013/14)

Q3: No of people with Autism or suspected autism recorded (out of total practice population as at end Q3 2013/14)

Q4: No of people with Autism or suspected autism who that have been seen by services recorded ever (out of people recorded with Autism or suspected autism)

Q5: No of people recorded with Autism or suspected Autism with carer status ever recorded (out of people recorded with Autism or suspected autism)

Q6: No of people recorded with Autism or suspected Autism recorded as having a carer (Latest ever) (out of people recorded with Autism or suspected autism)

Q7: No of people recorded with Autism or suspected Autism recorded as not having a carer. (Latest ever) (out of people recorded with Autism or suspected autism)

Q8: No of people recorded with Autism or suspected Autism who has a carer and their carers details recorded (age, Ethnicity or other details). (out of people with Autism who has a carer recorded).

Q9: No of people recorded with Autism or suspected Autism with employment status recorded (Latest ever employed/not employed codes) (out of people recorded with Autism or suspected autism)

Q10: No of people recorded with Autism or suspected Autism recorded as in employment ever recorded (Latest ever) (out of people recorded with Autism or suspected autism)

Q11: No of people recorded with Autism or suspected Autism recorded as not in employment ever recorded (Latest ever) (out of people recorded with Autism or suspected autism)

Q12: No of people recorded with Autism or suspected Autism and living arrangements (out of people recorded with Autism or suspected autism)

Q13: No of people recorded with Autism or suspected Autism recorded as living alone? (Latest ever) (out of people recorded with Autism or suspected autism)

Q14: No of people recorded with Autism or suspected Autism recorded as living in a care home? (Latest ever) (out of people recorded with Autism or suspected autism)

Q15: No of people recorded with Autism or suspected Autism recorded as living with a carer? (Latest ever) (out of people recorded with Autism or suspected autism)

Q16: No of people recorded with Autism recorded as also diagnosed with Learning Disabilities or Aspergers Syndrome (out of people recorded with Autism)

Q17: No of people recorded with suspected Autism recorded as also diagnosed with Learning Disabilities or Aspergers Syndrome. (out of people recorded with suspected autism)

Q18: No of people recorded with Aspergers recorded.(out of total practice population)

Q19: No of people recorded with Autism also diagnosed with Learning Disabilities or Aspergers Syndrome with a Learning disability health examination in last 15 months (out of people recorded with Autism also diagnosed with Learning Disabilities or Aspergers Syndrome).

Q20: No of people recorded with Autism or suspected Autism or Aspergers (out of total practice population)

Q21: No of people recorded with Autism or suspected Autism or Aspergers, recorded as also diagnosed with Depression ever recorded. (out of Autism or suspected Autism or aspergers)

Q22: No of people recorded with Autism or suspected Autism or aspergers, recorded as also diagnosed with Anxiety ever (out of Autism or suspected Autism or aspergers)

Q23:No of people recorded with Autism also diagnosed with Learning Disabilities and a Learning disability health examination in last 15 months (out of people recorded with Autism also diagnosed with Learning Disabilities).