

Gloucestershire's Physical Disability & Sensory Impairment Partnership Board

Monday 17th June 2024

Attendees:

- Jan Marriott – Co-chair
- Katie Peacock – Co-chair
- Louise Matthews – Commissioning Officer, GCC
- Paul Tyrrell – Inclusion Gloucestershire
- Paul Hepworth – Inclusion Gloucestershire
- Danielle Neale – CEO of the Gloucestershire Deaf Association (GDA)
- Dave Evans – Independent/Inclusion Gloucestershire/Co-Chair Neurology Subgroup
- Anna Peacock – Barnwood Trust
- Pete Wiggins - ME/CFS Friendship Group
- Jane Henderson – Parkinsons UK
- Nadine Blewitt, Commissioning Officer, GCC
- John Lane – Healthwatch/ ME/CFS Friendship Group
- Lewis Koprowski - Headway Gloucestershire
- Christian Drewitt – Founder of Accessible Gloucestershire
- Tasha Everall - Business Manager, Accessible Gloucestershire
- Magda Ede – GCC Quality Team
- Nicola Shilton – GHC – Partnerships Team, Inclusion Lead
- Glenda Prall – Sight Support West of England
- Jennie Goodrum – Training Development Coordinator, Active Impact
- Josaphine, Jennie's PA

Apologies:

- Linda Hending - ME/CFS Friendship Group
- Rachel Ephgrave – ME/CFS Friendship Group

- Emma Shibli – GCC
- Jacky Martel – Access Social Care
- Cathy Andrews – Orchard Trust

No	Item	Actions
1)	<p>Welcome, Introductions and Apologies</p> <p>Katie introduced the meeting and invited everyone to introduce themselves. No additional apologies given.</p> <p>It was noted the board met online the previous week for those unable to attend in person.</p>	
2)	<p>Neurology Sub-group Update (Dave Evans)</p> <p>Dave shared the work being undertaken and integrated care board links being built. This work includes people with acquired injuries, meningitis, intermittent illnesses including epilepsy and ongoing progressive conditions.</p> <p>Dave explained there are a wide range of neurological issues but many common things that bring them together. It is this common ground where the board is seeking to work on a common approach. Diagnosis is a key issue and working with ICB on this is a core aim.</p> <p>John: the ME friendship group have been working with an ICB task and finish group to implement ME NICE guidelines. Positive outcomes have been achieved as a result of collaborative working, bringing the real issues to light.</p>	

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	<p>Thank you to the NHS and social care for their involvement in getting Expert by Experience message across by sharing the impact on people's lives. Working as a collective group, gaps in understanding are being bridged to achieve improvements and involvement.</p> <p>Dave: speaking with the local council officers, the NHS and social care has improved communication and provided a shared understanding of the issues facing those with these illnesses. Online and face to face meetings have provided the communication mechanisms to enable change. The PD&SI Partnership Board have a crucial role in bringing the right people to the table.</p> <p>John explained that his online meetings attracted 200 members before COVID-19, but now, post COVID there are 740 members.</p> <p>The community neurological service presented to us and many illnesses (such as ME for example) were excluded from the service. A forceful letter was written in response to challenge this. There is no support for these illnesses unless other co-morbidities attract support.</p> <p>Neurological issues such as ME, FND are sometimes used as a catchall, to explain certain symptoms. But there is the risk of diagnostic overshadowing, which may hide other conditions.</p> <p>Katie: The Neurology Group is so important and needs to remain accessible.</p>	
3)	<p>Our survey – what we have found out so far (Katie Peacock and Jan Marriot)</p> <p>Paul T: Shared the background to the survey, explaining that we had asked people to choose their priority topics. As well as the online survey, the people who came to our online meeting also voted on these.</p> <p>Paul shared some of the things that people felt Gloucestershire do well, which was captured as part of the survey:</p> <ul style="list-style-type: none"> • Gloucester Pride • Our Partnership Boards and Subgroups • Stroke Care • Feedback through Healthwatch <p>There has been a broad range of issues raised in the survey including:</p> <ul style="list-style-type: none"> • The need for more disabled parking • Medical care at home • The criteria for getting, particularly a powered wheelchair <p>Katie shared the list of priorities.</p> <p>Jan: We now have an opportunity to have table level discussions. Jan posed the question: What should the group do over the next years?</p>	

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	<p>Jan also reflected the difficulty in engaging people with sensory impairments. For example, the board has achieved very little engagement with deaf people to date.</p>	
4)	<p>Your priorities – discussion and vote.</p> <p>Discussions about the priorities were had on each table. A representative from each table then relayed the contents of each discussion back to the wider meeting.</p> <p>During the group discussion, Paul T identified that although topics were important in isolation many needed to be considered in conjunction with related issues, from a strategic perspective</p> <p>Jan mentioned the meeting next week to discuss the best way of accessing the views of Experts by Experience. She posed the question about whether or not Experts by Experience should be paid for their time. It was acknowledged some people don't wish to be paid and are happy to give their time on a voluntary basis.</p> <p><u>Note:</u> the following are attached to these minutes:</p> <ol style="list-style-type: none"> 1. Charts showing the number of votes for each priority. 2. A table of the top three priorities mapped against some of the things people said. The comments are taken from both this meeting and those made in the online survey. 	
	<p>The CQC inspection of GCC (Jan Marriot)</p> <p>Jan mentioned Cheryl's presentation about the CQC inspection of GCC at the online meeting. Cheryl is looking for board representatives to share their experiences with the CQC. Please let Paul Tyrrell know if you would like to be involved, using the Inclusion Gloucestershire Partnership Boards email address: partnershipboards@inclusion-glos.org</p> <p>Jan mentioned GCC are keen to make the process accessible, working with people to overcome access issues.</p> <p>Jan reflected it might be good for people to attend who have applied for social care funding, but not received social care support.</p> <p>Dave Evans raised the issue of receiving social care in Gloucestershire but being funded from elsewhere. It appears unfair not to have a voice simply based upon where someone's funding comes from. Jan suggested that it was still relevant to be involved.</p>	

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5)	Outstanding Actions None discussed in addition to those noted at the online meeting.	
	Next Meeting: Online: Tuesday 13th August 11 – 12:30	

Please note 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.

Acronyms you may come across in our Minutes/Agendas

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