Gloucestershire's Physical Disability & Sensory Impairment Partnership Board

Tuesday 09th April 2024

Attendees:
- Jan Marriott – Co-chair
- Katie Peacock – Co-Chair
- Louise Matthews – Commissioning Officer, GCC
- Dave Evans – Independent/Inclusion Gloucestershire/Co-Chair Neurology Subgroup
- Megan Paul – You're Welcome Gloucestershire
- Emily Luckham – Inclusion Gloucestershire
- Paul Tyrrell – Inclusion Gloucestershire
- Vicci Livingstone-Thompson – Inclusion Gloucestershire
- Julie Reader-Sullivan – CEO, Headway Gloucestershire
- Linda Hending – ME/CFS Friendship Group
- Jean Waters – Chair of the Neurology Clinical Programme Group, Gloucestershire ICB
- Danielle Neale – CEO of the Gloucestershire Deaf Association (GDA)
- Lisa Carr - Programme Manager for Personalised Care, NHS Gloucestershire
- Anna Peacock – Barnwood Trust
- Jacky Martell (for part of the meeting) – Access Social Care
- Jo Scriven – ME/CFS Friendship Group
- John Lane – Healthwatch/ ME/CFS Friendship Group
- Lorna Carter – Gloucestershire Carer's Hub
- Cathy Andrews – Orchard Trust
- Karl Gluck – Commissioning GCC/NHS Gloucestershire
- Nikki Smith - Adult Social Care Operations, GCC
- Christian Drewitt – Founder of Accessible Gloucestershire
- Tasha Everall - Business Manager, Accessible Gloucestershire
- Magda Ede – GCC Quality Team
- Nicola Shilton – GHC – Partnerships Team, Inclusion Lead

Apologies:
- Rachel Ephgrave – ME/CFS Friendship Group
- Lewis Koprowski - Headway Gloucestershire
- Ann Lightfoot - Gloucestershire Sight Loss Council
- Ali Hendley – Parkinsons UK
- Jacky Martel (arriving late)

No	Item	Actions
1)	**Welcome, Introductions and Apologies** Jan introduced everyone. Katie went through the apologies.	
2)	**Health and Social Care Update (Karl Gluck)** Karl explained that Gloucestershire County Council (GCC) will be inspected from an Adult Social Care perspective by the Care Quality Commission (CQC). He said they had a dry run last year and lots of actions came out of that, particularly in relation to integrated services for Mental Health. These actions are being progressed. There is a tentative window for when GCC will be inspected. They know how long they will have to be prepared and plans are in place for how they will respond, both from a commissioning and operations perspective. GCC need to be clear on how Experts by Experience are included within that process; the CQC will want to speak to people who are using, or have used, services from the local authority. They will also want to speak to the front-line staff and managers. Karl said the CQC will be less interested in talking to people like him and more interested in people who use the services. GCC don't have a firm date, but it will be happening in the next 6 months.	

Nikki Smith added GCC have been given notice by the CQC that they will be inspecting us. They have not set a definite date yet, but we will be inspected in the next 6 months. GCC will receive further notification of timeframe in due course. Gloucestershire is the first local authority in the South West to receive this notice.

Karl explained that over the coming year the system will be involved in a big piece of work called 'Right Care, Right Person', which will be changing how the police respond to vulnerable adults.

Karl said there is an assumption that the programme is a Mental Health programme as there is lot of things in there that would give you reason to think that such as people going missing from psychiatric units…it's all age and covers people with different vulnerabilities. A big part of that will be about welfare checks for individuals. There will be a part about getting people to hospital.

Karl asked if this was something the board would like to hear more about.

Katie said: Absolutely, it's something we would like to continue to be involved in as it develops.

Lisa Carr explained that NHS England have produced a proactive care framework. They will be working with GP practices, looking at a digital tool to identify vulnerable people and reach out to people to help identify 'what matters to you'. People will then be able to coproduce care plans around their needs, wishes, preferences and strengths. GP's will be able to signpost to 'place-based' activities (social prescribing), or use supported self-management tools (peer coaching). At the moment, we have a digital hope programme. There is lots of work going on that is an interdependency with what the board is doing. Lisa has been co-designing a personalised care and support plan that people would like to use as a tool for sharing their information.

Katie said this was a good development.

Nicola Shilton asked Lisa for clarification – is there work happening to connect GP's and other healthcare providers?

Lisa's reply: The scope of the work is around looking at what would be called 'integrated neighbourhood teams', working with all healthcare providers and our voluntary community sector to come together in a particular place. There is a couple of workstreams associated with this: a digital tool, a holistic assessment tool, then a product of a personalised care and support plan. It's about coming together to share and cross fertilise information. There is an element for commissioners to look at how contracts are changing. The promise is to improve how we share information, improving our digital systems and, importantly, that health professionals all use the same terminology, asking people 'what matters to you'. We are all experts of our own bodies. Its about a different language and a change in culture. We also need to upskill our wider population to have a 'what matters' conversation.

	Jean asked how individuals can access the programme, as there are many vulnerable people who rarely, if ever, see a health professional. How are you going to disseminate that information and tell people? Lisa's reply: At the moment there is a scoping exercise where NHS England are working with partners and we're going through what is called a 'Human Centred System Approach'. A 4-stage approach – discover, define, develop, deliver. Part of that work is identifying the key stakeholders that will be part of the project. Gloucestershire is represented by the North and South Gloucestershire Primary Care Networks (PCN's). Jean said it was very difficult for many to get GP appointments and people feel what they are living with is not acute enough to contact their GP. There are going to be a lot of people isolated – what are we going to do to make it wider, so people know there is a system that they can engage with. Lisa said: Each GP or PCN has a patient participation group that you can register with. The PCN's want to reach out to anyone who is interested in getting involved. There is lots of work going on around the new roles that are being created, such as social prescribers, link workers, health and wellbeing coordinators and care coordinators. She is conscious of the agenda to get through – and this could be a whole agenda item where we could perhaps invite people, to a future meeting, who are closer to this work. Katie said that was a good suggestion. Jan said for people who just get on with their lives with all their problems and difficulties, but don't access the GP's, how can these people become classed as vulnerable in your discovery phase? Jean said the important issue is that the unmet need is getting bigger. The plan needs to think outside the box in how to address this unmet need.	Lisa Carr to suggest who might attend the board to talk more about the 'Human Centred System Approach', the new healthcare roles being created and how vulnerable people, who do not have much contact with their GP, will be recognised as vulnerable.
3)	**Neurology sub group (Dave Evans)** Dave said: The group has been meeting and progressing. The group has looked at its terms of reference to try and bring as wider group of organisations and people with lived experience together, so they can start identifying common ground. Karl took the Terms of Reference off to explore with other subgroups, to get a measure of consistency and to check we are trying to achieve similar things. It's important we have a clear idea of where the work of this subgroup and other Partnership Boards is feeding into, so we can evidence we are influencing outcomes, and it is not just a 'tick box' exercise. At the last meeting we had a range of different people participating and organisations represented. We are widening the net, slowly but surely. Communication and networking is at the heart of what we are trying to do. We are looking at the idea of developing 'video projects', with snapshots of different neurological conditions and the impact on lives, not just from clinical	

	perspective but a lived perspective. This project is taking shape. We will be looking to keep this group going and look at how we can cross over with other groups and get support where necessary. How we build those links is important and to enable people with the lived experience to be part of those conversations. Lorna Carter explained she is part of her GP's patient participation group and they have been talking about how they can improve representation. They would be happy to come along and explain the role of the group in a future meeting.	
4)	**Our survey** Katie said: when we last met we talked about coming up with priorities for the group moving forward. Katie explained that we want to develop a clear strategy for the board, having three clear priorities to focus on. Katie said we can talk to people over the phone or on MS Teams if they don't want to fill in a form. We will be asking people to choose their top 3 priorities from a list. Katie listed the priority topics: • Access to dental treatment • Access to social care • Advocacy • Benefits • Cancer screening • Employment • A holistic approach • Hospital care • Housing (including care homes and supported living) • Rehabilitation services • Social connections • Addressing Loneliness • Mental Health • Transport There is also an opportunity for people to add any topics they think we have missed. There is an optional question about a person's lived experience. John mentioned Barnwood Trust's work around employment. This is a very active project, working with local employers to improve how they recruit disabled people. John said it would be good if this board could collate all the work that is going on. Katie said: this is a top-level overview, trying to focus down on people's priorities. Katie acknowledged it is important work is not duplicated and that we are working together.	

	Jan said: We did once have a strategy for the PDSI, but we haven't had one for quite a long time. It is important we are not just a talking shop. Karl said one of his tasks in the next year is looking to see if we can develop a strategy. We might want something that is all encompassing, aligned to the local integrated care strategy and the four pillars underneath this. Katie said that would be wonderful. Julie asked about how widely we want the survey to go? Katie said: As far and wide as possible to get as much representation. We want it to encompass as many different people, with as many different impairments as possible. The survey with give us focus and steer. Emily explained who we are planning to reach out to with the survey and how: We will share it on our Facebook page. We have it in a couple of different formats; a Word document and an online form. Megan has checked it works with a screen reader, which was really helpful. We have approached GDA to see if they will do a signed version for us, which will be great. We are hoping to share the survey with: Care providers (through the provider forum and the provider forum newsletter), Headway, Leonard Cheshire and the Gloucestershire Carers Hub We are open to ideas of where or who else we can share the survey with. We want to get lots of feedback as we are just asking one question about priorities. Julie said that was helpful and asked if it would be helpful for Headway to collate their responses or do it as a workshop? Katie said if Headway are happy to do a workshop and collate the responses that would be amazing. We are open to whichever way is most accessible for people to contribute. Paul said he can coordinate the collating of the responses from various organisations and the distribution.	
5)	**Our in-person meeting – 17th June 12 – 2pm** Katie said: • We thought it would be good to get together once a year. • We are thinking about meeting at the Gloucestershire Deaf Association. • Katie wanted to ask people what they wanted to achieve at the meeting and about any access requirements? • Emily said, as we will have lots of feedback by then, we can start working on the priorities for the board, as in person it might be easier. • The face-to-face meeting would be instead of the online meeting on the 11th June 2024. People who can't attend would be able to email and let us know.	

- Katie mentioned the possibility of a hybrid meeting. Emily said that sometimes hybrid meetings can be challenging. Perhaps we could do an online summary for those unable to attend after the in person event, so they are still involved.

6) **Informal Advocacy - a presentation by Dave Evans**

Dave gave a brief background to Inclusion Gloucestershire. The advocacy project is called Nothing About Us Without Us and it has four different strands, but all with the same focus.

1. **One to one peer advocacy**, which is non statutory support. It is there to try and work alongside people who may need that little bit of extra help identifying what issues they are having and how we can support them to in getting their own opinions across. It is delivered by people with lived experience, who have an awareness of the individual's situation. We follow the national outline for advocacy. This follows the person's message, making sure they are speaking their own words and make sure they are listed too by the right organisations. The referral can be made by a professional or people can self-refer. Our mentors can offer support, or we can or talk with people and help them prepare what they want to say, giving them the skills and confidence to be able to say it.

2. **Speak Up groups (group advocacy):** This is where we bring people together. We are trying to get this more formalised. We are looking at doing two different strands of work. An open access virtual meeting, where people can find out information and share their experiences, and also where we can work with other organisations to facilitate a more focused groups. For example, we have run a speak up group at a Leonard Cheshire home.

3. **Drama Groups:** Inclusion Gloucestershire has been doing drama for a few years. We are looking to develop this, so it not just about regular engagement opportunities, but it is using drama to raise awareness of advocacy. We have developed several drama videos around advocacy, including the PIP process and GP assessments. It is another way we share advocacy knowledge with people.

4. **Volunteering Opportunities:** We have a number of volunteers at Inclusion Gloucestershire in different roles. We are trying to promote ways that people with lived experience can be fully involved in a variety of different settings. We have a dedicated officer, Amanda Eady, who works alongside these volunteers. Volunteering helps develop people's skills and confidence.

To find out more, contact advocacy@inclusion-glos.org

Questions

John – what depth are Inclusion Gloucestershire funded for advocacy? As background, John has supported someone for 18 months as an advocate.

	Dave's reply – We have found people who needed much more longer-term support and that is why we are trying to set up a befriending group. We are looking at shorter term support, helping with a particular issue. We are a part-time team, so we have our limits. It's about giving people the opportunity to at least explore their situation, to identify a way forward (including identifying other organisations better suited to support them). We are conscious about managing expectations.	
	John said Advocacy support in the county is overwhelmed. Jacky Martel said: Access Social Care can still support people with issues around social care. Jacky is happy to come and do some more training with the advocacy team at Inclusion Gloucestershire, about where Access Social Care might be able to help. Dave said that would be fantastic. It's an example of trying to work together to get the networking right and putting limited resources in the right place at the right time. Faye (the coordinator) will follow up with Jacky about this. Jacky said we have a 'chat bot' on our website where people can follow an ordinary chain of questions, which help people to get resources to advocate for themselves. Jacky is happy to do some training about this.	Paul to connect Jacky Martel (access social care) with Faye Longley (inclusion Gloucestershire) regarding possible training for the advocacy team about how access social care can help people.
	Vicci will follow up with Jacky if she would be interested in getting the 'chat bot' on the Inclusion Gloucestershire website.	Vicci will follow up will Jacky about getting the chat bot on the Inclusion Gloucestershire website.
	Karl said he thought Dave's presentation was very good. He has a couple of questions: - Have you linked with POhWER (the statutory advocacy provider)? - Have you linked with Simon Thomason (the advocacy lead at GCC)?	
	Karl has often thought it would be good to have some sort of plan or strategy about how advocacy works in Gloucestershire – how people can advocate for themselves, through to where people cannot advocate for themselves, to try and join things together. Dave said: we have had some contact with POhWER and we recognise the need to work closer together; it's just logistics. Our offer is at the informal, community end, not the statutory end. We are looking to support groups like POhWER. Karl said we recognised the limitations when we commissioned the statutory advocacy services. The primary focus and the funding could only stretch to statutory advocacy. But we wanted built into the contract things to do with volunteering and peer support. There is potential to link up, not least with training and career pathways. Dave said its about being clear what we can provide and the limitations we face. Getting to a wide audience is in everyone's interests.	Karl to suggest that Simon Thomason (the new commissioning lead for advocacy) attends the Board.

	Emily asked if Karl was suggesting some sort of map to make it clear where people can go for certain types of advocacy? We have our limits with our funding and the capacity. We don't want to get so overwhelmed we start disappointing people. Karl was thinking more about working together on things that are already in the POhWER contract. Inclusion Gloucestershire and POhWER could look at working on agreed approaches to training and quality standards. Dave said he thinks that's really important. We follow the national charter. There is a good foundation, the more we can build communication the better we can use our resources. Karl said anything Inclusion Gloucestershire are doing could be the foundations for making a business case for further investment. How long is the lottery funding? Dave said it is for 3 years. Katie said: It is excellent to hear of all the working going on. It is important this meeting provides a platform for people to talk about what is going on. Jan said would Barnwood Trust look at bringing people together involved with advocacy? Anna said she is happy to talk with Katie about this.	Anna to see if Barnwood Trust would consider facilitating a meeting of all the different organisations that play a role in advocacy.
7)	**Any Other Business/Outstanding Actions** Outstanding actions: Emily to speak to Simon Shorrick about getting some social prescribers' information to make sure we circulated the information about You're Welcome. Emily did that. She got the details for some of the regional social prescribers, and I have had confirmation they have shared this resource with the different social prescribing teams. Paul T – AOB: Is Personalised Care work explained by Lisa currently linked with the work Karl talked about ('Right Care, Right Person') Lisa said she will contact Karl. Lisa said to the group she would like to join up the work. John (AOB): Healthwatch Gloucestershire is now under a different parent company. Day to day operations of Healthwatch will not change, but you will see some changes in the software we use. In John's other role, he is working closely with Lisa Carr on developing the ME/CFS elements to the Orange folder. This is progressing well. This came about as a result of the PDSI board. They are working with Debbie Grey on the implementation of the NICE guidelines on ME/CFS. They are coproducing a report, which we hope to publish in May. John is very much for this group. Jacky Martel told us about the consultation on the charging contribution policy in social care, which is in response to the Norfolk judgement, which said they were trying to make an unfair policy that did not take account of the fact that some people were unable to work. Policies charge the maximum that they can	.

because they don't take into account earned income, which means if you are unable to work, you are left with a low amount of money. About 1/3 of benefits will be charged if you don't have any disability related expenditure in Gloucestershire. They have been pushing for a review. Access social care are running two sessions about this. Jackie is running two webinars: 19th April AM and the 24th April PM.

Link about the consultation shared by Lorna Carter in the chat:
Adult Social Care: Fairer Contributions Policy Consultation - Online Information session (govdelivery.com)

Access Social Care are trying hard to get the word out, as this is very important. Hopefully this will increase the money people are left with.

Dave said: I am so disappointed that there is no one from the charity (Leonard cheshire) here today because this is a crucial network and measures like that run the risk of not getting through.

Jacky said: It doesn't apply to those with a residential placement; it's concerning a non-residential placement.

Paul T said: People don't always know what counts as disability related expenditure.

Jacky M said: There are a lot of issues. Gloucestershire does not tell people about disability related expenditure or has a list about what can/can't be included, but it has to be discretionary, as for one person something might be disability related, but for another it is just a fun thing to have. Access Social Care has helped people to challenge their charging and recently had a success through the ombudsman. GCC are pursuing people with charging debts – the biggest group of people are adults with a Learning Disabilities living at home. The system is more unfair for some people than others. There is lots of disparity in the system. Jacky is happy to talk to people and help them understand disability related expenditure.

Gloucestershire County Council is inviting people to find out more about proposed changes to its adult social care fairer contributions policy at an online information event on Tuesday 16 April from 6.15pm to 7pm (via MS Teams).

Register your place here: Adult Social Care Fairer Contribution Policy Consultation Information Event Tickets, Tue, Apr 16, 2024 at 6:15 PM | Eventbrite

Attendees are advised to read the consultation booklet beforehand so that they can submit any questions they may have about it ahead of the session. Questions should be emailed to: ASC.consultation@gloucestershire.gov.uk

Katie (AOB) told people about the Facebook page and asked people to check it out. We are looking at the best ways to engage with people.

	Plug for the Big Health Day – 14th Friday June. Lorna kindly shared a poster that is attached to these minutes.	
8) `	**Summary of actions arising** - Lisa Carr to suggest who might attend the board to talk more about the 'Human Centred System Approach', the new healthcare roles being created and how vulnerable people, who do not have much contact with their GP, will be recognised as vulnerable. - Paul to connect Jacky Martel (access social care) with Faye Longley (inclusion Gloucestershire) regarding possible training for the advocacy team about how access social care can help people. - Vicci will follow up will Jacky about getting the chat bot on the Inclusion Gloucestershire website. - Karl to suggest that Simon Thomason (the new commissioning lead for advocacy) attends the Board. - Anna to see if Barnwood Trust would consider facilitating a meeting of all the different organisations that play a role in advocacy.	
	Next Meeting: **In person – Monday 17th June 12 – 2pm** **Venue details:** **Main Hall, Gloucestershire Deaf Association,** **Colin Road, Barnwood, Gloucester, GL4 3JL**	

Acronyms you may come across in our Minutes/Agendas

ASC – Adult Social Care
BBTL – Building Better Transport Links Group
CMT - Charcot Marie Tooth
CPG - Clinical Programme Group
EoL – End of Life
GHFT - Gloucestershire Hospitals Foundation Trust
GHCFT - Gloucestershire Health and Care NHS Foundation Trust
HD/HDA – Huntington's Disease/Association
H&SC – Health & Social Care
ICB – Integrated Care Board
ICS – Integrated Care Services
KPIs – Key Performance Indicators
LA – Local Authority
ME/CFS - Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
MND – Motor Neurone Disease
PBs – Partnership Boards
PDSI PB/PB – Physical Disabilities & Sensory Impairment Partnership Board
PCN – Primary Care Network
VI – Visual Impairment