



Partnership Boards; Learning Disability

13<sup>th</sup> December 2018 – Minutes

**In attendance:**

Jan Marriott – LDPB Co Chair	Caitlin Rose – Inclusion Gloucestershire
Tim Heaven – LDPB Co Chair/Inclusion	Andrea Frost – Inclusion Gloucestershire
Eva Fielding – Gloucestershire County Council	Anna Hansell – POhWER
Laurie-Ann Cook – Gloucestershire County Council	Jane Field - Gloucestershire County Council
Farooq Ismail – 2Gether NHS	Janet Hawkins – Inclusion Gloucestershire
Jacky Martel – Carers Gloucestershire/Parent Carer	Wayne Crook – Inclusion Gloucestershire
Lucy Mellor – Gloucestershire County Council	Rachel Child – Boccia Busters
Lara Gillman – Gloucestershire County Council	Rupert Thurston – 2Gether NHS
Holly Beaman - Gloucestershire County Council	Kevin Elliott – NHS England
Neryl Bice – Gloucestershire County Council	Donna Sayer – GCCG
Bren McInerney – Board Member	Stephanie Baker – Inclusion Gloucestershire
Jamie Muley - Inclusion Gloucestershire	Yvonne Smith – Parent Carer
Billy Jenkinson - Inclusion Gloucestershire	Sue Walter – Parent Carer
Jamie Muley – Inclusion Gloucestershire	Lesley Molnar-Pleydell – Langley House Trust
Andy Rozwadowski – Building Circles	

**Jan Marriott & Tim Heaven – Welcome & Introductions**

**Holly Beaman - Lead Commissioner Update**



Holly is passionate about partnership working and was involved in originally establishing the PD&SI partnership board many years ago. She is keen to raise the profile of people with a disability and is happy to attend and provide updates at all future meetings.

Holly mentioned the **good news story of Sarah Gordy** the actor who received an honorary degree from Nottingham University. This was the first ever awarded to a person with Down Syndrome. You can read her inspiring story here: <https://www.bbc.co.uk/news/uk-england-nottinghamshire-46536375>

She recently attended the Provider Forum where she updated on **Hospital Passports** in Cheryl's absence and there were a huge amount of issues raised. It was suggested that perhaps the LDPB could work with the Provider Forum to tackle these issues.

**Bren** – *This sounds ok but it is essential that the voice of the people is still heard so that it doesn't become all about the providers.*



**Crispin** – *The biggest issue in his opinion is the withdrawal of support when a service user goes into hospital. This means that they get no visitors and are completely cut off from support!*

**Jacky Martel** - *One example of potential problems for people with LD is what happens if there is a fire in the hospital? DO they know where to go or what to do? Also frequently there are no accessible changing areas in hospitals; they only have them on certain wards. Jacky is meeting with the LD nurses to discuss these issues with the hospital trust in the new year.*

**Jane Field** – *huge inequalities in health, purple butterflies are still hardly being used. She gave an example Where a person with LD was told that they only had 6 weeks to live even though they were alone at the time with no support! It's just not good enough.*

**Jan** –*In light of how many issues there seem to be we will organise a joint forum with the acute trust and LDPB representatives to tackle these issues.*

It is approaching the time when **contracts** are being re-negotiated and we are looking to involve more people with lived experience in the commissioning process.

We will be undertaking a review of the **Quality Review** process with Inclusion Gloucestershire in the new year.

### Crispin & Holly - Berkley House Update



Berkley House is a treatment and assessment centre for people with LD and mental health or behavioural issues. The NHS Transforming Care policy requires everyone to look at the number of beds across the country to ensure that counties have an even spread of beds. Some counties had too many and some not enough, we had too many so Westridge had to close and Hollybrook became Berkley House. It was refurbished into single person accommodation with individual kitchens and ensuites. It can only house 6-7 people. It has been quite the transition for staff as some moved over from Westridge and all had to go from supporting people in a ward environment to a people in their own home virtually. Some patients moved over from Westridge too which meant that Berkley was not meeting its aim of being a transitioning establishment from the outset. They are however putting great time and effort into getting the 7 residents back out into the community. We are reviewing the whole pathway of care so that people don't just get put in hospital as there is nowhere else for them to go. These are very complicated cases so finding packages and accommodation for them is difficult but is work in progress.

Independent people have created life plans with all the service users now but there are no firm plans in place for them to leave yet.

It is a frustrating situation for the families and the staff also as they have uncertain futures.

Holly agreed that this is a great piece of work and a great environment which is possibly why it is so hard to find anywhere else suitable for the residents to go.

**Jan** – *Peoples interests come first, it's not about financial gain, and it's in the best interest of the people who live there.*



**Jacky** – Berkley House staff have done great work but where can these people go to next? Field View? A collection of bungalow apartments decorated to people’s individual tastes. But really these are just another step down institution; we need to keep up the ambition that people can live in proper homes.

**Tim** – Both places, Westridge and now Berkeley house are great and we should pass on our thanks for their good work. Crispin agreed. Partnership board to organise a thank you for Berkeley House staff.

**Bren** – Asked what CQC attention Berkeley house might be getting regarding moving people on and what is our strategic leaders’ position on this?

**Holly** – We are looking into this and the JSNA also to identify needs in Gloucester.

**Jan** – Those around a long time know that we have suffered from not having clear strategy to move people into homes in the community as soon as they can.

**Eva Fielding & Lucy Mellor - Your Circle**



Presentation on the new Your Circle website. Please see attachment to the minutes for the sheet that was handed out with the 5 key messages on it. You can check out the website here:  
<https://www.yourcircle.org.uk/>

Does the website have talk over technology? **Eva** - No.

**Jan** - Could Inclusion Hub help with this? Janet said yes and possible Building Circles. **Eva** – It can be viewed in a variety of languages.

**Jan** – Presentation is not Easy Read.

**Bren** - suggested perhaps graphic display rather than easy read might be better.

**Jacky** – Not keen on the message ‘You know how to look after your health so just get on with it’ The NHS would disagree with this statement as many people do not know how to look after their health at all. Also ‘Take Pressure off Services’ what about taking the pressure off parents and carers! The overall message of ‘If you do it yourself it will help services’ is not going to wash with many people!

**Jacky Martel - Carers Update**



**Direct Payments** – They have one carer, caring for a person with PD and they are saying that pre payment cards are being forced on people. We thought that these were supposed to be voluntary but people are being told they must use them. They are also then being told that they can only use them for certain providers which is restricting choice another thing that was not supposed to happen.

**Sue Walters** – Margaret Wilcox had said that people have to have choice but its just not happening – perhaps it is a misinterpretation. Sue has emailed about this previously. Neryl to forward that email to Holly. **Holly** – Direct Payments cards can be good for fraud detection but there should be the option if you do not want to use the cards.

**Transforming Care** – Paula French is now in post so it is good that there is more focus in this area.



**Schools** – School budgets and SEN – The media are making it sound like kids with SEN are causing schools to not have enough money for other services. They are therefore overspending on special schools rather than making reasonable adjustments so that mainstream schools can accommodate these children.

**Kevin** – *There needs to be more support for children to stay in mainstream education. The JSNA has shown that there are a high number of exclusions.*

**Crispin** – *It is difficult to separate out the LD component as they are hard to identify*

**Yvonne Smith** – *Is there any advocacy for parent carers? For example support for attending MDT meetings? They can get very heated and a lot of what they say can go over your head and you don't like to stop them to ask what they mean so this can result in you leaving the meeting more confused than when you arrived. Pohwer was suggested but no they cannot offer support this kind of situation. Perhaps an Independent Supporter could assist?*

**Jacky** – *Has a friend with PD who can't find an advocate so has had to bring forward their needs assessment as they couldn't get help from an advocate until their case had been accepted by social care.*

**Anna Hansell** – *Do let them know about gaps in the sector. They can advocate in a 'spot purchase' situation if required.*

**Crispin** – *Thanks for raising this Yvonne, its very interesting on the back of the building your own circle presentation just before. Please do challenge professionals if they say things in meetings that you don't understand.*

**Holly** – *will discuss with Yvonne in the break to see if she can suggest more support.*

**Sue** – *Also for complaints meetings at GCC there is no support available therefore sometimes parents/carers can be unsuccessful.*

**Ann Attwood** - *wanted to raise how much stress is being caused by filling in DWP claim forms. The forms are very long and difficult and therefore very stressful!*

**Jacky** – *knows some people from the DWP who could attend a future meeting.*

### Janet, Tim and Wayne - Inclusion Glos update



Inclusion Gloucestershire moves offices on 6<sup>th</sup> December to: 2 St Michaels Court, St Michaels Square, Gloucester. New phone number is 01452 234003

**Inclusion Hubs:** St Mary De Crypt are coming to our Gloucester Hub on Friday 21st December to deliver their traveling Christmas service – open to anyone who would like to come - time 11.30am to 1.30pm. We now have a core group of people attending our Stroud Hub in Stonehouse. We are continuing to promote the Hub throughout Stroud to enable the Hub to grow. If anyone knows of anyone who might be interested in finding out about the Stroud Hub or any of our other Hubs, do get in touch.

**Tewkesbury Hub:** The Hubs in Tewkesbury are now starting to take shape. Friday's, we are encouraging people from the community to engage in activities already taking place at Marina Court. On Tuesdays, the Roses Theatre has provided a free space for us to develop a user-led group that runs in a similar way to our other Inclusion Hubs. In the New Year, we aim to organise courses through Adult Education and ArtShape to bring people together both from Marina Court and the community. For more information about any of our



Hubs, please contact Janet: [janeth@inclusion-glos.org](mailto:janeth@inclusion-glos.org)

**BME:** The Friendship Hub is due to open the week commencing the 21st January, in line with the Café launch date. It will run on Wednesdays and Thursdays from 10am-12:30pm, with the option of moving on into the café to share a meal. We have appointed a project worker and an expert by experience, both of whom have lived experience of BME communities and various disabilities. They have started working on the marketing and promotional materials in a variety of different sub-Indian continent languages.

Razeya has been supporting the development of culturally sensitive policies for the safe and supportive running of the hub, and both Razeya and Ismail have been building further connections within the community to promote the hub and encourage it to be seen as a positive thing; The leaders of three community groups are willing to promote the hub – which is a massive achievement! For more information, please contact Razeya: [razeyam@inclusion-glos.org](mailto:razeyam@inclusion-glos.org)

**Bereavement Project:** They had a good response from the pilot audience and will be touring the Bereavement Forum Theatre across the county at the end of December. If you would like more information, please contact Charlene at Inclusion Gloucestershire [charleneo@inclusion-glos.org](mailto:charleneo@inclusion-glos.org)

Also, look out at the end of December on our website for a new film on Medication Management, which shows top tips for staying on top of your medication. This will be shown at the Partnership Board at a later date.

**Glos Assistants:** The Glos Assistants website has now gone live. Stephanie and Jennie are out and about in the community to promote the website and would like to encourage people to look at the website, promote it and 'like' us on Facebook. For more information, please contact Jenny or Stephanie [www.glosassistants.org.uk](http://www.glosassistants.org.uk)

*Jan – Can we get PA or PA user to come along and speak to LDPB?*

*Stephanie – Sure! Once they have started using it fully a launch will be organised featuring some champions*

*Jan – Can you use Direct Payments to pay for your PA?*

*Stephanie – Yes.*

*Jan – Can it be used for Older people also?*

*Stephanie – Yes anybody with a direct payment or their own money.*

*Jan – Rachel, do you have a PA? If so do you prefer it to an Agency?*

*Rachel – Yes I have one but I actually prefer an agency as with a PA there is no backup if they fail to show up whereas an agency would just send someone else along.*

*Stephanie – It's about choice and control.*

**Pathfinder Project:** Funding has been agreed from Gloucestershire Community Foundation for our pathfinder project developing communication alert wristbands and delivering them with appropriate training in the Barton & Tredworth area. During our work on the JSNA we discovered that there were circumstances in which vulnerable people with communication impairments had been unable to access their communication alert cards, which meant emergency services did not know if a person required additional communication support, who to contact for an appropriate adult and in some cases, people have been deemed to be resisting arrest when really they just couldn't communicate.

We have developed a prototype alert wristband that will signal to emergency services that the person in



possession of the band has additional communication needs; whether those are related to learning disabilities, physical disabilities, autism, mental ill health, or a language barrier. We are being supported in the delivery of these wristbands and in training the tri-services HQ for the same by champions across Force Response, Force Control, Neighbourhood, Ability, and the Specials/PCSOs; as well as the OPCC and Victim Support. We aim to run the project between February and May. For more information please contact Catlin: [catlin@inclusion-glos.org](mailto:catlin@inclusion-glos.org)

**Jane Field** – *These will be great for people going into hospital too, just in case they aren't using the purple butterflies.*

**MHELO:** which is our user led group for people with lived experience of Mental Health have organised a social event at our new office on the 19th December, flyers are on your tables. The event is an opportunity for people to find out about MHELO and how that might be able to get involved. For more information, please contact James: [mjamesf@inclusion-glos.org](mailto:mjamesf@inclusion-glos.org)

**Peer Mentoring project:** Wayne shared his story of being a Peer Mentor and the difference it has made to his life. His confidence has increased so much, he is participating in lots more things and he described the experience as being 'TOTALLY EPIC!'

**Jan** – *Could we have a presentation from all the mentors at a future PB?*

**Janet** – *Yes absolutely, possible March meeting.*

## **Farooq Ismail – Experts by Experience programme**

Farooq introduced us to the 15 step challenge which is a new initiative for service users to assess the service received at NHS practices. They say that you know what quality of service you will receive within 15 steps into the building.

An easy read application form is attached to the email so if you are interested in helping please complete this and return it to the address shown at the end of the email. Training in areas such as recruitment is provided if required. For more information see: <https://www.england.nhs.uk/participation/resources/15-steps-challenge/>



**Expert by Experience Programme**

**Farooq Ismail**



Are you a 2gether NHS service user?



Are you a carer of someone who has used 2gether services?



Would you like to help 2gether?



Training staff



Interviewing staff



Making services better



Helping us with studies

## 15 Steps Challenge



The 15 step challenge is what service users and carers think about services.



You could become an Expert by Experience.



Ask me for an application form today.

## Joining up with Care Services Gloucestershire



2gether NHS Foundation trust and Care Services Gloucestershire are joining. We want to talk to you about this.

## Social Inclusion Team

Social Inclusion Team  
2gether NHS  
Foundation Trust  
Ambrose House  
Units 4 & 5 Meteor  
Court  
Barnett Way  
Gloucester GL4 3GG





**Jan** – Are there expenses available for this work?

**Farooq** – Yes the expert by experience will be paid £25 for up to 4 hours work plus travel expenses

**Billy** – Wanted to know if this would affect the money he gets from the government?

**Janet** – No this amount would be fine as it's quite small.

**Kevin Elliott - NHS 10yr plan briefing**



Please see Kevin's presentation attached in pdf format. The issues with Brexit mean that this has not been formally signed off yet. The plan outlines the NHS's priorities for the next 10 years. Having this co-produced and person centred is now more important than ever. There are already 6 LD advisors with lived experience working for the NHS. Reasonable adjustments are also high on the agenda.

We need to remember that this is an NHS plan NOT a Social Care plan. It highlights the increasing focus on the community to support primary care and hospitals. LD & Autism have been specified as a top priority so there should be an improvement in services and support in these areas.

**Jan** – What would be great would be if we could come up with our own ideas e.g. Big Plan 2

**All** – General agreement

Please click on this link for further information and updates [Learning Disability England - Long Term Plan](#)

**Tim Heaven - Health Films**



Tim introduced us to the Inclusion produced Diabetes, Mental Health and Shared Lives films. They can be viewed on the LDPB website: <http://www.glosldpb.org/ldpb-blog>

We met John who is a new ambassador for Shared Lives, he has just started so can perhaps have a more formal introduction at the March meeting.

**Any other Business**

**The new bus station** – Teething issues, the first problem so far is that bus drivers have not been pulling into their prescribed bays; this can result in people catching the wrong bus so they are talking to them to try and rectify this. There was also an issue with the Accessible toilet having an internal and external door that could unfortunately open at the same time. This has now been resolved by only having the outer door unlockable



after the bus station is closed. - If anyone has any other concerns regarding the new bus station please send them to Jane Field: [Jane.Field@gloucestershire.gov.uk](mailto:Jane.Field@gloucestershire.gov.uk)

**Journey Assistance Cards** – These cards can be shown to bus drivers to get assistance if required. These can be obtained from Stagecoach and they are free. Here is the link: <https://www.stagecoachbus.com/promos-and-offers/national/journey-assistance-cards>

**Funders' course** - Rachel mentioned that Bocciabusters are holding an '**Access to Local Funders**' course that you may be interested in attending. This course is being held by a local Fund Raiser - **Rowland Clark**, who has had over 20 years valuable experience in this role. It will be held in the Multi-activity room, Leisure @ in Cheltenham, Tommy Taylor's Lane Cheltenham, GL50 4RN. 2-5pm on Tuesday 15th Jan 2019. Please book tickets at the link below to enable a place to be saved. Numbers will be limited so be quick!!

<https://www.eventbrite.co.uk/e/access-local-funding-tickets-53951174415>

They are also hosting a **Boccia Leaders course** on Saturday 16<sup>th</sup> February 2019 from 9am – 2pm in the Main sports hall, Leisure @ in Cheltenham, Tommy Taylor's Lane Cheltenham, GL50 4RN.

#### **Suggestions raised for future Meetings:**

- Shared Lives Ambassadors – Johns story
- Christian Drewitt to update on Gloucester Accessible toilet review project
- Co-produced new strategy based on NHS 10yr plan and JSNA – Big Plan 2
- Direct Payments
- Hate Crime update

#### **Next Meeting Date:**

Thursday 21<sup>st</sup> March 2019

Time: 10:30 – 1.00

Venue: Meeting Rooms 1,2,3 Shire Hall

