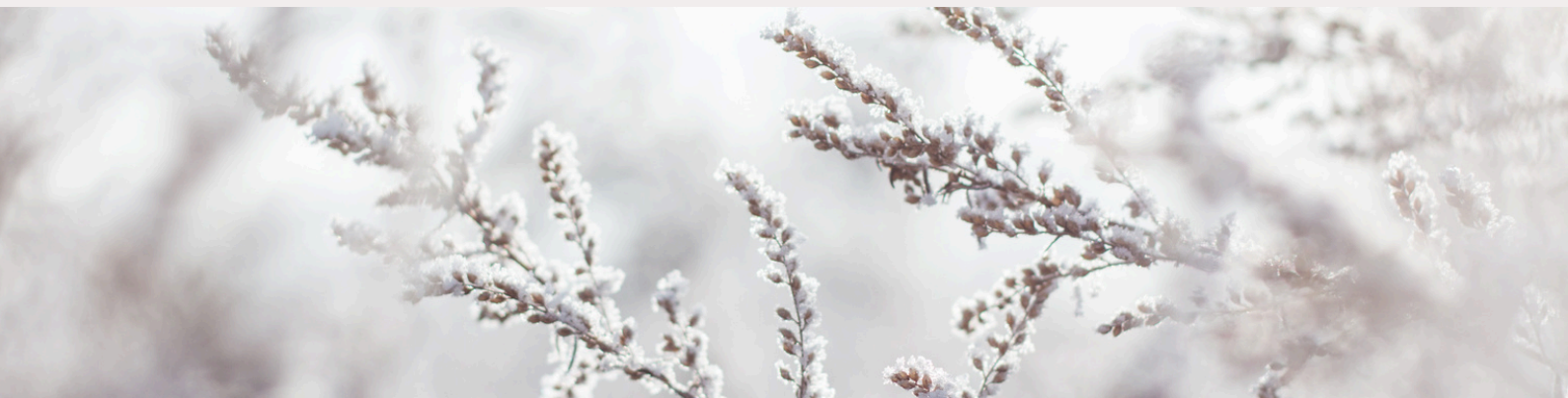


# DISABILITY, NEURODIVERGENCE AND MENTAL HEALTH IN GLOUCESTERSHIRE

Winter 2024/25  
Issue 6



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



Welcome to the Winter 2024/25 issue of Disability, Neurodivergence, and Mental Health in Gloucestershire.

This issue highlights the significant role of lived experience in shaping services, particularly in mental health support and recovery. The second Mental Health Network Event showcased the power of Experts by Experience in transforming services, while projects such as Ollie's Random Acts of Kindness (ORAOK) continue to create community-driven support for those navigating mental health challenges. As an attendee to this event I felt it was great to see the range of interesting topics covered.

As ever, this issue is built on the voices of those with lived experience, professionals, and community organisations who work tirelessly to improve inclusion, accessibility, and support for neurodivergent individuals, disabled people, and those experiencing mental health challenges. We extend our sincere thanks to everyone who has contributed their time, expertise, and perspectives.

We welcome your feedback, stories, and ideas for future editions—your experiences are what drive real change. Please do contact with any suitable contributions, dates for the diaries, ideas and comments.

Thank you for reading, and we hope this issue offers valuable insight, connection, and inspiration.

**Andrew Cotterill**

**Autism (and Neurodivergence) Partnership Board Chair**

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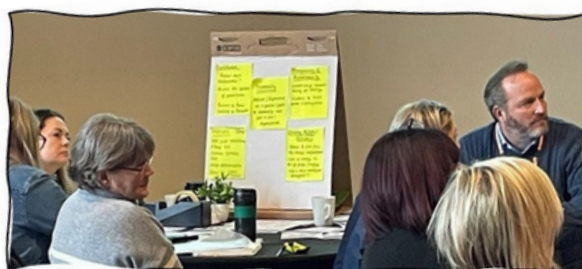
## **The All Age Mental Health, Learning Disabilities & Neurodivergence Clinical Programme Group Workshop Away Day on 16th Jan 2025**

Clinical Programme Groups (CPGs) oversee how many aspects of healthcare are delivered to the population of Gloucestershire. Each CPG covers a different specialism.

A successful workshop brought together many key stakeholders. to look at the future of the clinical programme groups. Over 40 attendees from Gloucestershire Health and Care NHS Foundation Trust (GHC), Gloucestershire County Council (GCC), the Integrated Care Board (ICB), Experts by Experience, and VCSE groups came together to represent people in Gloucestershire with Learning Disabilities, Mental Health difficulties, Autistic people and other types of Neurodivergence.

The workshop fostered strong engagement both during and after the event. Throughout the day, participants took part in four interactive exercises, providing valuable feedback on the new board structure and governance. Discussions centred around shared values, a common purpose, and opportunities to drive change within the current programme groups and the new board.

The event was expertly facilitated by members of the Improvement Community Team, ensuring a productive and insightful session.





**Neurodiversity Celebration Week** is a worldwide initiative that challenges stereotypes and misconceptions about neurological differences. It aims to transform how neurodivergent individuals are perceived and supported by providing schools, universities, organisations, and others around the world with the opportunity to recognise the many skills and talents of neurodivergent individuals, while creating more inclusive and equitable cultures that celebrate differences and empower every individual.

Active Impact's Neurodiversity Network is hosting a reception to kick off Neurodiversity Celebration Week! This special event is designed to highlight the incredible work being done in Gloucestershire to ensure leisure, social and wellbeing activities are inclusive of neurodivergent people.

**When?** Monday, March 17th, from 10:30 AM to 12:30 PM

**Where?** Council Chambers, Shire Hall, Gloucester

Please **register** at: <https://shorturl.at/wLIGC>

#### **What to Expect:**

- **Showcase of Inclusive Best Practices:** Hear from local organisations leading the way in neurodiversity support and inclusion.
- **Networking Opportunities:** Connect with like-minded professionals, share experiences, and build valuable connections.
- **Engaging Discussions:** Join conversations on the progress made in the neurodiversity space and discuss exciting next steps.
- **Resource Sharing:** Bring your ideas and learn about the latest resources available.
- **Tea, Coffee, and Conversations:** Plenty of time to mingle, reflect, and enjoy a hot drink while engaging in meaningful dialogue.

Whether you're involved in neurodiversity projects or simply a professional passionate about inclusion, this reception is a fantastic opportunity to celebrate best practice, collaborate, and look towards the future.

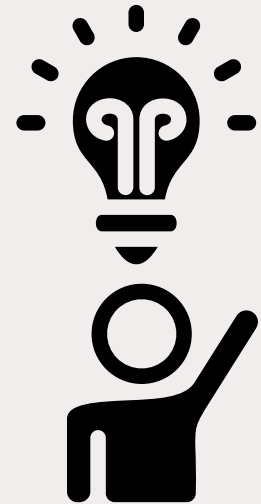


Gloucestershire's Autism Partnership Board brings together people with lived and professional experience of autism and neurodivergence to oversee the implementation of the local Autism strategy. Our local priorities reflect the six overarching themes of the National Autism Strategy. Some of this quarter's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

### Theme 1 Highlights

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

- In December, a neurodivergence mini-conference took place, bringing together a diverse group of attendees to raise awareness. Key topics included LGBTQIA+ experiences and the SPACE framework.
- Life In The MiND (a podcast for neurodivergent people for neurodivergent people) launched their second series and a new YouTube channel to host on. Check this out [here](#).



### Theme 2 Highlights

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

- Improved working with education is underway, to strengthen the autism and ADHD referral processes and encouraging access to support within settings and children on the graduated pathway.

### Theme 3 Highlights

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

- The Autism Employment Steering group met in February to review the Strategy's Action Plan and discuss activities for the next year. More details to follow.
- The Gloucestershire Employment and Skills Hub continue to support autistic and neurodivergent people into paid employment. They also continue to support employers raise their awareness by holding [lunch and learns](#).





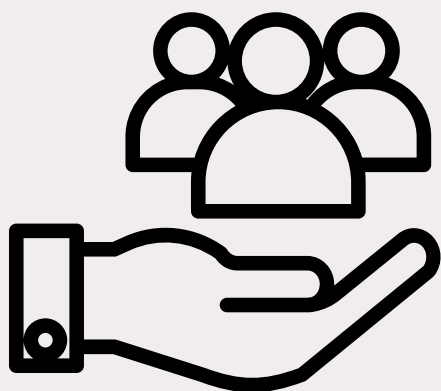


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### Theme 4 Highlights

#### *Tackle health & care inequalities*

- Work has begun exploring the potential for Autism pre-diagnostic support. Initial co-production efforts are underway to understand what individuals would find most beneficial.
- Working closely the Autism Liaison Officer to embed learning within the acute hospital pathway and take forward action for children, young people and adults.
- The Children's Autism and ADHD Assessment Service went live from 1st January 2025.



### Theme 5 Highlights

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

- Commencement of an autism-only project for children, young people and adults, to understand gaps and the needs in support for autistic people in the community reaching crisis.
- Continue to see an increase of children, young people and adults registered on Gloucestershire's Dynamic Support Register who are autism-only (with absence of a learning disability)

### Theme 6 Highlights

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

- Gloucestershire Constabulary have been doing a lot of work on how to make custody more neurodivergent friendly. Details to follow in a future issue of this newsletter.
- Police HQ are also holding a series of activities during Neurodiversity celebration week, to increase awareness amongst staff and ultimately improve support within criminal & youth justice systems.



**Partnership Board – December 2024**

The session began with a focus on sensory differences in neurodivergent populations. Following an introduction to the topic, Josh Jones, who is dual-diagnosed with autism and ADHD, shared his lived experience.

Next, Julia Wilde, Clinical Specialist Occupational Therapist within the Autism and ADHD Diagnostic Service, provided an overview of post-diagnostic autism support. She also explained what happens in an occupational therapy session, particularly regarding sensory processing challenges.

In addition, Faith Bowerman, Occupational Therapist from the Social Communication and Autism Assessment Service and CAMHS Neurodevelopmental Pathway, provided insights from a children and young people's perspective.

This discussion about sensory differences was particularly engaging, which unfortunately meant that the follow-up session on Autism Hospital Liaison had to be postponed until the next Partnership Board meeting in March. My sincere apologies to Jeanette Welsh and Martin Doddimeade for not managing the time more effectively.

Following this, we held a breakout session to explore what should be included in an information pack on sensory differences.

Finally, Jo Sutherland presented on ongoing co-production efforts across all Partnership Boards, including the development of an initial co-production charter.

**Next Partnership Board Meeting – Tuesday, 4th March 2025**

The next session will focus on the Clinical Programme Groups and their relationship with the Partnership Board. Dr. Mala Uhbi will lead this discussion on behalf of the Clinical Programme Groups. Dr. Uhbi also brings personal insight, as she is the parent of an autistic daughter.

Each issue, we will introduce a topic of interest in neurodivergence. Due to the summary nature, there is not space to explore the intricate detail and nuances that some of you will be aware of!!

Last Partnership Board we discussed neurodivergence and sensory differences. Here is a particular form of fairly common sensory issue within the neurodivergent population.

### **Sensory Issue: Misophonia**

Sensory processing differences are common among neurodivergent individuals and can shape how the world is experienced. While some people may be highly sensitive to light, touch, or movement, others have strong reactions to specific sounds, for example, struggling with textile and material noises like the rustling of plastic bags or velcro tearing, or water-related sounds such as dripping taps or the rush of a flushing toilet.. Sound sensitivity exists on a spectrum, from mild discomfort to extreme distress, and misophonia represents one of the more intense manifestations of this sensory processing challenge.

Misophonia, meaning "hatred of sound," is a condition where specific sounds trigger intense emotional reactions that can be overwhelming and difficult to manage. Research suggests that misophonia is more commonly found in neurodivergent populations, particularly among individuals with autism and ADHD. Misophonia is also prevalent among individuals with OCD and anxiety disorders, both of which frequently co-occur with autism and ADHD. While OCD is not always considered a neurodivergent condition in itself, its strong overlap with traits of neurodivergence highlights a complex relationship between sensory processing differences and emotional regulation challenges. Unlike common sound aversions, which may cause fleeting discomfort, misophonia can significantly impact daily life and relationships. It is often linked to neurodivergence, particularly in individuals with heightened sensory processing differences, and can exacerbate challenges related to emotional regulation and executive functioning.

### **What's Considered "Normal" Sound Sensitivity?**

Many people dislike certain sounds. The screech of a metal utensil on a plate, the high-pitched whine of a microphone, the hum of a fluorescent light, or the classic nails on a chalkboard sound might cause discomfort. However, these reactions tend to be momentary and do not interfere with daily activities. Misophonia, on the other hand, involves an emotional and often physiological response that can be severe and lasting, sometimes making it impossible to stay in an environment where the trigger sound is present.

### **Specific Triggers and Reactions**

For me, eating noises—even quiet ones—can provoke very intense emotional reactions that feel all-consuming at the time. These might include deep discomfort, disgust, instant rage, or intense irritation. Often, I struggle to separate my reaction to the sound from the person making it, even though I rationally know they are eating normally. I experience deep stress, rushing to create covering noises, but sometimes I find it impossible to do so effectively. The urge to leave the space can be overwhelming.





Each issue, we will introduce a topic of interest in neurodivergence. Due to the summary nature, there is not space to explore the intricate detail and nuances that some of you will be aware of!!

For others with misophonia, triggers may include repetitive or everyday noises, such as pen clicking, tapping, cutlery clinking on plates, zippers being zipped or unzipped, or even hearing breathing sounds from others.

Fortunately, my triggers are mainly limited to eating noises (I do have the odd others though) and only in quiet settings. I don't experience the physical reactions that some people with misophonia do. However, misophonia is surprisingly common and can present in more severe ways for others. In some cases, even the anticipation of specific sounds can provoke stress or anxiety. For instance, I once experienced an intense misophonic reaction while on a bus. Even though I couldn't hear the noise, just seeing a child eating messily a few seats down triggered the same overwhelming reaction.

### **Impact on Daily Life and Relationships**

These reactions go beyond mere annoyance and can feel overwhelming, significantly impacting daily life and interactions. **In a quiet room** with my partner, if she is eating and I haven't prepared something to mask or distract from the sound, it can wipe out my ability to function—running from the room is sometimes my only solution. My internal reaction can sometimes be so extreme that I suddenly feel as though I don't want to exist—not just in the room, but in a more existential sense, which is a disturbingly intense response. The fact that I can be relaxed and engaged in an activity one second, only to be completely derailed in the next, makes it particularly difficult to manage.

Even with awareness, with parts of my executive function being poor, I often struggle to implement noise-masking measures in time. This can be distressing for my partner, as it often reduces her enjoyment of meals due to her efforts to avoid triggering me. Fortunately she is understanding and nudges me to plan noise!

Understanding the distinction between common sound aversions and misophonia is important for providing appropriate support and strategies. For those of us who experience it, having our condition acknowledged and accommodated can make a profound difference in our ability to navigate daily life. However, I find it relatively embarrassing to talk about, as my reactions feel so out of proportion that I rarely discuss it.

### **Possible Causes of Misophonia**

The exact cause of misophonia remains unclear, but several theories provide insight.

#### **Neurological Factors**

Misophonia may involve abnormal connections between the auditory cortex and orofacial motor control areas, responsible for facial and mouth movements. This could explain why sounds like chewing or breathing are common triggers. Additionally, heightened activity in the limbic system, which regulates emotional responses, may contribute to the extreme reactions and fight-or-flight responses associated with misophonia.

#### **Genetic and Environmental Factors**

Some studies suggest a genetic predisposition to misophonia, indicating it may run in families. Additionally, many individuals report developing misophonia in childhood, often linked to negative experiences with specific sounds, such as family members eating. This suggests environmental conditioning might play a role.

While these theories offer insights, more research is needed to fully understand the origins of misophonia.







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!

### Zara Beth - Her Introduction:



"A safe space for everything neurodivergent  
I'm Zara, a content creator, artist, musician and writer from the UK 🇬🇧🌈"

I have **Tourette's Syndrome** and **Functional neurological disorder** alongside **mental health struggles** and being **autistic!** I make content sharing my advice, experiences and how I live day-to-day as a disabled person :D"

[https://www.youtube.com/@Zara\\_Beth/videos](https://www.youtube.com/@Zara_Beth/videos)

## Theme based resources of the issue!

### Tourettes

Above is a link to a highly followed tourettes and autistic youtuber

Here is a link to Tourettes Action which is a national organisation.

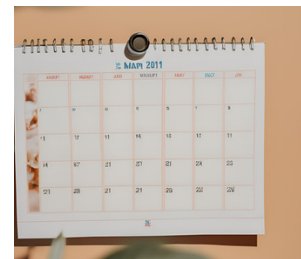
<https://www.tourettes-action.org.uk/>

They have a large quantity of resources about Tourettes and a wide range of information about support in different circumstances.



# DATES FOR YOUR DIARY

Here are support groups, meet ups or events happening around Gloucestershire over the next quarter. 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).

## **Neurodivergence 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).

## **The Youth Forum**

The Youth Forum is for autistic and other 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. It is a chance to meet other autistic and neurodiverse young people and support each other.

If you want to join the forum and have your say about things that are important to you, a parent or guardian needs to complete a consent form. For more information, email: [emilyl@inclusion-glos.org](mailto:emilyl@inclusion-glos.org).

## **Your next Autism (and Neurodivergence) Partnership Board**

Tuesday 4th March 2024 | 10.00am to 12.30pm  
Venue: Zoom [Online]

### **Main Topics:**

Hospital's Autism Liaison  
The Clinical Programme Group

### **Future Partnership Board Dates:**

Tuesday 3 June 2025 | 10.00am to 1.00pm  
Venue: Hybrid [TBC]

Tuesday 9 September 2025 | 10.00am to 12.30pm  
Venue: Zoom [Online]

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

Various locations - for more details visit

<https://www.grcc.org.uk/what-we-do/community-autism-support-advice-casa> or email [info@grcc.org.uk](mailto:info@grcc.org.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).

## **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](mailto:NEURODIVERSITY@GLOUCESTERSHIRE.GOV.UK).

## **MORE INFORMATION**

TO FIND OUT MORE, AS WELL AS READ PREVIOUS NEWSLETTERS, VISIT: [HTTPS://GLOUCESTERSHIRE.GOV.UK/HEALTH-AND-SOCIAL-CARE/DISABILITIES/AUTISM-PARTNERSHIP-BOARD/](https://gloucestershire.gov.uk/health-and-social-care/disabilities/autism-partnership-board/)





### From your Co-Chairs:

Wendy Wall and Jan Marriott



Since the last newsletter, the LDPB have met in person and online. Both meetings were well attended, with lots of people with lived experience joining us at the face to face meeting.

### December 2024

Brandon Trust came to our meeting and gave a presentation about 'What good supported living looks like'. Their presentation was led by two of their residents.

Gemma from Healthy Lifestyles Gloucestershire also came to talk about the service, which relaunched in April 2024.

### February 2025

One of the LDPB's priorities is Hate Crime and staying safe and this was the topic for our recent February meeting.

Lewis Whitter, from SkillZone, gave presentations about county line, grooming and knife crime. Steph Lawrence, from Gloucestershire Police, came to talk to us about hate crime and what the differences are between all the different types of hate crime.

### Don't forget our Communication Cards!

Some months ago the Board helped to design a communication card. The card explains the law and allows people to say how they want people to communicate with them. Please contact Inclusion Gloucestershire, via [partnershipboards@inclusion-glos.org](mailto:partnershipboards@inclusion-glos.org), if you would like them to send you some to give out to people.



### Our Next Meeting

**Our next meeting face to face meeting is in April 2025.** We will contact people with the date. We are also planning to hold an online 'mini' LDPB meeting, where we will summarise what we talk about at our last two meetings and catch up with members unable to join us face to face.

### Joining the Learning Disability Partnership Board

The Board meets every two months on a Monday at the Treasure Seekers Hub in Eastgate Street, Gloucester. If you would like to join us please either email: [partnershipboards@inclusion-glos.org](mailto:partnershipboards@inclusion-glos.org) or call Inclusion Gloucestershire on **01452 234003**



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

We are pleased to share highlights from our Mental Health and Wellbeing Partnership Board on January 23rd. The Board was well attended, and we had a packed agenda. In the absence of Jan, the meeting was chaired by Holly Beaman (Associate Director Urgent & Emergency Care) and Karl Gluck (Head of Integrated Commissioning for Advocacy, Mental Health, Autism & Disabilities).

**Discharge Project Update**

Karen Brzonkalik (leading Housing Officer) reported on the Discharge Project, which relocates individuals from unsuitable homes to better housing, including extra care housing. Collaborating with extra care schemes and Gloucester City Homes, the project addressed homelessness and supported hospital discharges. The successful pilot led to expanded funding and more discharge accommodation properties. In the past 18 months, none of the 140 referrals returned to hospital, resulting in significant savings and reduced acute bed usage. The discussion generated many questions and comments, particularly around hoarding and support available in the county. For advice or support on hoarding, please contact Dena at [Dena.BOUCHER@gloucestershire.gov.uk](mailto:Dena.BOUCHER@gloucestershire.gov.uk).

**Living Well Strategy**

Karl discussed the development of the Living Well Strategy. He stated, "Currently, we are at the data collection phase. Once completed, we will move on to engagement, consultation, and co-production. Our aim is to publish the strategy by autumn this year."

**Voluntary, Community, and Social Enterprise Mental Health Listening Events**

Alex Monks (Head of Programme Development, Rethink Mental Illness) shared updates from the VCSE Mental Health Listening Events held across the county. As part of Gloucestershire County Council's Mental Health Advice and Support Service, Mental Health VCSE forums are being established in five localities: Stroud, Cheltenham, Gloucester, Forest, and TWNS and Cotswolds. These forums aim to bring together VCSE and statutory organisations, along with Experts by Experience (EBE), to develop pathways, identify training and provision gaps, and co-produce solutions to local needs. The listening events have been positive, and the forums are expected to be ready by the end of February or early March.

**Joining the Mental Health & Wellbeing Partnership Board.**

If anyone is interested in the joining the Board or network meetings please email:

**[DisabilitiesCommissi@gloucestershire.gov.uk](mailto:DisabilitiesCommissi@gloucestershire.gov.uk)** or [Nadine.Blewitt@gloucestershire.gov.uk](mailto:Nadine.Blewitt@gloucestershire.gov.uk).



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

**Right Care, Right Person**

Karl presented on the "Right Care, Right Person" program, which aims to provide appropriate care and support to vulnerable individuals in the community, reducing reliance on police interventions and ensuring a healthcare-focused approach. The police will still be involved where there is an immediate risk to life, ensuring no one is placed unduly at risk. This initiative supports individuals of all ages, addressing a wide range of vulnerabilities.

**MHELO**

Ailsa Lane (Deputy CEO/Operations Director) provided an update. Their work in mental health includes MHELO – Mental Health Experience Led Opportunities, Community Mental Health Transformation – Mental Health Workshops, Community User-led Inclusion Hubs, Quality Checking, Mental Health Supported Living Housing project, and Research. For help, advice, or to get involved, email [mhelo@inclusion-glos.org](mailto:mhelo@inclusion-glos.org), or call (01452) 234003.

**Intensive and Assertive Community Mental Health Review**

Karl also presented on the Intensive and Assertive Community Mental Health Review. This NHS England initiative aims to evaluate and improve community mental health services for individuals with severe mental illness. The review focuses on assessing current services, enhancing patient engagement, and gathering feedback from those with lived experience to inform policy and ensure consistent, effective care. This collaborative effort, led by Integrated Care Boards, seeks to ensure that patients receive the necessary support and are not discharged due to non-attendance.

**MEAM – Make Every Adult Matter**

Caroline Lucas-Mouat (Gloucestershire Housing Partnership Team) gave an informative presentation on MEAM – Make Every Adult Matter. The Gloucestershire Housing Partnership, a collaboration of local councils, the County Council, the Integrated Care Board, and the Office for Police and Crime Commissioner, recently joined the MEAM network. This membership offers two years of support to improve outcomes for those facing multiple disadvantages in Gloucestershire. Caroline highlighted the MEAM network and the future direction of their work.

**Joining the Mental Health & Wellbeing Partnership Board.**

If anyone is interested in the joining the Board or network meetings please email:

**[DisabilitiesCommissi@gloucestershire.gov.uk](mailto:DisabilitiesCommissi@gloucestershire.gov.uk)** or [Nadine.Blewitt@gloucestershire.gov.uk](mailto:Nadine.Blewitt@gloucestershire.gov.uk).



This event was very much about celebrating Experts by Experience and the contribution they make both in delivering services and training but also in coproducing ways people can best be supported to live their best lives. Simon Price was our guest Chair and provided his usual enthusiasm and wisdom from a background of lived experience.

### **Ollie's Random Acts of Kindness (ORAOK)**

The first speakers were Oliver and Riley talking about ORAOK which is a community interest company they set up a year ago with their colleague Vee. It is run by people with lived experience for those living with experience. Oliver shared his and Vee's personal experiences and the people who had inspired them to make a difference for others. They are providing training to support professionals understand the benefits and to navigate the barriers to working with people with lived experience, as well as supporting and empowering new experts by experience. They attend gigs and festivals to offer support to people and inspire others to recover through their own experiences. ORAOK would like to find more volunteers to support them at gigs and festivals and other areas. They can be contacted on [olliesrandomactsofkindness@gmail.com](mailto:olliesrandomactsofkindness@gmail.com).

### **Gloucestershire Health and Wellbeing College,**

Holly Fry, an Occupational Therapist and Manager of the College explained that the College had previously been the Recovery College, predominantly focusing on mental health. It had now expanded to include recovery, self-management and living well with a range of long-term health conditions. It is a peer led, health education service with a shared belief that all experience is equal whether lived or clinical. Peer support workers are employed and paid as members of the team working alongside clinical staff but there also experts by experience who are volunteers but receive honorarium payments. The courses are available for people aged 18 years and over. The team provide a lot of support for people who are anxious about attending courses which are either face to face or online. Holly talked about people for whom the courses/experience had made such a positive difference to their lives and this was echoed by some of the people attending the event. The College can be contacted on 0300 4214414 or [ghwc@ghc.nhs.uk](mailto:ghwc@ghc.nhs.uk)

### **Living Well Strategy**

Karl Gluck, with the longest title as Head of Integrated Commissioning – Mental Health, Autism, Learning Disabilities and Physical Disabilities, talked about the new Living Well Strategy. He apologised for his presentation being dull in comparison to the other great presentations but people were very interested in understanding how they might contribute to this strategy, which will focus on social care support for adults.





### Young Gloucestershire (YG)

Ione Sim explained that YG are working on 55 projects and that young persons' experiences and co-production are at the heart of everything they do. Young peoples' experiences, voice and autonomy are central to the way they work. She talked about 3 of their current projects to illustrate this way of working.

- **Young Adults Service (YAS)** supports young people as they transition from Children and Adolescent Mental Health Services (CAHMS) but do not meet the criteria for adult services. The programme was co-designed and clinical support is provided in the community, where young people feel safe and led by young people themselves.
- **Arcus** supports families and young people who are exploring gender identity. The programme was designed by parents and young people. The training programme for the voluntary sector was designed and developed by young people to upskill the sector on inclusive practice. Young people and families talk directly to commissioners about their experiences of the programme and are being invited to contribute to strategies/approaches to diversity
- The **Hospital project** provides inpatient support for young people admitted to the children's wards for mental health or eating disorders and for 6 weeks after they are discharged. Advocacy is central but also learning about what might prevent/reduce crises and future hospital admissions.



### Making Every Adult Matter (MEAM)

Caroline Lucas- Mouat, Gloucestershire Housing Partnership Team, described the programme to improve support for people who have had multiple life disadvantages which lead to rotten lives. The audience was particularly struck by the numbers of women who are sleeping rough in Gloucestershire and the reasons why they are less likely to be seen sleeping on the streets. She explained that the MEAM vision is for everyone who has experienced multiple disadvantage can reach their potential and contribute fully to their communities. The approach helps local areas to work in a co-productive way to develop more effective, coordinated services and promote lasting changes to the way we all work.

Following a first workshop it was agreed that Gloucestershire would focus on "safeguarding rough sleepers with complex emotional needs". The vision is to create a flexible system where barriers are broken down and where services partner with the whole person and every adult is empowered to access the support they need to thrive. If we get it right for this group of people it is hoped we can embed this way of working for others with multiple disadvantages.

As we delve into our work at Ollie's Random Acts of Kindness CIC, we've uncovered a complex dynamic within mental health services that warrants deeper exploration. Through extensive conversations with mental health professionals, we've discovered that the integration of Experts by Experience (EbE) faces challenges that are more nuanced than initially anticipated.

What we're observing isn't simple resistance to change, but rather a multifaceted anxiety that permeates professional environments. Mental health professionals, despite their expertise and dedication to patient care, often find themselves navigating unfamiliar territory when it comes to working alongside Experts by Experience. This anxiety manifests in several ways:

First, there's the fundamental uncertainty about the role itself. Many professionals struggle to fully grasp what an Expert by Experience brings to the table. They grapple with questions about how to integrate lived experience with clinical practice, how to balance different forms of expertise, and how to create meaningful collaboration rather than superficial involvement.

Second, there's considerable uncertainty around governance and structure. Professionals often feel unsure about the protocols, policies, and procedures that should guide their interactions with EbEs. This uncertainty can lead to hesitation and, in some cases, complete avoidance of meaningful engagement.

The Expert by Experience movement, which emerged in the early 2000s with great promise, hasn't achieved the widespread integration one might expect after two decades. While some services have made attempts to involve EbEs, these efforts often remain superficial. We frequently see tokenistic involvement – perhaps an occasional consultation or a ceremonial seat at meetings – rather than genuine integration into service design, delivery, and evaluation.

This limited progress isn't due to a lack of value in the EbE perspective. Rather, it stems from systemic barriers rooted in professional anxiety and misunderstanding. The potential of Experts by Experience remains largely untapped, with their capabilities often underestimated or misunderstood.

A deeper layer of this challenge lies in unconscious stigma. Despite significant progress in mental health awareness, deeply ingrained biases about mental health experiences persist, even among mental health professionals. These biases often operate below the surface of conscious awareness, influencing decisions and attitudes without explicit recognition.





Research consistently demonstrates the transformative power of Expert by Experience roles, both for the individuals involved and the healthcare system as a whole. What often begins as voluntary engagement frequently evolves into paid professional positions within healthcare settings. This progression isn't just about employment – it represents a profound journey of personal and professional development that challenges traditional recovery narratives.

The data shows significantly improved recovery outcomes when Experts by Experience are integrated into mental health services. This improvement stems from multiple factors: the hope inspired by visible recovery examples, the practical wisdom shared through lived experience, and the transformation of personal challenges into professional expertise.

It is imperative that professionals receive comprehensive education about working with Experts by Experience, and crucially, this education must come directly from the experts themselves. This isn't just about transferring information – it's about transforming perspectives and challenging deeply held assumptions.

When Experts by Experience lead educational initiatives, they demonstrate their capabilities in real-time. They show themselves not as former patients seeking validation, but as skilled professionals bringing unique and valuable insights to the table. This direct interaction helps break down the artificial barrier between "professional" and "service user," revealing instead a spectrum of complementary expertise.

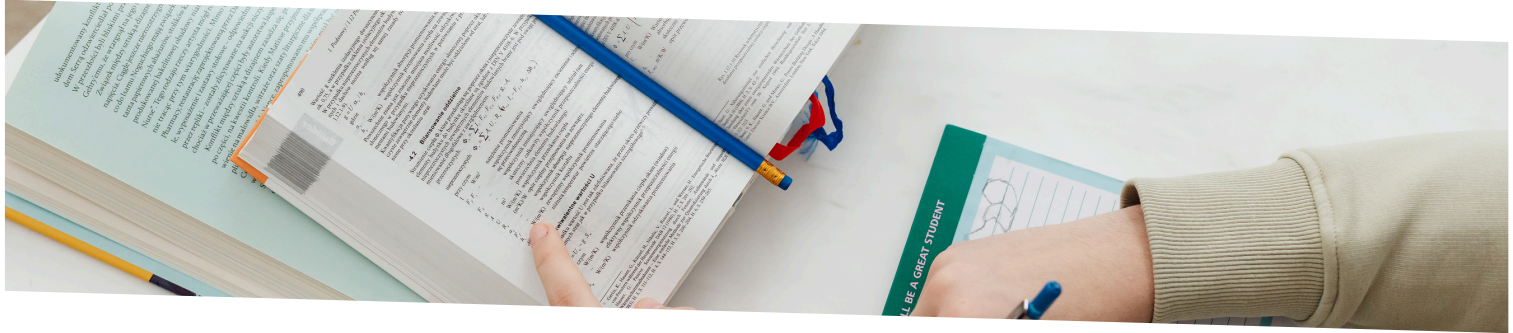
The relationship between mental health professionals and Experts by Experience needs fundamental redefinition. Instead of viewing EbEs through the lens of their past vulnerability, professionals must recognise them as individuals who have transformed their experiences into expertise. This strength-based perspective acknowledges that managing and recovering from mental health challenges develops valuable skills, insights, and resilience that can significantly enhance service delivery.

Consider this powerful testament from one of our Experts by Experience:

*"I was once labeled as 'therapy avoidant' – unable to access traditional services. Through my work as an Expert by Experience, I've found healing in ways I never imagined possible. I've become someone neither I nor those around me thought I could be."*

This shift in perspective isn't just semantic – it's transformative. When professionals truly see Experts by Experience as colleagues bringing complementary expertise, rather than as former patients, it opens up new possibilities for collaboration and service improvement.





Moving forward requires a systematic approach to addressing these challenges:

- **First**, we need comprehensive education programs, led by Experts by Experience, that help professionals understand both the value and practicalities of EbE involvement. These programs should address unconscious biases and provide clear frameworks for collaboration.
- **Second**, organisations need to develop clear policies and procedures that support meaningful EbE involvement. These should outline roles, responsibilities, and expectations while maintaining enough flexibility to accommodate different contexts and needs.
- **Finally**, we need to create more opportunities for direct interaction between professionals and Experts by Experience in non-clinical contexts. These interactions help break down barriers and demonstrate the value of lived experience expertise in practice.

The future of mental health services lies in genuine collaboration between clinical expertise and lived experience. By addressing professional anxiety through education, clear frameworks, and meaningful interaction, we can create services that truly benefit from the unique insights that Experts by Experience bring.

This isn't just about making services more inclusive – it's about making them more effective. The expertise gained through lived experience complements clinical knowledge in ways that can transform service delivery and outcomes. As we work to break down these barriers, we move closer to mental health services that truly reflect the needs and experiences of those they serve.

Imagine mental health services where clinical expertise and lived experience work in genuine partnership. Where recovery journeys can transform into professional expertise. Where helping others becomes a pathway to healing.

This isn't just an idealistic vision – it's already happening in services that have successfully broken down these barriers. The evidence shows that when we overcome professional anxiety and create genuine opportunities for Expert by Experience involvement, everyone benefits.



**From your Co-Chairs:** Katie Peacock and Jan Marriott  
And Emily Luckham (Inclusion Gloucestershire)

**Shining a spotlight on healthy lifestyles & digital inclusion in the county.**

Two key Gloucestershire initiatives - GRCC's digital equity work and the Healthy Lifestyles service - both making strides in supporting local communities with accessibility, connectivity, and well-being.

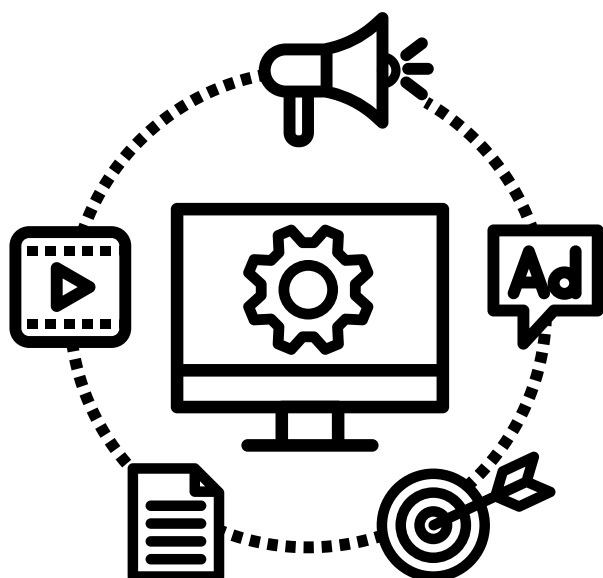
**GRCC: Championing Digital Inclusion and Accessibility**

Daniel Gale, Digital Equity Manager at Gloucestershire Rural Community Council (GRCC) and Manager of the DAISI (Digital Accessibility Inclusion Support and Innovation) Project, outlined their ongoing efforts to improve digital inclusivity. The organisation's work focuses on three key areas:

- **Rural Internet Access** – Addressing connectivity issues in remote areas.
- **Affordability** of Digital Support – Helping people access and use technology.
- **Website Accessibility** – Ensuring interfaces are compatible with assistive tools.

GRCC's digital equity work extends beyond accessibility to include digital poverty relief. Over the last year, they have managed the county's data bank, distributing SIM cards with six months of calls, texts, and data to those in need. In addition, GRCC partners with digital repair companies to recycle and redistribute essential tech, including mobile phones, tablets, and even drones.

With 181 community partnerships, GRCC tailors its support to local needs. They work with organisations to promote digital social tariffs and ensure people access the internet at the lowest possible cost. GRCC champions open-source software to eliminate unnecessary subscription fees and has been recognised nationally for its best practices, even presenting at the House of Lords.





**From your Co-Chairs:** Katie Peacock and Jan Marriott  
And Emily Luckham (Inclusion Gloucestershire)

**Healthy Lifestyles Service Relaunches Under ABL Health**

Gemma McKay, Outreach Engagement Officer, introduced the newly relaunched Healthy Lifestyles service, now operated by ABL Health, a national provider of health and well-being support. With an extended service contract that could run for up to nine years, Healthy Lifestyles is committed to helping residents of Gloucestershire live healthier, happier lives. The service offers:

- Weight management support
- Smoking cessation (including a unique harm reduction program for 12-17-year-olds who vape)
- Pregnancy-related health support
- Alcohol reduction support
- Guidance on increasing physical activity

All services are completely free and can be accessed multiple times. Support is available in-person and over the phone, ensuring flexibility for users.

**New Weight Management Groups and Workplace Initiatives**

Since end of January 2025, 20 weight management groups are running across Gloucestershire. Every venue is fully accessible, ensuring inclusivity for all. The service is working to support healthy workplaces, with businesses able to gain accreditation for promoting wellbeing.

**Eligibility and Next Steps**

Healthy Lifestyles services are available to anyone who:

- Lives in Gloucestershire or has a GP in the county
- 18+ (or 12+ for smoking cessation support)
- Meets specific criteria for weight management or pregnancy support

For those struggling with alcohol consumption above 14 units per week, referrals can be made to VIA Gloucestershire ([viaorg.uk](http://viaorg.uk)).

We're always looking for new members to join the Physical Disability and Sensory Impairment Partnership Board and Neurology Subgroup. If you're interested in getting involved or want to learn more, please don't hesitate to reach out. Together, we can make Gloucestershire a more inclusive and accessible place for everyone! Please contact:

- **Physical Disability and Sensory Impairment Partnership Board:**  
[partnershipboards@inclusion-glos.org](mailto:partnershipboards@inclusion-glos.org)
- **Neurology Subgroup:** [disabilitiescommissi@gloucestershire.gov.uk](mailto:disabilitiescommissi@gloucestershire.gov.uk)





**Chair:** Joanna Davies

**Vice Chairs:** Jenny Hinks (Adult Carer) & Helen Bond (Parent Carer)

Between July and September 2024, the Adult Carers team gathered feedback from carers on the support services available for unpaid carers in Gloucestershire. Our goal was to identify what is working well and areas for improvement. Since then, we have been carefully reviewing all responses and planning the next steps. We deeply appreciate everyone who took the time to share their insights, as this feedback is playing a vital role in shaping key projects designed to enhance carers' experiences in accessing support services. We want to share the **6 overarching themes that carer feedback has highlighted as being priorities for an effective carer support service:**

1. The need for easy navigation of services and accessible information
2. Recognition of carers and the importance of flexibility and inclusivity in services
3. The need for emotional, social, and community support
4. Improved service communication, collaboration, and follow-up
5. Sufficient training and awareness for professionals and carers
6. Effective crisis planning, carer assessments, and opportunities for breaks

We are pleased to say that this remains in line with our current overarching Action Plan, where we **want carers to...**



To ensure we stay on the right track, we will continue to seek feedback as these projects develop.

If you would like to share your input as the projects progress, please email

[commissioninghubadult@gloucestershire.gov.uk](mailto:commissioninghubadult@gloucestershire.gov.uk), including your name and preferred contact details.

*Please note that your contact information will be shared with our co-production partner,*

*Gloucestershire Carers Hub, who play a key role in ensuring carers' voices are heard and considered throughout these projects. Please then expect either ourselves or the Gloucestershire Carers Hub to be in touch with you in due course."*

### A Note From Andrew Cotterill:

There is often a very hidden difficulties and mental costs to being a carer. Do reach out if you already haven't. I myself was a dementia carer for many years and valued the contact with others both professionals and peers to learn and share our difficult journeys.

The next page details of some of the key support (hubs) for those caring for young through to adults. In addition there is a carers partnership board that guides the themes for (unpaid) carer service.

There are many carer support groups around the county, a few of which include

- **Elmbridge Together Carer Cafe at the** Lonsdale Methodist Church Gloucester
- **The Cornerstones Centre Carer Cafe in**, Whaddon, Cheltenham,
- **Carers Chit Chat and Activities at the** Phoenix Community Cafe, Matson Centre
- **Candi Carer Café in** Cinderford
- Online Supporting an Adult with Autism Lunch and Support group for Carers



For more details. [Click here](#)

Being signed up to such as the Carers Hub will give you access to regular news of these and other events. [Here](#) is a list of current events. Below is just a sampling of things that happened during Feb, and virtually all are free to you as a carer. For activities provided through the CarersHub you will need to be signed up though (it's free).

### Informational events

Examples include:

- Workshops for wellbeing: A workshop: Relaxation for Wellbeing
- YouCan Be You: Exploring emotions and feelings, coping strategies, positive wellbeing and the five ways of wellbeing. This session will give you an insight into taking time for you and how to support your overall wellbeing
- Direct Payments Session to hear about Independent Living Services and the Direct Payments offer which may be available to you for managing your care needs.

For a diary of these events through the Carers hub - visit their [website](#).



### Are you supporting someone?

This could be a family member, including a child with additional needs or a friend. You are a Carer if you provide support to someone, this could be due to a long term health condition, illness, frailty, poor mental health or addiction.

The following organisations can help you:

#### Are you over 18?

For free information and support contact the Gloucestershire Carers Hub.

0300 111 9000 [careraware@peopleplus.co.uk](mailto:careraware@peopleplus.co.uk)  
<https://gloucestershirecarershub.co.uk/>



#### Are you 8 - 24 years old?

For free information and support contact Gloucestershire Young Carers

01452 733060 [mail@glosyoungcarers.org.uk](mailto:mail@glosyoungcarers.org.uk)  
<https://www.glosyoungcarers.org.uk/>



#### Are you supporting a child with additional needs?

If you are a parent or Carer of a child, Gloucestershire Parent Carer Forum can offer free support.

[info@glosparentcarerforum.org.uk](mailto:info@glosparentcarerforum.org.uk)  
<https://glosparentcarerforum.org.uk/>



### Joining the Carers Partnership Board

The Carers Partnership Board is a forum for organisations and individuals wanting to raise awareness of the issues faced by carers and improve health and social care services for carers within the county. They meet quarterly online. **[Meeting dates and minutes](#)**. If you would like to find out more about being involved in the Carers Partnership Board, please email **[commissioninghubadults@gloucestershire.gov.uk](mailto:commissioninghubadults@gloucestershire.gov.uk)**