

Lambeth Living Well Collaborative Review



A rapid review into the past decade and the impact the Collaborative has had in Lambeth

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Aug-Nov 2023

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Methods

Public Service Works was commissioned to review the Lambeth Living Well Collaborative. The aim was to gain insights and views from a breadth of people, and to increase engagement from both local people and across the Lambeth health and care system to promote and inform a big one-day event. The event would thereby draw in diverse and passionate participants to identify priorities and potential solutions to the mental health needs of Lambeth people. The findings of the review are intended to help the Collaborative to re-focus its efforts and decide about its future.

The approach:

- ▶ 10 Interviews with people in senior and, or leadership positions in Lambeth Council, the NHS, voluntary sector and from the Collaborative. Interviewees were asked about the work of the Collaborative and its potential future. People who had been involved in the Collaborative from its early days and those with little or no involvement were interviewed.
- ▶ Three story telling sessions; one with Collaborative members, one with peer supporters involved with the Collaborative, and the third, organised by Healthwatch Lambeth, with people with experience of mental health services but no knowledge of the Collaborative.
- ▶ A workshop with Collaborative members to look back at their achievements and learning.

The findings from the interviews and story telling sessions informed the theme question for the large event held in November 2023 which was:

If there is no health without mental health,

*How can we work together to enable people who experience mental unwellness
in Lambeth live full lives?*

Interviews of local leaders

About the Collaborative

- ▶ The Collaborative is seen as an important, inclusive space that fosters partnership, user voice, relationship-building and mutual involvement in problem-solving. Its history of talking through differences and conflicts is a strength.
- ▶ The 3 Big Outcomes of the Collaborative remain important core principles and a 'golden thread' through the work. As statements that are both broad and focused on the individual, the Outcomes are viewed as holistic and relatable. Interviewees are keen to see how the Outcomes could be extended to include prevention and how the wider public health context for individuals & communities could be encompassed.
- ▶ The consistent and persistent support of senior figures over the years has been a vital and huge strength, providing 'corporate memory' and nurturing a positive Mental

Health eco-system.

- ▶ The importance of changing language used in mental health, especially clinical language (eg introduction rather than referral), in creating culture change.
- ▶ Sense of a lack of momentum, especially since Covid when meetings moved online and fewer senior people now attend. Concern about the impact if this situation continues.
- ▶ The Collaborative offers space and opportunity to complement partners' work and support initiatives with staff, but lacks visibility.
- ▶ Focus has moved to the Living Well Network Alliance (the alliance of providers of mental health services in Lambeth) since it was set up. This has had positive and negative effects on the Collaborative and its purposes (seen as eg more user involvement, better partnerships between statutory & non-statutory organisations, greater visibility and priority of mental health)
- ▶ But there remains much to do to translate these and other aims of the Collaborative into daily practice as experienced by service users and carers.

"It hasn't solved all our problems: too many people in A&E, too many gaps for young people, gaps post Covid, huge backlog of referrals. Still a lot to do on culture change"

- ▶ Nonetheless several interviewees were able to name 4 or 5 innovative projects or practices (at least 15 were mentioned) that matter to them and to service users.
- ▶ It was suggested the Collaborative could and should hold the Alliance to account
- ▶ Service user voice is recognised as the *raison d'être* of the Collaborative and a real strength but interviewees agree that new and diverse ways to promote genuine co-production are needed. The Collaborative could and should lead this. In any next phase, easier and wider involvement is a high priority.
- ▶ Interviewees had questions: what is new now? What is the next big thing? What are the next marginal places the Collaborative could focus on changing in relation to mental health?

Main differences and contradictions

- ▶ Views differed on the relationships between the Alliance and the Collaborative and agreed this needs clarifying and communicating.
- ▶ Some felt the achievements of the Collaborative were more about culture, climate, relationships and trust than the impact of specific projects. Others felt the opposite!
- ▶ Some thought the achievements were measurable and others asked how anything was being measured, suggesting that either way, there is a case for developing how impact is tracked.

Emerging questions

- ▶ How can we build practical projects with clinical staff, not just talk about change?
- ▶ What should the relationship be between the Collaborative and the Alliance? How can we establish and communicate this?
- ▶ How can we measure the impact of what we do in the mental health system in terms of patient and carer experience?

- ▶ How can we make co-production a reality?

Some quotations

We need to renew our juices. The same things are happening; people are becoming their diagnosis. The idea was to think outside the box. The label is disabling I know not everybody recovers but what's the best somebody can be? People can be well one day and not the next. The benefit system doesn't support this. I remember somebody saying "Don't ask me how I am, ask me how it's going." When somebody goes into hospital you lose your confidence so it's really important we take the mental out of mental health.

The Collaborative needs to use its good practice experience to develop the co-production muscle which has gone flabby since Covid.

[The Collaborative] is a touchpoint to test stuff and canvass opinion, a critical friend and an excellent network to plug into – they know other people to bring in as well. It's also a temperature check about what it's really like on the ground.

Six years ago providers and commissioners and service users would not have sat around the same table. We wouldn't have a strong delivery alliance if it hadn't been for the Collaborative.

The system is sick itself. We have to keep going turn the system on its head, to quote Shakespeare "therein lies the rub!"

Over time and a lot of discussion, we have all changed.

The early years were really lovely, we were under the radar. We didn't have to go back to boards we could just get on with it that was really important. What held us back came later.

The Collaborative has matured from confrontation and is a healthy place for inclusiveness.

The Collaborative is the lake that the Alliance is within, this brings in the wider context and all the range of stakeholders. The Alliance focuses inevitably on acute services being a formal configuration.. but the Collaborative looks at wider determinants – it's a public health space.

Standout moment when a black psychiatrist shared his perceptions and experience. This was a new perspective for us, helped us reframe and understand discrimination inside services.

I feel further from it than I ought to be. It is valuable and like everything needs continuing development. it needs a reset and reinvigorate the connections.

Covid pushed everybody back into a way of working that was restrictive and command and control, not creating connections across communities and organisations. We are further behind and the challenges are more challenging than those we had when we set out on this alliance journey. Cost of living, inertia in people

The Collaborative is the lake that the Alliance is within, this brings in the wider context and all the range of stakeholders. The Alliance focuses inevitably on acute health services being a formal configuration... but the Collaborative looks at wider determinants: it's a public health space

Story telling at a Collaborative Breakfast

At the 14th September 2023 Breakfast meeting people were asked to share their stories that were typical of the Collaborative.



I am leaving feeling really inspired. Pam's story was food for thought about continuity of care

Insights & issues

- ▶ Housing – the perennial issue
- ▶ Lack of representation from diverse communities
- ▶ Lack of joined up working and influence
- ▶ Some ward staff are not aware or knowledgeable of peer supporters
- ▶ Community Mental Health Team says 'no.' Still!
- ▶ Trust leads to honest conversations; a Collaborative characteristic
- ▶ The more representative the greater the strength of the Collaborative

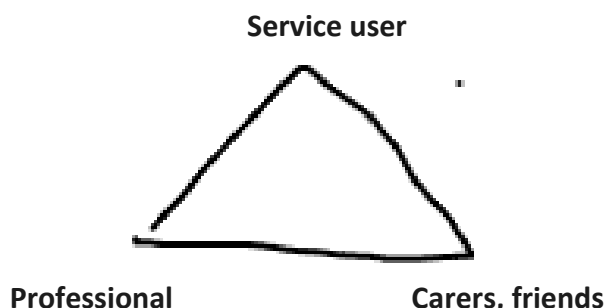
- ▶ What's important and needed:
 - solution focused, holistic help, early intervention
 - mind and body – nutrition, food, exercise
 - awareness – mental health prevention
 - battling stigma
 - layers of support
 - more peer support
 - to hear more from people with lived experience and their journey to recovery

Ah ha moments

- ▶ What's important and needed: understanding barriers to change
- ▶ Competing agendas and limited resources
- ▶ Laughter is the best medicine – prevention is so important
- ▶ IPSA [Integrated Personal Support Alliance – the first part of the Living Well Network Alliance to be set up] seems to work well – but they can house people
- ▶ Peer support – hugely valuable – still undervalued (by the systems)
- ▶ Personal relationships, empathy, continuity, humanity.

Questions these stories leave you with

- ▶ How can we reach out to communities, share learning, raise awareness?
- ▶ How do we overcome barriers to change?
- ▶ What does prevention look like?
- ▶ How do we measure prevention?
- ▶ If everyone knows there isn't enough investment in mental health, why doesn't the money come down to communities?
- ▶ We're glad it's there but why does it still not work? 'it's confidential'
- ▶ Do we have the leadership needed to make it all happen?



Closing comments

- ▶ *All brilliant – thought provoking*
- ▶ *Our attitude to risk plays a huge part in co-production, [we] may need a different stance... Lowering the bar and much more inclusiveness – but it didn't change bed use*
- ▶ *The battle [to be] asset focused but not possible with the current focus on risk*
- ▶ *Status and value [of] peer support – we are still miles away*
- ▶ *I feel uplifted – better, properly connected. Similar re peer support, the balance of the system in which peer support plays a small part*
- ▶ *Very much enjoyed, so much experience of the local area. I echo comments about peer support. Providing some sense of continuity, getting peer support into teams is a struggle. Work today is a struggle.*
- ▶ *I was unaware, quite refreshing to hear about different projects wanting to help each*

other.

- ▶ *I am curious, what will everyone come up with?*
- ▶ *Feeling of connection and meeting everyone. Would be good to extend outside this room. Working with Carers Hub, people are very involved in the services*
- ▶ *Inspired to be back in a room with humanoids. We have to keep going*
- ▶ *The Collaborative way feels right.. a group of people who trust each other. I look forward to it being tetchy again. We can ask those really scratchy questions.*
- ▶ *It made me think the Collaborative is a gift. I never expected this opportunity for trust and communication*
- ▶ *First Collaborative meeting for me it's nice to meet everyone and hear of your projects.*
- ▶ *Hopeful that there will be a real change in the world, not just about struggling.*
- ▶ *My first time at the Collaborative, I felt the impact so I will continue the connection. How can we assist?*
- ▶ *I am leaving feeling really inspired, Pam's story was food for thought about continuity of care.*
- ▶ *I feel privileged to be sharing questions and a-ha moments in this group, we really opened up. I am looking forward to the next step*
- ▶ *A real sense of belonging, sharing, gift, integrity. It's okay to get tetchy – I do tetchy!*
- ▶ *A real gem. A flower in the desert. To be watered. We need to do something about the slowness of change.*
- ▶ *I feel I've just come out of the ring – in my corner I've just been given water!*
- ▶ *Do we have capacity to touch base with current things. There was a murder in Angel Town*

Living Well Collaborative Workshop

Members of Lambeth Living Well Collaborative were invited to a half day workshop.

28 people attended

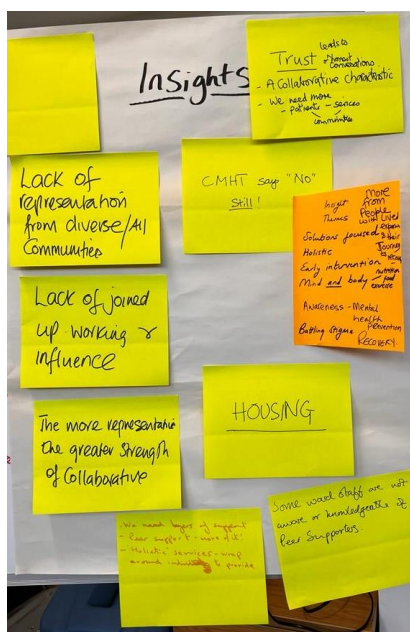
After introductions people were first invited to develop a timeline of the Collaborative since 2010

From your own knowledge and/or experience, write on the timeline. What has happened since the collaborative began in 2010. Main events, projects, key decisions and actions. Anything to make what the Collaborative has done together visible.

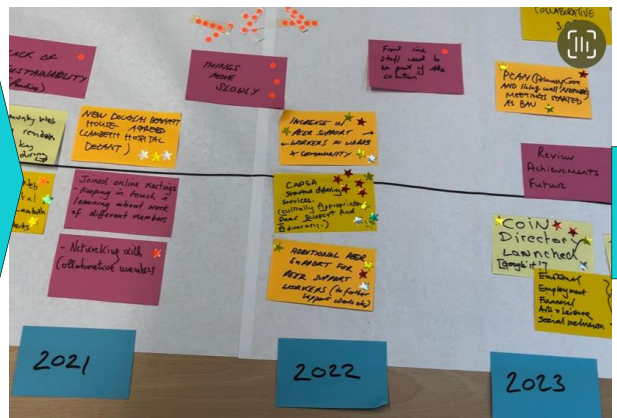
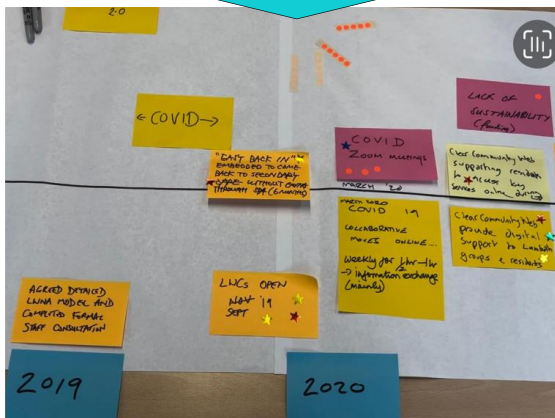
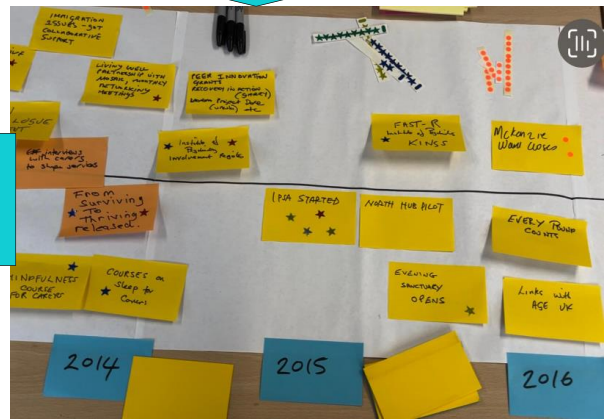
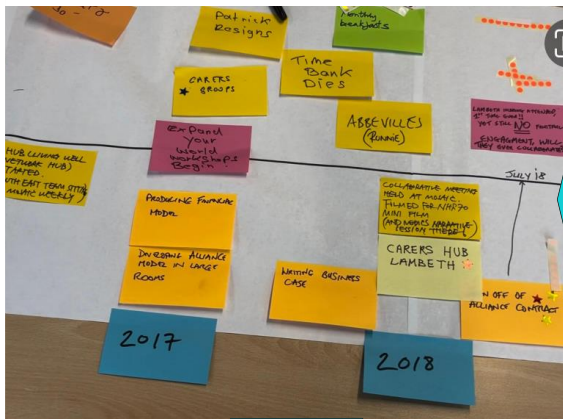
Then people were invited to walk the timeline and put stars on things that worked well and, or that they are proud of.

Next people were asked to take another look and put a red dot against the things that didn't work so well; the things we can learn from, **Or** what didn't work so well; things that remain tricky, frustrating.

Stars: What went well, **Red dots:** what didn't go so well



At the end of the workshop people made some suggestions about the question for the Open Space Technology event.

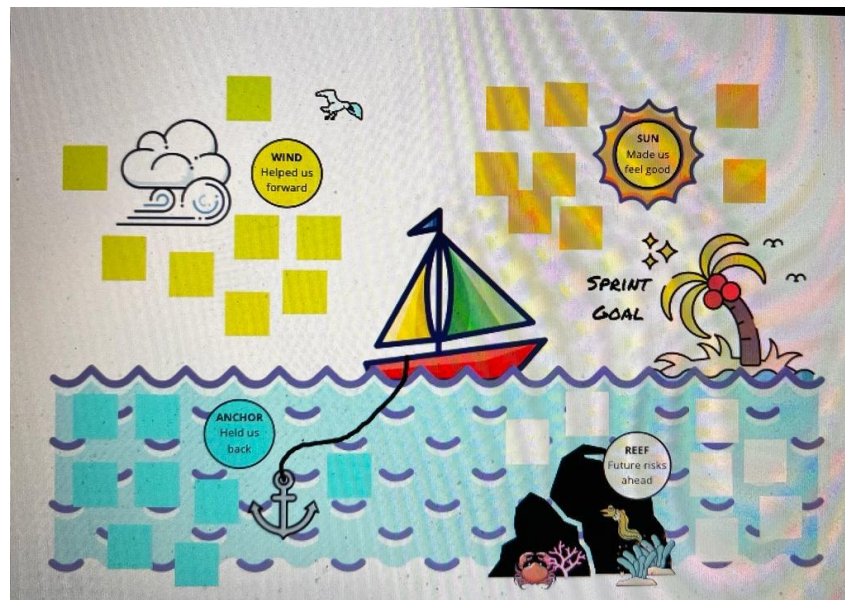


Story Telling Sessions

Two story telling sessions were held; one for Peer Supporters (attended by 12 people), and one organised by Healthwatch Lambeth for people with no involvement with, or knowledge, of the Living Well Collaborative (attended by 14 people).

Peer Supporters group story telling

14th of September 2023



“Peer support is the little digger trying to turn the massive tanker that is stuck in the middle of the Suez Canal. Sometimes it feels like that.”

The sailing boat retrospective

We used the image of a boat sailing towards an island. The island represents a place where the Three Big Outcomes;

- Recovery and staying well
- Making our own choices
- Participating on an equal footing with others in daily life

were well on the way to being met.

In the sea are rocks and the reef representing risks and blockages. There is also an anchor inviting people to say anything that holds them back. We then looked at the positive winds

that fill the sails and the sun that helps people with wellbeing and feeling good.

Rocks & the reef: risks and blockages

- ▶ Services and service users not knowing about peer support or how to make good use of people's experience and perspective
- ▶ Support not being widespread or consistent – e.g access complicated or attending networks where people don't always get back
- ▶ Not knowing where to go for information or help
- ▶ People want to be generous and help others but experience barriers such as;
 - Not having enough time as a Peer Support Worker to be effective for instance by being given other duties ('job creep') or asked to do tasks that are beyond their remit (eg assess patients)
 - Trying to understand the system; when you gain knowledge this isn't always welcome or it's taken for granted, or misused
 - Organisational and individual resistance to service users having a voice in the statutory sector (system fears losing power) eg lack of access to meetings intended to progress peer support
 - No career path or infrastructure – no help for what next
 - Finance cuts and short-term contracts [for peer supporters]: why not long term investment?
 - Reductionist approaches, psychiatric practice, human insight versus science
- ▶ General 'control freakery' of society
- ▶ What to do for work? *To keep well after my depression I didn't want to work for anyone. Volunteering at the Loughborough Farm wish you were here project helped*
- ▶ The Collaborative gave us a chance to test the water with a peer support approach, but having to tender for a contract and losing it to a bigger entity meant we lost a valuable resource and lots of know-how. For instance the model developed of visiting people on the wards was lost for a while. I hear people say there's nothing to do when they come out of hospitalwe are constantly reinventing the wheel
- ▶ Lack of face-to-face support during lockdown
- ▶ Nowhere to take my idea that I think can help people like me or only short term funding
- ▶ Creating an open learning culture in a competitive environment where the agenda is set by the paymasters
- ▶ Low pay versus executive pay – are peer supporters really valued ethically or economically when the discrepancy is so big?
- ▶ System moves too slowly – can't or won't respond to peoples' ideas or needs

From the conversations:

Quotes in bold italics were shared at the Living Well Collaborative workshop

A lack of person centredness. The whole health and mental health care industry continually wants to standardise.

Do you think they can standardise human experience and measure that, and then.... reduce

anxiety, [by] practising standardised rather than individualised approaches?

Everything is monitored and regulated... So that's quite a problem for people who want a human experience to be at the forefront of care and person centredness and compassion

Everyone has different needs because we're human and we're different. We're not machines

Sometimes organisations don't really know what peer support is, but they contract for it and get money [and] kudos, but they don't actually know what they're doing

Lack of knowledge about the role of peer support means you can't always follow your practice. As a result... [service users] keep coming back to the service so you can only do so much within your remit.

Also service users don't always know about peer support, I didn't hear about peer support until 2014 and my diagnosis was 1996. I think it would have been immense to have somebody who comes through and maybe different medications, or just more information that me and my family needed at the time. That would've helped a lot.

Your mindset and sometimes your trauma, what you've been through in the past, that can stop you even going on the journey and seeing if there is sunshine. Everyone's got a past.

People do want to help others but their generosity gets taken advantage of and there's nowhere to take ideas that I think will help people like me.

I've got a purely practical one, which is lack of access to meetings that are intended to progress peer support. I can remember some meetings where the acoustics were a nightmare. The people I was with had hearing problems and found the whole three hour meeting impossible to access so that was a scary kind of practical accessibility

Peer supporters used to be so emotionally supported and rewarded financially. Then it all got tendered out. The new organisation decided that people shouldn't be paid. They saw it as a passion, [that] people should give back and it wasn't about money. I think at that period peer support was actually destroyed because all the peer supporters left or became unwell and the ones we met with damaged by that transition.

Peer support can be offered briefly and then suddenly stop during transition from one service to another, so there are big gaps. It's not always consistent. As a peer supporter I personally found it challenging to be effective. Because in a role there might be other duties and you would get job creep. You found yourself being pulled into a support worker role as opposed to a peer support worker role because some people wouldn't hear the peer bit. It's been a bit of a challenge getting people to recognise the role, the value of the role and the value of lived experience.

Job creep yes, you've got peer supporters who have been trying to assess people, peer supporters shouldn't be assessing anyone.

It's difficult to keep the role defined when people are under pressure – it's a new role and it needs to be really clear to people what it is, I'm being pulled in various different

directions.

I think that's one of the things about co-production as well. It's about blurring the boundaries. You'd be sitting next to the commissioner and you saying this is how it is but then what is the blurring of boundaries, because it's still some sort of power thing?

Peer support workers won't have experience of working in depth in the NHS before. So it's a sharp learning curve and feeling that you have enough competence to be able to challenge people and say well, I'm sorry that's not within my role, my remit, which will be hard

But overall it was really positive you know the effects we've had on the team. The effect peer support has had

Referring back to the image from a year or two ago, peer support is the little digger and trying to turn the massive tanker that is stuck in the middle of the Suez canal. Sometimes it feels like that.

I remember the service director, he was a lovely man, and he said the NHS was a supertanker, and it's slowly sinking. If you want to be agile, get into a speedboat. They can go round and round, do whatever you want. You need to be agile, you need to get out there, get off the supertanker, get in to speed mode. But then he said you have to remember that supertankers have a lot more fuel than the speedboat. You will actually run out of fuel, so basically he was saying yeah you guys can go and do whatever you want, but you're gonna run out of money.

I went with my friend to see the psychiatrist. She was describing all the distress and madness she was experiencing. The doctor said, don't worry all the stuff going on in your mind is the result of a biological disorder and we can give you pills that will fix that. I was really tearful and challenged them. I was told I wasn't a doctor. I said I'm a friend and he said, yes but you're not a psychiatrist. It's that kind of alienation of human experience, seeing it as a biological disorder that's terrifying, quite frankly, to me and my friend.

So many referrals you get in the community, it's not always realistic. You can only provide so much support within your remit. You could go to the end of the Earth to do everything possible [but] only if the person that you are working with is willing to engage at that level. We started to experience that as a difficulty.

And sometimes the referrals aren't realistic, they probably need to go somewhere else where they will be able to provide support for that individual

It's about walking by the side of someone. You can't fix anybody else. That's what they've told us. Sometimes it's just about providing less not providing anything; just being there.

[Karen read the story of someone unable to attend the session – please see the end of this document.](#)

After a short break the group discussed: what are the winds that fill our sails and the sun that helps people with wellbeing and feeling good?

- ▶ From a service user's point of view – not feeling lonely, having support groups, the right care
- ▶ Empathy and warmth from others who really care
- ▶ Being understood because of shared experience
- ▶ Being kind
- ▶ Being in a higher level job in a position to help improve working situation for other peer support workers
- ▶ Belief by funders that paid peer support makes a difference and is worth investing in
- ▶ Being able to use your own life experience to support others and seeing a positive outcome
- ▶ Working alongside other peer workers
- ▶ Meeting up face-to-face
- ▶ Nature (including Loughborough farm); silence, birds, animals, not feeling a speck in the city
- ▶ Spirituality, God, angels, the universe
- ▶ Laughing
- ▶ My children
- ▶ Physical exercise of various kinds; gym, Aquarobics, cycling, gardening
- ▶ Changing perspective; I am not my illness, not having a victim mentality. Gaining the willpower to live and be like I was or even better before my illness; understanding myself; having dreams for the future
- ▶ Going home [to India, to Ghana]

From the conversations:

Spending time in nature throughout my whole life. That's what's helped to keep me grounded.

My spiritual life and just the bigger picture. Yes, we are spiritual beings and I'm with the people who mention nature. I feel free. The same cycle day in day out, you feel like a fish drowning. I love going back home (Ghana) for freedom and being among kids, smiling and laughing. I just feel like the sensible one. We're just in shorts and a T-shirt. I was just laughing [at] the sound of just walking barefoot on the sand I love it. I just to go outside and listen to the air – listen to the birds.

I can breathe in India even with so much population there are still places that are absolutely pristine. Bricks and I can't breathe because it's like my soul is dying....I don't know what it is. I mean people are nice where we live. I'm really thankful, but ... I never felt that I belonged and now I'm going back to India often. I'm thinking of retiring [there].

Laughing, yes, I forgot what I've missed. It's part of me. I haven't laughed like this since I was a kid at school, laughing so hard I started crying.

My spirituality, I'm not so much into religion but nature and animals. That's what keeps me going and also my GP. He makes a difference. I was really down and it's hard to get the support and care. Sometimes they see me and remember we met when we were crying

together. So I think I've been blessed or lucky and I have really good support....I think of my willpower to live and like I used to be before my illness. You know not to be the victim of my past. I'm dreaming of the future, understanding myself as well because I've learned a lot about myself. I used to blame others, but I've started understanding myself and stuff I need to change as well so I've changed a lot.

Being involved in Loughborough Farm.

And cycling, discovering cycling, getting out into nature learning about new things. That sort of independence, freedom, exercise, transport, doing various kinds of events and developing friendships in the cycle club. And when I need headspace, I can get out into the country, clear the cobwebs from my mind. I've been cycling for about 20 Years.

I've used the word good a lot. At the time we did have a good commissioners... We negotiated investment... in certain things we wanted to do, and they wanted to support. Good management is good. We used to have a good service; directors, managers, research so we did good research. Published in the academic literature; we got good responses from all over the world. We discovered safe emotional spaces are really important. People come to our base saying it's warm, it feels safe. Good environments, good relationships that to me is the approach that you continually learn.

I don't ever feel I can figure out what's going on, I mean it's beyond me, it's too much for one poor human brain to actually understand although I used to try. When my mentor was in his late 80s, he was a lovely man, he said to me, the older I get the more I realise what I don't know.

The winds would be the great mentors that we've had, great listeners who are encouraging. I think Vital Link and having a vocational plan.

...One of my criticisms of the whole Collaborative thing is thatpeople think the Collaborative [has] the money. We haven't got any money as such, but we've shaped ideas for people who have got the money.

Not just surviving but thriving. That's really important with peer support, when you see somebody 'step off the page' and they try and see what's important to them. The use of language, trying to learn the system language is like trying to beat people at their own game.

I was fortunate enough to work under a consultant on the ward who was very enthusiastic about peer support. It felt really important for me that she had my back, and she was championing and I think that did help shape things a bit. My colleagues and I had a very supportive and understanding line supervisor.

When everything was online it was so vital for us that we had our first away day; just getting in the same room and having all those chats, socialising and building trust.

In my current role, having access to a higher level has put me in a position to try and sort out helping to improve the situation, prepare workers on the role that I used to be in, bringing some of that learning about some of the real knotty problems that come up.

For me... it's just seeing peoples' experience validated by their experience of peer support. I've seen that be really powerful.

I've seen expansion of peer support into a different kind of creature called Open Dialogue I think that's a brilliant way for the statutory system to be willing to give up its power and control and be much more human and much less data driven.

I have heard service users talk about their experience of peer support as something that made them feel understood because of the shared experience. I usually hear that people feel less lonely. And for me on a personal level it makes a difference if I'm not being judged.

I don't want to be defined by some difficult things to do with depression that I experienced in the past. There are ways of recovery and I'm here not being judged as being unwell, as being someone who can recover.

Being able to use my own life experience to support others and get a positive outcome, that makes me really happy. I get asked, do you ever stop? No, I don't stop, I was thinking of ways to support people. And that's the thing for me, when somebody said, you really helped me, (and I'm not being a show off when I say I get a lot of that). People say you've helped me you know. I'm really pleased about that.

I speak to people [as a volunteer on a crisis line], especially men; they've tried to commit suicide. When you share your experience, sometimes I can sense they feel it's not only me that's going through this. Then he starts to ask questions, so how did you know what to do, and then it was ok. I say please breathe in and out. He's trying to commit suicide... and then we're talking, I'm just trying to get information.

I'm really about other committed people in the Collaborative. Knowledgeable people, experienced people, hearing people's stories. That was really important and inspiring. Denis was the commissioner, a driving force and initiator. I mean we wouldn't be here without him. I think people in spite of setbacks are trying to stick to the bigger idea of the bigger vision that we have. So far not losing hope. I think especially in the beginning we did have a bit of money and we managed to get together with flexibility and openness, to try some ideas, to listen to what people were saying would help and that was a bit of the engine at the beginning. We were really committed to working on the basis of what people said was needed to make things better.

Work life, great supportive environment, learning from other peers. Good training which developed into more self-awareness. A general feeling of just doing good. Personally, I think in the beginning of my diagnosis I was just rushing around trying to get jobs, trying to be like normal, what my friends were doing. And then suddenly they were starting to get married and kids I'm thinking like oh shit, I'm behind this already, so then I started to chill a bit, got a dog. That was an amazing 10 years. The dog was there for me.

I think getting involved with people who empathise; they ask how're you doing and you say you're struggling but they're still there. That meant a lot and meant I could travel. I walked across Spain [the Camino Santiago] three times and the good thing is you have a

thinking there's no help so learned to cope alone. "[The anchor] is not being able to ask for help, having trust issues."

"Being unable to reach out for HELP!"

Risks & Rocks

A carer with mental and physical health needs said: *the system is not self-reflective about why they fail*

Stigma:

Everyone will have some imbalance at some point in life and some think psychiatric when they hear the word mental health

The police:

the Police don't know what they are doing as they put all people in one basket

Are the police still going to come out to mental health cases? What's happening now?

On the ward:

There is no therapy [in hospital]. People on the ward get bored because they don't have anything to do.

...[Experienced] Acute Kidney Injury on the ward. Not given enough water, nearly died. King's A&E saved me!

Experience of racism, lack of cultural competency:

There was racism on the ward. Staff struggled to understand people whose accent was not British...like French and Polish people.

There's a lot of racism and discrimination. Need to teach about racism from a very young age.

NHS staff need to be more culturally aware and change the way they make treatment available. You are well when you fit in their model [of care].

Racism, discrimination, not fitting in being wrongly/badly judged.

Judging people by what someone thinks they should be like doing not by what they really are!

Inflexible services:

People don't get much support if you don't fit a particular model or diagnosis e.g. people with a drug addiction don't get wrap around support and physical health is not treated at the same time.

There is pressure to achieve a particular goal at a certain time in your life. If you don't

achieve, there must be something wrong with you, you have failed, but there are factors beyond our control so it should be OK if you don't achieve that goal. For example, material things are not so important. You have to do what is right for you.

The support wouldn't extend past three weeks. Referred to the Mental Health Team but refused. Kept sending letters.

Long waiting list for therapies; 18 months to 2 years.

18-year-olds classed as adults, so we run into 'privacy'.

The benefits system focuses on being/staying well, especially when on contributions based as you need to be 100% well before being able to try coming off as you can't get back on benefits if you relapse.

Not being able to advocate for yourself or have somebody to advocate for you.

Not being believed when I'm starting to be unwell leading to no help quick enough and ending up being sectioned.

Crisis:

[Adult child] onto the crisis line and they put the phone down three times. Their advice was to drink milk, listen to music, and don't sleep all day.

We rang Lambeth crisis line who serve 4 boroughs, you can't get through. It's the same number for all 4 boroughs.

The crisis plan doesn't get followed, it's me, the mother who rings. They come, lovely, but [adult child] doesn't engage so they can't help. [They've] been handcuffed, referred to the mental health team for three or four weeks and then they refer you on. Bad communication, lack of continuity. Wrong medication from the mental health team. They wanted to leave [adult child] for three nights without medication because they couldn't drop them off.

We couldn't access the night support.

When I rang 111, they said ring ambulance or police, but the police can only Section in the street not in your home.

The only options were Lambeth Home Treatment Team (LHTT) or A&E or being sectioned.

A&E has loads of mental health people there, there is no alternative, except a Section 136 [of the Mental Health Act].

15 to 18 hours in A&E because there's nowhere else to go.

If an ambulance comes, [paramedics] need to be gentle with you. Ambulance staff need to

be trained in counselling and supporting people who are in distress. Also, the issue is that staff are not allowed to touch the person.

Being restrained on several occasions, never ever justified and BADLY HURT each time.

Police should not be the first place to call for someone with mental health crisis as that makes it worse.

Gaps, lack of continuity, poor communication:

Lack of access to early intervention. At hospital, it's too late!

NHS feels fragmented, mismanaged, and inefficient, too easy to slip through the net.

Appendix 1. My journey of being bipolar

A service user who was unable to attend the discussion groups shares their own story

Having had multiple hospitalisations since 2005 and being diagnosed with bipolar in 2007. I felt traumatised, confused, lonely, isolated, shamed, shocked and angry.

Luckily, I have been admitted to hospitals locally, so family and friend have been able to visit me. As a result of being admitted into a mental health ward in a crisis (for me being manic or depressed) you are already in a state of confusion and utter terror of what lies ahead.

For me being admitted and sectioned has happened sometimes in the middle of the night. On two occasions the police have been called, as a vulnerable adult gone missing or refusing to go to hospital.

Once being psychically carried out of my family home. Another incident the police stopped a bus which I was on.

As a person on a mental health ward it is a very scary, loud, lonely, difficult and isolating environment to be in. Obviously on the ward everyone has different and individual care needs, but we are all locked in together.

The main problem is a lack of staff and lack of activities and structure. There are activities on the ward, but only for one hour a day. So I have participated in groups from Art therapy, music group, cooking, smoothie making, tree of life workshop, and even cute little dogs to pet and stroke. Unfortunately nothing happens at the weekend.

The only structure in a NHS mental ward is mealtimes 8am breakfast, lunch 12pm, dinner 5pm, 10pm supper. You look forward to this, but as you are now on new medication like mood stabilisers, which notoriously gain weight, you inevitably leave hospital bigger than when you were admitted. When you commence your new life after being in hospital, you most likely need to lose the weight you have gained.

Luckily, I have had family and friends support, love and care. My parents, brother, cousins and friends have all visited me in hospital. And unfortunately, that is still a rare occurrence for other patients.

As there is a lack of physical space, one hospital had only one waiting room for all carers and patients during visiting times. That means there is a total lack of privacy, and lack of provision of care that visitors and family need.

Recently having had a diagnosis of breast cancer and have gone through surgery, radiotherapy and chemotherapy, I can say there is a difference in care for cancer patients and mental health.

Cancer is now a subject that everyone can talk about, whilst mental health is still hidden, although slowly it is getting a bit better.

As a result of being admitted and sectioned in mental health hospitals, you lose any rights. You can't refuse medication, which to my detriment in the beginning of this journey, I didn't know. As a result, on my first admission was forcibly injected many times with a whole team taking me down.

Because, you have been admitted under crisis and difficult circumstances, you were no longer deemed to have capacity. You can't leave hospital, all and any leave from hospital must be signed off by a doctor. There are only nurses on duty 24/7, whilst doctors only attend during their visiting hours.

Admittedly, staff do their best, but there was a lack of staff during each shift (whilst I was on the ward). It meant that visitors were left outside, waiting, to be able to come in, to this locked ward. Also as a patient, sometimes you were not able to use your escorted leave with staff, because there was not enough staff on the rota. Staff were not available to leave hospital with you (you first get escorted leave and then build up to unescorted leave).

I think that at times there was a lack of respect, as staff saw you at your very worst and every one of the patients in the ward needed individual care and attention. Support that unfortunately does not exist in underfunded, underpaid and understaffed mental health wards.

Every time, I have been admitted and then released "back into the community" you have to start all over again. You have been institutionalised by the routine and semi structure of hospital life. You have to pick up the pieces and come to terms and recover from having been in one of the most scariest and traumatic environments ever. Once returned to "normal life" there is a different level of care for patients.

I have had CBT, mindfulness, Occupational Therapy, an excellent psychiatrist at Optima (a specialist bipolar unit), talking therapy and a number of care coordinators over the years. Only a few come to mind who have been extremely helpful at times. Unfortunately, there is no continuity of care; there have been a number of psychiatrists on a 6 month rotation. I now have a care plan, which shows some of my triggers and how to deal with them, when depressed or manic.

Peer support has been very valuable for me. I joined an organisation called Vital Link, funded by the then, Lambeth Primary Health Care Trust and delivered by Metropolitan Support Trust. We were a group of service users who had mental health experiences. We learnt what was happening in mental health services and our views and experiences were used.

One step led to another, through Vital Link I did a research course at South Bank University, I wrote a report on the Tree life workshop and marked course work for peer supporters to gain a certificate.

I was also on the SLAM Involvement Register, the Trust wanted service users' participation and views. I sat on interview panels for the trust and assisted in the appointment of staff. I was also involved in interviewing service users who had participated in the GOALS therapy (A way for service users to attain and reach their goals)

In conjunction, with this I was able to receive social housing, having been in a hostel. This meant independent living again. So having sorted out housing, some work, some therapy, and some, which included exercise, I walked, went to the gym and swam. I was able to access a fund of money that allowed me to buy a new bicycle. Also I had free circuit training and reduced gym membership, as well as dietary courses.

I realised I still needed some purpose and other goals and I have been doing some voluntary work regularly. I worked at the National Trust at Morden Hall Park, I worked at the Horniman museum, I am still working at the South London Botanical Institute and at a Cancer Research charity shop.

The next step for me was being creative. I use oil pastels to paint flowers; I have done a pottery course, basket weaving and a jewellery making class.

Peer Support for me was beneficial and helpful. At one point I had OCD and I didn't want to leave my flat, because I thought I hadn't locked the door properly or the gas was still on, or the windows or doors weren't closed. Luckily I received peer support, from a support worker. She would come to my flat and I would have a weekly session to work through my issues and problems. She even helped in completing my PIP form.

Recovery, I'm not sure you are ever completely recovered. However I think having a loving and supportive family and close knit friends around you. Obviously self-care, exercise, sleep is key and a big priority, goals, work, interests activities.

For me I've need a combination of love and support, goals and aspirations, voluntary work, to learn new things, therapy, being creative, being "nice to me", leisure activities and ultimately being able to enjoy life.