

# NEURODIVERGENCE IN GLOUCESTERSHIRE



News and updates from your local Autism Partnership Board



## Welcome to Issue 3

Firstly a big thanks to Liz Bell who initiated this newsletter and was the editor and creator of much of the content of the first two editions. She was with the Partnership Board for a year bringing her wide range of skills, enthusiasm and love of people to the work of the Board improving the lives of neurodivergent people in Gloucestershire.

We wish her well as she continues her work with neurodivergent communities. I am sure though her wide variety of work, including projects such as the ZIG/ZAG Peer Mentoring scheme, we will be hearing more from her!

No doubt you will pick up the evolutionary nature of the newsletter. As it develops, please feel free to pass any thoughts or potential content to [neurodiversity@gloucestershire.gov.uk](mailto:neurodiversity@gloucestershire.gov.uk).

I also want to recognise and thank Noor for all her work on this newsletter.

Andrew Cotterill

Chair of Gloucestershire's Autism Partnership Board

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Gloucestershire's Autism Partnership Board brings together people with lived and professional experience of autism and neurodivergence to oversee the implementation of the local Autism strategy. Our local priorities reflect the six overarching themes of the National Autism Strategy. Some of this quarter's highlights are shown below:

### Theme 1 Highlights

#### ***Improve understanding and acceptance***

- Neurodiversity Network Conference held in March 2024 to increase awareness & celebrate acceptance by and with neurodivergent people & professionals. More details on Page 6.
- Neurodiversity on agenda for Gloucestershire County Council's June's leadership conference - produced and presented by Neurodivergent colleagues.
- Gloucestershire Libraries in talks to promote neurodivergent friendly hours, coproduced with the Partnership Board.



### Theme 2 Highlights

#### ***Improve access to education & support positive transitions into adulthood***

- The Local Offer has been relaunched, sharing information about support and services available for children and young people with Special Educational Needs & Disabilities (SEND)
- Inclusion Gloucestershire are working with neurodivergent young people (16 - 25) to increase their confidence, advocate for themselves and ensure their voices are heard, supporting their transition into adulthood

### Theme 3 Highlights

#### ***Support more people into employment***

- Lunch and Learn sessions held for over 90 employers during Autism Acceptance Week in April. The Team also held an Autism-friendly job fair on World Autism Acceptance Day.
- New Autism Job Broker in post as part of Gloucestershire's Employment & Skills Hub.
- The Wellbeing Line's 'Let's Talk about Neurodiversity' conversations continue to grow with over 300 staff engaging across the ICS. More information on [Page 4](#)!

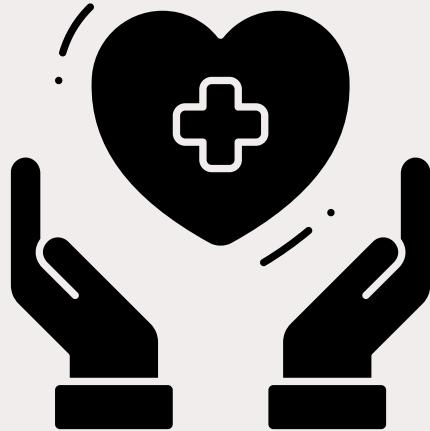


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### Theme 4 Highlights

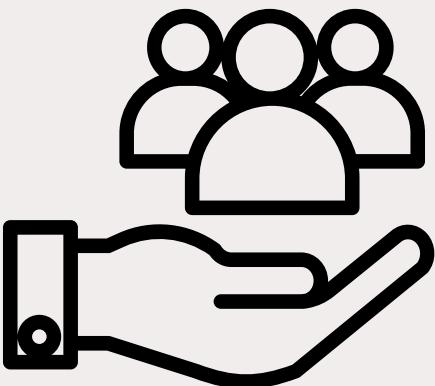
#### ***Tackle health & care inequalities***

- The Autism Liaison Officer, a new role for Gloucestershire's Hospital Trust, started in April 2024 to complement and work alongside the well-established Learning Disability Liaison Nurses. Martin will be an advocate for neurodiverse people and translate the part acute healthcare plays in a person's care.
- The Adult Autism and ADHD assessment service had a very positive whole team offsite, exploring service development. More on the outcomes in a later newsletter!



### Theme 5 Highlights

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



- The CYP NHE Keyworker Team continue to work with a wide range of children and young people across Gloucestershire, regularly connecting with commissioners to identify elements of good practice as well as gaps in service provision.
- The Dynamic Support Policy (inc Blue Light Protocol) has been implemented across the system (including autism only) and Strategic Oversight Group is now operational.

### Theme 6 Highlights

#### ***Improve support within criminal & youth justice systems***

- The Gloucestershire Probation Lead met with our Autism Partnership Board Chair to discuss support for neurodivergent people on probation and on licence.
- The Multiagency Reducing Reoffending & Rehabilitation for Mental Health, Learning Disabilities & Neurodiversity is currently reforming, with the hope to progress and unify the work under Theme 6.





During Autism Awareness Week 2024, the Employment and Skills Hub hosted a series of lunch and learn sessions specifically designed for employers, including managers, HR professionals, and business owners. These sessions focused on empowering attendees with the knowledge and tools needed to champion a thriving neurodiverse workplace. Attendees gained valuable insights into developing and promoting a work environment that celebrates the unique strengths that neurodivergent employees bring.

The sessions were enriched by the lived experiences of guest speakers, who led some of the talks throughout the week. Representatives from the Independence Trust and Gloucestershire Constabulary shared their experiences in implementing positive changes to their recruitment processes and gave insights into what support is available for neurodiverse employees. This provided invaluable inspiring examples for the (over) 90 attendees eager to learn and connect and resulted in many productive conversations!

*We would like to thank Andrew Cotterill and Josh Jones for their support & contributions to the week!*

### Let's Talk about Neurodiversity - The Wellbeing Line

Since October 2023, The Wellbeing Line has been facilitating 'Let's Talk about Neurodiversity Conversations'. The sessions have proven extremely popular, with over 300 staff members working in health and social care from across Gloucestershire's Integrated Care System (ICS) joining the conversations. They have provided an opportunity for connection and conversation around the subject of neurodiversity and supporting neurodivergence in the workplace. We have had neurodivergent people; people who want to understand more; people who want to support neurodivergent colleagues; and people who are engaged in thinking about policies and processes to support neurodiversity at an organisational level. Ultimately, the aim is to empower individuals to express what they need and want, and to inform and empower managers to know how best to support them. We also want to create a neuroinclusive and neuroaffirmative workplace culture.

The conversations started by exploring terminology, sharing experiences and workplace challenges and thinking about how to foster a safe work environment. We were privileged to hear from Dr Mala Ubhi, Gloucestershire GP and Clinical Lead for Learning Disabilities, Autism and Mental Health, who led a conversation on reasonable adjustments and the use of the SPACE (sensory, predictability, acceptance, communication, empathy) framework. We have since drawn on specific aspects of SPACE in our conversations, sharing individual experiences of helpful and unhelpful practices and thinking about how each aspect can be enhanced in the workplace. We were also delighted to hear Jess Meredith from Differing Minds talk about the social model of disability, support with and without diagnosis and about how neurodiversity applies to all of us.

An ICS Working Group has also been established, with a good mix of individuals with lived experience and those in organisational leadership positions. The group's aim is to co-produce a vision and think about what measurable impact there would need to be for this work to be successful. The Wellbeing Line has also developed a short awareness raising training session for teams, where key concepts such as terminology, spiky profiles and medical vs social models of disability are discussed. To find out more and get involved, please contact [hello@thewellbeingline.co.uk](mailto:hello@thewellbeingline.co.uk).

## Neurodiversity Network Conference

The Neurodiversity Network held a free conference during Neurodiversity Celebration Week 2024. The conference was a day of talks and workshops with opportunities to connect and learn as a community. It also provided a space for organisations to come together, joining with neurodivergent people to share experiences and best practices for neurodiversity inclusion.



For organisations providing arts, leisure, or wellbeing activities in Gloucestershire, the day was an excellent opportunity to learn more about welcoming neurodivergent attendees and increasing the accessibility of events. Participants were able to share projects and learn about local initiatives. The environment fostered connections and learning across organisations, with talks from neurodivergent individuals working in the sector offering valuable insights. For neurodivergent individuals or groups, the day provided a chance to actively engage in conversations about neurodiversity inclusion. It facilitated access to organisations behind many local events, offering discussions about experiences and requirements that would benefit both individuals and the broader neurodivergent community in Gloucestershire.

Following positive and constructive feedback, the Neurodiversity Network plans to host an online Lunch and Learn session at the end of June to build on this momentum. There are also plans to set up a Community of Practice event later in the year.

To stay up to date with Network news and event invitations, sign up [here](#); or click the link <https://forms.gle/1y5Qx38zRdtBnfLw7>. For all the resources shared following the conference, including slides from speakers, please visit the [website](#).

## Carers Week 2024 - Putting Carers on the Map

Carers Week is 10th – 16th June, an annual campaign which shines a spotlight on unpaid Carers, who dedicate themselves to supporting family members, friends or neighbours who are ill, disabled, have a mental health condition, or an addiction. The theme for Carers Week 2024 is "Putting Carers on the Map", which aims to raise awareness of the Carer role in society and ensures voices are heard loud and clear. Carers UK, the charity behind the campaign, highlights the need for increased visibility among policymakers, employers & communities.

It is also an opportunity to educate the wider community on the Carer role and raise awareness of Gloucestershire Carers Hub.

Throughout Carers Week, the Carers Hub will be in various locations around Gloucestershire, speaking about the services they offer. You can find them at the following locations:

- 9.30am – 3.00pm: Monday, 10th June - Forest of Dean Community Hospital, Cinderford
- 9.00am – 2.30pm: Tuesday 11th June - Cirencester Livestock Market
- 9.30am – 3.00pm: Wednesday, 12th June - Nailsworth Bus Station
- 9.30am – 3.00pm: Thursday, 13th June – Quedgeley
- 9.30am – 2.30pm: Friday 14th June 2024 - Big Health Check Day, Oxtalls Sports Park, Gloucester,

## LeDeR Reviews for Autistic Adults

LeDeR, learning from lives and deaths of people with a learning disability and autistic people - is a local service improvement programme funded by NHS England to help make services better. LeDeR works to:

- Improve care
- Reduce health inequalities; and.
- Prevent people with a learning disability and autistic people from dying too young.

When a person with a learning disability or autistic person dies, a LeDeR review looks at the health and social support they received and to see where care could have been better. It also aims to identify examples of good practice.

### Useful facts and figures:

- Average age of death for an autistic person is 55 years
- Average age of death for a person with a learning disability is 62 years
- Average age of death for general population is 83 years.

### Top 3 causes of death

- Suicide, misadventure, or accidental death.
- Respiratory
- Cardiovascular and stroke related.

We know that Gloucestershire have not been notified of many autistic adult deaths. Increasing these death notifications (aged 18 and over) will help us understand health inequalities better, lead to service improvements and work towards preventing premature deaths.



If you want to notify us about the death of someone who has died and they had a diagnosis of autism please go to <https://leder.nhs.uk/report> and fill out the simple form.

A LeDeR reviewer will carry out the review on behalf of our Integrated Care Board [ICB], involve the family and send a copy of the report when it is completed.

### Useful resources

- [Good work being done](#)
- [Action from learning report 22/23](#)
- [LeDeR Annual Report 2022](#)
- <https://leder.nhs.uk/resources>
- [Local LeDeR page - Inclusion Glos](#)

## Modernising support for independent living: the health and disability green paper

The government want to ensure that the UK have a welfare system that is fit for the future, a system that supports work for people who can, provides a safety net for people who need it, and that is fair to the taxpayer. There is a consultation open until 22 July 2024 seeks views on whether the government should

make fundamental changes to how we support disabled people and people with health conditions, and whether our system delivers the right support to people most in need. Click [here](#) to find out more & have your say, or follow the link. <https://www.gov.uk/government/consultations/modernising-support-for-independent-living-the-health-and-disability-green-paper>.



Each issue, we will introduce a topic of interest that is highly prevalent in autism or other types of neurodivergence. Please be aware that due to the summary nature of the “What is” introduction there is not space to explore the intricate detail and nuances that some of you will be aware of!! This issue is all about **alexithymia**.

Alexithymia encompasses a range of characteristics that affect emotional awareness, processing, and expression. These characteristics can significantly impact an individual's daily life, relationships, and mental health. It is present in a high percentage of autistic individuals (meta studies suggesting at least 50%). Research about presence in other types of neurodivergence is not so far along.

## Characteristics.

- 1. Difficulty Identifying Feelings: People often have trouble recognising and distinguishing between different emotions. For example: confusion about what they are experiencing emotionally, or unable to pinpoint whether they are feeling sad, angry, or anxious. As they struggle to identify emotions, people may instead report physical sensations, like headaches or stomachaches, as indicators of their emotional state.
- 2. Difficulty Describing Feelings: When asked to describe their emotions, people may find it challenging to articulate what they feel. They often have limited vocabulary for describing emotions and may resort to vague terms like "upset" or "not right". They may avoid discussing their feelings and emotions altogether because of the difficulty in verbalising them.
- 3. Externally Oriented Thinking: Their focus is often primarily on external events rather than internal emotions - being more concerned with the details of their surroundings and external activities. Often also tending to engage less in self-reflection and introspection, often unaware of their own inner emotional experiences. It's possible externally orientated thinking is brought on by the difficulties identifying and describing feelings.

## Various aspects can often be seen in alexithymic individuals such as:

- Limited Imagination and Fantasy Life (such as reduced daydreaming) leading to becoming more practical in their thinking - thought processes are often pragmatic and focused on concrete details rather than abstract or imaginative ideas.
- Displaying a restricted range of emotional expression. Facial expressions and body language may appear flat or subdued, not reflecting a wide range of emotions. Even when feeling emotions, expressing them can be challenging for people, resulting in a perceived lack of empathy or warmth.
- Impaired Emotional Awareness and Regulation: Being aware of and regulate emotions is often impaired leading to either emotional outbursts or a general emotional numbness. Often lack awareness of their emotional states may lead people to become overwhelmed or result in physical symptoms.

Alexithymic characteristics collectively may lead to significant challenges in social and interpersonal contexts:

- Forming and maintaining close relationships due to limited emotional awareness and expression.
- Experiencing social isolation or misunderstandings due to inability to connect emotionally with others.

Alexithymia is often linked with various psychological and physical health issues:

- Mental Health Conditions: Higher rates of depression, anxiety, and other mental health disorders are common.
- Somatic Complaints: people frequently report physical ailments that may be linked to unrecognised and unexpressed emotional distress.

**Personal perspective:** I (Andrew) am hyposensitive on many physical senses (externally and interoceptively) and wonder whether my ability to distinguish feelings (physical and emotional) stems from this. I recognise some personal issues, both as a child and adult, have either come from or been exacerbated by my alexithymia.

# LOCAL RESOURCES

This page is a list of Gloucestershire focused resources specifically for, or inclusive of, autistic and other neurodivergent conditions.



## All Age

**Your Circle** [[www.yourcircle.org.uk](http://www.yourcircle.org.uk)]: A directory to help you find your way around care and support and connect with people, places and activities in Gloucestershire.

**You're Welcome** [[www.yourewelcomeglos.org](http://www.yourewelcomeglos.org)]: An inclusive online directory and forum. Find social events, clubs, groups or places to visit. Listings include accessibility and inclusive practice information.

## For Adults

**Community Autism Support & Advice (CASA) Service** [[www.grcc.org.uk/what-we-do/community-autism-support-advice-casa](http://www.grcc.org.uk/what-we-do/community-autism-support-advice-casa)]: A service for autistic adults in Gloucestershire, and their families, friends, and support networks.

**Forwards Gloucestershire** [[www.forwardsgloucestershire.co.uk](http://www.forwardsgloucestershire.co.uk)]: All age, all disability service; supporting people with disabilities achieve employment dreams. Forwards can provide help to identify skills and job goals, improve confidence, manage anxiety and overcome barriers.

## For Children and Young People

**Child and Adolescent Mental Health Service (CAMHS)** [[www.ghc.nhs.uk/our-teams-and-services/children-and-young-people/camhs/](http://www.ghc.nhs.uk/our-teams-and-services/children-and-young-people/camhs/)]: Provides a range of specialist emotional wellbeing and mental health services for all children and young people under 18 years old.

**SENDIASS** [[www.sendiassglos.org.uk/](http://www.sendiassglos.org.uk/)]: Provides free, confidential, impartial advice and support on matters relating to children and young people with special educational needs and disabilities. Useful children and young people resource page at <https://sendiassglos.org.uk/support-organisations/>

Gloucestershire also took part in **Neurodiversity Celebration Week (18 – 24 March 2024)**, a worldwide initiative that challenges stereotypes and misconceptions about neurological differences. During the week, we aimed to raise awareness by signposting to resources, updating on activities across Gloucestershire, as well as celebrating the differences of local neurodivergent individuals. You can find the daily newsletters below:

- [Monday 18 March: What is Neurodiversity?](#)
- [Tuesday 19 March: Autism](#)
- [Wednesday 20 March: Employment](#)
- [Thursday 21 March: Children & Families](#)
- [Friday 22 March: Health & Wellbeing](#)



**Neurodiversity  
Celebration  
Week**

# OTHER SELECTED RESOURCES

Here you'll find some other selected autism/neurodivergent resources that may be of interest.

Please be aware that as the resources linked to this page are not created or provided by us, we cannot guarantee that all the content is perfect - merely that we hope you might find them of interest!

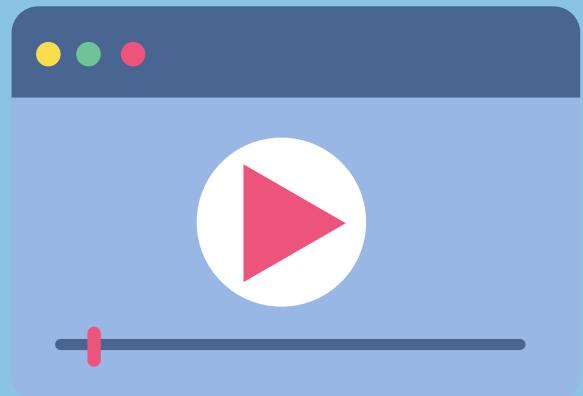


## **YouTuber of the issue!**

A few years ago as a newly diagnosed autistic adult, I (Andrew) spent some time exploring content about autism. Here is a set of content I benefited from, available on YouTube. It's created and presented by an autistic adult - Amethyst Schaber. Her 27 "Ask and Autistic" episodes cover a variety of topics, presented in an easy though informational way.

Topics include:

- What is Stimming
- What are Autistic Meltdowns
- What about eye contact.



The playlist can be found on

<https://www.youtube.com/@neurowonderful/playlists>



## **Theme based resources of the issue!**

### **Neurodivergence in the criminal justice system.**

Garden court chambers has over the last few months been putting on a series of webinars covering topics in the justice system. Their topic headings were

- Understanding Neurodiversity in the Justice system
- Representing Neurodiverse Clients
- Witness Handling
- Neurodivergent Children in the Justice System
- Neurodiversity in the Criminal Justice System
- Neurodiverse Lawyers

At time of release of this newsletter, most of the webinars had been uploaded. They can be found by navigating the link below:

[www.gardencourtchambers.co.uk/events/free-webinar-series-neurodivergence-in-the-justice-system](http://www.gardencourtchambers.co.uk/events/free-webinar-series-neurodivergence-in-the-justice-system)

# DATES FOR YOUR DIARY

Every quarter we highlight a few local support groups, meet ups or events happening around Gloucestershire. Let us know if you need anything relevant adding.

## Your Voice SW Neurodiversity Group

Meets online on the first Thursday of every month from

18:00-19:30. Contact Sammy Roberts on

[sammyr@inclusion-glos.org](mailto:sammyr@inclusion-glos.org)



## APB Autism Lived Experience Group

Meets online, usually once a month on a Monday from

14:00-15:30. Contact [Andrew@Cotterill.info](mailto:Andrew@Cotterill.info)

## Churchdown Autism Group

Meets at Churchdown community centre on the first

Thursday of the month from 14:00-15:30. Contact

[rachel.hodges-cox@nhs.net](mailto:rachel.hodges-cox@nhs.net) or [cashmir.martin@nhs.net](mailto:cashmir.martin@nhs.net)

## Community Autism Support and Advice (CASA) support groups and drop-ins

Various locations - for more details visit

[www.independencetrust.co.uk/CASA](http://www.independencetrust.co.uk/CASA) or email

[info@independencetrust.co.uk](mailto:info@independencetrust.co.uk)

## Gloucestershire Parent Carer Forum 'Listen To Me' Social Meet-ups

Various locations - for more information visit

[www.glosparentcarerforum.org.uk](http://www.glosparentcarerforum.org.uk)

## Your next Autism Partnership Board

Monday 3 June 2024 | 10.00am to 12.30pm

Venue: Zoom [Online]

### Main Topics:

Eating Disorders & Autistic Patients  
& CQC Inspection Update [Gloucestershire County Council]

### Future Partnership Board Dates:

Tuesday 10 September 2024 | 10.00am to 1.00pm

Venue: Shire Hall

Tuesday 3 December 2024 | 10.00am to 12.30pm

Venue: Zoom [Online]

## WANT TO JOIN US?

THE PARTNERSHIP BOARD MEETS ONCE PER QUARTER. IF YOU WOULD LIKE TO COME ALONG TO OUR NEXT MEETING, SEND A REQUEST TO:  
[NEURODIVERSITY@GLOUCESTERSHIRE.GOV.UK](mailto:NEURODIVERSITY@GLOUCESTERSHIRE.GOV.UK).

## MORE INFORMATION

YOU CAN FIND OUT MORE, AS WELL AS VIEW PREVIOUS NEWSLETTERS AT:  
[HTTPS://GLOUCESTERSHIRE.GOV.UK/HEALTH-AND-SOCIAL-CARE/DISABILITIES/AUTISM-PARTNERSHIP-BOARD/](https://GLOUCESTERSHIRE.GOV.UK/HEALTH-AND-SOCIAL-CARE/DISABILITIES/AUTISM-PARTNERSHIP-BOARD/)