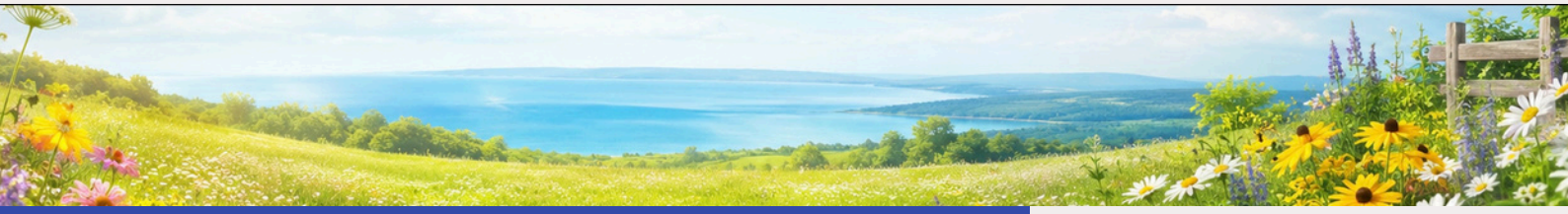
DISABILITY, NEURODIVERGENCE AND MENTAL HEALTH IN GLOUCESTERSHIRE

Summer 2026
Issue 11

Incorporating news and updates from Gloucestershire's Partnership Boards & Partners



Welcome to the Summer 2026 edition of Disability, Neurodivergence, and Mental Health in Gloucestershire.

This edition reflects a busy and active few months across Gloucestershire's Partnership Boards, networks and community partners. Across the pages that follow, there is a strong shared theme: people using their voices, experiences and expertise to shape services, challenge barriers and help make Gloucestershire more inclusive. Transport comes through clearly as a major issue, with updates on Building Better Transport Links, Better Transport Week and local work to improve access. We also look ahead to Big Health Day 2026, celebrate community research and insight, and share opportunities for people to get involved in shaping local change.

There is a strong focus on neurodivergence in this edition, including employment support, updates from CASA and Active Impact, young people's voices from the Let's Talk Well conference, and a "What About?" feature on demand avoidance. Mental health is also a key thread, with updates from the Mental Health and Wellbeing Partnership Board and the locality Mental Health Forums, including important learning on crisis support.

You will also find updates from the Learning Disability Partnership Board, the Physical Disability and Sensory Impairment Partnership Board, the Neurology Subgroup, and the Carers Partnership Board. Together, these updates show the value of partnership working, lived experience, co-production and persistence.

Thank you to everyone who contributes, attends meetings, shares insight, asks difficult questions and keeps pushing for better support across Gloucestershire.

As always, contributions, ideas and feedback for future newsletters are warmly welcomed.

Andrew Cotterill

IN THIS ISSUE

Building Better Transport Links

Working Together to Improve Travel Across Gloucestershire

Transport is consistently raised as a key issue across all five Partnership Boards, affecting access to work, education, healthcare and community life.

The Building Better Transport Links (BBTL) group brings partners, communities and service providers together to share experiences, identify gaps and influence how local transport is planned and delivered.

The purpose of BBTL is to provide a clear route for feedback from people and organisations across Gloucestershire, ensuring that real-life issues and ideas help shape future transport priorities, services and improvements.

BBTL meetings offer a valuable opportunity to hear what is working well, what needs to change and what matters most to local people. Insights gathered through these discussions are fed directly into transport planning and service development, helping to support more accessible, reliable and joined-up transport options.
BBTL meetings bring together a range of voices.

Alongside community insights, we're pleased to include contributions from Stagecoach West and Pulhams, who share how regular engagement through BBTL helps drive service improvements and why listening to lived experience, particularly around accessibility, is so important.
Feedback from Stagecoach and Pulhams: "Operator attendance at EP Forums plays a key role in supporting continuous service improvement, as it allows issues to be discussed in real time and informed by operational knowledge of how services run day to day.

Direct involvement means feedback can be translated quickly into practical actions, whether that is addressing reliability, vehicle allocation or driver awareness. It also gives us a direct channel to ensure passenger groups are aware of upcoming improvements to our services, and have the opportunity to ask direct questions of us regarding such changes, to help spread the word more widely.

Equally important is ensuring accessibility and lived experience feedback is central to these discussions. Input from disabled passengers and those with specific mobility, sensory or cognitive needs provides insight that operational data alone cannot capture, helping operators and the authority to better understand real barriers to travel and to collaboratively design services that are more inclusive, usable and customer focused."
We encourage anyone with an interest in transport—whether as a passenger, community representative or professional partner—to get involved and attend future BBTL meetings. Your voice can help influence better transport links for communities across Gloucestershire.

To attend future BBTL meetings or to be added to the mailing list, please contact megan.toomer@gloucestershire.gov.uk

Raise Your Voice!

Raise your voice for Better Transport Week

For disabled people, better transport means being able to make plans and travel with confidence. It means step-free access and lifts that work, trained staff, reliable assistance, people who respect priority spaces, accessible travel information, affordable fares, safe pavements and much, much more.

Better Transport Week runs from 15 to 21 June, celebrating transport that connects people and places

We want our community's voices to be loud and proud all week. If you post about what better transport means to you, tag us on social media and use #BetterTransportWeek.

Shape the Government's new strategy on mental health

We all need connection to the people and places that matter to us. Having the freedom to travel plays a big part in making that possible.

When transport does not work for us, disabled people can be shut out of our communities, lose independence, and miss out on enjoying opportunities. All of this can affect our mental health.

This call for evidence is a chance to make that link clear, and to have your say on other aspects of mental health. Respond by 10 July.

Accessible Homes Campaign

Thanks To Sara Croft, Public Health Manager GCC for sending this.

Please see below link to the Habinteg Insight group accessible homes campaign. The launch with took place earlier in the year in parliament. Some really thought-provoking presentations. The thing that struck me most was the visual at 8.59 on the video showing a bathroom in a housing that is classified as a visitable property.

See: https://www.habinteg.org.uk/latest-news/habintegs-insight-group-launches-accessible-homes-campaign-in-parliament-2912

Insight In Gloucestershire

Joining up Insight in Gloucestershire – what is it, and why is it useful?

Listening to people's experiences, and learning from them, plays a crucial part in the design and delivery of effective and safe support and services that make a positive difference to people's lives. People's stories, experiences, and feedback are a kind of qualitative data known as 'insight'. Insight can tell us things that other kinds of data cannot, particularly about how people feel about things.

There is lots of insight being shared by people in Gloucestershire with a huge range of health, care, statutory and voluntary organisations and groups. Some of this insight is directly about health and care, and some is about other things that impact people's wellbeing - like housing, education and training, employment, criminal justice, physical activity, the environment, and arts, culture and heritage.

Joining Up Insight in Gloucestershire was set up by a group of organisations in the county to provide a central online hub for gathering, collating and storing this insight - so that everyone can access it, add to it, learn from it and use it to shape and influence their plans. It is free, and people working and volunteering in health, care, statutory and voluntary organisations and other groups are welcome to join, and encouraged to add their reports and other insight to the collection.

Here's details of just some of the insight added over the last couple of months:

1.Rethink Mental Illness's Gloucestershire Mental Health Forum Digest - Co-occurring mental health needs and neurodivergence, reporting on conversations from the five locality Mental Health Forums

2.Tewkesbury Nature Reserve's Wildlife and Water for Wellbeing (3w) Impact Report 2025/26, sharing feedback and case studies highlighting the many benefits that connection to nature brings. This includes a wonderful YouTube video of people's responses to activities

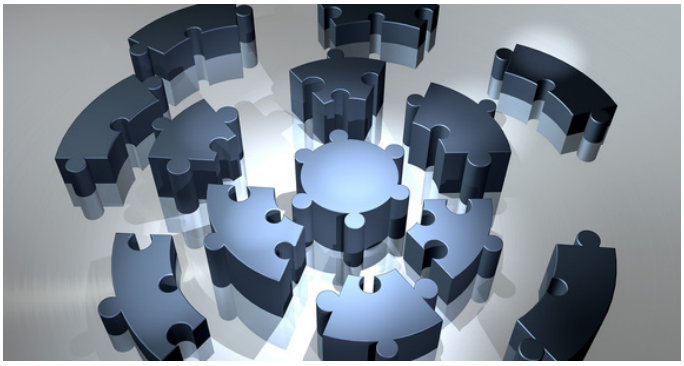
3.Wiggly Charity and Project Grow's Grow with Wiggly Report - Food Community Project in Gloucestershire, reporting on experiences of a farm-to-fork project empowering communities through growing and cooking food

4.The Keepers Community Hub's insight from investment in communications expertise to focus on connection with people in the local community and healthcare

5.The Roses Theatre's report on a year-long creative wellbeing programme to support older adults, people with dementia and carers in Tewkesbury.

That's lots more experiences and stories that people have shared with groups and organisations around the county, that we can now all learn from. Thank you to everyone who has uploaded their insights!

If you would like to join the Joining up Insight in Gloucestershire hub, to see these reports and many others, please email us at glicb.gig@nhs.net



ABLEISM AND NON VISIBLE DISABILITIES

DO YOU HAVE A DISABILITY OR LONG TERM HEALTH CONDITION PEOPLE CAN'T SEE?

DO YOU FEEL YOU HAVE BEEN TREATED UNFAIRLY BECAUSE PEOPLE CAN'T SEE YOUR CONDITION?

WE ARE DOING RESEARCH ON NON VISIBLE DISABILITIES AND WE WANT TO HEAR FROM YOU

WHO CAN TAKE PART?

Anyone over 18, living in Gloucestershire with a non-visible disability. This is a disability or health condition that is not immediately obvious.

WHAT WILL I HAVE TO DO?

- Attend 4 workshops at Inclusion Gloucestershire's office, where you will make a handmade magazine, recording your experiences, known as Zines. Reasonable adjustments and alternative ways to participate will also be offered, for example creating your zine from home.
- Zines can be made by anyone, you do not have to be an artist.
- The workshops will involve a chat about ableism and what it is, learning about zines and then making a zine about your experiences of ableism.

WHY SHOULD I TAKE PART?

- You will help our understanding of what is known as ableism and how it affects people
- You may feel empowered or relieved to tell your story
- The opportunity to share your experiences with people who can make changes

Email: research@inclusion-glos.org
Phone: 07517 994765

INCLUSION
RESEARCH
EXPERTS BY EXPERIENCE

Events

Big Health Day - FINAL REMINDER

The next Big Health Day is on Thursday 11 June 2026 (9.30am-2pm).

It will be at its usual venue: Oxstalls Sports Centre, Plock Court, Gloucester, GL2 9DW.

Big Health Day is an annual event for people with a physical or learning disability, sensory loss or mental health support needs. It aims to be a fun and inclusive event which encourages people to participate in sport, physical exercise and social activities and to engage with services and organisations which can provide support. It has run for 17 years at different venues. For the last few years it has been held at Oxstalls Sports Park in Gloucester.

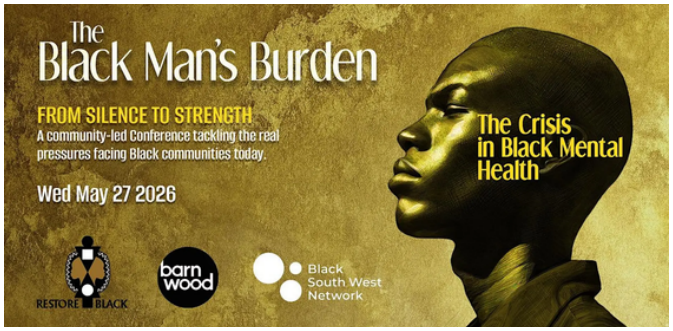
The aim of each Big Health Day is to:

- To deliver an inclusive event with the theme of staying healthy and active, meeting friends and having fun.
- To reduce health inequalities for people living with a learning disability, a physical disability and/or mental health problems

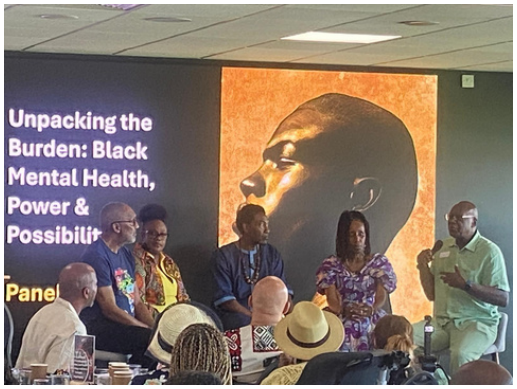
There will be stalls from many different organisations (120 in 2025), offering useful information and support. As usual the partnership boards will also be represented. There will also be lots of inclusive sports and activities for people to take part in.

For more information on the big health day, please see the 2026 Big Health Day Website.

Trailing for Next Time: Write up from The Black Mental Health Conference 2026: The Black Man's Burden



This "brilliant vibrant" event was held Wednesday 27th May 2026. Sadly too late for a write up this time … but next time!



Partnership Board Update

From your Chair: Andrew Cotterill

The Neurodivergence Partnership Board 3rd of March.
The March Partnership focused on employment, neuroinclusive workplaces, and practical support into work. Sessions included updates from CASA on key support needs, Forward on employment outcomes and Connect to Work, the DWP Disability Employer Adviser role, and National Star's work on placements, staff wellbeing and creating a neuroaffirming glossary.

The meeting also included lived experience contributions, GCC's Neuroinclusive Working Group, Barnwood Trust's session on disability, neurodivergence and the social model.

For those interested, a small employment networking group will be launched shortly. This will provide a space to share resources, updates and information about what is happening locally around employment.

Finally we had an introduction to Amy Rees as Adult Social Care Coproduction Lead.

The next meeting will take place on 2 June 2026 and will focus on the outputs from the Locality Mental Health Forums, whose December sessions explored neurodivergence and co-occurring mental health needs.

Want to join out partnership board or recieve partnership board related correspondance? Please email: neurodiversity@gloucestershire.gov.uk.

News from Active Impact

Good bye Mar

Mar will be moving on from their role with us as coordinator of the Neurodiversity Network. Before they finish, they wanted to share a personal message with you:

"Hello! I am moving on from my role at Active Impact and I want to thank all the amazing people I've met along the way. It's been a pleasure to work with you and be a part of these crucial conversations about neurodiversity and inclusion.

Thank you Neurodiversity Network members and thank you to my lovely team members at Active Impact – I know the Neurodiversity Network is in safe hands with you going forward!"

Thankyou Mar

We'd like to take this opportunity to thank Mar for their contribution to Active Impact, the project and for the support they've provided to partners and stakeholders throughout their time with us.

Thanks to the solid groundwork Mar has put in, our halfday conference series is thriving with our fourth event already lined up for later this year!
Thanks so much Mar, we will miss you!

Save the Date: Our 2026 Neurodiversity Conference is taking place in Churchdown on Oct 7th. We'll have our usual mix of speakers, workshops and networking all in an intentionally low key, neurodivergent accessible conference experience.

Opportunity: We will shortly be advertising for an MC for our conference. We'd like to offer this freelance paid role of hosting to someone with lived experience of neurodivergence and experience in public speaking. We'll share more details soon.

Active Impact's Inclusive Activities Network:

Our Aiming High network meetings bring together activity providers and support organisations from across Gloucestershire to share ideas, challenges, opportunities and support.

If you're working to make activities more inclusive for deaf, disabled and neurodivergent children and young people, we'd love to see you at our summer meeting next month

Book on: https://bit.ly/4tFk3oh

Tuesday 23 June | 9.30am–12.30pm, Northway Community Hub, Tewkesbury

ActiveImpact
Making inclusion happen

News from CASA

Dominic Manester has joined the Community Autism Support and Advice services (CASA's) team, running their fortnightly Gloucester Autistic Adults drop-in at St Mary de Crypt church's cafe on Southgate Street.

Emma, the project manager said "Dominic started attending our Cinderford drop-in about two years ago. After a few months, he began to help out at the drop-in as a volunteer, quickly becoming famous for his amazing baking skills for group snacks, and last year took the lead in finding the group a new venue when we needed one".

"Shortly after that, Emma asked me if I'd like to take over the running of the Gloucester drop-in as a paid facilitator," said Dominic. "It's going amazingly - it's been a lot of fun getting to know a good group and organising events and activities."

To find out about CASA's drop-ins and one-to-one advice for autistic adults across Gloucestershire use the following link https://www.grcc.org.uk/casa-community-autism-support-and-advice or email infocasa@grcc.org.uk

This is a picture of Dominic after one of our sessions of fidget tools.

CONTACTS

Email: infocasa@grcc.org.uk || Phone: 01452 317460 (Monday to Friday 9.00am – 4.30pm).
For more information, and links to leaflets and resources, visit https://www.grcc.org.uk/CASA.
For support groups and drop-ins, please see the dates for you diary page later in the newsletter.

Autism & Me Post Diagnostic Course

Pippa and Summer have just completed the first two cohorts of our CASA team's new "Autism and Me" post-diagnostic course.

The course runs as a small online group over six two-hour sessions, and aims to help autistic adults understand their autism diagnosis, and how autism affects them individually in areas such as relationships, sensory processing, communication, work, and wellbeing.
Judging from the participants' feedback, the course has been very successful in achieving its aims. Comments from the course participants included:

- "You have done a wonderful job creating a safe space to come together as a group to explore autism and our experiences as autistic adults"
- "I realised that although I am my own person, there are others like me, it's the most validated I've ever felt"
- "Thank you for giving these seminars, being so accessibly informative, making us feel so welcomed and safe"

'Summer and I were really thrilled with how the first two cohorts of the course went. We knew that we wanted to establish a safe, positive space for the group to grow and be themselves and it was great to see that not only could participants arrive and learn more about themselves but they gained so much more than that. The community and friendships they built through the course were a real highlight for us both. Both cohorts set up their own WhatsApp group and plan to meet together to continue supporting and sharing their experiences and strategies with each other showing us that the course is only the beginning of something that can become much bigger'.
Due to the popularity of the course, we are running another two cohorts in June, which are both full and will run the course again in September and have a couple of spaces left for anyone interested. For more information, email infocasa@grcc.org.uk

Employment News

Since the launch of Connect to Work in July 2025, we have received 76 referrals for individuals with autism. Of these, 32 customers have continued their employment journey with the programme, and 10 have successfully secured paid employment.

CONNECT TO WORK
Funded by UK Government

Telling Stories:
Brad began working with Brandon in early 2026, during their first meeting, Brandon spoke openly about his disabilities and the barriers he faced, including his autism diagnosis. He also shared details of his valuable work experience with Citizens Advice and the responsibilities he had undertaken there.

They met weekly at the Employment & Skills Hub or Gloucester Library, focusing on finding suitable administration roles. Brandon was honest about his challenges with confidence and interviews, so Brad supported him by referring him to a range of confidence-building and interview preparation workshops delivered by Connect to Work Tutor, Lucy.

Although Brandon secured several interviews, he didn't initially achieve the outcomes he hoped for, which at times affected his confidence. However, he remained committed and continued attending workshops and developing his skills throughout his time on the programme.

In early May 2026, Brad and Brandon identified several opportunities, including a Receptionist role with Norville Opticians in Gloucester city centre. Brad liaised with Managers Dan and Emily to gather further information before Brandon submitted his application. During the week commencing 11 May, Brandon attended four interviews, including one with Norville. Shortly afterwards, he was invited to complete a full-day work trial on 19 May.

Following the trial, Brandon shared the fantastic news that he had been offered the role and would be starting in a few weeks' time.

Reflecting on his journey, Brandon said:
"I just wanted to say thank you to Brad, Hannah, Lucy and the whole team who supported me. They have helped me not only maintain but improve my confidence when it came to job searching and interviewing.

GLOUCESTERSHIRE EMPLOYMENT AND SKILLS HUB

National Centre for Creative Health at Let's Talk Well Conference 2026
Adults Actually Listened to Us

The Let's Talk Well event, on the 27th March 2026 at Cheltenham Racecourse, was a focused day on children and young people's mental health, with a particular emphasis on supporting neurodivergent children and young people. It explored how neurodivergence intersects with areas such as anxiety, emotionally based school avoidance, self-harm and distress, eating difficulties, gender identity and related experiences.

It brought together practitioners, educators and professionals from education, health and social care, youth services, the charity sector and beyond. The day included keynote sessions from Dr Pooky Knightsmith, guest seminars, networking opportunities and stalls, creating space to share practice, deepen understanding and build connections for more inclusive support.

Leonie from ND Hub's Youth Council reflects on the Let's Talk Well Conference 2026

'I knew it was going to be a different kind of conference when adults started asking us questions instead of speaking for us.'

At first, I was nervous. I was carrying a microphone, interviewing other young people, and later I would be sitting on a lived experience panel in front of professionals from health, education and community services. Normally adults are the ones leading conversations like that, not 12-year olds. But at Let's Talk Well, it felt like our voices mattered.

We attended as speakers from ND Hub's Youth Council, supported by staff from the National Centre for Neurodivergence (NC4ND). I interviewed Hannah, 12, and Jasmine, 14. We talked about neurodivergence, masking, mental wellbeing, and what it feels like when people misunderstand you because your challenges aren't always visible.

One of the most powerful things Hannah said was that **young people know when adults are truly listening and when they are just pretending to.** Jasmine spoke honestly about **how exhausting it can be trying to hide parts of yourself just to fit in at school or avoid being judged.**

After the interviews, Hannah and Jasmine said:

'People actually listened to us here...usually, adults just talk about us instead.'

I kept thinking about that for the rest of the day.

The conference did not feel clinical or intimidating. It felt calm, welcoming and safe. Nobody made us feel silly for speaking openly. Nobody acted like our experiences mattered less because we were young. As someone who is neurodivergent myself, that meant a lot.

Young Peoples News

Image: (l-r) Leonie, Hannah and Jasmin speaking at Let's Talk Well conference

Sometimes adults underestimate how much young people understand about themselves. We know what overwhelm feels like. We know what masking feels like. We know when we are struggling even if we cannot always explain it perfectly. What made this conference different was that adults gave us space to explain.

Later in the afternoon, I joined the lived experience panel with Zaphira Cormack (CEO of National Centre for Neurodivergence/ND Hub Gloucestershire). I was nervous sitting in front of so many professionals, but I also felt proud. Instead of talking about young people, the conference made space for young people to speak for ourselves.

That changes things.

When young people feel psychologically safe and genuinely listened to, confidence grows. It becomes easier to speak honestly, connect with others and ask for support before reaching crisis point.

'For me, the biggest lesson from the day was that inclusion is not just inviting young people into the room. It is making them feel safe enough to use their voice once they are there.'

This is why the ND Hub Youth Council matters so much. It creates trauma-informed, neuro affirming spaces where young people can build confidence, develop leadership skills, share lived experience safely, and know they are valued. We are incredibly grateful to Let's Talk Well for creating a platform where young people were not only included but genuinely heard.

Young Peoples News

Image: (l-r) Hannah, Jasmin and Leonie, at the Let's Talk Well conference

If your organisation would like to engage with the ND Hub Youth Council, collaborate on participation work, or learn more about creating safe and inclusive spaces for neurodivergent young people, we would love to hear from you.

Additionally, we are also currently fundraising to support the Youth Council's upcoming summer camping trip and future activities. Donations and community support help create opportunities for connection, confidence-building and belonging for neurodivergent young people across our community.

Webpage: https://www.ndhubglos.org/youthcouncil
Email: info@adhdhubglos.org

Leonie Tackie-Tetley

ND HUB GLOUCESTERSHIRE belong. grow. thrive.

National Centre for Neurodivergence
LEADING NEURODIVERGENCE PRACTICE NATIONWIDE

A Leadership Reflection on Neurodivergence, Perimenopause and Burnout

By Zaphira

I Was the Woman Everyone Thought Was Coping.

I was the woman people described as capable, resilient and high-performing.
I chaired meetings, managed teams, carried safeguarding responsibility, supported everyone else, met deadlines, absorbed pressure, and kept going long after my nervous system had started sounding the alarm.
From the outside, I looked successful.
Behind closed doors, I was exhausted.

Like many women in professional and leadership roles, I had spent decades masking. I over prepared for everything because I was terrified of forgetting something important. I worked twice as hard to compensate for the constant mental juggling. I said yes too often.
I pushed through sensory overwhelm, emotional exhaustion and burnout because I believed that struggling meant failing.
What nobody saw was the cost.
The lists written everywhere so I would not forget.
The shame spiral after small mistakes.
The sleepless nights replaying conversations.
The overwhelm so intense that opening emails felt impossible.
The constant feeling that everyone else had received a handbook for life that I had somehow missed.

Then came perimenopause...

Suddenly the systems I had relied upon for years stopped working. My concentration disappeared. My emotional regulation deteriorated. The masking became impossible to sustain. I went from being the person everyone relied upon to someone privately wondering how much longer I could survive functioning at all.
And still, nobody recognised my ADHD.
Because I was articulate.
Because I was employed.
Because I was high functioning.
Because I had become exceptionally skilled at hiding how hard everything really was.
What looked like coping was actually chronic overcompensation

At our ND Hub's and National Centre for Neurodivergence, we increasingly hear similar stories from women across health, education, social care, leadership and community sectors, many reaching crisis point before understanding that they may be neurodivergent.

For many women, late diagnosis or self-identification is not simply a moment of discovery, it is a profound reframing of an entire lifetime. Understanding brings language to experiences previously interpreted as personal failure, inadequacy, misdiagnosed depression, or not coping well enough. Recovery often begins not with “fixing” ourselves, but with finally understanding ourselves. One of the spaces where this understanding has flourished is through our Creative Strategies sessions delivered in partnership with The Wilson Art Gallery and Museum on the third Wednesday of each month. These sessions create a trauma-informed, neurodiversity-affirming space where creativity becomes a tool for regulation, reflection, connection and self-acceptance.

For many attendees, particularly women who have spent years surviving in high-pressure professional roles, creativity offers something systems often fail to provide, permission to unmask. Through shared experience, creative exploration and compassionate understanding, women begin to reconnect with parts of themselves buried beneath years of expectation, performance and survival. This matters not only for individual wellbeing, but for workplaces and services too.

How many experienced, compassionate and highly skilled women are quietly burning out behind professionalism?
How many are being labelled anxious, disorganised, difficult or failing to cope, when they are in fact unsupported and exhausted?
How many leaders are carrying invisible neurodivergent needs while continuing to care for everyone else?
If we want healthier workplaces and more sustainable systems, we must become better at recognising the hidden realities behind high-functioning presentation. Sometimes the women most in need of support are the ones who look like they are coping best.

To join one of our Creative Strategies sessions on the third Wednesday of every month visit our website: https://www.ndhubglos.org/copy-of-home

The next date is Wed 17 Jun followed by Wed 22 Jul, Wed 19 Aug, at 6pm.

For more information please contact:
Zaphira: info@adhdhubglos.org or
Amabel: amabel@ndhubglos.org

FROM APRIL’S CREATIVE STRATEGIES SESSION

Demand Avoidance by Andrew

Most people experience moments when the more they feel pushed to do something, the harder it becomes to do it. Even when knowing something needs doing, pressure can make it harder to start.

For some neurodivergent people, this can be far more frequent, intense and disruptive. Tasks, requests, expectations and responsibilities can trigger anxiety, overwhelm, or a strong need to avoid the demand altogether. This is often called demand avoidance. school, homework, appointments, hygiene, meals, transitions and adult instructions.

Demand avoidance is widely discussed by neurodivergent people, families and professionals, but the research base is still developing. Most formal research has focused on autistic people and on PDA or “extreme demand avoidance”, rather than across all neurodivergent groups. Even so, it is useful because behaviour that looks like stubbornness, laziness or unwillingness is often driven by something different.

What is demand avoidance?

Demand avoidance means difficulty engaging with demands, expectations, requests or responsibilities. Demands are not limited to instructions from other people. They can include appointments, messages, forms, getting dressed, decisions, task-starting, or remembering something important. A useful way to think about demands is that they are anything that places an expectation on us. A demand can also be internal: “I need to reply,” “I should eat,” “I want to do this,” or “people are expecting something from me.” Even positive expectations, praise, choices, or wanted activities can feel like demands if they create pressure.

Most people avoid some demands sometimes. For some neurodivergent people, however, the response can be much stronger and can significantly affect daily life.

A useful distinction

It is easy to assume that if someone avoids doing something, they simply do not want to do it. But a person may understand why a task matters, genuinely want to complete it, and feel frustrated that they are not doing it. Yet starting or engaging with the demand can still feel extremely difficult. This is why “won’t” versus “can’t” arguments are often unhelpful.

Demand avoidance can look different with age

Demand avoidance may look different at different stages of life. In childhood and adolescence it can be especially visible because daily life is shaped by immediate external expectations: school, homework, appointments, hygiene, meals, transitions and adult instructions.

Children and teenagers may also have less self-awareness, fewer communication strategies, less control over their environment, and fewer ways to adapt demands. This can make demand avoidance look more obvious, intense or oppositional from the outside.

In later teenage years and adulthood, some people develop strategies that reduce how visible demand avoidance is: planning around difficult demands, using reminders, building routines, asking for adjustments, avoiding unnecessary pressure, or recognising early signs of overwhelm. This does not mean the demand avoidance has gone away. It may be better understood, hidden, or more manageable — and still become harder during stress, burnout, illness, uncertainty or loss of control.

Age also affects other overlapping neurodivergent differences. Self-awareness, communication, memory, emotional regulation, sensory tolerance, task initiation, processing speed and independence all change over time. In older age, strategies that used to work may become harder to use because of fatigue, health changes, bereavement, cognitive or sensory changes, loss of independence, or increased reliance on services.

Why does demand avoidance happen?

There is no single explanation. Clinical discussion, research and lived experience suggest that anxiety, sensory overload, uncertainty, past negative experiences, fear of getting things wrong, and loss of autonomy or control may all contribute. Demand avoidance can also overlap with other neurodivergent traits. Executive-function difficulties, sensory overload, slow processing, autistic inertia, anxiety, perfectionism, interoceptive differences, masking, burnout or past negative experiences can all make a person appear to be avoiding a demand. Sometimes the demand itself feels threatening or overwhelming. Sometimes the person has forgotten, cannot start, cannot switch tasks, cannot process what is being asked, or has already reached overload. From the outside these can look similar, but the support needed may be different.

For the person themselves, recognising these layers can be useful. If the difficulty is pressure, uncertainty, task initiation, sensory overload or lack of energy, the way through may be different. Naming what is happening can make the problem feel less like personal failure and more like something that can be worked with.

A helpful way to frame it is this: the demand may be being experienced as unsafe, overwhelming, or impossible right now — even if the task looks simple from the outside.

What can demand avoidance look like?

Demand avoidance can appear as procrastination, distraction, negotiation, delay, missed appointments, unanswered emails or calls, or distress when pressured. A person may appear capable in some situations while struggling in others. It is not always outwardly obvious. Some people may comply, people-please, mask distress, or force themselves through and crash afterwards. Others may freeze, shut down, or feel mentally “stuck” rather than openly refuse.

Demand avoidance can affect education, employment, relationships, health, and wellbeing. Tasks may build up, creating extra pressure and anxiety. Opportunities can be missed. Relationships may become strained, particularly if others misunderstand what is happening.

Many people describe becoming caught in a cycle: Demand → anxiety or overwhelm → avoidance → increased pressure → greater anxiety. Over time this can lead to frustration, guilt, shame, or low confidence, especially when others assume the person is not trying.

Stepping back from a demand can sometimes be protective. The challenge arises when avoidance affects participation, independence, wellbeing or quality of life. Not every unfinished task, forgotten instruction or delayed response is demand avoidance. Sometimes it is reluctance, tiredness, distraction, executive functioning difficulty, anxiety, overload — or a mixture.

What can help?

Demand avoidance often becomes harder when pressure increases. Repeated reminders, threats, shame, arguments, public correction, or power struggles may make the demand feel even less manageable. This does not mean there should be no boundaries, but how a demand is approached matters. Trust, calmness, fairness and feeling respected can reduce the sense of threat.

Many people find it helpful when demands feel manageable, predictable and collaborative rather than imposed. Helpful approaches from others may include reducing unnecessary pressure, offering choices, breaking tasks into smaller steps,

more preparation time, giving clear expectations, reducing sensory stress, and using collaborative problem-solving.

For the person themselves, it can help to notice what kind of difficulty is happening. Is the task creating pressure or threat? Is it too uncertain? Is there too much sensory or social load? Is the first step unclear? Has the task been forgotten? Is there not enough energy left today? These are different problems, even if they all look like “not doing the thing.”

Some people find it useful to spread stressful tasks across the day or week rather than stacking too many together. A to-do list can help if it allows the person to choose tasks according to what feels possible now, while still planning for one difficult or unavoidable task. Making one stressful phone call to book an appointment may look small from the outside, but the relief afterwards can feel enormous because the hidden load was much bigger than the task itself.

Other strategies might include reminders, scripts, visual steps, body-doubling, preparation in advance, reducing sensory load before starting, recovery time afterwards, or making the first step so small that it feels less like a demand.

Support is most useful when it responds to the reason underneath. If the main issue is pressure or threat, reducing confrontation and increasing autonomy may help. If the issue is forgetting, slow processing, sensory overload, task-switching, uncertainty or not knowing where to start, the person may need structure, prompts, visual steps, preparation time or help with the first step. If several things are involved, support may need to be both practical and low-pressure.

A note on Pathological Demand Avoidance

Some people identify with, or have been described as having, a profile often called Pathological Demand Avoidance (PDA), sometimes referred to as Pervasive Drive for Autonomy. PDA is not a stand-alone diagnosis in DSM-5 or ICD-11, and is often described as a profile within autism. Many people find the concept useful for particularly intense, anxiety-driven and autonomy-driven demand avoidance, although terminology, definition and diagnostic status remain debated. Whatever language is used, understanding the reasons behind demand avoidance is usually more helpful than assuming a person is simply difficult or oppositional.

Closing takeaway

If someone repeatedly struggles with demands, it can be tempting to assume they are stubborn, lazy, unmotivated, or deliberately difficult. In many cases, demand avoidance reflects anxiety, overwhelm, pressure, loss of autonomy, executive functioning differences, sensory overload, processing differences, burnout or challenges that are not immediately visible.

Understanding what lies underneath matters first for the neurodivergent person themselves. It can make the difficulty easier to recognise, name and work with, rather than feeling like a personal failure or an unexplained block. It also matters for families, friends, professionals and services, because better understanding can lead to better support and less blame.

The goal is not simply to “make someone comply.” It is to understand what is making the demand hard, reduce unnecessary pressure, and find ways forward that are realistic, respectful and sustainable.

SELECTED RESOURCES

Here you'll find some neurodivergent resources that may be of interest.

Please be aware that content linked to from this page is not necessarily provided by us, we cannot guarantee that all the content is perfect - merely that we hope you might find it of interest!

YouTuber of the issue!

Dyspraxia Magazine

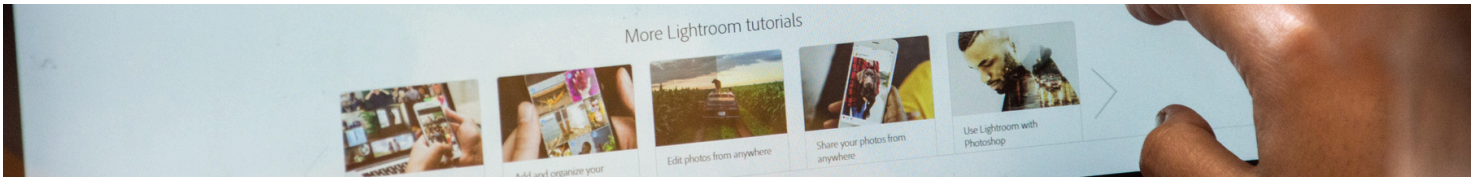
Krystal Bella Shaw brings her lived experience to her channel sharing about Dyspraxia (Medically now termed Developmental coordination disorder).

Youtube Channel:
https://www.youtube.com/@DyspraxiaMagazine

Theme based resources of the issue!

A few links to articles and resources on Demand Avoidance

- **National Autistic Society Demand avoidance pages:** https://www.autism.org.uk/advice-and-guidance/behaviour/demand-avoidance
- **The UK PDASociety:** A strong UK specialist charity page. https://www.pdasociety.org.uk/what-is-pda/
- **West Sussex Autism and Social Communication Team: Getting Started Guide to Autistic Demand Avoidance.** PDF booklet aimed at explaining differences between regular demand avoidance and PDA, with strategies and resources. https://www.esht.nhs.uk/wp-content/uploads/2021/07/Demand-Avoidance-Vs-Pathological-Demand-Avoidance-PDA.pdf



In National News Mar - May

Independent review into mental health, ADHD and autism published interim report
The Government's review, published on 31 March 2026, examines rising prevalence, diagnosis, referrals, distress and support systems for mental health conditions, ADHD and autism. It applies to England and is likely to influence future policy on diagnosis, support and demand management. [Source: GOV.UK]

The review triggered concern about a polarised diagnosis debate
Autism organisations and experts warned that rising diagnosis should not be treated simplistically as overdiagnosis. A key concern is that many people seek diagnosis because support, adjustments and recognition are still too dependent on having a formal label. [Sources: National Autistic Society; Science Media Centre]

Autism assessment waits remained extremely high
NHS England data for March 2026 showed 270,701 people with an open suspected autism referral, with 242,708 — 89.7% — waiting at least 13 weeks. The National Autistic Society described this as more than 270,000 people waiting, with around nine in ten waiting longer than the NHS-recommended timeframe. [Sources: NHS Digital; National Autistic Society]

The new Mental Health Strategy for England explicitly includes autistic people and people with ADHD
The Government's call for evidence for a new Mental Health Strategy for England says autistic people and people with ADHD often struggle to access responsive support. A ministerial statement also said the strategy will reflect the mental health needs of autistic people and people with ADHD, including appropriate adjustments to service design and delivery. [Source: GOV.UK]

SEND reform was the biggest education-related neurodivergence story
The SEND reform consultation for England ran until 18 May 2026 and proposes earlier, fairer support, clearer accountability and stronger inclusion. The Government says it will train over 200 more educational psychologists each year from 2026 and expand Mental Health Support Teams to all schools and colleges by 2030. [Source: Department for Education / GOV.UK]

Inclusion bases for neurodivergent and SEND pupils remained prominent
Government and media coverage described plans for mainstream schools, especially secondary schools, to provide inclusion spaces or bases for neurodivergent and SEND pupils. The aim is to provide more support within mainstream education rather than relying so heavily on specialist placements or exclusion. [Sources: Department for Education; The Guardian]

Dyslexia organisations responded to the Schools White Paper and SEND reforms
Dyslexia organisations welcomed the opportunity to improve support but stressed that all teachers and teaching assistants need better general understanding of dyslexia, alongside specialist support. They also noted calls from the APPG for Dyslexia for a National Dyslexia Strategy. [Source: Dyslexia Action]

Teacher training for neurodivergent pupils was flagged as inadequate
Research from York St John University and the University of Surrey, reported in March, found nearly 25% of teachers said they had received no training on supporting neurodivergent pupils, and many who had received training described it as brief and limited. [Source: York St John University / University of Surrey]

Workplace neurodiversity support remained weak
Acas reported in March that only 32% of employees thought their organisation effectively trained managers to make reasonable adjustments for neurodivergent colleagues, while 35% thought employers were ineffective. This is Great Britain data, but directly relevant to employers in England. [Source: Acas]

Healthcare reasonable adjustments became more operationally important
NHS England continued promoting the Reasonable Adjustment Digital Flag, which can record adjustments such as quiet waiting spaces, longer appointments or accessible information. NHS England described it as relevant to autistic people, people with learning disabilities and disabled people more broadly. [Source: NHS England]

Contribute to a study on Autistic Friendship

Gloucestershires Emma Whittiker. who is a co-researcher in the following project wished to highlight this opportunity to support some research into friendships in Autistic people and how they differ from non-autistic people. If you are feel able to share your lived experiecnce please goto https://shorturl.at/Ng5To for more information.

DATES FOR YOUR DIARY

Here are support groups, meet ups or events happening around Gloucestershire. Let us know if you need anything relevant adding.

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 or cashmir.martin@nhs.net.

Community Autism Support and Advice (CASA) support groups and drop-ins
For weekly updates about our Drop-in Groups and full details of drop-in venues and times, see our pages on Instagram and Facebook:
https://www.instagram.com/casagloucestershire/
https://www.facebook.com/CASAGloucestershire

Gloucestershire ND Hub Events
Various events and activities for young and adults
See ND Hub Events

Gloucestershire Parent Carer Forum 'Listen To Me' Social Meet-ups
Various locations - for more information visit www.glosparentcarerforum.org.uk.

The Youth Forum
The Youth Forum is for neurodivergent young people between the ages of 13 and 19. It is about having your say about how things can be better in Gloucestershire. Held as a monthly Zoom group it meets on a Tuesday evening between 5.30pm and 6.30pm. If you want to join, a parent or guardian needs to complete a consent form. For more information, email: emilyl@inclusion-glos.org.

Your next Autism (and Neurodivergence) Partnership Board

Tuesday 3 March 2026
10.00am to 12.30pm
Venue: Teams [Online]

Main Topic:
Employment

Future Partnership Board Dates:
2 June 2026, 10am - 12.30am
Topic Focus: Neurodivergence and co-occurring mental health needs.

8 September 2026 Topic Focus: Children and young people.

WANT TO JOIN THE PARTNERSHIP BOARD?

WE MEET ONCE PER QUARTER. IF YOU WOULD LIKE TO COME TO OUR NEXT MEETING, **EMAIL**: NEURODIVERSITY@GLOUCESTERSHIRE.GOV.UK.

MORE INFORMATION

TO FIND OUT MORE, AS WELL AS READ PREVIOUS NEWSLETTERS, VISIT: HTTPS://WWW.GLOUCESTERSHIRE.GOV.UK/HEALTH-AND-SOCIAL-CARE/DISABILITIES/AUTISM-AND-NEURODIVERGENCE-PARTNERSHIP-BOARD/

Partnership Board Update

From your Chairs:
Tammy Flook and Jan Marriott

We had two busy meeting. One at our usual venue in central Gloucestershire in February and the other at Churchdown Community Centre in April.

Highlights - information sharing from our meetings
We wanted to share some information from our friends at Access Social Care who have a new team of Peer Navigators. Keith Sexton from Access Social Care came to talk about what the Peer Navigators do and how they can help people at our meeting in April.
Please see their information poster below.

Courtney who works with Inclusion Gloucestershire and Access Social Care is also running some training on the Mental Capacity Act (please take relevant information from Courtney's email)

What else has happen at our recent meetings?

Amy has been keeping the LDPB up to date with her work supporting the Partnership Boards and helping GCC work together with people using services.
The members of the LDPB helped the organisers of the Big Health Day, in giving their feedback and telling them what they would like to see at the next Big Health Day on Thursday 11th June.

In February, we also heard about the progress of the GHC learning disabilities services review.

Date of the next meeting
Monday 29th June at Kingfisher Treasure Seekers, Eastgate Street Gloucester from 11am – 1pm
We look forward to seeing people then

Partnership Board Update

From your Co-Chairs: Jan Marriott and Simon Price

The Mental Health and Wellbeing Partnership Board met 26th April 2025.

Co-production and working together

The Board welcomed the introduction of Amy Rees, Gloucestershire County Council's new Adult Social Care Co-production Lead. Amy brings significant experience of working alongside people with lived experience and has a strong commitment to meaningful co-production. Her role will include supporting partnership boards, developing wider participation opportunities, and helping adult social care to make better use of lived experience and feedback in shaping services.

There was a helpful discussion about how co-production can be strengthened across Gloucestershire. Members reflected on existing tools and approaches, including the Gloucestershire Co-production Charter, the People Hub spectrum of participation, Arnstein's ladder of participation, and NHS England's co-production "flower" model.

Amy's current priorities

- Accessible information and communication, with a clear emphasis on this being coproduced
- Direct payments and individual service funds. Partnership Boards are keen to place more focus on this area.
- Increasing the influence of partnership boards
- Exploration of participatory budgeting: historically, the Learning Disability Partnership Board did have its own budget, which was linked to 'the Big Plan'.

Amy Rees wants to build a bigger pool of individuals – those with lived experience, and those from the voluntary sector – who might like to help shape adult social care – any interested to get in touch with Amy - amy.rees@gloucestershire.gov.uk

Commitment

Gloucestershire County Council has shown a clear commitment to co-production, particularly within adult social care, including by offering funding to help maintain administrative support for the partnership boards.

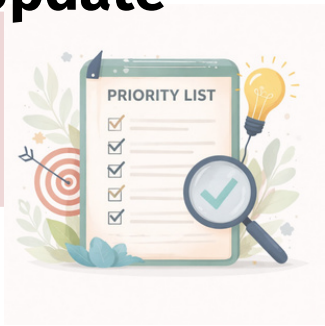
The discussion also highlighted the need for a stronger countywide, systemwide vision for co-production. Although a co-production charter had previously been launched, it was felt that it had not become widely embedded.

Joining the Mental Health & Wellbeing Partnership Board.

If anyone is interested in the joining the Board or Network meetings please email: **asc.co-production@gloucestershire.gov.uk.**

Partnership Board Update

From your Chair: Jan Marriott
And the Mental Health Partnership Board Team



Reflection on Overlapping priorities identified so far across Mental Health and Wellbeing Partnership Board and Mental Health Forums

The Board reflected on how the Mental Health & Wellbeing Partnership Board and local Mental Health Forums can work together to turn insight into action. The Board's role was framed as an action-focused space for shared discussion, sense-making and influence, drawing on priorities emerging from communities, people with lived experience, the VCFS and grassroots voices.

Several overlapping priorities were identified across the Forums, including mental health inequalities, housing, whole-person support, stigma, crisis support, system infrastructure, and co-occurring needs such as substance use and neurodivergence. Housing was highlighted as a particularly important theme, with points raised around gaps in provision, delayed hospital discharge, increasing complexity of need, and opportunities to influence Local Plans and accessible housing policy.

The conversation also covered wider opportunities for joined-up working across adult social care, prevention, housing, health, public health and children's services. The move of adult social care into Gloucestershire County Council, local government reform, and links with Children and Young People's work were all noted as potential opportunities to build a more integrated, whole-lifespan approach to mental health and wellbeing.

How can best insight move into action on topic of co-occurring mental health needs with drug and alcohol use – presentation

Sam Holmes shared themes and ideas for action from the five locality Mental Health Forums on co-occurring mental health needs alongside drug and alcohol use. Helen Flitton also gave an update on the drug and alcohol needs assessment, the co-occurring conditions steering group, national policy developments, workforce challenges, and new outreach and prescribing roles.

Housing was a key theme. Concerns were raised about people with substance use needs being excluded from housing, the impact of long waiting lists, and the challenge of balancing risk management with trauma-informed support. Examples were also shared of more flexible approaches, including alternative housing options that can offer stability for some people and may help reduce relapse risk.

The session also covered practical tools, workforce support, support for veterans, and the need to improve awareness of Local Community Partnerships for people working with complex cases.
Emerging actions were seen as strongly aligned with forum feedback, particularly around workforce wellbeing and VCFS involvement. It was agreed that the reinstated co-occurring conditions steering group, linked to the needs assessment, should be used to take this work forward rather than creating a separate structure.

Gloucestershire Mental Health Forums

'a space to work out together what would make things better'

The Gloucestershire Mental Health Forums bring people together to work out how local mental health support could be improved. They are facilitated by Rethink Mental Illness, but they're really owned by the people who take part.

They were set up because there was a clear need for more joined-up working across Gloucestershire. The aim is to bring different parts of the mental health system together, spot where there might be gaps in what's currently available (e.g. gaps in training and service delivery), and co-produce solutions to problems, with the people who care most about mental health outcomes across the county.
The Forums take place online every three months across a two-week period, covering Stroud & Berkeley Vale; Gloucester; Forest of Dean & TWNS; the Cotswolds; and Cheltenham.

Each series of Forums focuses on a different topic. The topics are suggested and voted for by Forum participants. So far, we've explored:

- Mental health needs alongside drug and alcohol use
- Mental health needs alongside neurodivergence
- Crisis Support

Who comes to the Forums?

The Forums bring together a mix of people, including:

- People with lived experience of mental illness
- People who support or care for someone with mental illness
- Staff and volunteers from the Voluntary, Community and Faith Sector (VCFS), and grassroots groups and organisations.
- People working in statutory services, including the NHS and local councils.

Turning insight into action

The Forums aren't just a talking space. They're linked directly with the Mental Health and Wellbeing Partnership Board, where priorities and insights from the Forums are shared. From there, actions are agreed and taken forward.
We think it's really important that people's time, experiences, and insights lead to real change, not just conversation. And as the Forums grow and gather momentum, we hope to have lots of progress to show people.

Interested in getting involved?

If you'd like to join a future Forum or find out more, you can get in touch by emailing: Rhiannon.Davis@rethink.org

Mental Health Forums Crisis Support

Please find below a hot of the press introduction Mental Health Locality Forums that tool place in March focusing on crisis support. Full copies of the forum digests will be distibuted, but below is a two page summary of many of the key aspects. Please do only take this as a summary, other important detail is within the main document. Many thanks for the contributors and Rethink for bringing together the digest. Anything key missed in the shortened summary below is my fault (editor). These will be discussed further at the partnership board.

Gloucestershire Mental Health Forums: Crisis Support

About the Forums

In March 2026, 129 attendees came together across five Gloucestershire locality forums — Gloucester, Stroud and Berkeley Vale, Forest/TWNS, Cheltenham, and Cotswolds — to talk honestly about mental health crisis support in the county. The Forums were facilitated by Rethink Mental Illness on behalf of Gloucestershire County Council, and brought together voluntary organisations, NHS staff, carers, statutory partners and 33 Experts by Experience, including people with lived experience of mental health crisis.

The Forums described crisis not as a single clinical event, but as something shaped by mental distress, trauma, poverty, housing insecurity, isolation, discrimination, substance use, caring pressure and long waits for support.
What we heard. The picture that emerged was consistent across all five localities. People are arriving at crisis because earlier support is not available, not reachable, or not joined up. Once in crisis, the journey to help is often confusing, exhausting and — for some — impossible. Key themes included:

Thresholds are too high and discourage help-seeking.
People are told they are not ill enough, come to believe they do not deserve support, and may avoid services after being turned away. Stigma — external and internalised — compounds this.

Access routes are fragmented and stressful.
Navigating 111, Crisis Teams, A&E, police, ambulance services and community options while in acute distress is often beyond what people can manage alone. Phone calls and A&E are not accessible to everyone, and carers are frequently left without adequate information or involvement.

Services are overstretched.
NHS crisis services, emergency services and VCFSE organisations are all under pressure. Community, charity and faith organisations are often trusted first contacts, but they do not always have the funding, training, supervision or support to safely hold crisis-level need.

Physical access is a serious barrier.
Crisis-equipped spaces are concentrated mainly around Gloucester and Cheltenham. Rural communities face significant transport barriers, and support that is technically countywide may still be unreachable in practice. Overnight or short-stay provision was also described as reduced, with Alexandra Wellbeing House now operating as a day service.

Compassion is not consistent.
People — particularly those with complex emotional needs — reported feeling judged, dismissed or unheard. This damages trust and makes people less likely to seek help again. Mental health and allied professionals experiencing crisis themselves may also find it difficult to access local services because of fear of judgement from colleagues.

Some groups face compounded risks.
Neurodivergent people, LGBTQ+ people — including trans people waiting years for gender-affirming care — people from marginalised communities, carers and people facing poverty, housing insecurity, domestic abuse or substance use may experience additional barriers that the current system does not always respond to well.

Without joined-up support, people cycle back into crisis.
Gaps between prevention, crisis response and recovery mean people can repeatedly return to crisis rather than being supported through it.

What needs to happen. The forum digest identifies six broad action themes, with a wider set of practical actions sitting underneath them. Drawing these together, **some** of the key practical recommendations that are pointed towards are summarised below.

1. A shared whole-system crisis approach

A single visible front door, shared understanding of crisis, clearer thresholds and exclusions, a "No Wrong Door" approach, and continuity across prevention, crisis response and recovery.

2. Clear, accessible crisis information

One reliable, regularly updated source of information about crisis support, including who services are for, how to access them, opening times, thresholds, exclusions, and what to expect. This should be available in plain English, Easy Read, translated formats, audio and non-digital routes, and shared through GPs, faith centres and community hubs.

3. More flexible access routes

Text, webchat, call-back, drop-in and other options for people who cannot manage phone calls, unfamiliar buildings or A&E when distressed.

4. Stronger community and VCFSE support

Proper funding, training, supervision and clear routes into specialist help for organisations that are already trusted first points of contact.

5. Expanded peer support and lived experience involvement

Building on what works, increasing diversity among peer workers, and involving people with lived experience in co-designing crisis pathways, language, information and support models.

6. Better training and support for staff, volunteers and carers

Training and reflective support covering compassionate language, trauma, cultural awareness, neurodivergent crisis presentations, suicidality, safeguarding and safety planning, alongside supervision and proper support for those holding crisis in community settings.

7. Consistent use of safety plans and mental health passports

Co-designed personal tools that record early warning signs, the person's own language for distress, what helps, what does not help, and how they want support to be offered. These should reduce repeated retelling and be recognised across statutory and VCFSE services.

8. The need for ,ore local, trauma-informed places to go

Crisis café-type spaces, community hubs, safe non-clinical settings and short-stay options, particularly outside Gloucester and Cheltenham.

9. Transport and rural access as part of crisis planning

Co-designed travel solutions, clear information, travel cards where possible, outreach and local access points in rural areas.

10. Stronger carer and family involvement

Better use of Triangle of Care approaches, clearer information-sharing routes, and dedicated support for carers and families, including young carers.

The overall message

The ingredients for better crisis support already exist in Gloucestershire — in its communities, voluntary organisations, peer networks and dedicated workforce. What is needed now is stronger coordination, clearer access routes, proper resourcing, and a commitment to making compassionate support genuinely reachable for everyone who needs it, wherever they live and however they present.

Partnership Board Update

From your Co-Chairs: Katie Peacock and Jan Marriott

Welcome to the latest PD&SI PB Partnership Board update — packed with positive changes, community news, accessibility projects, and exciting developments happening across Gloucestershire.

Recent meetings have focused on:

- Coproduction in Adult Social Care
- Accessibility (including an update from the Tewksbury Access Forum)
- Transport updates including about the Robin bookable bus.

Accessibility & Authentic inclusion for the deaf community.
A brief word on using AI note takers and Accessibility

In March 2026, the group discussed Gloucestershire County Council's current rules around using AI notetakers during meetings. GCC's data governance policy means that only Microsoft Copilot can be used. This does not work with Zoom and some of the PD&SI PB members prefer Zoom as a platform because of accessibility.

During the discussion some members explained that AI tools can act as a reasonable adjustment, helping people:

- follow meetings more easily
- revisit information afterwards
- support memory and concentration needs.

Amy Rees is looking into GCC's policy and will provide feedback at a future meeting.

The group also discussed whether meetings should continue on Zoom or move to Teams. A member poll has already been sent out.

Showing the impact of the PD&SI PB: a positive change for Parkinsons care in Gloucestershire

Jane Henderson from Parkinson's UK shared encouraging news...

Douglas Blair, CEO of Gloucestershire Hospitals NHS Foundation Trust has pledged to improve care for people admitted to hospital with Parkinson's, especially around receiving medication on time.

The hospital trust will now benchmark itself against 10 key recommendations create an action plan for improvement

Jane thanked the Partnership Boards and partner organisations for supporting this work. The PD&SI PB, together with the Neurology sub-group signed a letter alongside Parkinson's UK asking for this pledge. This success is strong reminder that collective voices really ca create change.

Amy Rees – Coproduction Lead, ASC, GCC

The board welcomed Amy Rees, Gloucestershire County Council's new Coproduction Lead for Adult Social Care. Amy started her new role in January 2026.

Amy has worked with disabled people and community organisations for nearly 20 years and brings extensive experience in: sensory impairment support, transitions services, mental health networks, learning disability services, coproduction projects

Last Newsletter introduced her in more detail!

The Robin Bus Service

Thea Rumer shared updates about The Robin, Gloucestershire's bookable bus service.

What is The Robin?
The Robin is a flexible, bookable transport service operating in:

- Tewkesbury District
- North Cotswolds
- South Cotswolds
- Berkeley Vale
- South Forest of Dean
- Newent

Unlike normal buses:
- there is no fixed timetable
- journeys are booked in advance

You can book: online, via the app, by phone 📞 0345 2638139
🕗Monday–Friday, 8am–4pm

More information is available here: https://www.gloucestershire.gov.uk/transport/the-robin/

The group discussed:* wheelchair access* booking difficulties, travelling between zones, late arrivals and clearer communication of contact arrangements after 4pm.

Each Robin vehicle includes one wheelchair space and Thea explained a multi-operator transport ticket is planned within the next 12 months

Tewkesbury Access Forum

Liz Peche introduced the work of the Tewkesbury Access Forum, which aims to make Tewkesbury more accessible for everyone.

The forum has been working on:

- improving accessibility awareness
- supporting local businesses
- creating accessible information and maps
- encouraging practical local changes

Liz highlighted that accessibility is about much more than wheelchair access alone and should include a wide range of needs.

🌟Positive Improvements

Recent accessibility improvements in the town include:

- Changing Places facilities
- Improved bus accessibility
- Projects at Tewkesbury Abbey
- Accessibility work at The Roses Theatre
- The Tewkesbury Museum access project.
- Trinity Hall and ArtShape developments

Contact: Tewkesburyaccessforum@gmail.com

ME/CFS Policy Coproduction

The group is now working with Gloucestershire Hospitals NHS Foundation Trust to coproduce a Gloucestershire-specific policy for supporting people with severe ME/CFS. (Myalgic encephalomyelitis / chronic fatigue syndrome)

This is another strong example of lived experience helping shape services directly.

New Advocacy Workshops Coming Soon

Juliet Newton from POhWER shared plans for a new set of advocacy workshops covering:

- Housing
- Finance
- Health & wellbeing
- Introduction to advocacy

The workshops will include:

- Easy Read materials
- BSL interpretation
- QR code resources
- Specialist guest speakers

They are being coproduced with local charities, organisations and people with lived experience.

📅 **Next PD&SI PB Meeting**

Tuesday 19th May 🕐 **11:00am – 12:30pm (via Zoom**

Thank you to everyone who attends our meetings, contributes, and continues to help make Gloucestershire more inclusive, accessible, and connected. I look forward to having you at our next meeting!

For more information:

Physical Disability & Sensory Impairment Partnership Board: partnershipboards@inclusion-glos.org

Neurology Subgroup Update

From your Neurology Subgroup Co-Chairs:
Jan Marriott and Dave Evans

Introduction to Dave Evans
Chair of the neurological sub-group.

My name is Dave evans and I am currently a resident at The Leonard Cheshire care home Gloucestershire House in Cheltenham. I am a person with lived experience of the neurological condition Charcot Marie-Tooth Disease, a hereditary condition caused by a problem with the genes passed on to me from my mother's side of the family. Technically it is a hereditary peripheral neuropathy, meaning that the nerves in my arms and legs have not developed correctly resulting in muscle wastage and the inability to use the affected limbs.

Although I have had this hereditary condition from birth it is one that slowly deteriorates with time, meaning I did not have a clear diagnosis until I was in my mid-20s. by this time I was a qualified youth worker with Kent County Council, and fortunately was able to continue this role even as my condition got worse. Eventually, in 2012, my health deteriorated to the point where I needed to start using a wheelchair. By this time, I was an Area Youth Officer for Worcestershire County Council who I worked for till my redundancy as part of the austerity cuts in 2015. In January 2019 I required sufficient help and assistance to justify moving into a care home, and thus I moved into Cheltenham.

I became involved in a voluntary capacity with the charity Inclusion Gloucestershire, before taking up part time roles with their transport project, their quality checking team and finally their peer support and advocacy team. My first involvement with the PD&SI was while I was working for the Charity, and I went on to further develop links with the Barnwood Trust Members Circle, Cheltenham Borough Council Access Group and Gloucestershire University Occupational Therapist students training. I was invited to chair the neurological subgroup when it was first established, and have worked to help establish this important networking opportunity. I am currently involved in working with the Access Social Care charity to help try and establish their peer navigator project supporting and promoting the 'Ask Ava' online support tool concerning the Care Act.

I believe that this range of lived experience helps me in my understanding of the situation facing people with disabilities; and my involvement with the sub-group enables me to promote, challenge and guide services to support those people with needs and highlight issues of concern.

Neurology Subgroup Update

Notes from the Neurology subgroup 14th of April

The neurology sub met on Teams on the 14th of April. A range of people with lived experience and people representing a variety of organisations attended the meeting.

There was a discussion under matters arising around issues concerning the changes within the health service which were delaying the moving forward and implementing the recent ME development which was noted as very frustrating. Hopefully there will be some clarity around changes and people's new responsibilities in the very near future.

The first item on the agenda was a presentation about a new physiotherapy company called Evoke, who are establishing a rehabilitation clinic at Calmsford. There seemed to be some positive opportunities and the director attending the meeting was given some useful contacts. It was noted that the centre would be looking to complement existing NHS services such as community neurology team and was also creating education opportunities for student physiotherapists. More information can be found on the website which is: evokeneurorehab.com

The second item on the agenda was a presentation around the findings of the recently published Parkinsons Healthwatch Report. Presentation was made by Susie Compton from Healthwatch and highlighted a number of findings from across 11 Parkinson's UK groups.

The report made a number of positive recommendations around diagnosis, clearer language from medical professionals, training for GP's and better support networks for those people newly diagnosed.

The group acknowledged the fact that numbers of these issues were comparable with the experiences of others with different neurological conditions.

There was also acknowledgement that the recent letter sent on the behalf of the PD&SI Board and neurological subgroup had been successful in helping to raise the issues around time appropriate medication for people Parkinson's with Parkinson's

Finally, the group acknowledged the fact that the wide circulation list for both agenda and minutes was useful to maximise connections but there should be regular checks to ensure information is being received by the appropriate people.

For more information on the Neurology Subgroup email: asc.co-production@gloucestershire.gov.uk

Introduction from Ben Newton - new Carers Partnership Board Chair

Having been appointed as Chair of the Carer's Partnership Board, I wanted to introduce myself. I am a parent carer to two autistic children and have been navigating the social care and education system for a number of years now. Last year I received a late diagnosis of Autism myself.

I have quite a mixed work history. I started in the NHS as a mental health researcher, having studied Psychology. I completed a PhD in health psychology and looked at why people with chronic pain don't feel believed by others. Needless to say, the experience of disbelief and not being taken seriously is a common theme for many parent carers who often face the offer of 'another parenting course'.....! I have also worked as an advocate in Gloucestershire and currently work as Director of an independent Occupational Therapy service.

I'm really looking forward to working with unpaid carers and staff who support carers. I want to work towards facilitating a system that clearly values the role of all unpaid carers and responds to their unmet needs and unheard voices. I want to ensure we take an inclusive approach to running the board and welcoming all input.

Best wishes,
Ben

FREE SUPPORT FOR CARERS OF ADULTS

If you feel unsure, confused or are struggling to understand what you are entitled to and how to communicate with your local authority please get in touch and we will organise a time that is suitable for a conversation with your Peer Navigator.



If you help another adult in any of these ways we may be able to help you.

Helping around the home

With washing, getting dressed or getting to and from the toilet safely or Cooking, cleaning, shopping or laundry

Helping to get out and about

to appointments or to meet with friends and family, or to get to community groups

Helping people with budgeting

paperwork or telephone calls

Helping people who care for others

Looking after another adult so the person who normally cares for them can get some time out or caring for children because their carers have physical or mental health barriers

PEER NAVIGATOR NATIONAL NETWORK

Access Social Care is a legal rights charity, supporting people and carers across the country to understand their rights in adult social care support and to achieve fair and equal access to support. Our Peer Navigators are based within your local community and can offer support online or, where possible, face to face at a community venue or carers group. The service is FREE and is designed to help you to understand what you and the person you care for are entitled to from adult social care services. We can support you to:

- Contact and communicate with adult social care
- Understand your rights and entitlements
- Create letters to send to the local authority
- Request a social care assessment for the person you care for
- Request a carers assessment for yourself and support you through the process

For more information please email enquiries@accesscharity.org.uk
Please mark the email FAO: Peer Navigator Coordinator
ASC Website: https://www.accesscharity.org.uk/

asc access

Gloucestershire Carers Hub

Gloucestershire Carers Hub supports unpaid Carers throughout the county of Gloucestershire.

We cover the you if you live in Gloucestershire, or if you support someone who lives in Gloucestershire but you live out of county

You maybe be supporting someone with physical or emotional needs, they could be living independently from you but require your support on a daily or weekly basis. This could be due to ill health, frailty, mental health or due to an addiction. They may also live in residential care/ support but you remain an active part of their support network.

There is no minimum requirement for the number of hours which you are supporting someone for. You may be supporting them:

- Via the telephone offering emotional support
- Taking someone to appointments
- Supporting with cooking, cleaning, shopping and other daily tasks
- Assisting with dressing, cleaning and other personal care needs
- Going in to check on someone regularly

Whatever you do to support someone else you are a Carer even if you don't think of yourself as one. The individual who you are supporting could be:

- A family member; spouse, husband, wife, child, adult child or partner
- A friend
- A neighbour
- An ex-partner

Whoever you are supporting we are here to offer advice, information and support to you to enable you to think about your needs whilst offering support to someone else.

If there are a number of people supporting someone, we welcome anyone providing support to someone to register with us to access information, support and our services.

If you look on the website, you can see the range of support that you can recieve from us along with up to date news from us. If you are not already, why not get in contact with us:

Call us 0300 111 9000 or email carers@peopleplus.co.uk

or refer yourself by clicking here: Self Referral – Gloucestershire Carers Hub

Our Montly Programmes (see the carers hub website for the latest)

Gloucestershire Carers Hub is here to support unpaid carers with a range of friendly and informative sessions. Our monthly programmes includes such as opportunities to connect with other carers, learn practical tips for managing your caring role, and take time for your own wellbeing.

The March programme is available here: Be-connected-march-2026

For full details and booking, visit Gloucestershire Carers Hub or call 0300 111 9000.