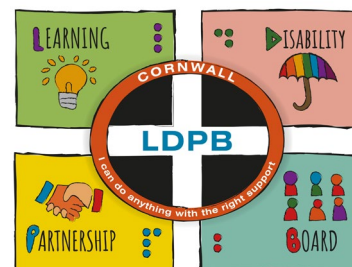


MEETING NOTES:	Meeting of the Learning Disability Partnership Board
DATE:	Thursday, 30th November 2023
LOCATION:	Truro Community Library and on Microsoft Teams

ATTENDANCE

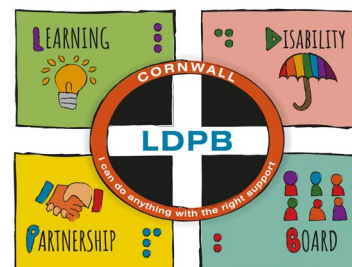
Name	Position	Organisation
Robert O'Leary (Chair) (RO)	Partnership Boards Lived Experience Officer	Healthwatch Cornwall
Mike Hooper (MH)	Partnership Boards Officer	Healthwatch Cornwall
Amanda Wilton (AW)	Parent carer of a young adult with profound and multiple LD	Patient Council Derriford UHP
Anthony Dunn (AD)	Peer Advocate and Lived Experience Lead	Citizen Checkers
Charlotte Day (CD)	Speech and Language Therapist	Cornwall Partnership NHS Foundation Trust
Charlotte Polglase (CP)	Co-Facilitator	Citizen Checkers
Christopher Jordan (CJ)	Self-advocate and Volunteer book keeper / Parish Councillor	Cornwall People First / Carn Brea Parish Council
David Burns (DB)	Self-advocate & Board Member / Partnership Boards Community Promoter	Citizen Checkers / Healthwatch Cornwall
Dina Holder (DH)	Community Engagement Manager / Divas Facilitator	The Women's Centre Cornwall
Ebony Rose Thomas (ERT)	Self-advocate and	Citizen Checkers
Fliss Hedge (FH)	Operational Lead	Cornwall People First
Sgt Flo Linscott (FL)	Diverse Communities Team Lead (Cornwall)	Devon and Cornwall Police
Jane Rees (JR)	Manager Learning Disability and Autism Team	Cornwall Hospitals NHS Trust
Jenna Pulley (JP)		Cornwall Partners in Policymaking
Jo Cope (JC)	Disability Employer Advisor	Jobcentre Plus
Jo Pike (JPi)	Screening Liaison Nurse, Primary Care Liaison Team	Cornwall Partnership NHS Foundation Trust
Karen Hooper (KH)	Interim Head of Commissioning for Learning Disability, Autism and Mental Health	Cornwall Council



Name	Position	Organisation
Karl Potts (KP)	Specialist Parenting	Cornwall Partnership NHS Foundation Trust
Kate Spenceley (KS)	Chief Executive Officer	Citizen Checkers
Kevin Beveridge (KB)	Area Director, Adult Social Care	Cornwall Council
Laura Keeper (LK)	Self-advocate, service user / and Trustee	Blantyre Day Services / Cornwall People First
Nory Menneer (NM)	Clinical Lead and Commissioning Manager for People with LD	NHS Integrated Care Board
Rosi Van Dam (RV)	Clinical Lead: Mental Health Liaison Practitioner	Cornwall Partnership NHS Foundation Trust
Samantha Clark (SC)	Chief Executive	Learning Disability England
Sam Edwards (SE)	Consultant Adult Learning Disability Team	Cornwall Partnership NHS Foundation Trust
Sam Maddern (SM)	Lead liaison and Screening Nurse, Community Adult Learning Disability Team	Cornwall Partnership NHS Foundation Trust
Sandra Ward (SW)	Parent carer of a young adult with profound LD, Director of Parent Carers Cornwall and Chair of Carers Partnership Board	Parent Carers Cornwall
Steve Dymond (SD)	Self-advocate and Partnership Boards Community Promoter	Healthwatch Cornwall
Tyrone Homes (TH)	Commissioning Officer, Adult Working Age Team	Cornwall Council
Vicki Allan (VA)	Strategic Commissioning Lead for Learning Disability and Autism, Working Age Adults Services	Cornwall Council
Zoe Rawlence (ZR)	Specialist Nurse	Specialist Parenting Service

APOLOGIES

Name	Position	Organisation
Cllr Jane Kirkham	Councillor Learning Disabilities Board Chair	Cornwall Council
Alex Seaman	Self-advocate	Brandon Trust
Alison Short	Advocacy Coordinator	The Advocacy People
Harley Jolley	Self-advocate	
Karen Gregory	Service Director	Mid-Cornwall Hub Day Services

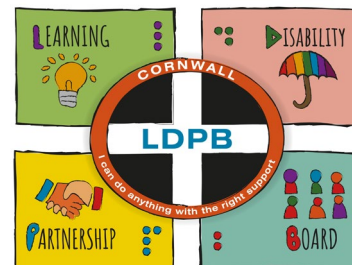


Name	Position	Organisation
Kate Alcock	Head of Commissioning – Older People and Carers	Cornwall Council
Marie Martin	Self-advocate and Partnership Boards Community Promoter	Healthwatch Cornwall
Neil Carpenter	Self-advocate and Champs Team Member	Healthy Cornwall
Pat Jolley	Parent Carer	
Paula Volkner	Transforming Care Project Coordinator	NHS Cornwall and Isles of Scilly Integrated Care Board
Rachel Mellor		Brandon Trust
Sam Mokkoram	Advocacy Coordinator	The Advocacy People
Dr Victoria Parnell	Clinical Lead, Specialist Parenting Service	Cornwall Partnership NHS Foundation Trust
Wayne Williams	Self-advocate	Mid-Cornwall Hub Day Services

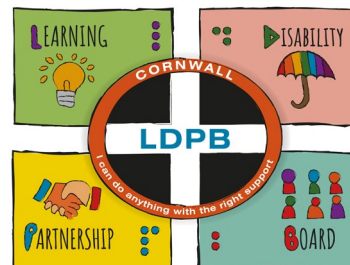
ACTIONS AGREED AT MEETINGS

Action	Responsible	Status
Learning Disability Strategy	Public Health	Ongoing. Updates as progress is made.
Share details of Cornwall Council vacancies for people with learning disabilities.	KH / PB Team	Ongoing. To be shared as vacancies go live.
Update on opening the Safe Places Scheme to neurodiverse individuals.	FL / SM	Ongoing. No update received. FL to follow up
Updates on Accessibility Advisory Group for RCHT as appropriate.	MH	Ongoing.
LeDeR report updates.	SS	Ongoing. MH to circulate LeDer reports when available.

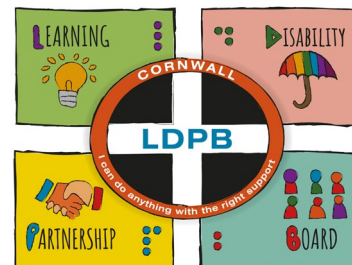
Item	What was discussed	Action
1.	Welcome, introductions and apologies	
	<p>As the Chair had submitted apologies, RO took the Chair.</p> <p>RO welcomed everyone and advised that the meeting was being recorded for minute taking purposes. Permission would be sought from individuals if it was to be shared beyond the meeting.</p>	



	<p>RO ensured that everyone understood the meeting etiquette and how to contribute to the meeting if they had joined online. AD agreed wholeheartedly that it was very important that everyone gave each other opportunity to speak and be heard.</p> <p>Apologies received were relayed as detailed above.</p> <p>RO invited everyone present to introduce themselves.</p>	
<p>2.</p>	<p>Minutes of and actions from the meeting held on 23 February 2023</p>	
	<p>The minutes of the previous meeting were confirmed as a true record.</p> <p>MH ran through the actions as detailed within the minutes of the last meeting. Continuing actions are detailed above.</p> <ul style="list-style-type: none"> • The Disability Strategy – NM updated the Board that the Council and Integrated Care Board met to plan the next steps on the strategy, commenced the Task and Finish Group in late November, with currently only two members this needs to be increased. The first stage is the joint Strategic Needs Assessment that Public Health are undertaking at the moment. Gathering information from this Partnership Board, Making Good Change Happen and Partnership Board review, as well as other consultations. All of which Public Health will include in their needs assessment document. Once the needs assessment is completed it will inform the Strategy in consulting with the Board, Healthwatch Cornwall has offered to be that point of contact on each stage of the Strategy, helping to avoid the same questions being asked for the last year. • MH – the first meeting for 2024 is preliminary booked for late February, NM confirmed that this would be timely following the consultation work. • Cornwall Council vacancies for people with LD, we have been informed that they will be shared as vacancies will go live. • Safe Places – Shelagh Mitchell had reported that discussions 	



	<p>were planned around opening up the Safe Places scheme to neurodivergent individuals. SM was not in attendance, FL informed members that no update has been received to date, other partners are also interested, such as the Independent Cornwall Autism Network (ICAN). FL to follow up.</p> <ul style="list-style-type: none"> • LeDeR – Sara Sanders had indicated that updates would be available in early December, at which point MH would circulate to the Partnership Board. 	
<p>3.</p>	<p>Updates from members</p>	
	<p>Healthwatch Cornwall MH updated members that the next Older Persons Partnership Board meeting would be for those with lived experience only. If members are aware of any service user over 55 that would like to participate, please get in touch with Healthwatch Cornwall. Information would be shared across the Boards and members were asked to share it widely.</p> <p>Cornwall People First FH updated members that the Sunflower Project work on death, dying and bereavement has been running for the last 18 months – 2 years, the report has now been completed, also in easy read. The report will be ready for sign off from NM shortly and can then be circulated to members. A little more funding has been received for Cornwall People First to hold a few more workshops in relation to the project, possible inhouse within day services.</p> <p>The practice partners have received some further funding, there are now Patient Participation Groups for Self-Advocates within 4 GP surgeries, there is also a further Self Advocacy Group set up within the Community, that will allow for sharing the learning from the GP groups.</p> <p>Cornwall People First have been working with Cornwall Council as part of their stakeholder consultation, regarding the recommissioning of housing and support services. A report has been completed and this can be shared with the next PB meeting if members agree. All Agreed</p>	



DH – Spoke to the members in May about the EOS Project, the DIVAs have been commissioned by Devon and Cornwall Domestic Abuse and Sexual Violence Commissioners, Devon NHS and the office of the Police Crime Commissioner, (also sub commissioning Rod Lanman from ARC). DH updated members that there has been fantastic engagement, the consultation has been completed across the Devon and Cornwall to understand what domestic abuse services feel and need to help them provide better services to those with Learning Disabilities and/or Autism. There have also been conversations with Learning Disability organisations to understand what they feel is missing.

A report has been completed and forwarded to the commissioners, and an end of project report will be completed in February 2024 to share some of the learning.

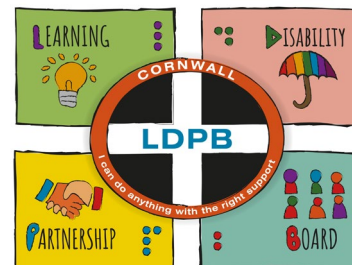
Training is currently underway and going very well across Cornwall and Devon. The DIVAs are often sharing the lead on the courses, the training is fully attended, and the feedback is very positive. In Cornwall 25 people attended part one of the training, which aimed at organisations that were not directly involved with domestic abuse, allowing them to increase their knowledge regarding the needs of those people with Learning Disabilities and Autism experiencing domestic abuse or violence.

An offer has been made from the Psychologists of the Learning Disability Team to provide consultations and they have also provided a lot of resources for DIVA to share.

A formal interim report has been presented to the Devon LD. Partnership Board. DH and the DIVAs have been invited to speak at their Annual General Meeting in 2024 as they feel it is such an important topic.

In summary; Cornwall and the DIVAs are doing working well in raising the awareness and understanding regarding the importance abuse within the Board.

One of the things that has been discovered is that there is little group provision for empowering men with learning disabilities.



Work has been funded for the Womens Centre and Cornwall People First, they will be jointly working to support the development of healthy relationships for men and women in relation to domestic abuse and sexual violence, this work will be starting in 2024.

Questions and comments:

ZH asked if there will be any more training available.

DH advised that there will be more training in 2024, the training is available for all agencies.

RO asked when an update would be available.

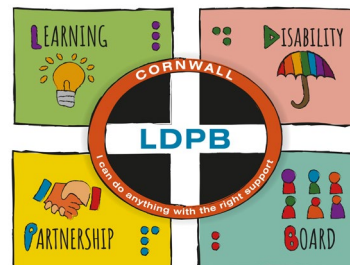
DH advised that an easy read presentation should be available in February.

Cornwall Partnership Foundation Trust – Primary Care Liaison

SM Updated members that the Primary Care Liaison team, including liaison screening, work with the GP surgeries across Cornwall. Their main function is to deliver Learning Disability Awareness training and focus on increasing the amount of Primary Care health checks for people with Learning Disabilities.

The aim of the Screening Nurses is to encourage the uptake of the national screening programmes for adults with Learning Disabilities in Cornwall.

Two GP training days on Learning Disabilities and annual health checks, were completed during 2023 for between 70-80 practice staff. At the last session on 14th November a number of the CHAMPS team members attended online, providing key insight and knowledge as well as some very positive feedback in relation to their experiences of annual health checks which was really useful for us all to hear. We have received good feedback from the training and as a result we have received more referrals to our service. Referral to the Screening Nurses are made to support people who experience difficulties, or opting out of the annual health checks. If someone does not attend their LD annual health checks after two invites the Primary Care Liaison Team will investigate why, this may be due to requiring reasonable adjustments such as easy read letters etc. All aiming to support people them in accessing mainstream Primary Healthcare.



SM asked FH to link in with the Primary Care Liaison Team regarding the feedback from the Patient Participation Groups for Self-Advocates.

Questions and Comments:

AD asked if some of the Learning Disability training has already been delivered previously, unfortunately people with Learning Disabilities are still unaware of who is their contact, making the process very confusing.

SM advised that people can telephone the service
When AD is referring back to the previous team there used to be 5 nurses. They have been operating with only been 2 nurses, recently increased to 3. AD feels that this is not enough.

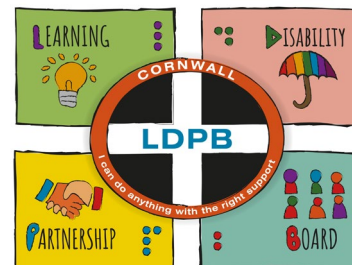
RCHT also has a more effective flagging system, the Community CPFT is undertaking work to improve their system, updates in due course.

AW asked how many GP surgeries in Cornwall do the Primary Care Liaison Team and Screening Nurses link in with? And how do you get them to engage initially with the Learning Disabilities training you provide?

SM advised that there are 55 GP surgeries in total in Cornwall and Isles of Scilly, the team link with them all. Emails are sent out to all the surgery contacts the team have, the Learning Disability and Annual Health checks are currently an element of the GP designated enhanced service, to meet the contractual requirements of this, the GP surgeries should be undertaking the relevant training. A range of email invites are sent, if no training is attended, the latter email will be more formal referring back to their contractual obligations. Initially there was little uptake from the GP surgeries, we forwarded information received from the ICB and the response improved, the ICB also added the training list send to the GP surgeries, all of which have improved the bookings and attendance.

AW asked - Can you confirm there are currently 3 nurses in the team at present?

SM advised Yes there are at the moment.



AW asked if there are any plans to increase this number of professionals.

SM advised there has been discussion about increasing the funding for the team, there is an unavoidable delay in completing the funding application and submission to the IPF process, which requires the application to be signed off by the different boards. As there were previously 5 nurses, is the funding still available? The dynamics of the team have changed, with the introduction of the screening nurse roles, there is now an equivalent of 5 full time nurses, providing a dedicated screening service. The funding application will hopefully be completed soon.

RO asked that the discussion be continued outside of the meeting.

Parent Carers Cornwall

SW updated members that many workshops and events have been held over the last few months:

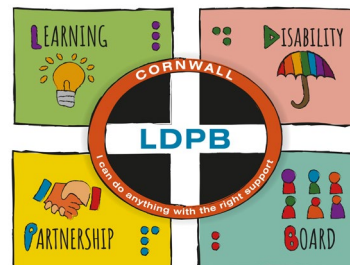
Preparing for Adulthood – the sessions at the Eden Project, Heartlands and online, were very well attended.

Workshops with Tigger Pritchard on Attention Deficit Hyperactivity Disorder (ADHD) support and Pathological Demand Avoidance (PDA), parents have found very useful in supporting their children and young people.

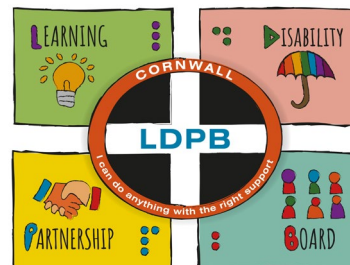
There is an acknowledgment that the Educational Health and Care plan (EHCP) and Education Out of School requests are increasing, there is a lot of work from the teams however, there remain delays in processing them.

In March 2024 at the Eden Project there will be a big information event for young people with Special Educational Needs (SEN) and their parents.

Members were reminded to always adhere to data protection legislation during the meeting.



<p>4</p>	<p>Specialist Parenting Experience of parents with Learning Disabilities</p>	
	<p>ZR Shared slides with the members</p> <p>The team is very small with 4 members and work with parents with learning disabilities in Cornwall. Funding was recently received to capture the views on our service and other relevant services in Cornwall from parents with Learning Difficulties.</p> <p>This presentation was aimed at the parents, but ZR wanted to present it to the members for their advice on wider sharing opportunities from members experience and comments were welcomed.</p> <p>The aim was to share:</p> <p><u>What the team wanted to know:</u></p> <p>2 questions were asked:</p> <ol style="list-style-type: none"> 1) What did parents think about the Specialist Parenting Service? 2) What were their experiences of being a parent with a learning disability in Cornwall? <p><u>How they found this out:</u></p> <p>The process the team planned and followed to capture honest and open comments, experienced independent people were recruited to run the sessions and different methods to gather the information in creative ways. The funding allowed for transportation to meetings where needed and vouchers for attendance.</p> <p><u>What the team heard from people</u></p> <p>The feedback on the Specialist Parenting Service was very positive with lots of very nice comments.</p>	<p>ZR</p>



The feedback on other services for parents with a Learning Disability in Cornwall has been captured in a report and the comments matched to the relevant service.

What the team intend to do with the knowledge:

Following the feedback process, the Specialist Parenting Team have made changes to their assessment process, focusing more on Mental Health and Adverse Childhoods Experiences (ACEs), aiming to increase trauma awareness that can impact on parenting.

Home Start Kernow attended feedback sessions, and the Specialist Parenting Team are aiming to work jointly with them to secure funding and run groups specifically for parents with Learning Disabilities, co producing the sessions with parents, providing more targeted support within the community.

The team have created a contract for facilitating better communication for parents, agreeing how best to work together. Working on a pledge for Specialist Parenting and would also like to create one for children of parents with Learning Disabilities. Videos have been created to allow for any diversity in communication providing feedback of learning assessments, which can be used for informing other services such as GPs.

The report on the work can be shared with members once completed.

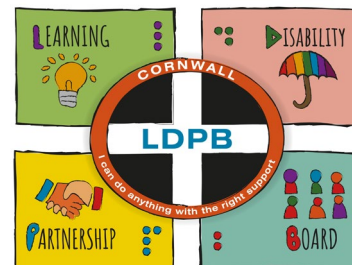
Some common themes identified were:

- Asking but not listening
- Repetitive information-lack of sharing
- Lack of flexibility of services- booking appts and transport etc.
- Assumptions

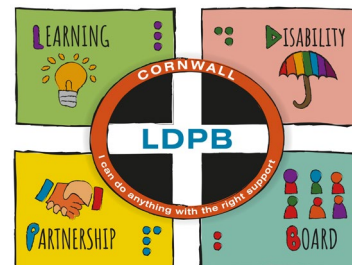
Video was played – user experience.

ZR asked for members’ ideas on how best the team can share the information with the NHS and other organisations?

RO requested that question and comments are placed in the chat please.



5	<p>Making Good Change Happen</p>	
	<p>KB had been called away from the meeting so was unavailable to update.</p> <p>MH informed the members on KB's behalf that KB is creating a proposed workplan for the Partnership Board, from the different streams of work of Making Good Change Happen.</p> <p>A draft of this workplan will hopefully be ready to circulate with members prior to the next meeting.</p>	
6	<p>Break</p>	
	<p>The Board had a 10 minute comfort break.</p>	
7	<p>Partnership Board – Agreeing the Way Forward</p>	
	<p>RO informed Board members, that unfortunately the people from CHAMPS involved in the work, were not present at the Board meeting to provide feedback. SC had previously shared a summary report of the work undertaken to the Partnerships Board, which had been circulated for reading.</p> <p>SC presented to the Board members and shared slides.</p> <p>The main aim was to agree how the Partnerships Board can work in a way to make the most difference. Through the use of surveys, gathering ideas, and holding meetings people were asked to share their ideas, three questions were asked to identify: -</p> <p>What had been good so far? How can the Board make a difference in the future? How the Board can be part of the Bigger Picture?</p> <p>A Leadership Group was formed and worked together to facilitate the review. SC thanked the members of the Leadership Group for all their hard work.</p> <p>In October 2023, the Leadership Group attended an extra meeting</p>	



to look at all the feedback that was provided.

SC provided two more pieces of feedback:-

Focus on making good change happen to allow those with Learning Disabilities in Cornwall live a better life.

Work in a partnership that includes more people; people from organisation, people with learning disabilities and families.

SC proposed break out sessions of work and feedback from Board members; as small groups think about the ideas and recommendations, as a whole group the Board to decide on the changes for new ways of working in 2024, in smaller groups again think about what can be done to make the changes happen.

The current thoughts for consideration are: -

Who will be part of the Board:

- Most places on the Board are filled by people with learning disabilities, 12 in total, and 6 places for family and/or carers.
- The Board will facilitate the feedback from different lived experiences.
- Board members will be from all over Cornwall
- The Board will be also have representative from relevant organisations Health, Social Services and Community
- Board members will be regular attendees, alongside this others will be invited as visitors to help with specific pieces of work.

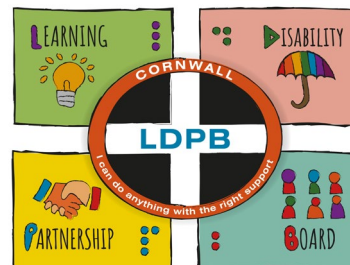
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Big messages from people: -

- Change ways of working
- Connect with People
- Wider sharing of information
- Celebrate the positives
- Continue to work on things that haven't changed

7 recommendations: -

- Make sure the leadership and roles on the Board are clear for all.
- The Board checks their work to ensure that changes have happened or not and what further work is required.
- Offer reasonable adjustments are available for all who join.



- Make sure links to other groups and organisations are actioned and maintained.
- Map other service changes that support the aims of the Board
- Recruit Co Chairs
- The work for the year ahead is planned and focused.

The Board members broke out into groups.

Feedback from the groups:

ERT from Citizen Checkers fed back the group ideas:

- One topic per meeting
- People with lived experience leading the Board
- More listening and more conversation between all Board members
- Less reporting more action- not having lots of paper base reports that are not actioned.
- People with lived experience need to take back control.

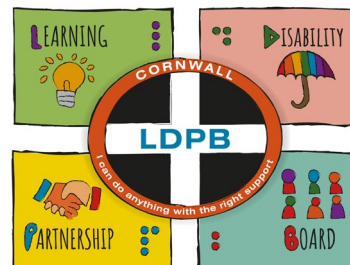
These changes can be made under the current headings

KH – fed back that: -

- The Board needs to be dominated by those with lived experiences,
- The Chair/Co Chair need to be a person with lived expertise, Professionals need to support them to raise their flag in relation to an issue or problem and the solution.
- The opportunity for a group of members to own a piece of work, identifying the solution together, reporting back to the Board to facilitate a wider working plan to make it happen.
- KH's group supported the call for one topic per meeting to allow for moving forward.

FH – added that there is a lack of overall self-advocacy for adults with lived experience, 12 Board members with learning disabilities is good, however, how do we capture the voice of all the others throughout Cornwall.

The current way of working shows that the professionals are leading the meetings and discussions then people with learning disabilities feed into the conversations, it should be the other way



round, allowing for the agendas to be set by people with lived experiences.

SC clarified with FH if Forums or Self Advocacy meetings, would be a way to raise the topics from many different perspectives, also covering more areas in Cornwall and feeding into the Board.

DB raised the point that there should be more local meetings all over the County allowing for people to , to then link with the Board perhaps online, allowing people with learning disabilities to raise the points for discussion.

SC clarified more meetings connecting to lots of different people, not just those Board members.

DH also supported this by raising the point of resource implication, to support the self-advocates.

VA Asked how do we know where the people with lived experiences are in our Communities? It's essential that we undertake some scoping and mapping to allow for a better representation, linking to formal, informal and friendship groups.

DH – fed back that the plan was a good idea to track the work.

AD – Peer advocacy needs to be available.

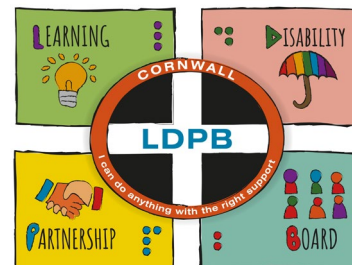
MH – fed back that the group in the room agreed with all the points raised by the other groups.

Other points raised in the room were: -

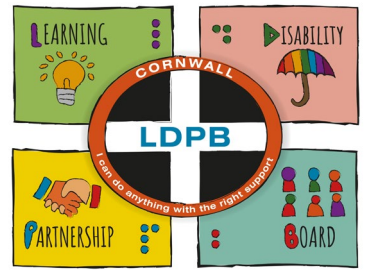
- The format of meetings – does the meeting be longer, perhaps 2 hours in the morning 2 in the afternoon.
- How would this impact on the Professional Board members
- Making sure the Co-Chairs receive relevant support for their role.

SC clarified with Board members that all are in agreeance with the points raised, and that there needs to be an action plan to facilitate this and support the networking to help make the changes happen. Who can help with what?

The Board broke out into small groups to identify; who can



	<p>support/help with different parts of the work that will be involved. SC pointed out that people who were not at the meeting could not be nominated.</p> <p>SC Requested that all online added their offer of help in the webchat.</p> <p>KH confirmed happy to be involved with this alongside people with lived experiences, and can provide a venue.</p> <p>SC asked, how do we support people with lived experiences to be involved. Citizen Checkers and Cornwall Partners in Policymaking suggest they facilitate three meetings/gathering linking into the principles of the Public Living Rooms and the Gloriously Ordinary Lives, to allow the shift of power and to take back the control.</p> <p>SC asked for people thoughts and all Board members in attendance agreed.</p> <p>SC asked can this work wait until the next Partnership Board meeting using the agreed principles.</p> <p>NM suggested the points that this work needs to have a dedicated meeting to focus on it. Involvement requires resources. Even in the design phase and onwards there will be requirements to be explicit in identifying the resources needed.</p> <p>RO suggested that the chat function be left open for people to add their offers of help.</p>	
<p>8</p>	<p>Any other business</p>	
	<p>SW informed the Board that the Mid Cornwall Hub has received a grant to install a new defibrillator to the outside of the building. SW asked If any Board members new of any Defibrillator training available for people with learning disabilities? St Johns Ambulance have been approached, but to date they have not responded.</p> <p>RO confirmed that the question had been noted for the minutes and the Board will await member feedback.</p>	



	<p>RO informed the Board that meeting dates for 2024 will be circulated to the Board in December.</p> <p>The meeting was closed and all members thanked for their attendance.</p>	
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