



# Gloucestershire's All-Age Autism Strategy 2022 – 2026

## Foreword:

"I'm proud to introduce Gloucestershire's coproduced Autism Strategy, which sets out our local goals, ambitions and creative vision for how we can support and enhance the lives of autistic people in our county.

I have always been passionate about coproduction and so am really pleased that with the help of our Partnership Board, this strategic document has been written with, and will be monitored by, those with lived experience. This strategy should not only be a structure and framework to which we as a system can work and hold ourselves to account, but also be a document where the voices and aspirations of our autistic community, and their families are at the forefront, which it very much is.

We have structured our strategy so that it is easy to read and sets out in a clear way what people told us worked well, where we need to focus more attention and how we'll be able to measure success. By working together collaboratively and more closely, together we can keep driving positive change for autistic people in Gloucestershire."

***Kim Forey, Director of Integration, NHS Gloucestershire***

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"My autism diagnosis in later adult life began my further exploration and understanding of many of the issues I had faced throughout my life and also led to me meeting my partner at an international autism conference. In 2019 I became a co-chair of the Gloucestershire Autism Partnership Board working closely with Judith North. Gloucestershire's Autism Partnership Board brings together key organisations and representatives of Autistic people including people with lived experience and their carers to oversee the delivery of the local strategy. I now also chair the associated Lived Experience group.

The first theme in this strategy is "Improving understanding and acceptance of autism", which remains critical throughout and is key to the delivery of the other themes in the strategy and in developing an autism friendly society. Significant steps have been made since the development of the first Gloucestershire Autism strategy. From inception, this strategy has been taken as all-age, which should ensure continuity within services right though the age range from infant through to old age. For the first time the overlap with the range of other neurodiverse conditions and their need to be recognised has begun to appear in the strategy which is very positive.



Developing this strategy has enabled focused thinking around what is necessary for us to achieve while recognising the realism of resource and change limitations. What is important now is the next steps of identifying, implementing, and measuring effectiveness of plans that achieve this strategy. We must remain focused on what truly counts, which is the beneficial effect on the lives of on Autistic individuals along with those close to them.

To be recognised in all of these activities are the very broad range of people involved with identifying and delivering change. There are too many to be named, this includes: those with lived experience (whether autistic or close to them); educational and health professionals; employment services; the various charity sector organisations who provide commissioned or non-commissioned support; commissioners themselves and many others. The work of other partnership boards in the county should also be acknowledged, in particular the Learning Disability Partnership Board which has a significant overlap, working together across these group is important to make effective change.”

**Andrew Cotterill (Partnership Board co-chair)**

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## Introduction:

“Autism is lifelong neurodevelopmental condition affecting people in wide ranging ways with varying degrees of severity and impact to life.

There are medical criteria for an autism diagnosis that have evolved over the years. Core to these are:

- social and communication difficulties,
  - repetitive and restrictive thinking and behaviours (including focused interests)
  - unusual sensory responses (for example significant over or under sensitivities within the body senses).
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However what matters more to autistic people is how their own presentation of autism affects them and those around them and what is necessary both for themselves to do and what reasonable adjustments can be made around them that support living as fulfilling and healthy a life as possible. This is more a social model of the condition.

Individual presentations of autism vary widely. Additional areas of difference may include:

- difficulties understanding how others think or feel
  - difficulty with the unexpected and/or adapting to changes in routine
  - differences and difficulties in enjoyment of social situations
  - difficulty getting needs met;
  - problems with executive function (e.g. planning and organising)
  - extreme and enduring stress and anxiety, which can lead to meltdowns or shutdowns, often occur as a result of all the issues being present.
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There can often be several co-occurring conditions that present with the autism. Examples include;

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- significant mental health issues
  - attention deficit hyperactivity disorder (ADHD)
  - obsessive compulsive disorder (OCD)
  - learning disabilities
  - learning difficulties
  - gastrointestinal conditions
  - eating disorders.
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While some people express satisfaction with their life as an autistic person, and feel autism provides them with qualities and skills that neurotypical people may lack, many find living with autism challenging and are likely to suffer low mental health and quality of life as a result. It is vital that the uniqueness of each person's autistic make-up, and changes over time and across environments, is understood by those supporting or even just interacting with autistic people in order that they achieve their potential and a good quality of life.”

### ***Autism lived-experience group***

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It is estimated that 1% of the population is Autistic. In line with Gloucestershire’s demography, this means approximately 5,000 people (children and adults) have Autism. The population is estimated to rise by 13.1% between 2017-2035, with data suggesting the number of Autistic people in Gloucestershire be around 5,600 by 2035.<sup>1</sup>

NHS Gloucestershire, Gloucestershire County Council and Gloucestershire’s Autism Partnership Board (APB) are committed to developing Gloucestershire into an Autism inclusive county where Autistic people can lead rewarding lives and can access:

- the support they need pre and post diagnosis
- National Institute for Health and Care Excellence (NICE) compliant Autism assessments
- professionals who have a good understanding of Autism
- community provision which is Autism inclusive
- education and employment which is adapted to their needs

The national strategy for Autistic children, young people and adults: 2021 to 2026 is the government’s strategy for improving the lives of Autistic people and their families and carers in England.<sup>2</sup> Similar to "Think Autism", the first national Autism strategy, it

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<sup>1</sup> One Gloucestershire (2019), Learning Disabilities and Autism Strategic Needs Assessment, 2018-2019 [accessible at: <https://www.gloucestershire.gov.uk/media/2112214/your-voice-matters-report-final.pdf>]

<sup>2</sup> HM Government (2021), The national strategy for Autistic children, young people and adults: 2021 to 2026 [available at:



places an expectation on local councils and health services to develop plans to ensure Autistic people that live in their area get the help they need.<sup>3</sup> This strategy was developed with professionals, Autistic people and their parents and carers, it replaces the Gloucestershire Autism Strategy 2018-2021 and sets out the intentions and future priorities for the improvements in attitudes, support and services for Autistic people of all ages.

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[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1004528/the-national-strategy-for-Autistic-children-young-people-and-adults-2021-to-2026.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-Autistic-children-young-people-and-adults-2021-to-2026.pdf)

<sup>3</sup> HM Government (2014), Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update [available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/299866/Autism\\_Strategy.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf)]



## Background

The first Gloucestershire Autism Strategy 2013 – 2016, focused on adults with little recognition of the needs of children and young people. That strategy was updated and replaced with all age Gloucestershire Strategy for people with Autistic Spectrum Conditions (ASC) 2018 – 2021. In this strategy ten priorities were identified; these are set out in the table below with the progress made against these priorities. It has also been cross referenced to the current National Strategy to clarify whether this reflects the current national priorities.

Priority 2018 - 2021	Children and Young People progress	Adults' progress	Does this remain a priority? (2022- 2026)
Post diagnostic support that helps people and their families to learn about, live with and manage the implications of being neuro-divergent.	National Autistic Society post diagnostic training courses were piloted. The NHS has now been commissioned to develop post-diagnostic training courses to be delivered by NHS professionals which will also link families into community support. The Gloucestershire Parent Carer forum signposts to peer support groups and now have an Autism Family Support Worker.	Community Autism Support and Advice (CASA) was commissioned to support autistic adults in the community via one-to-one, peer-support and drop ins. Gloucestershire Carers Hub offers support groups for carers with autistic adults,	Yes ( <u>Improve Acceptance of Autism and Tackling health and care inequalities for Autistic people</u> )
Local services for people with the most complex needs, some of whom are currently accessing out of county services.	A Dynamic Keyworker Team was introduced to work closely with families of children and young people at risk of admission. The Positive Behaviour Support Service (PBS) also works intensively with a small number of families of children with learning disabilities and/or Autism who could be at risk of a family breakdown. Gloucestershire maintains a very low	The Integrated High Needs Team was introduced in Gloucestershire as part of the Transforming Care Programme. Since the initial pilot phase the Team has increased its capacity and is able to continue supporting discharges from mental health in-patient settings into community provision. One of the Team's main priorities has been to	Yes ( <u>Tackle health and care inequalities for Autistic people</u> )



	number of children being admitted to Tier 4 hospital settings due to the work of the Learning Disabilities Child and Adolescent Mental Health Service (LD CAMHS) and Learning Disability Intensive Support Service (LDISS ).	support moves back into county for adults who have been placed within in-patient settings in other areas. A substantial number of individuals have moved back into Gloucestershire and work continues to bring everyone back.	
Early identification and intervention	Gloucestershire County Council continues to focus on early identification and intervention through the Graduated Pathway and training. The increasing demand for pre-school Autism assessments indicates a high level of awareness in Early Years Settings and the community.	The Community Autism Support and Advice Service drop ins are established to understand some of the needs of local autistic people.	Yes ( <u>Improve Autistic children and young people's access to education, and supporting positive transitions into adulthood and tackling health and care inequalities for Autistic people</u> )
Improve transition from young people to adult services.	Preparing for Adulthood information is now available on the Local Offer. A Transition Operational Group manages the transition planning of young people likely to need support from Adult Services. Transition Panels are in place for young people at risk of going on to become Not in Education, Employment or Training (NEET).		Yes ( <u>Improve Autistic children and young people's access to education, and supporting positive transitions into adulthood</u> )
An up to date, comprehensive and easily accessible on-line central point of information and connection for people with ASC, their families and professionals who support them	Information for families and young people will be made available on the Local Offer which is under development. There is also a digital project working on improving the experience of children and young people and their families whilst they are waiting for an assessment.	Information for all will be made available on Your Circle.	Yes ( <u>Tackle health and care inequalities for Autistic people</u> )



<p>Ongoing workforce development to ensure the needs of people with ASC are recognised and understood</p>	<p>Oliver McGowan training was rolled out across Gloucestershire to improve awareness and understanding of Autism and learning disabilities.</p>		<p>Yes (<u>Tackle health and care inequalities for Autistic people</u>)</p>
<p>Improve access to diagnostic services</p>	<p>A new Social Communication and Autism Assessment Service for children under 11 years old has been developed. The NHS has worked in partnership with a private provider to reduce the waiting lists due COVID-19.</p>	<p>The adult autism pathway is being reviewed. The NS has worked in partnership with a private provider to reduce the waiting lists due COVID-19.</p>	<p>Yes (<u>Tackle health and care inequalities for Autistic people</u>)</p>
<p>Support for families with children, young people and adult family members with Autism</p>	<p>Grants were distributed to community groups to offer activities and peer support to children and young people and their families. The Graduated Pathway is used to ensure children and young people get the support they need.</p>	<p>The Community Autism Support and Advice Service drop ins are established to understand some of the needs of local autistic people.</p>	<p>Yes (<u>Tackle health and care inequalities for Autistic people</u>)</p>
<p>Development of provider services to ensure provider organisations fully understand and can meet the needs of people with Autism</p>	<p>Education settings can access Autism training.</p>	<p>The Health and Social Care Framework Providers can access Autism Training</p>	<p>Yes (Build the right support in the community and supporting people in inpatient care)</p>
<p>Understand the needs of all people living with Autism 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</p>	<p>The Social Communication and Autism Assessment Service has been developed in partnership with the Parent Carer Forum and has ensured harder to reach groups will be able access assessments. A Reasonable Adjustments flag is being introduced which will support the collection of data and ensure autistic people are able to get the support they need to access services.</p>	<p>A Joint Strategic Needs Analysis was completed to understand local need. The Community Autism Support and Advice Service drop ins are established to understand some of the needs of local autistic people. Reasonable Adjustments flag is being introduced which will support the collection of data and ensure autistic people are able to get the support they need to access services.</p>	<p>Yes (<u>Improve Acceptance of Autism and Tackle health and care inequalities for Autistic people</u>)</p>



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The priorities outlined in this strategy are aligned with and reflect the priorities identified in the following strategic documents: -

- Local Strategy Review Action Plan and Learning from COVID-19 engagement work with the Autism Partnership Board
- [National Autism Strategy 2021 – 2026](#)
- [National Disability Strategy 2021](#)
- [SEND Code of Practice: 0-25 \(Statutory Guidance\)](#)
- [Education Inclusion Strategy 2022-2025](#)
- [Special Educational Needs and Disabilities \(SEND\) Strategy for Gloucestershire 2022-2025](#)

Both locally and nationally there is a move towards considering neurodiversity rather than Autism as a single condition to ensure everyone's needs are recognised and met. Whilst Gloucestershire is making significant progress in this direction, this strategy is aligned with the National Autism Strategy 2022-2026 which currently only focuses on Autism.

#### **Structure of this strategy:**

The local Autism Strategy uses the six themes from the National Autism Strategy to ensure our local focus is aligned with national priorities. Each section will summarise the current position in Gloucestershire and outline what NHS Gloucestershire and Gloucestershire County Council sets out to achieve in the duration of four years of this strategy.

#### **The six themes are:**

- 1) Improve understanding and acceptance of Autism
- 2) Improve Autistic children and young people's access to education and support positive transitions into adulthood
- 3) Support more Autistic people into employment
- 4) Tackle health and care inequalities for Autistic people
- 5) Build the right support in the community and support people in inpatient care
- 6) Improve support within the criminal and youth justice systems



NHS Gloucestershire and Gloucestershire County Council are committed to deliver the following: -

### **Improve Acceptance of Autism**

- Increase the number of National Autistic Society, Autism Friendly Awards given out
- Publicise Autism friendly services such as Autism Hour
- Develop a network of Autistic people and allies
- Hold regular awareness and engagement events in Gloucestershire
- Improve accessibility of public transport
- Create a media campaign to promote understanding and acceptance of neurodiversity

### **Improve access to education and support positive transitions into adulthood for Autistic children and young people**

- Ensure children with additional needs are well supported in education settings
- Ensure schools can access support from professions in Health, Education or Social care
- Develop the SEND sufficiency in Gloucestershire
- Increase the number of schools with an Autism Quality Mark
- Ensure all the information on Preparation for Adulthood is available on the Local Offer
- Improve the way Autistic young people are listened to and have their voices heard.

### **Support Autistic People into Employment**

- Increase the number of Autistic people supported into work by the Forwards Employment Team
- Develop a best practice model for employment and support of Autistic people
- Support employers to become confident in hiring and supporting Autistic people
- Have accessible voluntary, work experience placements available

### **Tackle health and care inequalities for Autistic people**

- Have a National Institute of Care Excellence (NICE) compliant Autism diagnostic assessment service
- Improve pre and post diagnostic support
- Implement Reasonable Adjustments flag across the Integrated Care System
- Introduce a digital solution to improve communication for families waiting for an assessment.

### **Build the right support in the community and support people in inpatient care**

- Embed the Dynamic Keyworker Team to support young people who may be at heightened risk of hospital admission and/or placement breakdown
- Develop a network of neurodiverse support providers in the community
- Increase awareness of housing grants and opportunities
- Hold an all-age Dynamic Support Register

### **Improve support within the criminal and youth justice systems**

- Pilot an Autism Toolkit to use in all police stations countywide
- Improve the collection of Autism specific data within the criminal and youth justice systems
- Re-commission the Appropriate Adult Service
- Improve the use of the Autism Alert Card

Whilst training is not specifically mentioned in the commitments above it is critical to delivery of this strategy.



## 1. Improve understanding and acceptance of Autism

Improving understanding and acceptance of Autism is essential to ensure Autistic people and their families can live fulfilling lives. Nationally there is increasing representation of Autism in the public

domain and in the media; it is important that we continue to develop awareness and understanding to build on this momentum. It is recognised within Gloucestershire that the general awareness of Autism has increased in line with national representation, however there is still further changes to be made in order to establish what Autism means to Gloucestershire, and how as a county we support our Autistic community. Evidence from the All-Party Parliamentary Group on Autism (APPGA) “The Autism Act, 10 Years On” shows children and young people often feel misunderstood or judged by their peers because of their behaviour. This can impact their ability to engage and succeed in education.<sup>4</sup> It is expected all children and young people will be taught to understand and embrace diversity.

I just want to be able to go about my day without any problems. There is no understanding Autism is a different style of communication

NHS Gloucestershire and Gloucestershire County Council’s ambition is to help change people’s perception of Autistic people and their families through: -

- The education of children and young people in Early Years settings and schools
- Working with local businesses and organisations to promote inclusion and accessibility of services
- Supporting the development of a network of Autistic people and allies to raise awareness of the needs of Autistic people and support the inclusion of Autistic people in society.

### **Current activity in Gloucestershire:**

- The Annual Autism-Awareness Week Bulletin which provides information on what support, advice, guidance and provision is available in Gloucestershire for people diagnosed with autism, and those who identify as autistic
- Investment in the provision of Autism-inclusive activities for children and young people to ensure they and their families, are supported in their community.

### **By 2026 we commit to:**

- Increase the number of Gloucestershire businesses and Voluntary and Community Organisations that are awarded the National Autistic Society, Autism Friendly Award

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<sup>4</sup> All Party Parliamentary Group on Autism 2019, The Autism Act, 10 Years On, National Autistic Society [Accessible at: <https://pearsfoundation.org.uk/wp-content/uploads/2019/09/APPGA-Autism-Act-Inquiry-Report.pdf?msclkid=752b6769cf9d11ecaa8590137bdf7132>]



- Increasing the use of Gloucestershire Directories (Local Offer and Family Information Service (children) and Your Circle (adults) to promote opportunities
- Develop a network of Autistic people and allies
- Hold regular awareness and engagement events in Gloucestershire, particularly targeting marginalised groups
- Ensure Autistic people feel welcome, supported and safe when using public transport
- Coordinate a local media awareness campaign to promote understanding and acceptance of neurodiversity

**In order to deliver the commitments above NHS Gloucestershire and Gloucestershire County Council will:**

- Increase the awareness of inclusion with businesses and Voluntary and Community Organisations and support them to become Autism inclusive. There is a need for wider awareness and acceptance of Autism amongst businesses which the public regularly access e.g., Supermarkets, Cafés, and Retail Shops. The Autism Friendly Award should be used to recognise and celebrate organisations who make reasonable adjustments to ensure everyone can access their services.
- Ensure that online directories (Local Offer, Family Information Service and Your Circle) include information on Autism inclusive businesses including “Autism Hours” where the environment is adapted to suit the needs of Autistic people. The directories will be comprehensive, up to date and accessible. Functionality and navigation of these directories will be continually reviewed to ensure they are purposeful.
- Create an ongoing local awareness media campaign co-ordinated between the Autism Partnership Board, NHS Gloucestershire and Gloucestershire County Council. Further use of social and interactive media will be made, such as webinars, forums and other online meetings to share information more effectively and efficiently with the people who need it. Awareness and acceptance of Autism should be increased by collating and sharing impactful lived-experience stories, which people can relate to.
- Hold local Autism focussed events, including people who are undiagnosed or think they may be Autistic and would benefit from information and support to increase awareness and reduce stigma. Work with identified marginalised groups, ethnic minorities and carers is already taking place and needs to be further explored. It is recognised that statutory services will need to adapt their ways of working to make engagement sessions accessible to Autistic people and ensure all voices are heard.
- Develop a network of Autistic people and allies in Gloucestershire, to provide a peer support opportunity and allow individuals to have a safe space to talk



about their identity. This network should expand, support and strengthen the Autistic voice, linking Autistic people to providers, schools, colleges, businesses and the general public. Consideration needs to be given to how Autistic people are enabled to feedback to services, for example through a dedicated email inbox or 'feedback forms' to ensure service delivery is continually reviewed and improved.

- Re-establish the transport accessibility group, where statutory services help the public to be more mindful of passengers, including those who are Autistic and the challenges they face when using the public transport system.

#### Training Requirements

- Inclusive services/activity training for local businesses and organisations including transport providers
- Inclusion training for businesses and Voluntary and Community Organisations

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## 2. Improve Autistic children and young people's access to education, and support positive transitions into adulthood

This theme explores how Autistic children and young people, aged 0-18, access education and how their experience can be improved, through further development of inclusive schools and by providing greater support for education professionals. In addition, the theme considers how Autistic young people prepare for transition into adulthood.

### **Current position in Gloucestershire:**

- The Education Inclusion Service is in place to support children and young people to attend school and to support schools with inclusion.
- Autism training is available for schools and Early Years Settings.
- "Speak Up" groups gather feedback from Autistic young people. This is reviewed and informs Commissioning decisions.
- Educational Psychologists and the Advisory Teaching Service provide specialist support to schools
- There are excellent examples of inclusive practice in schools and early years settings where all children with additional needs, including Autism, are well supported
- New SEND and Inclusion strategies have been approved and are moving into implementation phase.

### **By 2026 we commit to:**

- Through the delivery of SEND and Inclusion strategies Gloucestershire County Council will work with and support early years settings and schools, to strengthen inclusive practice across the county and ensure children are able to get the right support at the right time via the Graduated Pathway.



- Ensure schools and early years settings can access support from professionals in Health, Education or Social Care when they need it and that professionals will work together to meet the needs of Autistic children
- Increase the number of Special Schools within Gloucestershire to meet the needs of the young people.
- Increase the number of schools with an Autism Quality Mark (AQM) to recognise good practice across the county – in 2022 there were 11 Schools who had been awarded this and 6 schools are actively working towards it
- Ensure Autism training is available to all staff in Early Years Settings, Schools and other education settings, including post-16 and promote the uptake of this training
- Ensure all the information on Preparation for Adulthood is available on the Local Offer in an accessible format
- Improve coproduction and ensure services to listen and respond to the views of Autistic young people and their families

## Accessing Education

### Inclusive Schools

It is recognised not everyone will want to pursue a formal Autism diagnosis, or may be waiting to receive one, and therefore support and reasonable adjustments should always be made based on presenting need.

Gloucestershire County Council will work with schools to identify best practice in supporting children presenting with Autism (formally diagnosed or not) to access education and develop models to share and embed this practice across the county.

A growing number of children and young people are being diagnosed as Autistic, with special educational needs data suggesting 1.8% of all pupils in England now have an Autism diagnosis. We know many Autistic children and young people are still having poor experiences within school, are not reaching their potential, and are struggling in the transition to adult life.

*The national strategy for Autistic children, young people and adults: 2021 to 2026*

Gloucestershire County Council will promote Autism awareness and the development of an Autism-inclusive culture within the education system. All schools and settings will be encouraged to appoint an Autism champion in their senior leadership team to ensure the needs of Autistic children are considered. Schools and settings will be supported to develop Autism friendly school policies, so the school community celebrates individual personalities and behaviours.

Autistic children who are struggling to access mainstream education will be supported by the Education Inclusion Service who will work proactively with the school, the child and their family to ensure all reasonable adjustments are in place. Where necessary, options including short term access to alternative or specialist provision, will be explored for Autistic children and young people to enable access a formal education whilst being supported back into a school environment. Gloucestershire County Council is seeking to improve their outreach model of Alternative Provision. The aim of this is to better support young people to remain in their mainstream setting, where this is appropriate, by providing the additional support they need to access education.



The overall intention is to provide better early intervention for young people and thereby ensure Special School placements are used only where this is the most appropriate setting for the young person. However, it is recognised that there is currently a lack of special school spaces in Gloucestershire and the SEND strategy outlines the plans to address this which includes the opening of two new special schools in September 2022 and 2023 respectively.

Nationally and locally children with identified SEND needs continue to be disproportionately excluded from school. This is a priority area for action in the Inclusion Strategy. Commissioners and Health and Education professionals will work closely with the Education Inclusion Service to understand how many of these children have Autism, support the work of the Education Inclusion Service to better understand this issue and develop plans to reduce the number of children with SEND being excluded from school.

#### A proactive approach to school exclusions

- 17% of Autistic children have been suspended from school
- 48% of these had been suspended three or more times
- 4% had been expelled from one or more schools.

*National Autistic Society*

The number of Autistic children currently not attending school will be reviewed to understand their needs and establish how to respond to improve their access to education. To inform this work when a child is withdrawn from school, schools will be encouraged to undertake exit interviews to gather feedback from families. Any learning from these interviews shared with Gloucestershire County Council will inform understanding of the situation and enable the system to work closely with schools to make improvements.

#### **Support for Education Providers**

Early Years Settings, Schools and Colleges will be able to access specialist education services such as the Advisory Teaching Service and Educational Psychology Service to enable them to meet the needs of Autistic children and young people. Countywide School Autism Forums will be held to raise awareness and give education professionals, specialist education services and other Autism specialists an opportunity to work together, to understand the needs of Autistic children and young people and share evidence-based interventions to enhance the support Autistic children receive.

Health, social care and education systems will continue to work closely together using the Gloucestershire Graduated Pathway to support children and young people holistically before their needs escalate. The pathway for schools to access support and assessment services will be defined and clearly communicated. Schools and local mental health services will work more closely together to ensure Autistic children get the emotional support they need at the right time and when needs escalate the support is accessible.

#### **Transition across educational settings**

It is recognised the transition between educational stages, including to further or higher education, can be challenging for all children with SEND, but particularly Autistic children and young people. As part of SEND and Inclusion strategies the



Education System is reviewing the quality and effectiveness of all educational transitions. The intention is to identify when and where it is appropriate for enhanced transition support to ensure young people have the appropriate help in place to move onto their next setting.

### **Engagement**

It is well known, the best way to ensure services meet the needs of children and young people and their families is by working with them when planning services and developing policies. Co-production with the local Parent Carer Forum, parent carers and children and young people themselves will continue to be integral to the successful delivery of this strategy. To ensure a wide range of views of Autistic children and young people are represented a “Speak Up” group has been introduced to gather feedback to inform commissioning decisions. An email address will also be created and shared so that Autistic people and their families can communicate with Commissioners who will ensure their views are shared with the right professionals and reflected in the development of services.

### **Training Requirements**

- All education staff to be offered Autism specific training to increase their knowledge of the variety of ways Autism may present and understanding of sensory difference. Training will further increase the skills of education professionals to identify signs of stress and know how to offer support and put plans in place to meet the child’s individual needs.
- Support the introduction of Autism awareness lesson for children and young people. This will be important in enhancing and supporting schools and early years settings understanding of Autism and improve Autistic children’s experiences of education as well as their ability to succeed.

### **Preparation for Adulthood**

The importance of Preparing for Adulthood is relevant to all elements of the Autism Strategy. Work under each theme of this strategy will identify how to respond to needs concerning preparation for adulthood. Ensuring preparation is recognised under all themes as it not something to be managed in isolation or by one team.

Preparing for adulthood can be one of the most turbulent times in a person’s life and is often exacerbated for a young person who has additional needs such as Autism. It is important services can offer adjusted support to Autistic young people who are planning their transition to adulthood.

The areas highlighted below are detailed within the Gloucestershire Preparing for Adulthood Strategy 2020-2023. They are particularly important for Autistic young people and are relevant to all themes within this strategy.

### **Information for Families**

It is recognised there are a number of complexities to the transition into adulthood for Autistic young people. The availability of accessible information on Preparing for Adulthood is essential for families to understand what their child’s move to adulthood



and potentially adult services will look like. Every transition is different and should be tailored to meet the needs and wishes of each young person and their family.

The current information available for families will be amended, updated and enhanced to improve accessibility as well as key information and contacts for services. This information will be available on the Local Offer. The Local Offer is where all information should be available relating to support and advice for children with additional needs. Transition to adulthood should be no different. Where there is information located in other areas this will be removed and linked to the Local Offer, to ensure there is a consistent and comprehensive message to families on what *Preparing for Adulthood* means in Gloucestershire for all young people.

Information designed for young people themselves will be easily accessible and available on the Local Offer. It will include details on how changes directly impact them and how to manage. Easy read versions will be available where needed. All information developed for young people will be co-produced with young people, to reflect their views and ensure the right information is being shared at the right time.

### **Named Transition Lead**

The *Preparing for Adulthood Strategy 2020-2023* says young people who are known to Statutory Services should have a named Transition Lead who manages their care going into adulthood.<sup>5</sup> The purpose of the Transition Lead is to be fully aware of what is happening in all aspects of the young person's transition, for example their housing plans, health needs, and education provision. The Transition Lead will be a professional who has a good relationship with the young person who will ensure transition plans are in place across health, education and social care. For individuals with an Education, Health and Care Plan (EHCP) the development of the EHCP portal (launching September 2022) will enable families to track progress of plans and decisions themselves. Families will be able to go directly to their Transition Lead with any concerns or issues, which can then be directed to the relevant professional.

The Education theme of the Autism Strategy links closely to the Gloucestershire Education Inclusion Strategy and the Gloucestershire SEND strategy and is part of Gloucestershire's SEND Improvement Programme.

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<sup>5</sup> Gloucestershire's Joint Health, Social Care and Education (2021) *Preparing for Adulthood Strategy (2020-2023)* [accessible at: <https://www.gloucestershire.gov.uk/media/2107903/gloucestershire-preparing-for-adulthood-strategy-2020-2023.pdf>]



### 3. Support Autistic People into Employment

This theme is about getting Autistic people into work, considering how existing barriers can be broken down to enable Autistic individuals to access employment. Also the theme will consider how as a county we can encourage Autistic people into employment and how we prepare and support employers to make 'going to work' a good experience. We will increase employer awareness, improve conversations with Autistic adults about how they can be supported in the workplace and offer information to young people on how to share information with employers when they reach adulthood.

#### **Current Position in Gloucestershire:**

- The Employment Service is supporting Autistic people to get into and remain in employment
- The Forwards Employment Service is delivering the Assisted Internship Model (AIM). This acts as a steppingstone to support young people into employment
- There is a Disability Employment Adviser (DEA) in every Job Centre to help people find the right job for them

#### **By 2026 we commit to:**

- Increase the number of Autistic people who are supported into work by the Forwards Employment Team
- Make NHS Gloucestershire and Gloucestershire County Council an example of a best practice model for employment and support of Autistic people
- Use existing networking platforms to ensure more employers are confident in hiring, supporting and retaining Autistic people
- Provide accessible voluntary work experience placements and career opportunities for all

NHS Gloucestershire and Gloucestershire County Council need to collectively progress on closing the employment gap for Autistic people in Gloucestershire. This

I have been working for years but sometimes it gets hard to cope with change. More needs to be done to adapt workplaces and environments to the person, rather than expecting people to 'fit in'

means more people who are able and want to work can and those who have found a job are less likely to fall out of work. The data currently shows that nationally only 21.7% of adults diagnosed with Autism are in employment, and a report by the Office for National Statistics shows Autistic people are the least likely to be in work of any

other disabled group.

#### **Gloucestershire's Employment Service**

In Gloucestershire, there is a strong Supported Employment Service known locally as the Employment and Skills Hub, whose vision is to enable people with disabilities and health conditions, including Autism, achieve their employment aspirations. The Employment Service provides people with the structured specialised support they



need to promote independence and fulfil ambitions. They work closely with a range of partners including health providers and the voluntary sector. They have had many positive outcomes over the years. Whilst they have supported many people, the service needs to be more widely promoted to showcase the support available, including Gloucestershire's retention offer for those currently in employment.

### **Supporting Employers to Support Employees**

As part of the national Disability Confident campaign, Gloucestershire is already working to deliver better support for individuals who want to get into employment. However, NHS Gloucestershire and Gloucestershire County Council want to support even more Autistic people into sustainable employment. Using and publicising existing networking platforms will ensure more employers become confident in hiring and supporting Autistic people, as well as improving Autistic people's experiences of being in work. Through the promotion of good practice (from in and out of county), the stigma associated with Autism can be reduced. Employers will be supported to make application and interview processes more accessible as well as workplaces.

The Employment and Skills Hub will do more work to develop people's self-understanding particularly for those who have recently been diagnosed. This will help people to be aware of what support and reasonable adjustments they need. It will increase the confidence of Autistic people to disclose their diagnosis, empower them to get the reasonable adjustments they need and get the support they need to achieve a health work/life balance. The additional health inequalities for Autistic people who are at risk of long-term unemployment will begin to be addressed if more employers understand reasonable adjustments needed for Autistic staff to maintain their health and wellbeing.

### **Transition into Employment for Young People**

The Forwards Employment Team will work with schools to improve the diversity of careers education, to include representation for Autistic adults in employment. Professionals working with young people will encourage them to aim for their goals whilst ensuring these are achievable. Young people will learn about the benefits of disclosing their Autism diagnosis to their employers and the requirement for employers to make reasonable adjustments as well as where to go for support if they need it.

The Forwards Employment Team deliver an Assisted Internship Model (AIM). The AIM programme is a way of helping young people with a disability or barrier into employment and take their first steps towards a paid job. AIM provides opportunities to gain a practical work experience and improve employment prospects. People will be assisted in the workplace by job coaches who will develop the skills required to succeed and take a first step onto the job ladder. Whilst young Autistic people are supported by AIM there is not a specific offer to support them. Forwards aims to develop their offer to Autistic people.

### **Data Capturing**

Data available on Autistic people across the county needs to be improved. NHS Gloucestershire and Gloucestershire County Council will explore how to establish



better data recording with the potential to link in with the reasonable adjustment flag initiative. This will provide a better picture of how many Autistic people in Gloucestershire are in employment.

#### Training Requirements

- Employers provided with reasonable adjustments awareness through networking platforms

## 4. Tackling health and care inequalities for Autistic people

This theme is about how the health and care inequalities of Autistic people can be reduced. For example, it considers the diagnostic pathways for children and adults as well as post-diagnostic support and reasonable adjustments.

### **Current position in Gloucestershire:**

- The Social Communication and Autism Assessment Service in place for children and young people aged 11 and under
- Significant investment was made to address long backlogs and waiting times for assessment for both adults and children
- There is increasing demand for Autism assessments, particularly for children and young people following the pandemic
- The current post diagnostic support offer for children has been reviewed and a new service put in place.

### **By 2026 we commit to:**

- Having NICE compliant Autism diagnostic assessments in place for all ages
- Having improved pre and post diagnostic support available for all ages
- All health and social care staff undertaking Autism specific training
- The Reasonable Adjustments flag to be rolled out across the NHS Gloucestershire
- Develop a children and young people's digital solution to improve communication and ensure families are supported whilst waiting for an assessment.

Receiving a timely Autism diagnosis is vital in getting the right support and helping Autistic people and those supporting them to better understand their needs. Currently there are long delays for a diagnosis, both in children's and adult services, partly due to increasing demand on services due to growing public awareness of Autism. Without an Autism diagnosis and support from professionals, Autistic people can miss out on many adjustments needed for them to participate in life including attending medical appointments, which can lead to poor health outcomes

1,850 adults with Autism are known to GPs in Gloucestershire. This represents 0.3% of the number of people registered with GPs in the county. If, as already stated, the



prevalence of Autism is 1% of the general population<sup>6</sup>, this means the figure in Gloucestershire is approximately three times lower than the national prevalence. This may be a coding error or people may be choosing not to be identified as Autistic in their health records, or people may be undiagnosed. NHS Gloucestershire awaits the outcome of a national pilot project led by NHS England and NHS Improvement which is testing opportunities to improve coding within primary care for Autistic people. Gloucestershire will take forward any recommendations for improvement from this national work.

The available evidence indicates Autistic people die on average 16 years earlier than the general population.

*Premature Mortality in Autism Spectrum Disorder, The British Journal of Psychiatry, 2016)*

### **Children's Autism Pathway (Age 0-18)**

The Social Communication and Autism Assessment Service (SCAAS) provides NICE Compliant Autism Assessments for children and young people, aged 0-11. SCAAS will continuously develop its offer based on national best practice and learning.

Services in Gloucestershire will ensure families are linked into the community network of support at the earliest opportunity so they can access continuous peer support and additional help if they need it. The community network includes community clubs and activities for Autistic children and young people. The Dynamic Keyworker Team, that provides support for young people at risk of mental health hospital admission will support those in crisis to navigate the system across health, education, and social care.

A digital solution will be developed which will help families to understand the Autism pathway and help them to feel more supported whilst they are waiting for an assessment. The digital solution will be useful to families to see where their child's referral is within the system and will help professionals to communicate with families for example requesting additional information or sending clinic letters as well as providing recommended resources tailored to the child's needs.

NHS Gloucestershire and Gloucestershire County Council will build and develop the post diagnostic training offer to ensure all families understand their child's diagnosis and what it means for the child and for the family. The training course will follow promptly from diagnosis and will be designed to be sustainable, available and consistent even in times of system pressures. The training will respond to the needs of families in content and delivery. Courses will be available for families to access at times other than immediately post diagnosis, for example if they need additional support when their child becomes a teenager.

### **Adult's Autism Pathway (aged 18+)**

#### **During engagement people told us:**

- We need to undertake Autism friendly assessments, with Autistic people involved in the process and provide support afterwards.

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<sup>6</sup> Brugha, Traolach S et al. (2011), 'Epidemiology of autism spectrum disorders in adults in the community in England.' *Archives of general psychiatry* vol. 68, pages. 459-65



- Individuals should be contacted following diagnosis, and offered support at a time when the person is ready and has come to terms with the results
- We need to explore whether technology can improve wait time.

Commissioners will work with the local Autism Diagnostic Team within Gloucestershire Health and Care NHS Foundation Trust and service users, to review the existing service. This will include how it is accessed, address the backlog of assessments and how it may be possible to reduce waiting times. NHS Gloucestershire will analyse the current pathway, to ensure it can offer NICE Compliant assessments to meet the demand. Communication with people on the autism waiting list will improve to ensure they feel supported while they are awaiting an assessment, this should offer resources and other useful information on how to access support without a diagnosis to ensure people are getting the help they need, when they need it.

Follow up after diagnosis is necessary but at a time when the person has come to terms with the results

NHS Gloucestershire and Gloucestershire County Council will develop appropriate post diagnostic support, for people who want it and will offer ongoing support to people who need it. Help will be provided with any challenges that people face, including accessing available services and community provision. NHS Gloucestershire will ensure post-diagnostic support takes a person-centred approach that is of most benefit to people, for example identifying reasonable adjustments people need or considering personal strategies to manage day to day life. When a person is diagnosed, the Autism Diagnostic Service will work with them to understand their diagnosis.

Post-diagnostic support should exist – at the right level

The Community Autism Support and Advice (CASA) service was commissioned as part of the previous Autism Strategy (2018-2021). The service includes information, advice and support to help Autistic individuals live a fulfilling life in the county. It is countywide and supports pre and post diagnostic assessment. CASA offers a wide range of interventions and support, including one-to-one and peer support where Autistic people can meet others with similar interests. CASA also offers drop-in experience sessions for Autistic people, which are well received and will be continued. Commissioners will review and recommission this service, involving Autistic people with the intention to further build and develop the offer.

The lower age limit of the CASA Service is currently 18. The aim is that this will be reduced to 14 to directly support young Autistic people with advice and guidance as they begin to prepare for the transition to adult services. Young people and their families will be able to self-refer to CASA, making it accessible to young people who may not be in touch with statutory services.

## Reducing Health Inequalities



There is a national and local aim to reduce health inequalities for Autistic people. Autism Annual Health Checks are being trialled across the country, but Gloucestershire is not a pilot site for this. NHS Gloucestershire is awaiting the outcome of the national pilot and will take forward any recommendations once published.

For those people with a Learning Disability and Autism, promotion of the Learning Disability Register and Annual Health Checks will continue to support people to remain healthy and develop a good relationship with their GP.

The learning from lives and deaths (LeDeR) Autism reviews will be used to improve health outcomes for others living in Gloucestershire.

#### Training Requirements

- All health and social care staff will access Oliver McGowan Mandatory training
- All health and social care staff will understand how to make reasonable adjustments for Autistic people and why it is important
- Specific training will be developed for targeted professional groups such as primary care staff, education professionals, Early Help and family support workers to enable them to identify and support Autistic people
- Health care staff will be made aware of the reasonable adjustments flag, its importance and how it should be used.

## 5. Building the right support in the community and supporting people in inpatient care

This theme is about how provision can be developed in the community and within inpatient hospital settings to ensure Autistic people get the support they need. The theme explores early intervention and prevention as well as the impact of housing and support provision.

### **Current position in Gloucestershire:**

- The Dynamic Keyworker Team is in place to support children and young people up to the age of 21 who have learning disabilities and/or Autism and are at risk of admission to a mental health hospital.
- New short breaks provision is being developed for children and young people
- Grants were given to voluntary and community sector organisations to develop Autism inclusive community activities for children and young people
- An Autism Housing Group in place to improve accessibility of housing to Autistic people
- Additional investment was made into the Integrated High Needs Team for those in crisis to reduce hospital admissions to specialist units
- Gloucestershire Health and Social Care provider frameworks are now in place

### **By 2026 we commit to:**



- Develop a co-ordinated network of community neuro-disability support providers
- Increase both autism friendly housing availability and awareness of housing grants and opportunities, as well as amend the Housing with Care Strategy to recognise the needs of Autistic people
- Hold an all-age Dynamic Support Register

#### **During engagement people said:**

- Services working with their children should be collaborating to ensure they offer the right support earlier and identify when interventions are not having the intended outcome.
- Families feel processes for accessing services need to be more person-centred, so young people do not reach a point of crisis
- There is a gap in appropriate housing provision for Autistic people in Gloucestershire
- There is a gap in service provision for young people with an Autism-only diagnosis (no learning disability) who reach crisis point.

#### **Prevention and Early Intervention**

The use of prevention and early intervention methods are a key tool in reducing risk of crisis and resulting hospital admission. Under the Mental Health Act 2005 NHS Gloucestershire and Gloucestershire County Council have a responsibility to identify people at risk of hospital admission provide support to avoid it.

As part of the national Transforming Care Programme, NHS Gloucestershire is required to hold a Dynamic Support Register, which identifies individuals with Learning Disabilities and/or Autism who are admitted or at risk of admission to an in-patient hospital. In Gloucestershire children and adult services have worked together to create an all-age Dynamic Support Register. The Transforming Care Programme looks to prevent admissions to hospital through early intervention approaches to enable individuals to remain safe within their community environment.

Young people with an Autism-only diagnosis may not be being supported by statutory services other than involvement with Education. Therefore, NHS Gloucestershire will work jointly with the Education Services within Gloucestershire County Council to ensure young people of concern are supported through a multi-agency approach. This means specific and specialist services can get involved more quickly to avoid crisis, where this is required. Young people preparing for adulthood are recognised as being at a higher risk of hospital admission because of the amount of change in their lives. Change is difficult to manage and often required additional support.

#### **NHS England Keyworker Function**



The development of the Keyworker function is part of the NHS England Long Term Plan<sup>7</sup>. The purpose of the Keyworker function is to help children, young people and their families navigate the health, social care and education system. Gloucestershire was successful in becoming an Early Adopter site for the Keyworker Function during 2021 and the Gloucestershire Dynamic Keyworker Team went live in Spring 2022.

It is nationally recognised, people with an Autism only diagnosis often miss out in accessing the right support because statutory services do not focus on delivering support specifically to Autistic people. The Dynamic Keyworker Team will be able to offer help to these families and support them to access provision to meet their needs.

### **Short Breaks and Community Support Provision**

A new Short Breaks contract for Children and Young People with Disabilities will begin in 2023. The tender incorporated consultation with families who said there was not enough short breaks provision across the county, what is available has limited capacity and there are often pockets of provision rather than county-wide accessibility.

A survey was undertaken in 2021 to gauge how families would like community support delivered, NHS Gloucestershire and Gloucestershire County Council offered local organisations grant funding to develop clubs, activities and support sessions for children, young people, and their families. The survey highlighted young people should not need a diagnosis to access reasonably adjusted clubs and activities which are tailored to their needs. NHS Gloucestershire and Gloucestershire County Council will endeavour to ensure these activities remain accessible and inclusive for the lifetime of the grant funding, between March 2021-March 2023.

Over this time, statutory services will work closely with the Voluntary and Community Sector (VCS) to ensure initiatives meet the needs of Autistic children and young people continue to be developed and become sustainable. NHS Gloucestershire and Gloucestershire County Council will be developing a network led by one or more VCS organisations will coordinate community providers to encourage the growth of inclusive community provision and work collaboratively to support organisations when sustainability becomes challenging. Regular engagement with parents, carers and young people will continue to ensure the offers are meeting population need and growth.

Gloucestershire County Council is managing the National Holiday Activities and Food (HAF) programme initiative that is backed by central Government until 2025. The HAF programme is ensuring there are accessible activities for children with Special Educational Needs. A service was commissioned to deliver training to all hosting providers to encourage inclusive opportunities, as well as the development of specific SEN sessions through close links with Special Schools and charitable organisations supporting children with additional needs and their families. There is

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<sup>7</sup> NHS England Long Term Plan, published January 2019 [available at: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>]



recognition that Autistic young people and those with other additional needs may not be able to eat the food available as part of the sessions they attend and so Gloucestershire County Council has provided a separate food offer which is available on request from parents.

## Housing

The National Autism Strategy states that Autistic people are often able to live well in their own home, but their environment needs to be adapted to meet specific needs. Local Authorities offer a range of grants including Disabled Facilities Grants (DFGs) which can be used to make adaptations, such as sound proofing walls. Working closely with the Housing with Care team a communication campaign will be launched to raise the awareness of DFGs and how to access them.

An Autistic Housing Needs multi-agency group was set-up in 2022, to help statutory services recognise the specific needs of Autistic people when it comes to appropriate longer-term housing. The group will produce a needs analysis, identify specific locality gaps and implement plans on how to ensure Autistic people access the right housing first time, in line with Gloucestershire's Housing with Care Strategy.<sup>8</sup> For young people who are beginning to prepare for adulthood, Children's Services will be working closely with Housing Teams and Adult Social Care to begin earlier planning for young people who will have specialist housing needs when they become adults. This work will take place at both an individual transition planning level and a strategic level to ensure there are the resources and housing stock available to manage the flow through the system.

## Social Care and Providers of Care

Not all Autistic people will need, nor be eligible for, social care support (as described in the Care Act 2014), but in cases where they are, they will need access to both mainstream and specialist providers.

According to latest Learning Disabilities and Autism Strategic Needs Analysis 2018-2019, there are 370 adults diagnosed with Autism in receipt of a social care package of support.<sup>9</sup> Even though formal diagnosis is a task for trained clinicians, social care staff have a key role to play in identifying people who maybe Autistic. When a person receives a diagnosis, strong links between health and social care are important to ensure continuity of care and prevent people "falling through gaps". All staff therefore need knowledgeable, prompt information about supporting Autistic people. Social care teams will be regularly informed as to the local support available for Autistic people.



Increase provider understanding in the complexities of severely Autistic adults

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<sup>8</sup> One Gloucestershire (2020), Housing with Care Strategy [accessible at: [https://www.gloucestershire.gov.uk/media/2108909/housing-with-care-report\\_17feb\\_21.pdf](https://www.gloucestershire.gov.uk/media/2108909/housing-with-care-report_17feb_21.pdf)]

<sup>9</sup> One Gloucestershire (2019), Learning Disabilities and Autism Strategic Needs Assessment, 2018-2019 [accessible at: <https://www.gloucestershire.gov.uk/media/2112214/your-voice-matters-report-final.pdf>]



Housing services also commit to providing suitable housing options for people with complex needs, supported by well-trained and motivated staff. All care providers on the Gloucestershire Health and Care Procurement Framework will have Autism training as a mandatory requirement in their contracts. Providers will only be commissioned if they are able to demonstrate that they can meet the needs of Autistic people. Experts by experience quality checks will continue to be commissioned to review support service settings and ensure they meet needs of those with Autism. Learning from these checks will be taken to inform future commissioning intentions and continue to work regularly with providers, through a provider forum to feedback and explore general learning points as well as address common issues.

### **Hospital Admissions**

Autism is not a mental health condition, but many Autistic people develop separate mental health issues.

- In total 2,030 Autistic people and people with learning disabilities are in inpatient mental health hospitals in England.
- 1,185 (58%) of these people are Autistic.
- Around one in seven (165) of these are Autistic people under 18

NHS Gloucestershire will continue to work towards targets in the NHS Long Term Plan to reduce the number of Autistic people admitted to in-patient mental health services who could be supported within their community; improve the treatment of Autistic people and prevent an avoidable admission to in-patient care.

For those who do need to be admitted to in-patient settings, improvements to the quality of support provided will continue to be made by tailoring support to individual needs and ensure community discharge as soon as they are well enough to leave. It is vital all health professionals understand Autism and the needs of Autistic people (including communication and sensory needs) across the whole spectrum.

During the last Autism strategy period (2018-2021), an engagement exercise was carried out with Autistic people and their families to better understand the issues faced locally by those who also have mental health needs without an associated Learning Disability. During the development of this strategy, a lack of support and general awareness of co-existing conditions (e.g. eating disorders and anxiety with an Autism diagnosis) were identified as well as limited alternatives to therapy. During the pandemic, the use of technology and digital innovative options have been invaluable. This will be explored further as to how it may be used effectively for Autistic people in inpatient settings and need of therapeutic support.

NHS Gloucestershire aims to reduce the number of hospital admission for people with an eating disorder and an Autism diagnosis. There is a disproportionate number of people with an eating disorder who have a diagnosis of Autism, with research suggesting 23% of anorexia nervosa patients are also Autistic.<sup>10</sup> Many do not have an Autism diagnosis when they present at times of crisis and may go on to be

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<sup>10</sup> Westwood and Tchanturia 2017; 'Autism Spectrum Disorder in Anorexia Nervosa: An Updated Literature Review', *Current Psychiatry Reports*, vol. 19



admitted to an in-patient setting where they are diagnosed. In light of these findings, coordination with the Eating Disorder Service needs to be improved. Often people are supported by services when they are in crisis and/or placed within in-patient settings but were not previously known to services. By services working proactively together, people can be supported within the local community and with their support networks around them.

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## 6. Improving support within the criminal and youth justice systems

This theme is about the delivery of support within the criminal justice and youth justice systems, within Gloucestershire including the development of Children First and the Appropriate Adult Service.

### **Gloucestershire Current Position:**

- The Children First panel was introduced to offer alternative approaches to young people accessing the youth justice system
- Speech and Language Therapists are part of the Youth Support Team to offer training and support the identification of communication difficulties
- An Appropriate Adult Service is commissioned and in place
- Youth Justice and Criminal Justice representatives at the Autism Partnership Board
- Channel Panel was introduced to support young people who are at risk of becoming involved with radicalisation movements

### **By 2026 we commit to:**

- Roll out the Autism Toolkit to all police stations across the county
- Improve the collection of Autism specific data within the Youth Justice and Criminal Justice systems
- Ensure all Youth Justice and Criminal Justice professionals access Autism training
- Re-commission the Appropriate Adult Service
- Improve the use of the Autism Alert Cards for Autistic people who come into contact with the Youth Justice and Criminal Justice Systems

### **Understand the experience of the Youth Justice and Criminal Justice systems for Autistic people**

National evidence indicates Autistic people are over-represented as people who come into contact with the criminal justice and youth justice systems as victims, witnesses or defendants. Some Autistic people may be vulnerable to criminal acts against them or become unwitting accomplices to criminal activity. The All-Party Parliamentary Group on Autism (APPGA) inquiry has shown Autistic people often have poor experiences when they come into contact with the Youth Justice and



Criminal Justice systems.<sup>11</sup> There are many reasons for this, including poor understanding of Autism among professionals as well as challenges with getting adjustments they need to engage in processes. This lack of understanding can cause staff to misinterpret Autistic people's behaviour, resulting in missed opportunities to divert them from the Criminal Justice and Youth Justice systems.

Commissioners intend to work closely with Autistic people, their families and professionals to consider the whole Criminal Justice and Youth Justice process, with the aim to make changes to improve the experience for Autistic people in Gloucestershire. This will include:

- Understanding how Autistic young people come into contact with the Youth Justice System and Adults come into contact with the Criminal Justice System
- Identifying the type of support Autistic people may need across court, prison and under probation supervision.
- Improving the police and wider Criminal Justice and Youth Justice System staff's understanding of Autism, so Autistic people get the right support, adjusted to their needs.
- Ensuring different parts of the justice system become more Autism-inclusive.

#### **Liaison and Diversion Team**

The Liaison and Diversion (L and D) Team has practitioners in the custody area of the Police Station as well as operating an out of hours support line for Police. Their main role is to complete assessments in the community if they have not been seen in custody. The Team completes a health assessment to ensure young people's individual needs are identified and met. They also provide support to the Police regarding ways to work appropriately with people, including how best to support young people who have additional needs. The visibility of this Team should continue to be publicised to ensure the Police are delivering the right level of support to people they are working with.

#### **Children First**

Gloucestershire Youth Justice Service (YJS) aim is to prevent offending and reoffending by children and young people under the age of 18 and ensure the best outcomes for children by seeing the child first and the behaviour second. It is recognised young people who offend are often vulnerable and traditional criminalising sanctions can be ineffective, inappropriate, and disproportionate.

The revolutionary diversion scheme, Children First, was introduced in Gloucestershire in 2018 is now well-established and recognised as the primary route for the majority of children who commit an offence. In 2020/21, 144 (55%) of the 261 outcomes were diverted away from the formal Youth Justice System and processed through Children First pathways, with only 85 of the most complex children entering the formal Youth Justice System. Between its inception and the end of 2020, 622

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<sup>11</sup> All Party Parliamentary Group on Autism 2019, The Autism Act, 10 Years On, National Autistic Society [Accessible at: <https://pearsfoundation.org.uk/wp-content/uploads/2019/09/APPGA-Autism-Act-Inquiry-Report.pdf?msclkid=752b6769cf9d11ecaa8590137bdf7132>]



children in Gloucestershire who had offended were prevented from being unnecessarily criminalised through effective diversion. This means two thirds of the cohort who had offended avoided formal interventions which otherwise could have a detrimental impact on their future life chances.

In addition, as the diversion scheme is an efficient system these young people have had their needs identified and addressed in a timely manner, thereby increasing the likelihood of preventing further offending. The Youth Justice System remains committed to increasing workers' understanding of the impact of health needs on children and young people's offending behaviour. There are concerning numbers of young people presenting with undiagnosed Learning Disabilities and neurodiversity, particularly Attention Deficit Hyperactivity Disorder (ADHD) and/or Autism. Due to poor school attendance many miss formal diagnosis, but it is very likely recognition of these needs may have prevented behaviour they may have been excluded for, leading into risks of offending behaviour and poor emotional health.

In 2020/21, of those young people whose youth justice interventions ended, 29% had an Education Health Care Plan, 76% had identified SEND, 97% (44 out of 45) had experienced at least one school exclusion, and 64% of these had been permanently excluded. Professionals will be supported to identify these needs and are aware of how to access assessments and support.

### **Education Needs of Young People know to Youth Justice Services**

Educational needs of young people coming into the Youth Justice System is an area of focus for the Youth Justice Management Board. There are high levels of exclusions among the young people who work with the Youth Justice Service and the educational provision available for them to access is often limited. In order to address this the Youth Justice Management Board will work with Education Services to consider how best to improve the education provision available to young people who have come into contact with the Youth Justice Service and encourage young people to re-access education.

### **Improving the environment**

Police Stations can be daunting and even more so for any Autistic person being brought into one as a suspected offender. NHS Gloucestershire and Gloucestershire County Council jointly with the Office of the Police and Crime Commissioner (OPCC) will work with experts by experience to consider the environment and the process from the perspective of an Autistic person and make the necessary changes to improve. In addition, a greater use of Voluntary Interviews which can be undertaken at the Police Station within the local area the Autistic person lives and are carried out in a much more relaxed environment to help support the individual.

### **Appropriate Adult Service**

The Police and Criminal Evidence Act 1984: Code of Practice states Autistic people should have access to an Appropriate Adult. This is someone who ensures a suspect is treated fairly by police and is able to take part in interviews, irrespective of



their vulnerability.<sup>12</sup> The Appropriate Adult's role provides non-judgmental moral support to the person (whilst held in the cell) and to ensure their legal rights are upheld. The Appropriate Adult monitors the welfare of the vulnerable adult during police interview.

Caring for Communities and People (CCP) have delivered the Appropriate Adult service in Gloucestershire since 1993. This 24-hour countywide service provides trained volunteers to act as "Appropriate Adults" for young people aged 17 and under and adults with mental health difficulties or learning disabilities when held in police custody and whose parents, guardians or carers are unable or unwilling to attend (as required by law). This service is due to be recommissioned in 2022/2023.

### **Autism Alert Card**

The National Police Autism Association promotes the Autism Alert Card which is a document Autistic people can carry to help communicate their needs as an Autistic/neurodivergent individual to Police Officers or other officials when they are away from home. The card states the person's details and advice for the officer. Alert card schemes are run in most police areas across the UK.

The card is available from the National Autistic Society. Awareness of the Autism Alert card will be improved both with Autistic people as well as organisations and staff across the Criminal Justice System. At the point of diagnosis an Autism Alert Card should be included in the information provided to the person. These will also be championed by the Appropriate Adult service to encourage uptake for those who become known to the youth or criminal justice system.

### **Autism Toolkit**

Gloucester HQ, Compass House, have introduced low-level lighting in cells and interview rooms. They also developed a physical 'toolkit' which can be used to make time in custody easier for Autistic people. There are further improvements to be made to the cells and interview rooms to ensure it best meets the needs of Autistic people and can be used as a best practice model, being rolled out across Gloucestershire. To improve this, current cells should be reviewed by Gloucestershire Constabulary jointly with Autistic people to consider how best to improve them and ensure they meet the needs of people who may benefit from low sensory-stimulation and a quieter environment. Gloucestershire can also learn from other areas who are making strides in improving their cells to make them more appropriate to meet the needs of Autistic individuals, for example Nottinghamshire Police.

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<sup>12</sup> Home Office (2013), Police and Criminal Evidence Act 1984 (PACE) codes of practice [accessible at: <https://www.gov.uk/guidance/police-and-criminal-evidence-act-1984-pace-codes-of-practice#pace-codes-of-practice>]



### **Training Requirements**

- Engagement in Autism training to continue to be mandatory within the Appropriate Adults Service, which is regularly delivered to local custody sergeants.
- Autism training for all staff in Youth and Criminal Justice including recognition of needs and how to communicate with Autistic detained persons.
- Continued awareness and training for legal representatives who support individuals throughout the process from custody to court

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## Next steps

The details of how Gloucestershire will implement this strategy will appear in an Action Plan that sets out what will be specifically done under the six themes. Each theme will be assigned an owner or owners, who will oversee the resourcing requirements and delivery of the actions.

Task and finish groups will be convened to implement the action plan. Membership of these groups will include Autistic people and family members, relevant professionals, support organisations and commissioners. The groups will report to the Autism Partnership Board on a quarterly basis.

The strategy action plan will be updated annually to reflect latest developments.



## Glossary

### **All Party Parliamentary Group on Autism (APPGA)**

All-Party Parliamentary Groups (APPGs) are informal, cross-party, interest groups of MPs and Peers interested in a particular issue. This group specifically focuses on Autism.

### **Assisted Internship Model (AIM)**

AIM or the Assisted Internship Model, is a way of helping young people with a disability or boundary to employment take their first steps towards a paid job.

### **Autism Toolkit**

The Toolkit provides items to autistic individuals to support them whilst they are in custody. This includes items such as headphones and fidget spinners.

### **Autistic Spectrum Conditions (ASC)**

Autism is a spectrum condition and affects people in different ways. Like all people, Autistic people have their own strengths and weaknesses. Autism is a lifelong developmental disability which affects how people communicate and interact with the world.

**Child and Adolescent Mental Health Service (CAMHS)** CAMHS provides a comprehensive range of specialist emotional wellbeing and mental health services for all children and young people aged under 18 who are registered with a GP in Gloucestershire. This is also a subcontracted partnership working with Teens in Crisis (TiC+) for those with a lower level of need.

### **Community Autism Support and Advice (CASA)**

The service is commissioned by Gloucestershire County Council to provide support, advice and guidance to adults with a diagnosis of Autism and their families.

### **Disability Employment Adviser (DEA)**

A Disability Employment Adviser can advise adults on job seeking, training and new skills, government schemes and disability-friendly employers in Gloucestershire.

### **Children First**

Children First is an initiative that has been effective since 1st January 2018 in the Gloucestershire area. The aim is to divert young people from the criminal justice system. The objectives are early intervention, practical and effective partnership working, information sharing and the progressive replacement of criminalising sanctions with restorative practice approaches in child offender cases.

### **Comorbidity**

Comorbidity occurs when a person has more than one disease or condition at the same time. Conditions described as comorbidities are often chronic or long-term conditions. They are also referred to as co-occurring conditions.



### **Disabled Facilities Grants (DFGs)**

The DFG is a means tested grant available to anyone who has a disability, to help meet the costs of adaptations to a property for a disabled occupant. Both for homeowners and tenants. The district councils in Gloucestershire work with Gloucestershire County Council to provide Disabled Facilities Grants (DFG) to people who have been assessed by an Occupational Therapist and are eligible for help with the costs of home adaptations

### **Dynamic Keyworker Team**

Developed through an NHS England initiative to support Children and Young People with learning disabilities and/or Autism, who are at risk of or who are already admitted to mental health in-patient units. The purpose of the Team is to support services to collaboratively to taking a person-centred approach to delivering care.

### **Dynamic Support Register**

An NHS England requirement to be held by all Integrated Care Boards to be aware of and actively case manage all individuals with learning disabilities and/or Autism who at are risk of or being admitted to mental health in-patient units.

### **Education, Health and Care Plan (EHCP)**

An EHCP is a legal document where the special education, health and social care needs of a child or young person are outlined. It lists all of the special education needs of the child. This legally binding document also sets out the provision to meet each of the needs and this has to be detailed and quantified. An EHCP also lays out the location, school, and setting that will provide the provision.

### **Education Inclusion Service**

This service supports young people and schools to ensure the right provision is in place for young people to be able to access their education effectively and in a way that meets their needs. The Education Inclusion Service focuses particularly on supporting young people and education settings where there is low attendance.

### **Employment and Skills Hub**

This hub provides a central source of information around skills and employment for Gloucestershire residents. The Hub also offers access to specialist coaches who will work with individuals around their needs. A tailored package and ongoing support will be made available to an individual, whether they need training, are looking for a new career, advice, support, or even an apprenticeship.

### **Forwards Employment Service**

Forwards is a service supporting people with disabilities achieve their employment dreams. Forwards can provide career help to identify skills and job goals, improve confidence, manage anxiety and overcome barriers. Anyone can come to Forwards if they have a disability, health condition or need some support to gain confidence.

### **Gloucestershire Youth Justice Service (YJS)**



A set of processes and practices for managing children and young people who have committed, or allegedly committed, an offence.

### **Graduated Pathway**

The Graduated Pathway is Gloucestershire's response to ensuring the right support is available to all children, young people and their families with additional needs, whether these are educational, social or emotional needs or a disability.

### **Integrated High Needs Team**

As part of the national Transforming Care Programme, Gloucestershire has developed an Integrated High Needs Team to manage the cohort of individuals which sit within this specification, providing support to Services, Providers and individuals to avoid mental health in-patient hospital admissions and to facilitate community discharge for individuals with learning disabilities and/or autism.

### **Keyworker Function**

This is NHS England's official title for the service in Gloucestershire known as the Dynamic Keyworker Team (see above).

### **Learning from Lives and Deaths of people with a learning disability and Autistic people (LeDeR).**

The LeDeR programme, funded by NHS England and NHS Improvement, was established in 2017 to improve healthcare for people with a learning disability and Autistic people.

LeDeR aims to:

- Improve care for people with a learning disability and Autistic people.
- Reduce health inequalities for people with a learning disability and Autistic people.
- Prevent people with a learning disability and Autistic people from early deaths.

### **Learning Disabilities Child and Adolescent Mental Health Service (LD CAMHS)**

LD CAMHS provides specialist support for children and young people with a Learning Disability who are in a special school and presenting with behaviours that can be described as challenging.

### **Learning Disability Intensive Support Service (LDISS)**

The Learning Disability Intensive Support Service (LDISS) provides an all age specialist service for individuals with learning disabilities who have behaviours that can be described as challenging, and/or mental health needs that cannot be met in mainstream services.

### **Liaison and Diversion (L and D) Team**

Liaison and Diversion (L&D) services identify people who have mental health, learning disability, substance misuse or other vulnerabilities when they first come into contact with the criminal justice system as suspects, defendants or offenders.

### **Local Offer**



The Local Offer is an information directory where individuals with SEND aged 0-25, as well as their parents or carers, can go to find out what support or provision they can expect to be available in their local area. All Local Authorities are required to have a Local Offer as written in the SEND Code of Practice.

### **National Institute for Health and Care Excellence (NICE)**

NICE guidelines make evidence-based recommendations on a wide range of topics. These include preventing and managing specific conditions to planning broader services and interventions to improve the health of communities.

### **Not in Education, Employment or Training (NEET)**

Young people who are NEET – not in education, employment or training – sometimes need help in finding their path in life. In Gloucestershire the Youth Support Team offer specialist support to prepare young people who are 16+ for the world of work, and to help them find the jobs and training opportunities that are right for them.

### **Neurodiversity**

A term used to describe a range of natural (neurological) variations in the human brain, this includes conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and Autism.

### **Oliver McGowan Training in Learning Disabilities and Autism**

This training is named after Oliver McGowan, whose tragic death in 2016 highlighted the need for health and social care staff to have better training in learning disabilities and Autism. All of the training is fully co-designed and co-delivered with people with a learning disability, Autistic people, family carers and people working within learning disability and Autism services.

### **Parent Carer Forum**

Gloucestershire Parent Carer Forum is a voice for those with lived experience of being a Parent Carer (This means parents and/or carers of children with any disability, SEN, condition, impairment or additional need). The Parent Carer Forum creates a bridge to the providers of statutory services to help build better services for all families of disabled children in Gloucestershire.

### **Preparation for Adulthood**

The time in a young person's life, generally at around age 14 years onwards, where thought and planning is given to what a young person may want from their future as they become an adult.

### **SENDIASS**

SENDIASS Gloucestershire provides free, confidential, impartial advice and support on matters relating to children and young people with special educational needs and disabilities (SEND). The service is offered to parents and carers of children and young people aged between 0 and 25 years old.



### **Social Communication and Autism Assessment Service (SCAAS)**

SCAAS is a multi-agency team comprising of Clinical Psychologists, Speech and Language Therapists, Paediatricians and an Occupational Therapist who work closely with Education colleagues to assess children under the age of 11 for Autism. Children and young people over the age of 11 will continue to be assessed in the CAMHS Neuro Clinic.

### **Special Educational Needs and Disabilities (SEND)**

Special educational needs and disabilities can affect a child or young person's ability to learn.

### **Statutory Services**

These services are across health, social care and education, for example the GP, hospital, adult social care teams or schools.

### **“Time Out” spaces**

Often used in education settings this environment offers a calm place for Autistic young people (and often those with other additional needs) to de-escalate their feelings before returning to their lessons or classroom environment.

### **The Learning Disability Register**

The learning disability register is the GP's list of people who have learning disabilities. Doctors use it to make sure that people with learning disabilities get the right support in the right ways. Being on the learning disability register tells healthcare staff that they need to adapt their support to the person's situation.

### **Transforming Care Programme**

The Transforming Care Programme is a national priority that focuses on improving services for children and young people with learning disabilities, autism or both, and who also have challenging behaviour or mental health conditions.

### **Transition Operational Group**

A multi-agency meeting to support and manage the transition planning of young people who are likely to require support from statutory services in adulthood.

### **Your Circle**

A directory to help adults find their way around care and support and connect with people, places and activities in Gloucestershire.



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