



## Gloucestershire Strategy for people with Autistic Spectrum Conditions (ASCs)

“

Autism is like a spectrum of light.  
Some exist in the visible range,  
it's obvious they are different, but  
vast majority live in the invisible  
range. We go un-noticed and  
unsupported. Don't forget those  
that live in the infrared and  
ultraviolet”.

**James Walford**  
**A local man with lived  
experience of autism.**



2018-2021

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## Introduction

Gloucestershire County Council, Gloucestershire Clinical Commissioning Group and Gloucestershire's Autism Spectrum Condition Partnership Board (ASCPB) are positive about and celebrate the contribution made to our community by people with ASCs.

We know that the number of people with ASCs is increasing. We both want and need to ensure that people with ASCs living in Gloucestershire are able to lead full lives. To support this, our services need to be available, appropriately designed and well informed.

"Think Autism", the National Strategy, places an expectation on local councils and health services to develop plans to ensure that people with ASCs who live in their area get the help that they need. This strategy responds to that expectation.

In Gloucestershire a multi-agency ASCPB oversees the Autism strategy. The first local strategy covered the period 2013 – 2016 and was focused on adults with Autism. This strategy updates and replaces that. It covers the period 2018-2021.

Gloucestershire is working to a ten-year policy (2014 – 2024) called "Building Better Lives". That sets a direction of travel towards an **all age, all disability** approach. In line with that, this strategy sets out future priorities for people with ASCs of all ages in Gloucestershire.

## How this strategy was developed

- A needs assessment was undertaken in 2012
- An on line consultation with members of Gloucestershire's ASCs Network Group and Parent – Carer Network was undertaken in August 2016
- A self assessment framework was completed for the Department of Health in October 2016
- A listening day took place on 13th September 2017 where groups and individuals with an interest in ASCs in Gloucestershire shared their perspectives on what needs to be in this strategy
- A consultation day took place on 17th October 2017. There, people with ASCs and their families, as well as professionals and organisational representatives worked together to review the messages from all of the work that's been done and co-productively identified the strategic priorities set out in this paper.<sup>1</sup>

<sup>1</sup>There were many more "themes" raised on the consultation day (17th October, 2017) than eventually featured as priorities. **Appendix 2** summarises issues or themes that arose on the day as important but were not collectively viewed as highest priority.

## How this strategy will be used

This paper represents the collective view of people with ASCs and their families as well as professionals and organisational representatives, on priorities for people with autism in Gloucestershire for the next three years.

We have deliberately chosen to maintain a focus on the themes that have arisen through consultation, work and development that families, people with lived experience and organisational representatives view as needed in the future. Strategies usually start with where we are now, set out work undertaken as part of the previous strategy, future needs and priorities. We've chosen to focus on the future and not dilute the message by detailing work that's already been done. We are not underestimating the effort that has gone into developing services and support for people with ASCs over the last three years, but are choosing to focus on the future.

**Occasionally this strategy refers to developments needed, which are already being addressed. In this instance readers should read this as an endorsement of the work already being done and the importance of securing that for the future.**

There are many different views on what the priorities should be. Given the wider national context in public service funding, there is no new money. What needs to be achieved must be done within existing, and possibly reducing, resources. Everyone involved in producing the strategy therefore agreed that focus and clarity is key. Our aims were:

- To get as clear about the priorities as we could
- To accept that tough choices have to be made about the use of limited resources
- To support commissioners in making choices by identifying criteria against which decisions could be measured (the criteria generated on the consultation day are included at **Appendix 1**)

This strategy is agreed it will be used to produce a commissioning plan that sets out what can and will be done to respond to the needs identified.



## What this strategy covers

This strategy is about and for people with an ASC.

There are many definitions of what an ASC is, whom it affects and what impact it has.

People who have contributed to this strategy are working to the following definition. We've chosen this because it's simply put, endorsed by people with lived experience, is not excluding, doesn't describe people as "impaired" and is not medicalised.

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**Autism is neither a mental illness nor a disease. It is neurodevelopmental in nature and reflects a difference in the wiring of the brain. This means you think, feel, perceive and react differently to the world around you and often have a different set of strengths and limitations. You learn that there are certain environments you feel more suited to than others. The challenge is finding the right settings that support the abilities".**

Autism is life-long. This strategy therefore considers the needs of and strategic priorities for Gloucestershire citizens of all ages living with or impacted by ASCs.

On the consultation day (17th October, 2017) participants put forward the following vision:

**Every individual with ASCs living in Gloucestershire has the best life they can.**

**Just coping or managing is not enough.**

**We wholeheartedly and collectively reject all deficit-focused definitions of ASCs.**



## Summary of strategic priorities

Ten strategic priorities have been identified for 2018 – 2021 for people of all ages living in Gloucestershire with ASCs.

The strategy is laid out in order of priority set by participants on the consultation day (17th October 2017) and in line with the criteria in **Appendix 1**.

### The priorities are:

- 1 Post diagnostic support that helps people and their families to learn about, live with and manage the implications of being neuro-divergent
- 2 Local services for people with the most complex needs, some of whom are currently accessing out of county services
- 3 Early identification and intervention
- 4 Improved transition from young persons to adult services
- 5 An up to date, comprehensive and easily accessible on-line central point of information and connection for people with ASCs, their families and professionals who support them
- 6 Ongoing workforce development to ensure that the needs of people with ASCs are recognised and understood
- 7 Improved access to diagnostic services
- 8 Support for families with children, young people and adult family members with ASCs
- 9 Development of provider services to ensure that provider organisations fully understand and can meet the needs of people with ASCs
- 10 Understanding the needs of all people living with ASCs in Gloucestershire including people who are harder to reach like children and young people who are home schooled and adults living independently and in employment



## 1. Post diagnostic support (to adults, children and young people with ASCs and their families)

*The provision of post diagnostic support was identified through consultation as the highest strategic priority for Gloucestershire.*

Almost without exception families, professionals and organisational representatives stress that while a diagnosis can be helpful as a gateway to some statutory services, it primarily identifies a “problem” and not what to do about it. People with ASCs and their families say that getting support after a diagnosis, grows understanding and knowledge of how to manage living with a diagnosis makes a fundamental difference to the quality of people’s lives. People with ASCs and their families tell us that just as the condition is life long, so too is the need for support. The amount and type of support needed varies, depending on age and circumstances.



Getting a diagnosis can be difficult for people with ASCs and their families. Often, neither knows much about what autism is and it is not uncommon to meet people who have been diagnosed for some time who don’t understand their diagnosis, or the implications of living with ASCs. Having a diagnosis is not useful if you don’t know what it means or how to help yourself or a family member who has been diagnosed.

Adequate post diagnostic support was identified as the highest priority in Gloucestershire because it affects everyone in a range of ways, including their mental health, their independence and way of life. It’s not only people with ASCs who need support post diagnosis. Parents, siblings and close friends want to provide support, but often don’t know what to do or how to do it. The impact of a diagnosis on families can be significant.

There’s a risk that when we talk about “post diagnostic support” we end up thinking about all of the services and supports that are and could be available to people with ASCs and their families. Some post diagnostic support is in place. For example advisory teachers support parents post diagnosis, although they are working within the context of limited resources.

For clarity, people with ASCs and their families, as well as professionals and organisational representatives, have focused on those supports they believe are most needed in the Gloucestershire context. Those mentioned are listed on the next page.

## Advocacy

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**Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need”.**

### **(Advocacy Alliance definition).**

There are many “types” of advocacy. Some of the best known are:

- self-advocacy (when people speak up for themselves)
- peer advocacy (when people with shared lived experience help each other)
- paid advocacy (when organisations offer paid independent people to help a person speak for themselves)
- legal advocacy (when a solicitor or lawyer speaks on someone’s behalf)

People with ASCs and their families say they need advocacy services which fully understand the needs of people with an ASC. Without this understanding advocates are considered unable to advocate for people.

Ensuring that advocacy services are confidential and kick in at the start of a diagnostic pathway or pre statutory assessment is important. Early gateway complications can arise from misunderstandings, for instance when a person with an ASC presents in a way that does not communicate the impact that autism has on their life, their families life and well being. Well-informed advocacy can prevent this significant misunderstanding. There is currently considered to be no appropriate advocacy support for people with ASCs who are most vulnerable in Gloucestershire for people who:

- fall between eligibility criteria for specific services
- have complex presentation or are in high / extreme levels of distress
- have ASCs and don’t use words as a first language

## **Health, mental health and access to professional support**

People with lived experience and families describe general mental health services (including crisis and inpatient services) as limited in their ability to support people with ASCs and associated mental health conditions. Whilst there are some specialist mental health services for people with ASCs (e.g. a clinical psychologist for children and young people and an adult diagnostic service) people with autism and their families, as well as professionals, raised concerns about those with autism who reach crisis. While the numbers are understood to be relatively small, their needs are high and life situations can be distressing.

The approaches suggested include:

- improved training for general mental health service practitioners
- better understanding of the needs and numbers of local people that reach crisis
- a clearer understanding of how these needs can and are being met in other parts of the country

Growing preventative investment in the emotional wellbeing and mental health of children and young people through programmes such as the National Autistic Society (NAS) Healthy Minds programme is considered to be essential in assuaging later complications.

Gaps in health, mental health and professional support locally have been identified as:

- specialist practitioners (such as advocates, trainers or qualified professionals with an in depth understanding of ASCs) to provide consultation and intervention with generic services and provider organisations
- occupational therapy assessment and specialist ongoing support with developing strategies that emphasise strengths and minimise the challenges of living with ASC. This will include sensory processing assessments and strategies; lifestyle adjustments (including reasonable adjustments required for education, employment and accessing statutory services) and environmental assessment, design and adjustment
- for adults, access to a consultant psychiatrist with an understanding of the medication needs of people with ASCs and their impact (Priority 5)
- GPs with a good understanding of ASCs and the ability to make reasonable adjustments (such as longer appointment time slots) to facilitate access for people with ASCs who need that
- for adults, care management assessment and care coordination from practitioners who understand ASCs. Care coordination is considered important so that families don't need to keep retelling their story
- adjustments to FACE care needs assessment to ensure that it is ASCs friendly

Families and people with lived experience have asked that wherever possible consideration is given to services like mental health services being based in communities throughout Gloucestershire in order to improve connection and accessibility.

Developing information prescriptions, modeled on local work for people with dementia, has been identified as a simple way of improving health care support for people with ASCs, as it supports health care practitioners in their treatment of people with ASCs.

“

**An Information Prescription is a source of personalised information that lays out clearly and simply the salient points about an individual's consultation with a healthcare professional about their diagnosis, treatment and/or care plan and points the way to other relevant sources of high quality information and support. It is designed to improve the dialogue between patients and health professionals and enhance the valuable face to face time within consultations”.**

Additionally families and people with lived experience stress the importance of coordinated information sharing between and across organisations that are involved (e.g. schools, health, social services).

## 2. Support for people with complex needs

*Strengthening provision and support for people with complex needs was identified through consultation as the second highest strategic priority for Gloucestershire.*

People with ASCs are impacted by their condition in different ways and to different degrees.

ASCs affect people with all levels of intellectual ability. Having autism does not mean that you also or necessarily have learning disabilities.

Some people have ASCs and learning disabilities and can need high levels of support. Others can be of average or above average intelligence and still experience significant challenges as a result of neurological difference.

In this section we refer to people with ASCs whose needs are complex by which we mean people with ASCs and:

- behaviour that can be described as challenging
- mental health needs
- at risk of or in crisis or significant distress

Building strong local supports and capacity to support these people locally is considered by families, professionals and organisational representatives to be a high priority.

Improving the communication between services about people with high level or complex ASCs related needs is seen as key to improving services for them. People with ASCs and their families, as well as professionals and organisational representatives recommend that mapping the resources available to support people with complex needs and identifying gaps is a key first step to progress.

It is believed that there are significant gaps in the provision of suitable local services for people with ASCs who are at risk of or in crisis or significant distress including:

- suitable specialist mental health services for people with ASCs
- community treatment services including crisis prevention and post crisis discharge and community support following inpatient admission
- robust community support services for people with complex ASCs related support needs, challenging behaviour and mental health needs such as intensive outreach services
- appropriate, robust housing

### 3. Early identification and intervention

*Strengthening early intervention and preventative support was identified through consultation as the third highest strategic priority for Gloucestershire.*

It is widely accepted that small amounts of practical and social support following diagnosis can significantly benefit people with ASCs and their families. This also has the potential to mean that more intensive services are needed less frequently and people are more able to support themselves with the help of family and friends.

#### Practically focussed prevention

Practical **preventative** support needed as a strategic priority in Gloucestershire includes:

- early and timely intervention and access to mental health support where needed for all ages
- access to a central point of information and clear sign-posting to local services
- sufficient local practitioners trained in assessment and standardised tools for assessment
- occupational therapy resources\* to provide support for sensory difficulties in adults
- well resourced:
  - pre-school social communication pathway
  - school-aged social communication pathway
  - transitions from children and young people's to adult services
  - an adult diagnostic pathway
  - a senior diagnostic pathway



(\*Resources in this instance includes governance, administration, trained practitioners and resources to support their work)

- systematic early intervention programmes for children and families pre and post diagnosis (to potentially include the Hanen programme, EarlyBird, Healthy Minds, 9+ parent programmes or similar and parent workshop days for all families with a child diagnosed with ASCs)

## Socially focussed prevention

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Socialising and communicating can be challenging for many autistic people. Many really do want to make friends and form relationships but find it hard.

There may be difficulty reading social cues and knowing when to speak or listen, and facial expressions can be impossible to read resulting in social isolation”.

*(National Autistic Society)*

Social preventative support needed as a strategic priority in Gloucestershire includes:

- more social activities for children and young people with ASCs and their siblings, which provide opportunities for them to be more involved in their communities
- mainstream social activities that are ASC friendly and accommodating
- improved support for adults with ASCs who are socially isolated, including funded social hubs throughout Gloucestershire
- promotion of social activities available through the Local Offer



## 4. Transition

*Improving support for young people in transition to adult services was identified through consultation as the fourth highest strategic priority for Gloucestershire.*

Transition and change can present a big challenge for people with ASCs. In particular, moving between different stages of life such as school, college and work, is particularly tough.

Many people with ASCs and their families will need more support than they are able to provide for themselves, when going through major transition. Keeping processes simple, clear and well planned helps a lot. One key life transition is the move from school or college to adult services.

Resources and support available to adults with ASCs are very different (and usually less) than those provided to children and young people. This makes transition from school to adult services stressful for young people and their families.

Work has been done and is still under way to improve transitions from young people to adult services in Gloucestershire. People with ASCs and their families, as well as professionals and organisational representatives, are keen that it remains a visible priority.

Suggested actions to continue to improve transitions include:

- Setting the upper age cut off for children, young people and educational services at 25 years of age
- extending the availability of and eligibility for valuable services that provide consistency and predictability, like college and activities into adulthood, to ease the stress of transition and moderate it to an individuals pace
- improving joint working between children and young people and adult services to include opportunities like “taster days” to support young people to make informed decisions about their future
- ensuring that adequate and well informed support is available for families and young people with lived experience at all stages of transition
- the use of the ‘Ready Steady Go’ transition programme where appropriate for children transitioning in health services



## 5. All age interactive information platform for people with ASCs and their families in Gloucestershire

*Developing an all age interactive information platform was identified through consultation as the fifth highest strategic priority for Gloucestershire.*

Developing a robust all age, interactive platform for people with ASCs that maps local supports and offers a single source of signposting and a point of connection for families and professionals was identified as a high priority by people with ASCs, their families, professionals and organisational representatives. The current provision of information for people with ASCs is considered to be poor, insufficiently robust and inconsistent. This leads to confusion and does not encourage the development of peer support.

Aspirations are that an on-line information platform will be developed with people with lived experience, their families and professionals to possibly include:

- descriptions of and signposting to all statutory and other services and support available to people of all ages with ASCs who are citizens of Gloucestershire
- information about health services available to support people with ASCs - for example occupational therapists, and speech and language therapists
- information about the benefits system and housing
- signposting on how to get a diagnosis if you think you or your family member may have ASCs
- a platform for parents of people with ASCs and people with autism of all ages to connect and provide peer support (to reduce the emotional and physical impact of caring / living with a diagnosis)



## 6. Understanding ASCs, training and learning

*Ongoing work to strengthen local competence and training was identified through consultation as the sixth highest strategic priority for Gloucestershire.*

Families and people with lived experience tell us it is vital that key staff in mental health services and acute settings have robust training in understanding and responding to the needs of people with autism. Significant time, effort and energy has already been invested in training to improve understanding of ASCs, with the aim of improving practice in supporting people with ASCs in Gloucestershire. For example, the schools advisory service provided basic training to over 1500 teaching and support staff in one year and the adult diagnostic service has seen good uptake of training by some health staff including GPs. There is recognition of the need for more specialist training for health staff. E-learning has been useful in increasing awareness but not in informing clinical input. There are a number of sources of training including that offered by health practitioners (occupational therapists, psychologists and the advisory teaching service), diagnostic teams and the schools advisory service, as well as training commissioned by the workforce strategy for adults. The ASCPB is currently mapping all sources of training to help identify strengths and gaps.

Despite this investment, however, people with ASCs and their families, as well as professionals and organisational representatives continue to identify groups of professionals where take up of training is lower, or understanding of the needs of people with ASCs needs to be strengthened. Some of these are hard to reach and / or engage. Nonetheless, engaging and supporting them is vital to the overall well being of the ASCs community. Professional groups identified as having low take up of ASCs include:

- GPs
- social workers
- fieldwork assessors
- mental health crisis services
- advocates
- appropriate adults
- staff in <sup>2</sup>gether NHS Foundation Trust
- Department of Work and Pensions (DWP)
- Criminal Justice Liaison Team
- police
- schools and early years provision



It is suggested, by people with ASCs and their families, as well as professionals and organisational representatives, that the local workforce development strategy is supported with simple ways of engaging hard to reach professionals, including:

## Resources

- developing an ASCs “virtual tour” that is short, fun and interesting and can be used to quickly engage and teach professionals about the absolute basics
- improving the effectiveness of training via specific, individualised bespoke training focused on the needs of specific individuals and approaches that meet their needs e.g. intensive interaction or sensory needs

## Strategy

- influencing the Primary Care Commissioning Strategy to take account of the needs of people with ASCs
- making training attendance mandatory in key organisations, and/or for key professionals
- training that provides specific guidance on how to use knowledge and awareness using an improved of ASCs to make reasonable adjustments to the way that services are offered or delivered – for example, the design of application forms or how to interview someone with ASCs in a way that maximises their communication ability

## Co-production

- mobilising families and people with lived experience to raise the importance of understanding ASCs with their GP practices and provide resources and support
- ensure that are more in depth follow ups to basic training that include delivery by people with lived experience and families
- forming a network of ASCs Champions across the county which is virtually linked and supported and works co-productively with people with lived experience. This should link with providers, schools, colleges and employers

## Reasonable adjustments

- training to be provided to the Department of Work and Pensions to encourage benefits assessments and processes to become more ASC friendly
- systematic training for professionals working with children aged 0-5, to enable them to identify ASC and other related problems

## 7. Diagnostic services

Referral rates for adult diagnosis increase year on year. Reducing waiting times is the priority. The adult diagnostic service is working closely with referrers to reduce the number of inappropriate referrals which will help reduce the wait for appropriate referrals.

## 8. Support for families

*Throughout the consultation on the strategy, families and organisations set out their views on where priorities lie for them. Increased awareness of family members as carers, the right to an assessment and information about where to get help is an all age priority.*

For children and young people priorities were identified as:

- increased provision of training courses such as NAS Early Bird Plus programme for families with children aged 4 – 8 to ensure that all families are able to access the programmes in a timely way, giving them the confidence to support their child
- increased sibling and family support - particularly groups to support social, emotional and mental health and wellbeing
- increased opportunities for respite for families, particularly in the school holidays, as well as before and after school provision, to enable working parents to work
- adequate support for young people, in particular through the transition to adult services. The age band for children and young people's services would be best set at 0 – 25 years old
- increased understanding of the needs of children and young people not in educational settings is needed along with better understanding of why educational settings are not accessible to them. Sometimes families choose to home school their child because they have struggled to thrive in school due to their ASC. Schools need to be supported to meet the needs of children and young people with autism so they are able to return to an educational setting or another shared arrangement

## 9. Provision.

*Educational settings, social and health care providers make up the bulk of provision to people with ASCs and their families and yet the understanding of ASCs even in services specifically designed for them can be variable.*

People with ASCs and their families, as well as professionals and organisational representatives stress the importance of commissioning services that adopt a strengths focused approach to their work. Where decisions about provision need to be made for specific individuals, it is important that these are taken early so that people can be well prepared and transitions can be well planned and executed.

In particular the following priorities have been identified as important areas of skill and knowledge for all providers:

- understanding of sensory processing and the impact of sensory issues on service design
- the ability and flexibility to design working practice and environments that work for people with ASCs
- skilled support staff who understand ASCs and are confident in their approach to working with people with a diagnosis, understanding that different people have different needs
- for children and young people, work is in place to ensure that educational settings gain the Gloucestershire ASCs Inclusion Quality Mark (priority 8). This promotes inclusion in mainstream schools. As well as ensuring that this work is ongoing, families would like educational settings to explore the feasibility of shorter holiday periods, to help children and families manage change more effectively
- in adult services, people with ASCs and their families, as well as professionals and organisational representatives stress the importance of improving connections with housing. Specifically, to facilitate appropriately designed housing and simple reasonable adjustments that make a big difference for people, like the facility to keep pets

Given the complexity of getting it right and current under-provision, the development of suitable accommodation for people with complex needs requires ongoing attention and focus.

Getting into work and holding down a job continues to be a high priority for many adults with ASCs or without a learning disability. The number of adults with ASC without an additional learning disability remains low. The key issues for this group are:

- recruitment – not everyone has insight into the impact of ASC on how they present
- reasonable adjustments and training for employers
- job retention

In terms of reasonable adjustment and job retention employers find it difficult to know what adjustments to make without support.

## 10. Understanding need

*It is easier to support communities well when they are known to statutory services, their needs are identified and mechanisms are in place to ensure that plans are co-produced.*

Gloucestershire has a growing understanding of the community of people with ASCs from:

- a needs assessment in 2012
- an audit of GPs on patient numbers in 2014
- an online consultation in 2016
- a self-assessment exercise in 2016

Whilst the needs of people in contact with statutory services are better understood there is a lack of information about sub-sections of the ASCs community who are, arguably, harder to reach and / or identify. These include:

- children and young people who are not placed on the GCC Graduated Pathway
- people with ASCs over the age of 65
- women and girls, in part due to difficulties with identification and diagnosis of women and girls with ASCs
- people with ASCs and without learning disability going in to work, or who want to work
- people living alone or with family
- people with ASCs who do not have a learning disability

In addition, **Appendix 2** includes a summary of data from an audit of ASCs undertaken in primary care that highlights the following areas for action:

- continue to improve the identification of people with ASCs, focusing on localities with lower recorded prevalence
- improve process for identifying and recording the details of carers to enable the provision of carers assessments
- improve the recording of employment status and living arrangements among people with ASCs
- increase the proportion of people with ASCs and learning disability who receive an annual health check, particularly in Cheltenham and the North and South Cotswolds
- improve access to psychological support for people with ASCs and ensure that providers make reasonable adjustments to promote positive outcomes and experience

## 11. Commissioning and next steps

This strategy sets out strategic priorities for the next three years that have been co-productively identified and prioritised by people with ASCs and their families, as well as professionals and organisational representatives. The strategy was finalised in March 2018 following which it went through the necessary statutory approvals processes.

Once the Strategy was approved commissioners at Gloucestershire County Council and Gloucestershire Clinical Commissioning Group drew on the priorities to produce a commissioning plan (effectively a response to the strategy) signed off by the ASCPB in September 2018.

The 8th draft of the commissioning response has been incorporated into this document. Not all actions have been allocated and agreed and subsequent updates of the action plan are expected. However, the original strategy and the commissioning response are now included in this final version of the strategy for administrative completeness.

No further versions of this strategy will be issued after this.

For more information on the strategic priority owners, please contact [disabilitiescommissioning@gloucestershire.gov.uk](mailto:disabilitiescommissioning@gloucestershire.gov.uk)

## 12. Commissioning Plan: Response to the Autism Strategy

### 1. We heard...

After diagnosis, there needs to be clear pathways for all ages:

1. children of pre-school age social communication pathway
2. children of school age social communication pathway
3. transitions from children and young people's to adult services
4. an adult diagnostic pathway post diagnosis
5. a senior diagnostic pathway post diagnosis

Access to a central point of intervention and clear sign-posting is needed.

### Our current position...

A pre-school social communication pathway is in place.

Work has commenced on a school-aged social communication pathway which will be finalised and published shortly.

The IMPACT team (Specialist Advisory Teachers, and Speech and Language Therapists) work closely with the Educational Psychology Service, clinical psychologists, school nurses and health visitors.

The team works with children and young people aged 0-25 and visits schools to observe and offer additional training. The Gloucestershire Autism Inclusion Quality Mark (GAIQM) is an opportunity for schools to be recognised for what they are doing to promote the inclusion, motivation, progress and welfare of children and young people with autism and communication needs.

### Our plan is...

To review the current pathways so that they are readily available for individuals to access and understand. This will be undertaken by a project manager within Disabilities Commissioning. The pathways will identify how timely intervention is delivered. This work will be reported to the ASCPB. An all disability transitions pathway from children and young peoples to adult services is currently being mapped and developed for people who present with eligible needs. We will invite key partners (to be agreed with the ASCPB) to consider and debate proposals. A transitions team is being set up and they plan to get involved at a much younger age to enable successful transitions. The transition pathways for education health and social care need to be considered.

The Autism Post Diagnostic service will capture data on individuals who are diagnosed and accessing their service- whether or not they have Care Act eligible needs.

Resource has been requested from NHS England to map the autism pathway in Gloucestershire.

We will continue to monitor the work of IMPACT, including and motivating pupils with autism and communication needs team, for meeting the needs of children within school/college settings. Measuring exclusion rate prevalence will be part of this work. We will also continue to increase the number of schools/colleges that achieve the Gloucestershire Autism Inclusion Quality Mark (GAIQM).

We will carry out a consultation with individuals/ parents/carers/professionals to understand the mental health needs faced by those with ASC, who do not have an associated learning disability.

We will commission post diagnostic support that includes advice and support to help individuals acquire or keep employment or go into education or training; and to develop independent living skills. This will consider the specialist interventions required, e.g. assessment and advice regarding reasonable adjustments.

## 2. We heard...

Early intervention programmes and social support for children and families pre and post diagnosis are needed (to potentially include the Hanen programme, EarlyBird, Healthy Minds, 9+ parent programmes or similar and parent workshop days for all families with a child diagnosed with ASCs).

### Our current position...

A wide range of services which are outlined in the Local Offer, some examples include:

**The Hanen programme** – focusing on early childhood language development.

The EarlyBird (under five years) and EarlyBird Plus (ages four to eight) are support programmes for parents and carers, offering advice and guidance on strategies and approaches for dealing with young autistic children. Both programmes work on understanding autism, building confidence to encourage interaction and communication and analysing and managing behaviour.

**The EarlyBird Healthy Minds programme** is a six-session parent support programme to help promote good mental health in children with autism (including Asperger syndrome). Healthy Minds has been developed in response to recent evidence which indicated that a high percentage of autistic children are at risk of experiencing mental health problems in adolescence and adulthood. The programme aims to help minimise this risk.

**The 9+ parent programme course** is designed for the parents of pupils between 9 and 12 years of age with a recent diagnosis of autism. The course is 6 weeks, with each session lasting approximately two hours. The course helps parents to develop their own strategies and build on the experience they already have. By meeting with other parents they can also share experiences and become mutually supportive.

**Allsorts** – offers sports and activities to disabled young people and their families, including those with ASCs.

**Forest Pulse** – provides out-of-school social, sport and recreational activities for disabled children and young people up to the age of 19, giving them the opportunity to meet up with friends, have fun and learn alongside their non-disabled peers. The charity also provides guidance, advice and support to parents and creates opportunities for families to meet and share experiences.

**Glo Active** – activities for disabled and non-disabled people of all ages. Activities include independent cooking followed by a sit down meal, a singing group, boccia, sports, disability dance, drama and art, work on community allotments, wood work, sports including boccia, tennis and swimming.

**Hop, Skip and Jump Centre** - offers opportunities for young adults with learning difficulties and/or complex needs aged 18+, physical disabilities, sensory impairment, mental health conditions and autism. They offer use of the sensory rooms, soft play facilities and art rooms, small group activities, organised games, arts and crafts, cookery lessons, life skills, drama, dance, music, sports, story time and animal visits

**Of Course We Can** – Inclusive activities for disabled and non-disabled young people together, offered to those who have learning disabilities, autism or physical/sensory impairments.

**Orchard Trust** – a range of activities for adults with disabilities.

**SHARP** - Learning sessions for adults with a disability, mental health issues or brain injury. Sessions include: IT, literacy and numeracy, daily living skills, preparing for work, communication and social skills, cookery and healthy eating, understanding your rights and your responsibilities, personal awareness, safety awareness, pottery, art and craft, music and drama, gardening, recycling, healthy living, sport and fitness, singalong, playalong, visits to places of interest.

**Spring Centre** – offering life skills to young people aged 18-30 with learning disabilities, physical disabilities, mental health issues and autism. Activities include shopping, cooking, Internet and technology skills, money awareness, digital photography and arts and crafts.

**St Rose's/St Martin's** – day respite activities offered during term time and school holidays for people with ASCs.

**Inclusion Gloucestershire** – inclusion hubs (activities, support, information and courses) are available across Gloucestershire for people with a disability.

A Challenging Behaviour Family Development worker supports families of children and young people with learning disabilities and/or autism who display behaviours deemed as challenging.

**Managing Anger workshops** (designed by the NAS) are also available for parents/carers/teaching assistants/personal assistants etc. who support children and young people with high-functioning autism.

Continued delivery of parent workshops on glosfamilies directory and Local Offer.

## Our Plan is...

We will ensure that all existing and new social activities suitable for children with ASC are readily available and promoted through the Local Offer. Functionality and navigation of the directory will continue to be improved.

We will provide social prescribers with training in autism and ensure that they have adequate information in relation to activities and ensuring people are supported to be actively involved within their communities.

We will review outcomes for early intervention and parenting programmes and consider future direction and strategy. These will be reviewed by Children's Commissioning and Education and Disabled Children's and Young People service.

We will review the current pathways for diagnostic services for children and see if they are compliant with NICE, National Institute for Health and Social Care, guidelines.

### 3. We heard...

Advocacy services need to be available for people with ASCs at the start of a diagnostic pathway; specifically for those most vulnerable who:

- fall between eligibility criteria for specific services
- have complex presentation or are in high / extreme levels of distress
- have ASCs and don't use words as a first language.

### Our current position...

Gloucestershire provides the following types of advocacy:

- Independent Care Act Advocacy
- Independent Mental Health Advocacy (IMHA)
- Independent Mental Capacity Advocacy (IMCA)
- NHS and Social Care Complaints Advocacy
- Children's Services Advocacy

Advocacy is provided for individuals if they meet the criteria through existing services or through specifically commissioned support. Advocates are able to work with people who do not use words as a first language. Independent supporters are available on a case by case basis for individuals who have an ASC and are in an inpatient setting. The objective is to ensure a person-centred approach through providing an independent supporter for the individual as an impartial source of support through the journey from an inpatient setting into the community.

Independent supporters are available on a case by case basis for individuals who have an ASC and are in an inpatient setting. The objective is to ensure a person-centred approach through providing an independent supporter for the individual as an impartial source of support through the journey from an inpatient setting into the community.

### Our plan is...

As the advocacy contract has been recently recommissioned we are monitoring this on a quarterly basis. We will request that ASC is added to this monitoring process (which will include ensuring appropriate training).

We will continue to fund Independent Supporters via the CCG.

#### 4. We heard...

Improved training should be available for general mental health services to better understand the mental health needs of people with ASCs.

#### Our current position...

Gloucestershire's Autism Training Pathway - a staged pathway of autism training and development has been available to multi-agency partners, largely delivered by NAS, with co-facilitation by people with lived experience. Training offered has received consistently positive feedback from delegates and a well regarded autism professionals' forum has been established (now called the autism community of practice). Bespoke training sessions have been delivered to some groups e.g. DWP, GPs, social workers and local learning resources have been developed and widely circulated (pink autism awareness booklet and new film – all co-produced). The training pathway meets the NAS good training practice guidelines. Our local Autism Network Group identified the target groups for training within Gloucestershire's public services workforce. Please see the Autism Workforce Development Strategy 2017 – 2020 in **Appendix 2**.

Autism Awareness learning resources are available online via Skills For Care -  
<https://www.skillsforcare.org.uk/Documents/Topics/Autism/Autism-awareness-learning-resources.pdf>

#### Our plan is...

We will evaluate and revise our training offer in relation to autism. This will include:

- 1) Supporting professionals to make reasonable adjustments inclusive of GPs;
- 2) Training at a range of levels and in a range of formats;
- 3) Availability of training for GPs, social workers, fieldwork assessors, mental health crisis services, advocates, appropriate adults, staff in 2gether NHS Foundation Trust, DWP, Criminal Justice Liaison Team, police, schools and early years provision)

Contract Frameworks for support providers will stipulate training attendance as mandatory.

We will continue to liaise with the service manager, Youth Justice, from the Youth Support Team.

## 5. We heard...

A better understanding of the needs and numbers of local people with ASCs who reach crisis is needed.

## Our current position...

We currently collect data on the Transforming Care programme which includes individuals of all ages with autism. This is captured through Blue Light meetings and Care and Treatment Reviews (CTRs).

## Our plan is...

A report on how many people who reached crisis last year have an ASC. This will include case studies and which services they were open to alongside summary recommendations from Blue Light Meetings and CTRs.

A scoping activity to research how the needs of people with ASCs are being met in other parts of the country (both at home and with paid support). This will be fed back to commissioners and ASCPB.

## 6. We heard...

Strong local supports and specialist mental health services need to be built with a capacity to support people with ASCs whose needs are complex and have a behaviour that can be described as challenging, mental health needs or are at risk of or in crisis or significant distress.

### Our current position...

Learning Disability Intensive Support Service (LDISS) has the ability to provide additional support to prevent or manage a crisis 24/7. This support can be accessed at home, or in other appropriate community settings, including schools and short break/respite settings. Currently this can be accessed by individuals with ASCs and a learning disability.

The Mental Health Acute Response Service (MHARS) aims to intervene quickly when needed to minimise distress, minimise deterioration and reduce the risk of harm to people experiencing crisis and their carers. It can be accessed by people with ASCs.

The service aims to minimise admissions to hospital and reduce the severity and duration of crisis. The service provides:

- Access to urgent mental health care removing barriers for individuals contacting the service
- Accept open referrals from all sources including self-referral, carer and other agencies
- Equity of access to urgent mental healthcare for people in mental health crisis / acute psychological distress from 16 years and 14 years for those under the care of the Early Intervention team (Gloucestershire Recovery in Psychosis) (GRIP)
- 24/7 single point of access for urgent requests for help and advice across organisations
- 24/7 mental health triage and assessment for people in mental health crisis / acute psychological distress
- 24/7 access to intensive treatment at home to avoid hospital admission
- Information, training and support to other professional groups, families and the public about the recognition and effective management of a mental health crisis

Provision of Support for People with Complex Needs – this service includes supporting Service Users with complex needs and behaviours which challenge services. This includes supporting people with ASCs to live locally and in their community, lead meaningful lives where they enjoy being included in society, have the opportunity to access employment, develop skills and maintain strong links with friends and family who feel confident in supporting them.

### Our plan is...

LDISS will be expanded in the future to include people with a sole diagnosis of autism.

The items relating to post diagnostic clinical support will be fed into the Learning Disabilities and Autism Clinical Programme Group to respond to. It is anticipated that this will lead to supplementary action points to ensure reasonable adjustments are being made. One example could be a review of mental health services and their ability to support those with an ASC - led by the ASCPB.

The number of people with ASCs accessing MHARS will be recorded and reviewed.

## 7. We heard...

Additional post diagnostic support is required for people with ASCs that is not currently being provided.

### Our current position...

2gether NHS Foundation Trust currently offers the following post diagnostic support package:

- group programme for service users
- one session of carer education
- consultation clinic (10 per year on an 'as and when' basis)
- specialist training packages (3 per year)
- 6 x two hour post diagnostic education sessions which try to skill clients up with knowledge about ASC and how to "live well" with the condition.
- 1 x 2 hour session for clients to bring a relative, friend or colleague; the content of this session informs the relative about ASC and strategies that are helpful

The Independence Trust offers day services for adults with mental health problems and ASCs. These include courses and support groups. 'safe spaces' are offered where clients can undertake meaningful and satisfying activities, socialise with others, receive individual support, develop life skills and pursue mental wellbeing.

### Our plan is...

The items relating to post diagnostic clinical support will be fed into the Learning Disabilities and Autism Clinical Programme Group to respond to. It is anticipated that this will lead to supplementary action points to ensure reasonable adjustments are being made. Points will include:

Occupational therapy assessments and specialist on-going support with developing strategies that emphasise strengths and minimise the challenges of living with ASC.

Access for adults to a consultant psychiatrist with an understanding of the medication needs of people with ASCs and their impact.

Care management assessment and care coordination from practitioners who understand ASCs to ensure families don't need to keep retelling their story.

Consider adjustments to FACE care needs assessment to ensure that it is ASC friendly.

Development of information prescriptions/passports for individuals with ASCs. This will be a succinct summary of key information and specific needs for individuals. Examples of this in other areas are dementia and learning disability hospital passports.

## 8. We heard...

Community treatment services including crisis prevention and post crisis discharge and community support following inpatient admission are needed for people with ASCs who are at risk of or in crisis or significant distress.

### Our current position...

Learning Disability Intensive Support Service (LDISS) provides additional support to prevent or manage a crisis 24/7. This support can be accessed at home, or in other appropriate community settings, including schools and short break/respite settings. Currently this can be accessed by individuals with ASCs and a learning disability. LDISS operates in the crucial area between specialist services / hospital admission and community life for an individual. The team supports service users who have accessed inpatient services to successfully move back into the community on a long-term basis.

MHARS aims to intervene quickly when needed to minimise distress, minimise deterioration and reduce the risk of harm to people experiencing crisis and their carers. The service aims to minimise admissions to hospital and reduce the severity and duration of crisis. It can be accessed by people with ASCs.

### Our plan is...

LDISS will be expanded in the future to include people with a sole diagnosis of autism.

## 9. We heard...

Appropriate robust housing is needed for people with ASCs who are at risk of or in crisis or significant distress.

### Our current position...

There is a housing broker in place who works across disabilities. Regular meetings take place with housing providers in order to develop housing stock. Regular meetings also take place with strategic planning officers to evaluate planning applications for supported living accommodation within the county. Regular update meetings take place with operational teams from GCC and <sup>2</sup>gether NHS Foundation Trust to examine and assess new development opportunities that are available. There is a new 'Housing with Care' strategy; the housing broker is leading on this strategy in relation to the Integrated Disabilities Hub (which incorporates autism).

Community Based Support (CBS), commissioned by the Council and provided by P3 and Greensquare, is a flexible service for adults, supporting people who are in crisis and at risk of losing their home.

### Our plan is...

A specification for ASC specific housing to be developed in conjunction with <sup>2</sup>gether Trust, underpinned by a bespoke needs analysis.

Housing with Care Strategy to incorporate those with ASC.

## 10. We heard...

Mainstream social activities to be organised that are ASC friendly and accommodating.

### Our current position...

- The following support groups are currently available in Gloucestershire:
- Mental Health and Wellbeing Service
- Cheltenham Autism Support and its weekly group Rainbow Days aims to provide support for families with a child who has been diagnosed or is suspected of having autism
- National Autistic Society Gloucestershire Branch - For parents/Carers of children and young people with autism
- Cotswold Aspies and Friends - For adults with autism and/or Asperger's and their carers
- Asperger's Support Group - For parents, professionals, adults and their carers
- Autism & Asperger's Gloucestershire - For parent carers to meet and share experiences
- Asperger Syndrome Peer Support Group - Primarily for those with Asperger's to meet for a friendly chat and build confidence but carers may accompany them.
- Asperger's & Autism Support Group - An informal support group for families in the Tewkesbury area who have children affected by Asperger's Syndrome or Autism.
- Gloucester Autism Support for Parents

### Our plan is...

Promotion of social activities already available through Local Offer, Your Circle and Community Wellbeing Services.

Recommissioning of the Mental Health and Wellbeing Service will include improved support for adults with ASCs who are socially isolated, including consideration of funded social hubs throughout Gloucestershire.

Groups to include support for siblings and family members of people with ASCs.

Know Your Patch workshops – networking and information sessions to discuss and identify practical actions that support local communities.

## 11. We heard...

Improvement is needed regarding support for young people in transition to adult services

### Our current position...

We currently work in line with the 'Special educational needs and disability (SEND) code of practice: 0 to 25 years' guidance which means that children, young people and parents are provided with the information, advice and support necessary when planning for their transition to adult life, the future and how to prepare for it, including their health, where they will live, their relationships, control of their finances, how they will participate in the community and achieve greater independence.

The Care Advice Line service in Gloucestershire provides free information and advice to help people plan to pay for their care. Advice can be provided to young people who are transitioning to adult services.

### Our plan is...

The upper age limit for children, young people and educational services will be set at 25 years of age.

'Taster days' will be held to support young people to make informed decisions about their future, which will be developed in conjunction with the ASCPB.

Commissioning will assess whether the 'Ready Steady Go' transition programme is appropriate and will use it when required.

A transitions team is being set up and they plan to become involved at a much younger age to ensure smoother transitions. They will liaise with other teams, such as Employment and Enablement to ensure they can support people with ASCs to live locally and in their community and lead meaningful lives. The team will consider personalised support to inform decision making, which may include personalised planning.

Children's and adults' commissioning will assess whether advocacy pathways for individuals is appropriate.

## 12. We heard...

A robust all age, interactive platform for people with ASCs that maps local supports and offers a single source of signposting and a point of connection for families and professionals is required.

### Our current position...

The 'Your Circle' website is a directory to help adults living in Gloucestershire find their way around health and care and find out how it works and what services that are available. It also helps them to connect with people, places and activities in Gloucestershire by listing what is available in the community, with sections including: home and housing; travel and transport; work, learning and volunteering; things to do; money matters and benefits; health; care and support; caring for others; keeping safe; information and advice.

The <sup>2</sup>gether NHS Foundation Trust post diagnostic support package offers a six week course to help individuals understand their diagnosis of autism, and signpost them towards support groups and other local services.

### Our plan is...

A description of, and signposting to, all statutory and other services and support will be made available to people of all ages with ASCs who are citizens of Gloucestershire. This will include information about health services that are available and the benefits and housing system. Platforms will be reviewed to ensure that they are autism friendly and as interactive as possible. This will be hosted on Your Circle and the Local Offer.

## 13. We heard...

Co-production is an important part of supporting people with ASCs.

### Our current position...

An ASCPB

The Gloucestershire's ASCs Network Group

### Our plan is...

A network of ASC Champions will be formed across the county. This will link people with lived experience to providers, schools, colleges and employers.

## 14. We heard...

For families with young children with ASCs, increased opportunities for respite should be available, particularly in the school holidays, as well as before and after school provision, to enable working parents to work.

### Our current position...

The Stroud short breaks residential service provides for children across the whole of the county.

Overnight short breaks are available with the following providers: Step-A-Side in the Forest of Dean; St Rose's in Stroud; Hilltop in the Forest of Dean; and James Hopkin's Trust in Gloucester.

Of Course We Can has several two night residential opportunities that exist within the inclusive activities for disabled and non-disabled young people together, offered to those who have ASC, learning disabilities or physical/sensory impairments.

The Lodge (Stroud) and St Vincent's and St George's (Cheltenham) can be used by parents to spend time with their child outside of the family home or the child can attend with their carers.

Family Link Plus is a fostering service which provides overnight short breaks for disabled children in foster carers homes and day time support in the child's home.

Acorns in Worcestershire is a service for children with life limiting conditions. This service provides support to the child in the form of overnight breaks away from the family home with the parents being able to stay on site if wanted. The provision provides emotional and bereavement support to the family.

Several weekend activity provisions and summer holiday play schemes are commissioned across the county and delivered through voluntary community sectors and provide short breaks of up to 4-6 hour sessions.

## 15. We heard...

Providers who support people with ASCs must have an understanding of neuro diversity, including sensory processing difficulties, communication difficulties, repetitive behaviours and difficulty with changes to routine, and the impact of these issues on service design. They must be flexible and have skilled support staff who understand ASCs.

### Our current position...

Provision of support for people with complex needs – this service specification details that providers must offer autism specific specialist training to all staff.

### Our plan is...

Providers will only be commissioned if they can assure they are able to meet the different needs of people with ASCs. For adults this will be included within both residential and supported living frameworks and will form part of the assessment process to be an accredited provider.

## 16. We heard...

Employment is a high priority for many adults with ASCs – there should be training for employers and reasonable adjustments should be made for people with ASCs in the workplace.

### Our current position...

The Disability Employment Strategy includes provision and support for people with an ASC. The strategy brings together employment provision and looks to ensure a holistic approach to ensuring people with ASC have the support to access and retain paid employment.

Specialist provision includes the Forwards Employment team which is an all age all disability service. They support people with ASCs in their 1:1 service and in Forwards Work Clubs. The Going the Extra Mile (GEM) project helps to move people closer towards education, training, volunteering or work, including self-employment. AIM Supported internships for young people with Education Health and Care Plans are offered to those in their last year of education and this has now extended to young people with higher functioning autism.

The Forwards Employment service offers individual training for individuals with ASCs. They refer to the NAS and the Autistic Spectrum Service for generic training and will also signpost employers to LearnPro for tailored e-learning. They promote the Access to Work scheme as part of the employer engagement and will do a full risk assessment and employment assessment around which any support is based.

Other employment programmes can help people with ASC to gain and sustain work. The Interdependencies Group chaired by GCC ensures that other employment providers, including those commissioned by DWP, understand the needs of people with ASC and can provide them with the appropriate support.

### Our plan is...

The ASCPB will have a point of contact with the Forwards Employment Service and the Strategic Lead for Disability Employment will be invited to the Board meetings to ensure good communication between the service and the Board.

LearnPro e-learning will be promoted to all employers across hubs.

The Autism Post-Diagnostic service will include provision for training.

## 17. We heard...

The process for identifying people with ASCs should be improved, with more focus on localities with lower recorded prevalence. There should also be a process in place to help identify and record the details of carers to enable the provision of carers assessments.

### Our current position...

For children, when referrals come to Children and Young People Services a paediatrician's diagnosis is requested to record on the child's records.

For transitions from children and young people's to adult services it is expected that individuals with ASCs will have already been diagnosed and be clearly identified at the point of referral.

<sup>2</sup>gether NHS Foundation Trust offers an ASC assessment service, which accepts internal and external referrals, to identify people with ASCs.

Primary care audit

## 18. We heard...

More people with ASCs and learning disabilities should receive an annual health check.

### Our current position...

If a person with ASCs also has a diagnosed learning disability and they are registered on the GP learning disabilities register they are invited to attend for an annual health check.

## Appendix 1 - Criteria used for priority setting in this strategy

In considering the strategic priorities for people with ASCs in Gloucestershire there was broad acceptance and understanding of the financial and social policy context in which priorities were identified and in which decisions and future work programmes would need to be agreed.

People with ASCs and their families, as well as professionals and organisational representatives generated a list of criteria to support them to identify the priorities set out in this document from a much more aspirational list of actions that could improve the lives of people with ASCs and their families.

Priorities set out in this strategy were identified by applying the following prioritisation criteria:

- early intervention has the greatest impact. For instance, if everyone was identified as a child there would be no need for an adult ASCs diagnosis service
- invest in things that make the system more efficient (not in silos) and make the system easier to understand
- act on and invest to have the biggest impact on the most people (wide reaching)
- act on and invest in approaches for which there is an evidence base to show that they increase individual wellbeing and improve people's lives
- invest in work programmes that are sustainable, save money and reduce distress and suffering

## **Appendix 2 – Themes that arose in consultation but were not collectively prioritised (or are subsumed under other priorities) in alphabetical order.**

- A single point of contact for each person (key workers) – don't make us keep retelling our story
- Access to assessments for family carers
- Autism friendly DWP Assessments
- Autism friendly job support
- Capacity to provide training to increase understanding of autism in families, social care, educational settings and health
- Comprehensive data for children and young people without an education & health care plan, +65 year olds, women and girls people with autism and no learning disability, people with autism in or going in to work and people living alone with family
- Designing services and supports that make sense to people with ASC, that create a clear "point" to life plan objectives for the person
- Education provision with shorter holidays to help families manage change
- Increased access to sensory assessment and support
- Increased respite for families particularly in school holidays
- Increased sibling and family support, particularly groups to support social, emotional, mental health and wellbeing
- More clearly signposted diagnostic pathways
- More friendly and accommodating social activities for children, young people and adults with ASC and their siblings to develop participation in their communities formed as "hubs" where access can also be provided to professionals
- More individualised housing, accommodation and community facilities for adults as well as accommodation searches that work for people with ASC
- Reasonable adjustments to universal services such as social work, benefits and general health services
- Resources to support the preschool communication pathway especially practitioners trained in assessment and standardised tools for assessment
- Resources to support the school-age social communication pathway; governance, administration, resources, trained practitioners
- Suitable local treatment (admission) services for people at high risk of distress with preventative and post discharge support
- Support for carers (adults)
- Systematic training for professionals working with children 0-5, 5-11, 11-18, 18-25, to be able to identify ASC and other related "problems" (sic)
- Tailored physical activity for people with ASC (not always in groups)

## **Appendix 3 - Key points and priorities for action from Quarter 3 2016/17 Primary Care ASCs audit**

Since the 2013/14 primary care audit on ASCs there has been an increase of 0.1% in the diagnosed prevalence of ASC. This takes the total to 0.3% which remains below the estimated total population prevalence of around 1%. Recorded prevalence in 2016/17 ranged from 0.1% in the North Cotswolds to 0.4% in the Forest of Dean locality (see table 1).

### **\*PRIORITY FOR ACTION: Continue to improve the identification of people with ASCs, focusing on localities with lower recorded prevalence**

In the last three years there has been a small increase in the proportion recorded as having a carer, taking the total to 26% at the time of the audit, this was highest in the Forest of Dean locality (40%). Across all localities few records (3%) included details of the carer.

### **\*PRIORITY FOR ACTION: Improve process for identifying and recording the details of carers to enable the provision of carers assessments**

There has been a small increase recording of employment status (12% to 14%) and living arrangements (19% to 25%) recorded. However, on-going improvement is required to address low overall levels of recording. 12% of people with ASC were recorded as being in employment, this represents 85% of those with an employment status reported. The high level of recorded employment among people with ASC may be affected by a potential bias towards recording the employment status if individuals are employed, as opposed to not recording the employment status of those who are not employed.

Of the 25% of records that include living arrangements, over half (54%) of those with living arrangements were recorded as living in a care home. This is likely to be an over representation of the living arrangements of the total population of people with ASC. Having good healthcare information about people living in supported settings is important so the bias although inaccurate is considered positive. The need to encourage improved recording for those not living in a care homes is an obvious corollary to this.

### **\*PRIORITY FOR ACTION: Improve the recording of employment status and living arrangements among people with ASC**

There has been little change in the proportion of those with ASC and learning disabilities receiving an annual health check (53% to 54%), coverage is similar to the coverage of the overall LD population.

### **\*PRIORITY FOR ACTION: Increase the proportion of people with ASC and learning disabilities who receive an annual health check, particularly in Cheltenham and the North and South Cotswolds**

Between 2013/14 and 2016/17 there was a small increase in the recorded prevalence of depression among people with ASC (9% to 11%). This is higher than the recorded depression prevalence among the total population of Gloucestershire (8.4% in 2016/17). A larger increase was seen in the recorded prevalence of anxiety (15% to 21%).

### **\*PRIORITY FOR ACTION: Improve access to psychological support for people with ASC and ensure that providers make reasonable adjustments to promote positive outcomes and experience**

	Number of people with ASC/suspected ASC	Total practice population	Recorded prevalence (%)	Seen by services (%)	Recorded as having a carer (%)	Employment status recorded (%)	Living arrangements recorded (%)	Received annual health check in last 15months	Depression (%)	Anxiety (%)
Cheltenham	367	152659	0.24%	92.30%	18.30%	17.30%	15.30%	35.5%	14.70%	21.50%
Gloucester City	597	169705	0.35%	91.70%	31.20%	16.00%	21.00%	53.7%	9.30%	20.80%
North Cotswolds	36	28993	0.12%	97.10%	16.70%	11.80%	11.80%	25.0%	15.50%	25.90%
South Cotswolds	103	57843	0.18%	94.70%	16.50%	19.40%	21.40%	34.8%	13.80%	15.80%
Stroud and Berkeley Vale	415	119249	0.35%	98.00%	18.80%	11.70%	34.40%	64.4%	10.20%	20.60%
Tewkesbury, Newent and Staunton	152	42084	0.36%	87.00%	17.10%	12.30%	28.10%	57.1%	9.70%	21.00%
The Forest of Dean	261	63013	0.41%	93.60%	39.80%	9.90%	30.60%	60.5%	11.60%	19.00%
<b>Grand Total</b>	<b>1931</b>	<b>633546</b>	<b>0.30%</b>	<b>96.70%</b>	<b>25.10%</b>	<b>14.30%</b>	<b>24.40%</b>	<b>54.0%</b>	<b>11.20%</b>	<b>20.50%</b>

