Gloucestershire's Autism (and Neurodivergence) Partnership Board Minutes

Tuesday 4th March
10.00am to 12.30pm; Zoom

Name	Organisation
Andrew Cotterill (AC)	Lived Experience Co-chair
Noor Al-Koky (NA-K)	GCC/ICB Senior Commissioning Manager Autism
Nadine Blewitt (NB)	GCC/ICB Commissioning Officer
Colleen Harris- Stinton (C H-S)	Parent
Nicole Hastie (NH)	Active Impact Development Manager / Parent Carer
Josh Jones (JJ)	Barnwood Trust
Sheila Banga (SB)	ICB VCSE Impact Manager
Sam James (SJ)	GCC
Karl Gluck (KG)	GCC/ICB Head of Integrated Commissioning
Marco Cetara (MC)	PEAK (Parenting Empowered Autistic Kids)
Lidia Bojczuk (LB)	Barnwood Trust
Julianna Friend (JF)	DWP
Ione Sime (IS)	Young Gloucestershire
Mel Brozakalik (MB)	National Star Transition Support Manager
Leah Rosagro (LR)	Senior Commissioning Manager / Children's & Families Hub
Stuart Saxon (SS)	National Star
Zeb Nawaz (ZN)	HHPDA (Horses Helping People with Depression & Anxiety)
Aylisha Howard (AH)	Affinity Trust
Sam James (SJ)	GCC
Martin Doddimeade (MD)	NHS / Autism Liaison Officer (GRH)
Alice Brixey (AB)	Senior Project Manager: Learning Disabilities & ND
Mar Plowman (MP)	Active Impact / Neurodiversity Network Coordinator
Dr Mala Ubhi (MU)	NHS / GP
Pippa Baker-Walsh (P B-W)	GRCC / CASA
Imran Atcha (IA)	GCC / Commissioning Officer
Tasmin Morgan (TM)	Glos Parent Carer
Ida Poschel (IP)	Active Gloucestershire / Senior Project Officer for Health & Disability
Chris Atkins (CA)	GCPA
Abbas Veshmia (AV)	GCC / Engagement & Participation Officer
Rachel Hall (RH)	Fine Artist / Lived Experience Researcher
Karen Julke (KJ)	Artlift
Marco Cetara (MC)	PEAK (Parenting Empowered Autistic Kids) / Founder /
Jacky Martel (JM)	ANG member/advocate

No.	Item	Lead
1.	**Welcome / Introductions**	Andrew Cotterill
	Apologies for absence and any declarations of interest Apologise from – Jane Blackett, Ethan Easton, Dr Marie O'Neill, Emma Evans, Shelly Thomas, Mark Wilde, Jackie Baker, and Emma Whittaker (Not Read out)	Disclosed to the Lead.
2.	**Partner Update & Questions & Answers** **Martin Doddimeade – Autism Liaison Officer (GRH)** **MD**, Autism Liaison Officer for Gloucestershire Hospitals NHS Foundation Trust, has been in this role since April 2024. He is registered with the Health Care Professionals Council as a Paramedic and has previously delivered prehospital care for London Ambulance Service & Southwestern Ambulance Service Foundation Trust, he has worked as a Heath Care Professional at a specialist SEND Educational College with a residential provision. Martin supports individuals with a formal autism diagnosis at Gloucestershire Royal Hospital or Cheltenham General Hospital, meeting patients face-to-face or over the phone to understand their needs and determine necessary reasonable adjustments. Most of Martin's patients are at Gloucestershire Royal Hospital. His role involves pre-planning for scheduled appointments and assisting unscheduled emergency patients, ensuring necessary reasonable adjustments are made for their hospital stay. Referrals to Martin come through various channels, including a GHNHSFT IT tool that flags patients with autism-related keywords, hospital staff, support groups, GP surgeries, and self-referrals. Positive feedback on forums has increased awareness. Martin recently completed the NHS England / Anna Freud, National Autism Trainer Program, Oliver McGowan training, and Nelson Trust Trauma Informed training. He commented on challenges in tracking and flagging patients with autism, noting NHS England's work on a reasonable adjustments digital flag. Internally, the hospital is considering an interim digital flag for vulnerable patients. Martin collaborates with the Brown Hills team to support autistic patients with eating disorders during their inpatient stay. A second phase walkthrough of the GRH adult and paediatric emergency departments identified the need for more bays with environmental adjustments to create a low-stimulatory environment for autistic patients. Andrew commented on the benefits of walkthroughs and mentioned his upcoming visit to Wotton Lawn's wards. Martin agreed that walkthroughs should be replicated across both Cheltenham and Gloucestershire hospitals once initial changes have proven to be effective. He highlighted challenges at Gloucester Royal,	Martin Doddimeade

	such as high capacity and the physical environment, but noted that small changes can have a big impact on the patient experience. Andrew commented that reasonable adjustments could benefit both short and long-term stays, providing a business benefit to the hospital. Martin agreed, explaining that stays vary from Emergency Department visits to several months of ward admission. Building rapport with long-term patients helps them engage with their healthcare needs, potentially reducing readmissions. Martin's engagement with patients depends on their immediate healthcare needs, and adjustments are documented and shared to ensure continuity of care. Regarding eating disorders, Martin collaborates with the MDT of professional's team to understand the interplay between autism and dietary needs, ensuring adjustments are made without enabling the eating disorder. Martin's role is inpatient-focused, supporting safe discharges and advocating for patients' needs, including housing issues. Andrew asked about key learnings and future plans. GHNHSFT aims to create sensory-friendly waiting and treatment areas in the emergency department for autistic, learning disability, dementia, and mental health patients. Another goal is to streamline the process for patients with eating disorders. Despite the hospital's size and older facilities, he praised the fantastic staff at all levels. Noor asked about the most rewarding moment in Martin's role. Martin finds face-to-face interactions with patients the most rewarding, valuing the opportunity to understand what autism means for each patient in a healthcare context. Andrew commented that discussions about needs can be more valuable than expected, applauding Martin for highlighting this aspect. Pippa asked for advice for a client who became overstimulated in A&E. Martin suggested: 1. Autism Health Passport: Offering insight into that autistic person's autism in the context of their healthcare needs. 2. Reasonable Adjustments: Receptionists can access GHNHSFT reasonable adjustment policies from the intranet. Patients can provide a phone number to be contacted on to facilitate remote waiting and not miss being assessed. 3. Alternative Waiting: Suggest waiting outside or in a car to reduce overstimulation, while remaining contactable by phone.	
3.	**Breakout Room Discussion** **Questions** What support would you like to see from Martin's role in the future? Have you any questions from Martin's presentation? The meeting broke out in three breakout rooms to discuss.	All

Returning from the breakout rooms:

The first group focused on health. The second group discussed the challenge of supporting A&E, a 24/7 service, with only one person working a 37-hour week. They also talked about the Autism Health Passport, how to obtain it, and its importance for patients and their loved ones.

There were conversations about strategic communications to clarify the role and available support, and the use of sunflower lanyards to signal the need for extra help. The third group echoed concerns about support outside of 9-5 hours and discussed the need for Autism Champions in different teams, more training, and awareness.

Questions were raised about how information added to patient records is shared with patients and the existence of an autism awareness card to avoid repeated explanations.

Answer from Martin: Reasonable adjustments are discussed with patients and documented in their electronic records. However, the current IT system lacks the capability to easily share this information across visits. While an electronic system would ensure continuity of care, it needs regular updates to reflect changing needs. A paper record can be more current but doesn't integrate well into the hospital system.

Andrew noted that health passports often need to be redone as patients may not bring them back, and the hospital environment can change the relevance of the information. Further discussions on health passports are planned.

Closing: Thank you, Martin, for your work and presentation. We look forward to hearing more from you and welcome any feedback or questions you have for us.

The Hospital Passport (Which you can find here) was discussed as a mechanism to support patients whilst undergoing treatment. This is currently aimed at those with a learning disability but could easily be adapted for autistic patients. Nicole Hastie said the Parent Carer Forum could support the development and would send some information to Martin directly. A working group to develop what works for autistic people in Gloucestershire may be a good idea. Details and/or update to follow.

There is also the National Autistic Society (NAS) autism health passport, which you can find here: https://www.autism.org.uk/advice-and-guidance/topics/physical-health/my-health-passport

Martin explained that it's the responsibility of the patient / caregiver to complete the health passport if they have one and their responsibility to update as and when their needs change. They should hand over the document to any Healthcare professional (HCP) they come into contact with (eg: nurse, consultants, dentist, optician, GP etc). It is then the responsibility of the HCP to

	take a few minutes to read it to better understand their patients' needs prior to engaging with them, in order to get the best outcome.	
	Guest Co-Chair: Dr Mala Ubhi: **Introduction** Dr. Ubhi, a GP in Cheltenham with nearly 20 years of experience as a doctor, serves as the Integrated Care Board (ICB) Clinical Lead for Learning Disabilities, Autism, Mental Health and Neurodivergence, Inequalities, and Digital. Additionally, she holds a digital role within NHS England. Dr. Ubhi brings valuable lived experience, as a parent of an autistic child with ADHD, providing her with deep insights into managing daily challenges in healthcare and education. Recently, Dr. Ubhi conducted independent research on the usability of the NHS App for autistic individuals, with the NHS App being one of the most downloaded healthcare apps in England with over 30 million downloads. Her research focused on whether the technology supports neuroinclusive and neuroaffirmative design. With the help of colleagues, she gathered significant insights through focus groups and surveys, highlighting the App's potential as an effective communication channel and the need for increased personalisation and utility.	Dr Mala Ubhi
4.	Dr. Ubhi shared the research findings both locally within the Integrated Care System (ICS) and nationally through her role in NHS England's Transformation Directorate. Her feedback reached NHS teams, design teams, and the autism team, aiming for positive changes. She emphasises the importance of understanding users' challenges with technology to optimise it for better healthcare access for autistic individuals, addressing health inequalities they face. Dr. Ubhi's strong commitment to neurodivergence stems from her personal experiences, driving her continuous efforts to improve and learn more in this field. **Context Setting – Introduction to Clinical Programme Group** The discussion today focused on changes in the Integrated Care System and board structures, and how the Autism and Neurodivergence Partnership Board can connect to these changes. The aim is to explore ways to collaborate more effectively and ensure that the voices of those with lived experience are represented at all levels without duplicating efforts. Dr. Mala Ubhi presented a slide deck. Feedback from the Mental Health and Neurodivergence, Learning Disabilities, and Autism Clinical Program Groups (CPGs) highlights the Integrated Care Board's structure of clinically led groups focused on medical specialties. One	

goal of the new All-age Board is to improve the visibility of issues, celebrate successes, and provide clearer strategic direction.

To achieve this, the new all-age Mental Health and Neurodivergence, Learning Disabilities and Autism Board has been formed, bringing together representation from stakeholders from these Clinical Programme Groups with Executives across the System for discussions.

In January, over 40 people from Gloucestershire MH and ND, LD and A stakeholders, including Gloucester Health and Care, the County Council, and the Integrated Care Board met at Gloucester Guildhall. Attendees included Experts by Experience, the VCSE (voluntary and community sector) and members of the Quality Service Improvement Team, who facilitated a workshop focused on feedback regarding the new board structure and governance. Shared values, common purpose, and opportunities for delivering change were discussed, identifying several main themes.

The structure discussed includes four horizontal layers. The fourth layer comprises the Clinical Programme Group (CPG) for Learning Disabilities and Autism (an all-age group), the CPG for adult Mental Health (expanded to include Neurodivergence), and the Programme Board for Children and Young People's Mental Health (expanded to include Neurodivergence). The SEND board remains unchanged. All Clinical Programme Groups report to the Clinical Program Board (CPB), which will continue to communicate with the new All-age Board for Mental Health, Neurodivergence, and Learning Disabilities.

This new board aims to unite across all ages, mental health, learning disabilities, and neurodivergence, addressing common risks, processes and elevating objectives. The board will focus on strategy, ensuring outputs and directives from NHS England are tailored to the needs of mental health, neurodivergence, and learning disabilities. The chair is the Chief Nursing Officer, Marie Crofts, with executive representation from other providers. The board feeds into higher levels, including the Integrated Care Board Strategic Executive, the Joint Commissioning Partnership Executive, and the Health and Wellbeing Board.

Dr. Ubhi highlighted governance and structure, shared values, common purpose, collaboration, change delivery, and board expectations. Governance issues included the need for Expert by Experience representation, clear communication, and renaming the learning disability and autism CPG to reflect other neurodivergent conditions. Vicci Livingstone-Thompson, CEO of Inclusion Gloucestershire, and Matt Leonard, representing the voluntary and community sector, were noted as key representatives.

Shared values emphasised integrity, collaboration, equity, inclusion, action, change, trust, and kindness. The common purpose focused on improving healthcare journeys, reducing inequalities, accountability, and a person-centred approach. Collaboration and change delivery involved strengthening links for innovation, encouraging co-production, and ensuring transparency. The board

aims for clear leadership, accountability, prioritisation, and transparent resource allocation.

Dr. Ubhi summarised the discussions, noting the importance of expertise filtering through to the board and a truly collaborative approach. Expectations from the board include clear leadership, accountability, prioritisation, and transparent resource allocation, addressing the challenge of disseminating information across the system.

Question & Answers Sessions

AC: Could you mention the work done with the LD and autism clinical program group and the overlaps with this partnership board?

Dr. Ubhi: Yes, there's significant overlap, which can validate our focus on the same issues and provide extra evidence. However, overlap can sometimes lead to duplication of work or addressing issues in the wrong place. The Learning Disability and Autism Clinical Programme Group have previously discussed whether we were meeting the needs of people with Learning Disabilities and those of autistic people effectively. Initially, it is understood that the origins of the CPG was focused solely on Learning Disabilities, but it expanded to include autism, mainly reflecting those with both conditions. Stakeholders expressed that there could be a gap in advocating for autistic people without learning disabilities. This led to broadening the mental health groups to include neurodivergence. NHS England now has a clinical director for

mental health and neurodivergence, recognising the need to address autistic individuals without learning disabilities. We're trailblazing in renaming the Clinical Programme Groups and considering autistic people with ADHD and other conditions separately. It's important to keep discussing and iterating our approach, involving the right people, and being open to change. NHS England is undergoing changes, adding to the uncertainty, but we aim to adapt pragmatically and be informed by experts.

NH: Is there a place for a standing agenda item for direct feedback from the partnership board SILAP (Send Inclusion Local Area Partnership), similar to the parent carer feedback in the local integrated special educational needs partnership?

Dr Ubhi: I agree. Andrew and I have discussed this. Andrew, chair of the Autism Partnership Board, and Jan Marriott, chair of the Mental Health and Wellbeing Partnership Board, are stakeholders of the clinical program groups. I've asked Marie Crofts, the chief nurse, to invite them to the board, and she agreed. Vicci from Inclusion Gloucestershire suggested representation from the Collaborative Partnership Board at the all-age mental health learning disabilities neurodivergence board, but it's complex due to funding and structure issues. I believe we need to ensure direct feedback links from the Partnership Boards. (NB The Clinical Programme Groups for MH and ND have

since included updates from both Jan and Andrew in the latest board meeting this March).

NH: There's a big difference between being at the board and having time to speak. SILAP had to push for its agenda item to be prioritised, ensuring clarity of voice from those with lived experience.

AC: Mala has been a strong advocate for crossing between partnership boards.

KG: I agree with Mala's point about "autism only" being unhelpful. It can diminish the needs of autistic people without learning disabilities. We should change this narrative locally before it becomes entrenched.

JJ: Thank you, Mala. I appreciate your openness. My point relates to language, and I agree with Karl. I was invited to an "autism only" event and wondered if it was for me. My question is about combining neurodivergence and mental health. Does the program board view neurodivergent people as mentally ill, or recognise that ableism and barriers cause mental illness?

Dr Ubhi: I understand this question and on a personal level wonder why neurodivergence and mental health is combined together in so many forums across the health service. My lived experience has led me to understand that an authentic identity as a neurodivergent person does not automatically link in with mental health. It incorrect to think all neurodivergent people are mentally unwell. Statistically, autistic people are more likely to have certain co-occurring mental health conditions, such as anxiety for example. Combining neurodivergence and mental health them is partly due to policy and service provision. Neurodivergent services in Gloucestershire tend to sit under psychiatry. We recognised that while autistic people may access mental health services, it doesn't encompass their entire experience nor identity. The combination reflects process directives from NHS England and commissioned services, not the belief that all neurodivergent people have a mental illness.

JJ: That makes a lot of sense. Thank you. There's tension but being honest and open helps. These discussions are beneficial and can change how we engage with the work. I appreciate it.

MD: My role is funded for formal autism diagnosis, but in the Southwest, autism roles are often combined with learning disability liaison nurses. Gloucestershire stands out for having a standalone autism liaison role. Most autistic patients have multiple layers of complexity, including learning disabilities, mental health issues, and trauma. Separating roles helps develop a more person-centred approach, understanding and hearing individuals better.

LR: Adding to Josh's point and Mala's response, the 0-25 Mental Health and Neurodiversity Program Board had good education buy-in, which led to broader conversations on neurodiversity. While combining neurodivergence and mental health seemed sensible, it's important to recognise when things aren't working

	and be open to change. Structures don't have to remain the same if they aren't effective. **Dr Ubhi:** Neurodivergence is a state of being, not an illness. Autistic people can maintain health and wellbeing but commonly lack of reasonable adjustments and adverse environments contribute to ill health. Good communication, empathy, and acceptance can create neuro-inclusive environments. Current structures may not allow for nuanced thinking, but there are individuals in Gloucestershire advocating for the right changes. While we haven't got it perfect, we have people with insight working on these issues. **ZN:** As someone diagnosed late with autism and ADHD, I resonate with Mala's points. Navigating the process privately was challenging, and mental health issues are secondary. There's a lack of clinical support before, during, and after diagnosis, which is a UK-wide issue. Without support, neurodivergent individuals can go into crisis, impacting available resources. Misdiagnosed with depression and anxiety, I see the need for change. Support for professionals and better diagnosis processes are crucial. This requires thinking outside the box and utilising available resources. **Dr Ubhi:** Reasonable adjustments for people with differences or disabilities often take longer to put into place than providing services for people without requirements for Reasonable Adjustments and are therefore often deprioritised because these adjustments may feel harder to enact. Life as a carer is different, and many tasks take longer. NHS services must legally make reasonable adjustments under the Equality Act, but this isn't always built into service provision. It's a complex issue, but it's essential to prioritize these adjustments. **ZN:** We should discuss what provisions are available and how to make effective changes within existing resources. Many people would support this effort to improve support systems. **JM** comments from the chat: Interestingly in Stroud Neurodiverse universe - they are saying that some things like attachment or schizophrenia is a neurodivergence. Some mental health conditions are a temporary illness that can be "fixed" others are just a long-term state of being. I think there are some common issues around reasonable adjustments, advocacy, appropriate social care support, breaking down stigma. Jacky also added that some people with bi-polar see it as their "superpower"	
5.	**Breakout Room Discussions:** **How do we work collaboratively between the Clinical Programme & the Partnership Board?**	

	How can we ensure that experts by experience are adequately represented and have a meaningful voice? **How can we enhance communication and transparency in our Board processes to ensure all stakeholders are informed and engaged?** **Dr Ubhi** was first to feedback to the group and she expressed gratitude for the group's honesty and transparency, noting the authenticity in the autism partnership board's discussions. The group talked about supports for those with lived experience through parent carer forums like CASA, suggesting that Andrew could help access these groups for feedback and sense-checking. They discussed the difficulties and journeys of pre-diagnostic and post-diagnostic support, questioning its accessibility and resources. Dr Ubhi emphasised the need for cultural change to better meet the needs of neurodivergent individuals and their families, reflecting on the complexity and sometimes overwhelming nature of these challenges. They also highlighted the importance of using lived experience voices and expertise at the ICB level to find solutions. Noor and Leah had a productive conversation in another breakout room. They discussed reviving the feedback loop, referencing a previous impactful discussion on the Autistic SPACE framework (Docherty et al) presented by Dr Ubhi. While the VCS has adopted the framework, some clinical staff are still unaware of it. They questioned its sector-wide implementation and noted the feedback loop's absence. They emphasised informing experts by experience about the outcomes of their contributions and explored creative ways to capture expert preferences, such as through arts. They also suggested reconnecting with Nicole. Leah added that they discussed broader methods to gather feedback, considering focus sessions or specific groups to ensure more voices are heard beyond the partnership board. Lastly, Andrew commented on the importance of clear communication between the clinical program group and the partnership board, emphasising the involvement of lived experience in shaping services. He noted that messages improving interaction with services could be disseminated through various networks. Andrew thanked Dr Ubhi and everyone for their contributions and assured that the conversation would continue, with communications maintained between partnership boards and clinical program groups as they develop. Dr Ubhi expressed gratitude for being included and appreciated everyone's honest insights.	
6.	**Other Business:** Neurodiversity Celebration Week is from the17th to the 23rd of March.	

Mar Plowman from Active Impact invited members of the board to Active Impact's Neurodiversity Celebration Week Reception which will be kicking off this year's Neurodiversity Celebration Week. She went on to explain that the event will take place on Monday, March 17th from 10.30am to 12.30pm at the Council Chambers in Shire Hall, Gloucester. This is a fantastic opportunity to discover some of the incredible work being done to support neurodiversity and inclusion. It's also a great chance to connect with others who share your passion for neurodiversity and to have meaningful conversations about how we can all work together to make a positive impact.

Whether you are involved in neurodiversity initiatives or just interested in learning more, we'd love to have you join us and of course, there will be tea, coffee and plenty of good conversation.
We really hope to see you there and look forward to celebrating your neurodiversity together.

Andrew added that's its Autism Acceptance Day on the 2nd of April 2025 dedicated to fostering understanding and acceptance of autistic individuals. The whole of April is indeed recognised as Autism Acceptance Month.

Abbas explained that through engagement with unpaid carers across Gloucestershire, the adult social care website has been revised. Abbas encourages everyone to visit the site, check its navigation and accessibility, and complete a short six-question feedback form.

This input is crucial to improve the site for everyone. In the past, accessing and understanding this information at crisis points has been challenging, and delaying service access. Feedback is needed directly to the team for continual improvement. Initially, the focus has been on the older person's cohort, but more service areas will be covered in due course.

Besides providing feedback, Abbas asks everyone to share the link with their networks, especially unpaid carers networks, as their trusted voices will help ensure the information is accessible and easy to navigate.

Information, Advice & Guidance (IAG) - Professionals & VCSE Partners/Organisations - https://forms.office.com/e/qK3316kycN

Information, Advice & Guidance IAG - Carers Feedback - https://forms.office.com/e/mf0BE9SQpT

The surveys close on the 30th April, 2025.

Please contact Abbas.veshmia@gloucestershire.gov.uk if you have any questions.

Contributions for the Disability, Neurodivergence, and Mental Health in Gloucestershire Newsletter for 2025 – Spring Edition can be sent to us at any time and are always gratefully received.

	Please email them to the following email address: neurodiversity@gloucestershire.gov.uk. **We hope to send out the newsletter and publish on the Council's website week of 19th May.**	
7.	**Meeting Closes:** • **Next Meeting:** Tuesday 3rd June 2025 (online)	

Action	Responsibility	Deadline	Notes
Share relevant information between Children's and Adults' services to address overlapping challenges.	Partnership Board Members	Ongoing	Ensure better collaboration and sharing of resources across age groups.
Include transitional support and Care Act Assessments in future discussions.	Principal Social Worker and Children's Team	Future Partnership Board Meeting	Explore opportunities for collaboration and practical resources for transitions.
Share resources related to sensory needs beyond diagnoses in the newsletter.	All Partnership Board Members	Before next newsletter publication	Focus on inclusivity by addressing sensory needs for all individuals, diagnosed or not.
Submit items and feedback for the next newsletter.	All Partnership Board Members	Before the next publication	Provide relevant content and comments to improve the newsletter's reach and quality.
Explore opportunities to connect Principal Social Worker Jo Sutherland with key stakeholders.	Autism Partnership Board Chair/Relevant Members	Ongoing	Facilitate discussions on topics like transitions, assessments, and support services.
Gather and share feedback from the Neurodiversity Network Reception.	Active Impact & Organisers of the Diversity Network Conference	After the conference	Use feedback to shape future events and initiatives.
Create/update a good standard passport to include guidance.	Chair Pippa Baker-Walsh Nicole Hastie Dr Mala Ubhi	Ongoing	Need to improve and update usage within the system

*Please not that for transparency and accountability information held on behalf of a public authority should be treated as information held by that public authority and may be subject to the Freedom of Information Act.