Community Mental Health Framework

Discovery phase

Engagement undertaken in Bristol, North Somerset and South Gloucestershire between December 2020 – January 2021

Full report

February 2021
This version v1.3

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1. **Foreword**

We are living in unprecedented times, with many challenges and changes going on around us all. For mental health support, this is no different. Additional funding coming to mental health support is welcomed, and also an opportunity to assess what is working well, what isn't and what needs to change. Some of what needs to change we already know, following years of people with lived experience of mental health problems stating the key issues and how we can move forwards.

The *community mental health framework for adults and older adults* [1] *is* an opportunity for us to implement what we already know and ensure new funding coming to local health systems is spent in a way that will make a fundamental difference to the lives of many. It is an opportunity to hear more voices and truly 'co-produce' with people with lived experience of mental

health problems, ensuring those holding decision-making power are sharing that power and going beyond merely consulting and engaging.

The framework covers five key areas:

- Eating Disorders
- Mental Health Rehabilitation
- Personality Disorder / Trauma Informed Approaches
- Transitions (Young People / Adults)
- Transitions (Adults / Older Adults)

This report brings together additional engagement we have done across these areas as an organisation run by and for people with lived experience of mental health problems, influencing what the implementation of the community mental health framework looks like locally. It identifies many key themes that need to be addressed, many that build on what we already know, with others adding new ideas. It will challenge thinking about how

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[1] https://www.england.nhs.uk/publication/the-community-mental-health-framework-for-adults-and-older-adults/

support can be delivered in creative ways that also address the [wider social determinants of health](#), [2] which we know can have such a fundamental impact on a person's wellbeing.

This is just the start of the work and it will remain vital to ensure people with lived experience of mental health problems remain at the heart of the work, bringing to life and giving meaning to rhetoric of 'patient-centred approaches' and seeing people as the whole person.

Thank you for taking the time to read this report and do get in touch with the team if you would like to discuss any aspect of it or get more involved in our work.

Thomas Renhard

Thomas Renhard
Chief Executive Officer
Independent Mental Health Network
February 2021

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[2] https://fingertips.phe.org.uk/profile/wider-determinants

About IMHN

IMHN is a user-led organisation bringing together individuals and groups from across the Bristol, North Somerset and South Gloucestershire area to have a collective voice in improving mental health services. IMHN work hard championing co-production, innovation, openness, inclusiveness, honesty and building high-trust relationships where voices of those with lived experience are truly valued and empowered.

Our belief...

We believe that with one in four people being affected by mental health problems each year, it is vital that services are providing the best possible care and access for patients. We also believe that there needs to be more parity of esteem between mental and physical health, and that stigma surrounding mental illness must be challenged.

Our vision...

To have excellent and improved mental health services that listen to everyone who has used; is using or intending to use mental health services across Bristol.

Our mission...

Promoting an effective voice to improve mental health services for all.

Our values...

- **Inclusivity –** being open to all people with lived experience of mental health, regardless of their age, gender, race, sexuality, ability or religion.
- **Bravery –** speaking out, sharing our experiences and making sure our voices are heard.
- **Respect –** listening to others' mental health experiences without holding any judgement.
- **Determination –** ensuring mental health services meet the needs of users, and worthwhile change is created in our local area and beyond
- **Innovation –** creating lasting solutions for improving access to mental health services across the area

For more information please visit:
http://www.imhn.org

Email: **engagement@imhn.org**

Methodology

This programme of engagement consisted of both specific focus groups looking at a particular aspect or area; followed by a wider *Mental Health Conversations* event bringing all our findings together.

Focus groups were lived experience-led, with mental health professionals in attendance to support the discussion and provide background or clarification if required. Each group was facilitated by a member of the IMHN team, ensuring the discussion remained open, honest and safe for all to contribute and share their views.

The timetable of focus groups and number of attendees can be found below.

- **Peer support approaches** (session one of two): Tuesday 8 December 2020 (17)
- **Trauma-informed approaches** and personality disorders: Monday 14 December 2020 (15)
- **Transitions of adult care to older adult care:** Tuesday 15 December 2020 (11)

- **Mental health rehabilitation:** Tuesday 15 December 2020 (18)
- **Eating disorders:** Wednesday 16 December (9)
- **Transitions of children and young people to adult care:** Thursday 17 December 2020 (12)
- **Trauma-informed approaches and personality disorders** (session two): Monday 21 December 2020 (7)
- **Peer support approaches** (session two of two): Tuesday 12 January 2021 (12)

Each session was recorded for the purpose of writing up the discussions. The write-ups, reproduced in appendix 1, captured the themes and experiences that people raised, without being verbatim transcripts.

The *Mental Health Conversations* event took place on Monday 5 January 2021. A full report of this event is included in appendix 2.

We also invited written submissions. We did this as we recognised that not

everyone was able to attend either a particular focus group or the set date for the *Mental Health Conversations* event. Additionally, discussions about the topics were reflected on at both the Bristol, North Somerset and South Gloucestershire Mental Health Lived Experience Steering Group; and LGBTQ+ Mental Health Lived Experience Steering Groups. These are groups of individuals that provide a lived experience view into local mental health system transformation and service improvement.

Executive summary: key outcomes and recommendations

This executive summary covers the key findings from the discovery phase. The conversations and dialogue were rich and nuanced, and we must remember that everyone's experience of mental health difficulties is unique to the individual. In summarising the outcomes and recommendations, this is taken into account.

Eating Disorders

1. People with an eating disorder diagnosis, or disordered eating, may present very differently. Services and professionals must be able to look past stereotypes and typical key indicators (the example of the body mass index, or BMI measure, was cited) in identifying whether a person needs support. Many factors can be missed in a primary care setting, and referral pathways must take account of this. Criteria-locked views can impact a person accessing the right care at the right time.

2. It was also recognised that a person who has received support to address an eating disorder may need care after becoming 'well', in order to address the trauma of the disorder.

3. High thresholds can result in support being difficult to access, particularly if a person appears 'stable' or 'normal'. The value of lived experience in professionals, (for example, dieticians) was particularly recognised as a way of overcoming this.

4. Peer support in particular can be greatly effective, but in the right setting. Experiences were shared where peer support for eating disorders in a community setting actually exacerbated a person's condition, whereas peer support within an inpatient setting can be hugely helpful.

5. Specific lackings in the local system were also raised; for example Bristol's lack of a day-patient service for eating disorder.

Mental health rehabilitation

6. Service inflexibility, and inequality of access across the combined Bristol, North Somerset and South Gloucestershire area, was a key aspect of discussions about mental health rehabilitation services. A person-centred, 'no wrong door' approach, and improved outreach, was strongly advocated for.

7. More specifically, meaningful activity, and the importance of focusing on life skills; as well as improved criteria and systems for identifying those needing rehabilitation, was recommended.

8. Integration of the service within the wider mental health framework was also considered.

9. It was emphasised that for some people, living with mental health as a long term condition is a reality; and this needs to be through of as rehabilitation - i.e. *if life is liveable - that is rehabilitation.*

10. There was a feeling that 'discharge as soon as possible' should be moved away from. Time and flexibility is key, so that individuals can meet their personal needs rather than the limitations of what a service considers 'recovered / functioning'.

11. In this topic area, more than any other, the discussion about 'recovery' as a concept was most present. Viewing rehabilitation as a journey may make individuals feel as if they had failed if they didn't reach the 'destination'. Services must promote hope and create an environment where people can recover, no matter what 'recovery' means to an individual.

Trauma-informed approaches and personality disorders

12. Trauma-informed approaches have been the subject of much recent work. It must be recognised that these approaches are applicable to all aspects of all mental health support. Additionally, there is much relevance of trauma-informed approaches to supporting people with diagnoses of personality disorder. However, it is essential that the two are not seen as synonyms for each other. Personality disorders often involve an aspect of trauma; but that does not mean that trauma implies a personality disorder.

13. It was felt that organisations that provide support must be trauma-responsive, and not just be trauma-informed, from the 'front door to senior managers.' They must do this whilst also recognising that people often have lasting trauma from accessing mental health support in the past. Training to embed this must not be seen as a tick-box, but must be understood and championed by all staff at all levels in a service.

14. The stigma, and common misunderstanding of personality disorder diagnoses, was recognised as being present and persistent. We must ensure that a diagnosis of Emotionally unstable personality disorder (EUPD) is not solely considered, as this can often lead to inappropriate care pathways.

15. If people are presenting with symptoms or behaviours associated with another condition, there is a culture of it being 'a given' that symptoms/behaviour associated with a personality disorder means a person will be in services for the long term. Additionally, first-hand experience was shared of treatments that someone may be receiving changing abruptly when a diagnosis changes from/to a personality disorder.

Transitions: support for young people transitioning to adult services

16. The experience of the CAMHS (Children and Adolescent Mental Health Services) 'cliff-edge' is well documented, and formed a large part of discussions on this topic.

17. Inflexibility of pathways, for example referrals from GPs being 'bounced back', and mis-referral to CAMHS instead of specialist teams, were cited. A lack of onward signposting and information was also recognised, meaning that parents in particular are unsure of how to proceed.

18. The voice of young people needs to be heard in conversations, in order to ensure that the right support is available in the right setting. For example by working with, and delivering intervention in, schools/colleges and universities

19. Additionally, there is no place other than a hospital setting available for young people experiencing a mental health crisis. This, amongst other things (including out of area placements) impacts on the trauma experienced by many young people when received care, that will act as a barrier when accessing support in later stages of their life.

20. There is a lack of knowledge of ASD (Autism Spectrum Disorder) among mental health professionals, particularly in young people's services. Transitions of care can be particularly hard for those with ASD. Not addressing or recognising these issues may cause a person to disengage with support entirely, meaning that a person's mental health may continue to worsen.

Transitions: adult to older adult care

21. Above all, treatment during different stages of the life course is definitely not a 'one size fits all' situation – we must not assess what care people should receive solely on age boundaries. People will need different responses at different times in their life, based on their own experiences. An inter-disciplinary model should be adopted in order to achieve an 'ageless' model.

22. Change can of course destabilise; age must therefore not be treated as a threshold where the needs of a person suddenly change. We must recognise the things that might have happened during a person's life course; for example prison, substance misuse, children; whilst also recognising the needs and issues that exist within marginalised/harder to reach communities.

23. The involvement and support of GPs - as GPs can pick up on changes in people's lives that may affect mental health – was discussed. Additionally, we must encourage a sense of mental health awareness in both older adult services and acute hospitals.

24. Other specific aspects of mental health support were considered. Digital support can represent exclusion and barriers to those attempting to access support. A lack of specialist expertise for adults with serious mental illness was cited. Utilising other pathways, such as social prescribing, was identified - information is important. The use of language was discussed; for example, 'frailty' can mean different things to different people.

Peer support

25. As a mode of support, peer support was present across all discussions. Indeed, the finding was overwhelmingly that peer support can be greatly effective, but needs to be done properly in order to serve its intended purpose.

26. From an organisation's point of view, peer support need adequate resource. It cannot be seen as mental health done 'on the cheap', with proper provision for supervision for people across all roles required.

27. The unique offer that peer support has must remain central to its delivery. People felt that being supported by other people with common experiences; rather than a professional saying 'what's best for you', was extremely valuable. Other principles, such as mutuality, equality, shared experiences, respect, an 'open door' approach, and non-judgemental acceptance and understanding within groups were also seen to be essential.

Themes present across all topics

Professionalisation of peer support must be avoided to retain these aspects; however people recognised that certain elements (such as safeguarding, training, and facilitation) are required for delivery of peer support within organisations.

28. In many cases, people shared experiences where peer support, that did not specifically focus on mental health, were the most useful. Peer support represents the opportunity to actually speak to peers, maximising the value of interpersonal relationships; and operates on a spectrum – it is unhelpful to try and use peer support to solely focus on 'fixing' things.

29. People felt that it is currently seen that a person can't become a peer until they are 'recovered', 'well', or 'out of services'. This is not the case – being a peer is rewarding and validating.

30. Mental health stigma is still present and impacts on people accessing support, or receiving a mental health diagnosis.

31. The needs of marginalised or harder-to-reach communities in Bristol, North Somerset or South Gloucestershire must be taken into account as a fundamental of transformation. This includes, but is not limited to, the needs of the LGBTQIA+ community; Black, Asian and Minority Ethnic communities; and Bristol's Somali community.

32. The mental health and wellbeing needs of transgender people remain misunderstood across mental health services and support.

33. Support and referrals are complex and confusing. This means that parents, carers, and people close to those with mental health needs often find it difficult to support them in accessing and receiving mental health care.

Appendix 1 – Focus Group writeups

Each focus group followed a similar format. Each session opened with a round of introductions from lived experience participants, professional in attendance to support the conversation, and members of the BNSSG CCG team.

A member of the CCG team introduced the Community Mental Health Framework programme. The discussion was then opened with the facilitator posing a question to the group, with additional follow-up questions posed depending on the topic.

Each session closed with a member of the CCG team explaining the next steps of the programme.

In each write-up, questions posed are marked as headers. Statements in bold type capture a theme of the conversation, with corresponding remarks included beneath.

Writeups are presented in chronological order from when the focus group took place.

Abbreviations used in focus group writeups

- **AMHS:** Adult mental health services
- **AWP:** Avon & Wiltshire Mental Health Partnership NHS Trust
- **BAME:** Black, Asian and minority ethnic
- **BMI:** Body mass index
- **BNSSG:** Bristol, North Somerset and South Gloucestershire
- **BPD:** Borderline personality disorder
- **CBT:** Cognitive behavioural therapy
- **CCG:** Clinical Commissioning Group
- **CIT:** Crisis intervention team
- **CMHF:** Community Mental Health Framework
- **CPA:** care plan approach

- **COVID:** coronavirus (COVID-19)

- **EIP:** Early Intervention in Psychosis

- **EMDR:** Eye movement desensitisation and reprocessing

- **EUPD:** Emotionally unstable personality disorder

- **GP:** General Practitioner

- **LGBTQ+:** Lesbian, Gay, Bisexual, Transgender, Queer

- **NICE:** National Institute for Health and Care Excellence

- **OTR:** Off the Record [3]

- **PD:** Personality disorder

- **PTSD:** Post-traumatic stress disorder

- **RiO:** AWP's clinical records system

- **SCM:** Structured Clinical Management

- **SMI:** Severe mental illness

- **STEPS:** AWP's eating disorder service

- **VCSE:** Voluntary, community and social Enterprise

An interactive glossary with more terms can be found at:

https://www.imhn.org/imhn-guidance/glossary/

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[3] https://www.otrbristol.org.uk

Peer support approaches (session one of two)

Tuesday 8 December 2020

Question 1: What does peer support mean to you?

Understanding that it can be a range of models, styles and people

It means lots of different things. It's acknowledging the different types of peer support as well. Some of it is in the voluntary sector, some of it is unpaid. It's going right from people who've got common experiences, almost in a friendship. Or people mentoring and doing one-to-one. Or more structured, intentional peer support where it's mutual.

The peer support service that I'm involved in offers a lot of different types of peer support. Not just physical activities but also more focussed sessions around particular topics where people share experiences as members of a group. So it's not a professional telling you what is best or might work for you, it's people who have actually experienced the same thing. It's kind of sharing things that have worked for different people. Services are often telling you what to do but this is offering solutions without expecting you to follow it.

For me, it's the physical side of peer mentoring. I really miss the swimming. And the walk and talk is really good. And the book club is good, because after the group discussion, you have a book to read, and I find reading quite therapeutic.

Peer support can be a spectrum, it's not just about external groups or organisations.

Providing immediate accessibility

I have been using the services in Clevedon for over 15 years. It was better with how it was originally. It was always open and you could go in without a pre-booked appointment. I had somewhere I could go, when I needed to, where the door was open. You could chat to whoever was there or not chat, whatever you wanted to do. I miss that face-to-face. I know that COVID has changed everything, but the changes to the services available has restricted me and had a negative impact on my mental health.

Peer support is a lifeline where you can go somewhere where you can just turn up and speak to peers, people in volunteering roles and get support when you need to. That's really important to me.

Embracing mutuality of experience

Also it's the mutuality of it. It's rewarding and validating to be able to share with somebody else who has the same experience and to help them. To me that helps yourself as well. So I think it's a role that can switch between peers.

There is an expectation that you can't become a peer until you are recovered and well. But one of the things we really value is that sometimes we are able to offer support and other times we could receive support as well. That was really valuable.

I have relied on mental health services all my life. And prison services and social services. So here is something that is kind of like an organic role. To say that someone has to be a year free of say substance or something like that says that they have no value. That's not a good way to look at it. I think that everybody has got a value.

Someone doesn't need to be out of service to be a peer. Good wellbeing support and policies for peers can be provided instead.

For me it's making the systems more human, connecting human to humans. Making friends, making relationships. That's what lost in our systems. And I think that we currently take someone with lived experience, and we train them to a 'bigger system' way of thinking, but then we lose the essence of what they can provide on a basic human level. So it's less about structures, procedures, boundaries and policies; all these terms that even I am still getting my head around and I've done a degree in it. It's just that real human connection and that ability to listen and to be with and empathise. Those skills that supporters already have, real life human-ness.

Another strength for me in peer support, which isn't the same as in support groups that are not mental health, is that I've found people to be accepting and understanding, as they've been there themselves. It's ok in the group if you're having a bad day, you don't feel judged, or dismissed.

What is great with peer support done well is that it is made up of people that are willing and able to be real. Therefore, I believe they will represent all. I think many 'professionals' represent us but are not able to share due to policies, procedures and restrictions.

Validating the role of peer supporters

The ambition is to have 4700 peer support workers across the areas. It's a question of where it all sits. Will the competence framework be embedded, and will the importance of people who take up these roles be reflected in salaries that are not taking the mickey by paying them Band 2 or Band 3? Otherwise we are just going to get issues around recruitment and retention. I hope that there will be the aspiration of a career, and not just a flash in the pan. Like Healthy Living Centres. They were funded for three years, then the community had to find the funds to keep them going.

Around peers being employed, will the funding cover people employed by the NHS as peers? There is a wealth of experience and resourcing within voluntary organisations. I think it's really important for peers to be valued and their roles to be really defined. So that it doesn't just become a cheap resource to provide kind of whatever project assistance or whatever. I think that there a whole issue around boundaries as well which can be raised.

Regarding the Mental Health Peer Support Work Competence Framework, providers should start to embed the Framework in their practice or better still made this a contractual requirement.

If we use the term Experts by Experience, it can empower and encourage peer support workers to be open.

I draw huge benefit from the Community Rehabilitation Service, with a dedicated Peer Support Worker. In terms of my care, he was held with the same importance as the rest of the care team. I think that now is an opportunity to really get services to get more of that. In crisis services, this happens as well. So it would be a missed opportunity if we didn't build on that.

Employed peer support workers need to feel supported to feel confident about sharing their lived experiences. They need training and guidance from the organisations as peer workers.

This has been identified as a challenge by other NHS mental health trusts. Where peer support work is a paid role, some policies/procedures/restrictions can be barriers to peer workers sharing experience and being open.

Engaging with hard-to-reach communities

To make a success of this with people who are had to reach, people of colour, people from diverse communities, how do we engage them so that they achieve positive outcomes? How do we get those communities together so we help them? Unconscious bias plays a part in all of our lives, in where we are comfortable to talk about mental health, who we're comfortable talk to. And biases play into that.

Regarding exclusion and accessibility, groups and communities can't be expected to come to the service if there are barriers. We need to go directly into those communities proactively and have those conversations.

Dealing with conscious and unconscious bias

With unconscious bias being a barrier, can these be surfaced and written down, especially by those who face them so we know what to tackle. Maybe someone has done that? Tackling them should be included in training.

Gatekeeping is where conscious or unconscious bias is a barrier. We should always look at gatekeeping as something. Is it necessary, can it be removed?

Implementing models that are joined up, effective, sustainable

For me, one thing that has always been missing is that there is not a clear productive kind of marriage... that kind of realises that peer support cannot be defined as just about mental health. Sometimes it's mental health and drug abuse makes it worse. There is no joined up model. I hope that peer support does not end up being like mental health teams and drug teams are like, they are not married up. You have to tell your story ten times, that type of things. This has been spoken about many times. We have these little initiatives, but whether that becomes a sustainable thing for communities, that's another thing altogether. We are in a period of time where we can be creative and take some risks in the way that we think about these problems and the way that we approach them.

I wanted to talk about communities and co-creation, making things that service the community. And making meaningful activities that would improve people's mental health. And we are very keen not to be seen to be taking risks, but to empower people to co-create their own systems and activities to support themselves, and that are meaningful to their community. So we are not just a service provider, with solutions dropped in from on high.

Ensuring that service providers listen and respond to service users

When they closed Clevedon, we were given three months, with no idea what would happen after those three months. All the services users got together and as a powerful peer support group in action, we fought for the right to access a local wonderful mental health service. But the CCG were ignorant, rude, disrespectful. They kept cancelling meetings at the last minute, and they didn't really listen or sympathise.

Regarding telling your story more than once, often repeating the story, here is where Personalised Care Support Plans can come into place.

Ensuring continuity of support for users

What I'd like to see is something that would really develop within the local community, not just a drop in service. There is a lot of mutual feeling around having to repeat your stories, and I know that one. Personally I'd like to be able to develop my story and move on from having to repeat, so I have a different story to tell. And peer support could be a valuable way to help do that, simply by when you're having a shared experience. I am talking about 15, 20 or 30 years of peer support. I don't want just a couple of years out of it, I want to make lasting connections within my community.

Supporting and empowering supporters

It's not just about having a membership of a group but also having correct facilitation for peer support. And offering guided peer support around specific mental health issues and needs. So not just an open space where people can have coffee, but something pro-active to help people with support in their particular mental health needs, and actually helping them to recover.

What I see as the barrier to problem solving when being a peer mentor is where the power is. Things like accessing services, benefits, getting work, housing. The power is with the authorities who make the decisions.

And the peer mentor is in the position of having to plead the case for someone while not being empowered. Services don't give support workers power; it has to be taken by the peer mentor. And that can't be done by them on their own. So in funding, there has to be a strategy for empowering the peer support workers to pitch in on behalf of the person they are supporting to solve their problems. A lot of the mental health issues don't get remedied because they're caused in society such as unemployment, benefit medicals, things that cause untold stress. Peer support organisations should be able to take authority to speak on behalf of mentees.

Part of a holistic approach

Its important to have activities that underpin therapies. We talked a lot about gardening or other social activities, walk and talk, that kind of stuff, where there is another focus other than mental health. That was really important. We spend our entire lives kind swimming around in this mental health thing and actually you need to distract your mind from it a bit, that is a really excellent thing.

Six sessions of Weight Watchers is not NICE approved. We are getting away from what supports people. It isn't going to be the medication that's going to support people. It's what peer support workers can offer in terms on engaging and networking within their community, looking not at people's deficits but strengths and connecting them with their interests and that. That's where the Personalised Care Support Plan would take over from the care plan approach (CPA). Ultimately personalised plans will give someone a plan around their holistic wellbeing, rather than the one-focus CPA. But I'm concerned how that sudden transition will occur. Nobody is picking up the figures, so how can we scrutinise this plan?

Having a place of non-judgemental acceptance

Being in a support group where you can actually help other people and give non-prescriptive advice is empowering. Even though you might be suffering at the time, you help others. Because everybody is the expert in the room. That is where I see peer support in group form works the best. The non-judgemental aspect of a peer support group is just so important. You just feel accepted for who you are.

I have found in mental health services, statutory services, even primary care services, is that people don't have the time to actually sit with somebody, through their distress. Not trying to fix it necessarily. As peers sometimes we struggle, but usually it's wonderful for someone just to sit with you and hold your hand and listen. Just having that level of tolerance. A lot of health professionals really struggle with just sitting with distress. They feel like they have to fix it. But I feel accepted in peer support groups they can accept that, and that is so important.

Question 2: What does good peer support look like? What does maybe 'not so good' peer support look like?

A safe space

I've had a few different experiences with peer support. I have noticed that the best support that I've received hasn't been intentional. I've done a lot of almost prescribed groups around bereavement peer support, but in terms of mental health, especially youth services, I have found that the best support is when it's not intentional. Or at least you, as the service user, don't know it's intentional. In groups, it's facilitated by the users themselves, and that creates an opportunity to get rid of some of the barriers that some people have when engaging with support groups. When groups are not official, but happen anyway, it's a nice balance with more official mental health services and formal support groups. They can feel intimidating for a different reason, if that makes sense. But that balance creates a safer space.

Authenticity and mutuality of experience

The workers that I connect with often have lived experience themselves, but there are a lot of barriers around being professional. And safeguarding and stuff. This means that they can't always be as open as it needs to be. Talking in a peer support group means that you don't have to worry about those barriers in quite the same way. So that makes it easier to have honest discussions.

Authenticity in peer support is extremely important. Having professionals in that sphere with lived experience to actually be able to share that experience, done properly, can really enhance peer relationships and community relationships. Because it gets rid of that sort of negative power dynamic of the professional and client. So it's about humanising it.

Inclusive of all communities

What needs to be addressed when it comes to good peer support is around health inequalities and diversity. I have been banging my drum for a few months now about marginalised communities not getting the support that they need during this time, having not received it for quite sometime. I am specifically representing the LGBT+ community, but there are also the black and ethnic communities, communities of people with specific disabilities, autism & Asperger's communities, communities of people living with HIV. These communities are not particularly well represented at the moment. Part of the work done on the LGBT Steering Group is to bring this to the attention of organisations, CCG and NHS services. Anything to do with the Community Mental Health Framework needs to have a keen eye on how marginalised groups are actually supported through this.

There is a real issue around diversity and making sure that organisations make sure that we have a really diverse range of supporter peers as well. Because it was mentioned earlier, about how important it is to see that kind of mutuality and solidarity in a peer relationship. If you have a diverse range of people, then that will help a diverse range of service users.

Inclusive of a wider spectrum of mental health issues

With marginalised groups, there is the question of what is deemed enough mental health illness to be part of a group and get support. There's a lot of gate-keeping when it comes to accessing some support and some services. Serious mental illness is a specific term for a set of very specific conditions. Those aren't the only mental health conditions that exist. It depends on the person's experience. They could have serious mental illness as defined by clinicians, but actually to be doing OK. But there could be others like myself who don't have serious mental illness as defined, but are actually really struggling. So the concept of serious mental illness needs to be carefully considered so that people with any mental health issue are not excluded because they don't fit into that category. Peer support could help facilitate that quite a lot, but there is a need to be cautious and not load peer support with all the stuff that mental health services won't deal with, because it's not part of their criteria. It's about addressing the current strict rigorous criteria and making sure that people aren't excluded because they don't fit the opinions of clinicians.

If gatekeeping is removed I don't think services and support will be overwhelmed. People might access lots of services and support but will settle on those most appropriate for them and when they need them. So they gate- keep themselves.

Wider integration with all mental health services

The current mental health services other than Crisis Care Service and things like Recovery and Early Intervention Psychosis, what you see is a service that predominantly works Monday to Friday, 9am to 5pm. I would never suggest that the hours should be extended, but there is something about how peer support workers could integrate within crisis care services. This is mentioned within the Community Mental Health Framework. Peer support workers can be a bridge when there is pressure on services. It just needs a bit of lateral thinking about how evenings and weekends can be catered for, how services can respond to people's needs.

GPs often don't refer or recommend peer support when seeking help for mental health support. I think it's something that professionals often forget exist or don't view it as worthwhile support.

Not enough GP's are aware of the support in the community and don't recommend peer support enough. Peer support can prevent the use of other services and hospitalisations.

Good peer support should include anyone who self identifies with whatever the common experiences are.

Peer support around trauma can work in a lot of different ways. Sometimes it's a talking group (which needs proper facilitation) but it can also be more around creative groups, outdoor groups, and activities which help trauma processing in a mutual setting.

Peer support is about prevention of crisis. But CCGs feel that preventing crises is really boring; it's harder to measure outcomes or understand the actual work. So many times we get side tracked about mental health crises, because it's where all the action happens and it's really tangible stuff. We need to realise that doing the basic stuff, and connecting people will prevent people going into crisis. It will mean that there will be a safety net.

Supporting the support workers

Employed peer support workers need to feel supported to feel confident about sharing their lived experiences, training and guidance from the Organisation as peer workers sharing can sometimes affect others adversely as well as positively.

This has been identified as a challenge by other NHS mental health trusts where peer support work is a paid role, policies/procedures/restrictions can be barriers to peer workers sharing experience and being open.

Peer support organisations can't expect to make use of people's expertise by experience unless they provide the right support when they need it.

Professionals are over cautious about peer support I think and not empowering to it. Their profession's approach and expertise isn't the only one.

Another challenge that NHS mental health services have recognised in employing peer support workers is that "professionals" or other team members do not value them as they are not "qualified" - lived experience is just as important as qualifications in peer roles. But I've witnessed Peer Support workers being bullied by other team members and treated as second rate workers purely because they don't have the qualifications.

There is a big part of the conversation that is around how we as organisations do everything we can to help peers stay well. The very best peer dynamics are when there's a tangible benefit to the peer's wellbeing as well as the person being supported. There is something in there around how organisations such as Second Step avoid professionalization of peer support. And how we make sure that there is a significant and noticeable gap between what we ask support workers to do and making sure that we hold on to the unique value of peer support. So we don't find ourselves in the position of not capitalising on all that kind of really unique expertise that peers have. This is a warning to organisations to make sure that we don't do that.

A peer support organisation should provide back-up advocacy or link with it so the peer and mentor or support worker can call on that back up e.g. benefits, work, housing etc.

Providing the most appropriate services

It's important to co-produce the activities that are required in each individual community, and that they are suitable for that community, and not just foistered upon them. And in an ideal world, with all the money in the world, that they would be open. And we wouldn't use medical language like 'self-referring' and things like that. It would just be a group of people who happened to get together who fit that community group and who happen to be funded from mental health money.

Early and Flexible Access

These sorts of peer groups can actually... this is what I was saying about being able to drop in to the 1 in 4 project... I didn't need to go there for three weeks, and then I might be having a really bad day. I work, I've got a job, but that could enable me to actually get to my job just by going in there and seeing somebody. And then because I was able to get to my job, I wouldn't lose my job. So it's a tiny little thing. It's not just about sitting round drinking tea, it's about that kind of support in a crisis is really important. Crisis services can be expensive, but they are costly to us also as service users. Going into crisis and being taken into hospital when we could have been supported in the community, it might not have got to that point. This is the problem with the gate keeping and the bar being set so high in secondary services that you have to be really unwell to get that support. It would be better and nicer for us as service users if we could actually be supported before we got to that point.

Question 3: How can further peer support be rolled out as part of the support people are able to access?

Acknowledge the need for employment flexibility

We need to recognise that when we take on peers in a paid role, they bring loads of experience and richness and skills and diversity to the team. But they also have mental health problems or issues or conditions. And these don't go away just because they are in employment. Having lived experience is really valuable and these people bring a lot to the role. So we need to take into account that they may need more support such as adjustments to their roles, more sick leave or terms of service flexibility.

All organisations need to get their heads around the reality that peers are an incredibly precious resource. It's up to the organisations to do the bending and the flexing.

Use the resource effectively

There is a slightly different role called Community Connectors (called Social Prescribers in some areas) which would be more of a signposting role. These people are in the community and they get to know people in the same way as peer support, but they then hand people on to the most appropriate group. It's really important to differentiate between ongoing peer support and this more short-term support.

Involve service users in decision making

I would strongly advocate consulting service users and they must be involved with the funding allocation and the funding centres. We need funds to do all this.

People with lived experience should have core involvement in funding decisions. I would like to see Peer Support projects staffed, managed and led by people with lived experience.

Promote a Joined-Up System Approach

Trauma-informed approaches and personality disorders

Monday 14 December 2020

Question 1: what does a trauma-informed approach mean to you?

It is characterised by person-centred, holistic support, tailored to the individual's needs

I think that a service that has professionals from different backgrounds, in joined-up or integrated services, that approach would be welcomed. You would see the service and what is available at first had, rather than being on a particular focus ward. So seeing how you would progress with certain professionals over a given time.

It's not to be for everyone, everyone will have different perceptions of what they are looking for. It's a complex area.

Adversity and trauma are common and have very real impacts. To say 'trauma-informed approaches' means to support people with their mental health in a way that takes account of and recognises a person's own unique experiences in the support they may receive.

A good trauma service is individual to every different person that uses that service. When I accepted the diagnosis of emotional intensity disorder, the recommended treatment was through AWP. I was denied long term talking therapy because of the 3-4 year waiting list. And they told me that the evidence didn't support it and it might not work for me. Therefore, I was directed to Structured Clinical Management which is the go-to AWP treatment for personality disorder and trauma. There were coping strategies like distraction and mindfulness which could have their place, but until I unpick the trauma, the voices will continue to hound me. I really need the help of long term talking therapy to open up that whole can of worms for me. You are not allowed to talk about certain issues in structured clinical management (SCM) because it may trigger others, and I was made to feel like I was naughty and attention seeking because I needed to. I need to talk about those issues, but in the safe environment of talking therapy.

I think that there is a real difference between telling your story over and over again and giving your case history.

I think personally that complex post-traumatic stress disorder (PTSD) or other trauma diagnosis is not a one size fits all, it's very unique to us personally. You reach out to people for help, and if they can't help you, what chance have you got? We go into services because it's the last resort for some of us and we are desperate for help.

It has a much broader approach to defining trauma

There are different levels and complexes of trauma, psychological and physical. Trauma in society as a whole is a big thing. Even with COVID these days. People disassociate themselves because of shame and guilt, or feel like they are being shut

down and not to seek help or speak about it. I do believe that are a lot of areas to work on around in society and the mental health framework and services. For example, ex-prisoners, people coming back from war, people who have suffered being bullied at school or felt rejected and abandoned. Or neglected in their home. There's a lot of people who don't talk about this stuff and they anaesthetise themselves with alcohol and drugs.

Trauma is broad, there are different complexes of it. And it's a generational thing as well.

One of the things I feel very strongly about from a personal perspective is around trauma not being used as a justification for the difficulties of diagnosis. Trauma can be cumulative, it's not all the same.

It understands the importance of addressing the trauma

Around 18 months ago, I suffered a trauma within mental health services. My team were able to make the parallels of linking it to the trauma I experienced as a child. Because I was too traumatised to engage with the face-to-face appointments, it meant that I couldn't access the help I needed. The personality disorder (PD) boundaries that were put in place offered absolutely no flexibility. So I've been left with 18 months of unresolved trauma, which has been a barrier to receive help when I was in services; and is now a barrier for me to self-present to try and access help.

A big thing for me is when you do present and reach out, health care practitioners have made a lot of bias and assumptions about me, which then becomes very difficult to unpick that because you're already dealing with all this other stuff. So trying to unpick those assumptions that they have made about you and correct them and say no, that bit is wrong can actually be quite difficult on its own. Which then kind of wrecks what relationship you've got or trying to build. To me it's really important to unpick the trauma. The mindfulness and things like that and distraction techniques are brilliant and all really helpful, but it's kind of like putting sticking plaster on a heart attack victim to me. You might do some good, but you're not addressing the underlying problem and it's inevitably going to come back and probably worse.

If you are diagnosed with a personality disorder, if you want to be seen for having a trauma-related intervention or support, you seem to have to have a diagnosis to be taken seriously. If you've had a trauma in the last couple of years, say you are a refugee from Somalia or Ethiopia, there is a pathway for you. But if you've had trauma a long time ago when you were young, you would blank it off to survive, and not connect it with your personality disorder. And professionals don't connect long-past trauma to it. Being an educated, middle-class white person who can articulate, it's almost as if my concerns were rational and cognitive and therefore acceptable. My childhood trauma was discussed with my clinical psychiatrist but when it came to recovery, that wasn't in terms of my trauma, it was in terms of a course of treatment and how I can be signed off. here is pressure to find some sort of completion, to give you a recovery outcome or some end point that is acceptable to the system and society, so you can move on. This is simplistic social engineering. I still have all the

voices in my head, somehow it hasn't improved them, but I am regarded as professionally recovered.

The trauma that we've gone through may have been over many years. And it can be misdiagnosed so many times. You constantly go through a revolving door of going back through services because it's been missed. Or another issue has occurred because the trauma wasn't dealt with in the first place. I've been diagnosed with bi-polar, then complex PTSD, all these different labels. They have recognised that I have something wrong with me. And because you don't get the support you need.

We have found that the first 6-8 weeks of any therapy is just about validating the shit that people have been through, and just how bad it is for people. And then to have that validation, then someone can start to move on and find what they can do. It's what's happened to you and how we can then move forward with a really good relationship of trust with the therapist.

It has appropriate and effective trauma-specific therapies and support

I think that in any trauma informed service, you need to have actual trauma therapies and trauma support. I think that more needs to be done to develop those systems. And I'm just not seeing any at the moment. There is some basic stuff, but not the approaches that could really make a difference for someone who is actually traumatised.

'Trauma-informed' should not be a buzz word. It's bandied about quite a lot at the moment, and now it's a case of services needing to walk the walk as well as talking the talk. It's been completely diluted and misconstrued in terms of what the actual grass roots service user believed it to be.

Support needs to be trauma responsive. It's one thing having the knowledge but it's another thing entirely being able to actually act in a proper trauma-informed responsive way. The key to it is holding onto the needs and aspirations of people. Trauma is recoverable with the right help. It might be a long and very complicated process, but it is possible with the right help.

I did have proper trauma-informed psychotherapy which I really celebrate that I got, because it did make a huge difference for me. That was in North Somerset. But there is far too little of it for the difference it can make to somebody's like. It needs to be resources. I know that psychology is very expensive, but it stopped me having hospital admissions which is even more expensive I believe. To if you are looking at counting beans from a commissioning point of view, spend the money on psychologists and get the trauma informed psych therapy in there, so people avoid heavy duty services. That seems to make sense to me.

There is an increasing demand for psycho-therapists. However, a long term therapeutic approach, whilst it may not deliver immediate results, it would help support people in a way that cognitive behavioural therapy (CBT) doesn't.

Treatment needs to be resourced adequately.

It has longer time-frames for care pathways

Those relationships are long-term; trauma- informed approaches cannot just process people through and think that's the end of it. You've got to develop solid relationships with the people that you're working with.

It's not enough to do 6, 12, 18 or even 36 sessions of psychotherapy. It should be a lot longer. Otherwise people anaesthetise on it, not just with alcohol and drugs, but with other things as well. Trauma is a complex issue. Recovery should be a life-long process.

I suffered complex trauma when I was a kid: sexual, physical and emotional. I then fell into drug addiction and alcoholism. I was anaesthetising myself to shut down what I was feeling and thinking. I was given 12 sessions with a psycho-therapist and then referred for another 24. I disclosed myself to this guy but it left me feeling raw. I needed more to unravel some stuff that was still there that made me feel guilty and ashamed.

It's not like we will work for you for 6 months and then that's it, they tick the box. And then you're sent back to your GP. It is long term. Some of the trauma we have lived with has stemmed from childhood and been with us many years.

Yes, having the same care co-ordinator is really important to build up that trust, because for me, in terms of what happened to me, the thing that I struggle with most is that I never got over the shame. And I can't discuss the shame with somebody I don't trust. The services that I have received from AWP, I have had the same care co-ordinator for 18 months, but it's been so boundaried and time-limited that it's not given me the chance to fully open up. It takes me a long time to trust anybody.

It has a relational approach to care, focused on building trust

Going into services for me has been basically going into my childhood again. It's authoritarian and intimidating. People don't listen to you. People minimise you. People can be, I hate to say it, but out and out abusive to be honest. Some practitioners that I've encountered have been very unsupportive and just done even more damage. And I've seen therapists who have basically pushed and pushed, and done irreparable harm, re-traumatising me. And taken no responsibility for it. So services need to really look to their own organisations and get their house in order when it comes to ensuring that staff develop really positive relationships and uproot negative relationships that can build up. Otherwise this can result in second and third hand trauma, which is all connected.

A trauma-informed practitioner should be compassionate, and I feel that's lacking.

I don't think that services realise the importance of relationships. This confuses me because mental health is all about good relationships. So I think a bit of attention needs to be put on developing supportive, and where appropriate, nurturing relationships. Because for some people coming into services for trauma, they have

never had that before. They will be coming in and not trusting, expecting the worst. It's quite terrifying when someone approaches you and they're genuinely decent people who care and want to look after you. You immediately think what's your angle? But a good trauma-informed service must be able to recognise that response in someone and reassure that the agenda is to help them, to help them get better.

It's normal to start the process of moving forward with someone who generally does care about your wellbeing. That is the most important thing, the real back-to-basics with people. Rather than using jargon, and telling people that they should be doing this or that. Like putting your face in freezing cold water! It doesn't work for everybody. So it's finding that individual thing for people that they can do. They learn from those positive experiences and it's wonderful to see these people just blossoming and moving forward.

You have to trust someone to start opening up because of the shame.

It has a long-serving and committed service staff

Trauma informed practice at a staff level is a reflective practice, and it's life-long. You can't go into this sort of piece-meal. If you do this, you have to do this for the rest of your life, and you will be committing forever. You have to commit to it for the rest of your life. If not, it's not going to work. In the same way as trauma is generational, trauma-informed has to be generational too.

What's important to me is staff consistency. Having the same care co-ordinator for 5 years, I didn't realise that many people were not getting that. I hear stories from people about being on their sixth care co-ordinator in a couple of years. No wonder the relationship side of things is a real struggle. If we can get enough happy staff that want to stay in the job to support people well enough and build up those relationships, that is what is going to make a massive difference. If you have staff turnover that is through the roof, how will those relationships ever form and help people?

It means trauma issues are recognised, acknowledged and not judged by all clinicians

Also from professional practitioners for trauma to be fully recognised and properly acknowledged. And for assumptions around a person's behaviour not to be made. I am thinking of instances where you might be going to an appointment. You're really anxious and not too great about being around people in authority who you find intimidating. You can shut down and not present any obvious signs or symptoms of trauma, as a defensive thing to help protect you from that situation. Or you can become hostile or resistant. And you get judged on those things. Instead of the practitioner understanding that the person may be experiencing high anxiety around a traumatic incident in their life, they say something like you are just resistant to authority. It's those assumptions that actually prevent us from being able to have a proper conversation about our trauma.

A good trauma informed approach or environment would not judge to what degree each person is traumatised or their life events that have resulted in trauma played

down. To that person, the trauma is real. So we need to have this degree of believing.

When we reach out, some services people dismiss you or say you're not traumatised enough. It feels to me to reinforce what my family and abusers told me as a child (as many abused people are told) that I was making it up no one would believe me or that I would disgust people. Guilt, and more so shame, are major issues for me that I've never had support from mental health services to deal with.

One of the biggest things is the validation of the shit people have been through.

Being able to articulate can sometimes also create bias as you're seen to be 'functioning'. Therefore, you're not ill enough to get services.

The attitude of you can't possibly be mentally ill because you speak so well and are very well educated drives me wild.

Intelligence and insight have been a blessing and a curse for me. They empower me with self-management but they also disempower mental health services' ability to recognise my additional needs beyond my insight and intelligence, which are not always enough on their own.

Trauma is about what happened to me not what's wrong with me; it was what happened to me that's wrong.

It gives timely diagnosis and support

It took me 30 years to get the trauma-informed support that helped me. I've been massively lucky to get it and wish it for everyone that needs it. It doesn't take away psychosis or mood disorders but helps me feel less bad about accepting help for them.

It removes barriers to access

My personal experience is that I spent a very long time trying to get into services. And I met quite a bit of bias in accessing that. I was turned down for 4 years, despite the fact that I was going in with a great deal of mental distress. I was self-harming and suicidal at one point. And they were just like oh you don't meet the criteria. One of the psychiatrists who made that decision about me, bearing in mind that they never actually met me, basically said that I had presented with complex trauma, so I was dismissed, because I didn't fit the criteria they had for serious mental illness. I didn't have any other clear diagnosis, even though I told them what was going on. It took a number of attempts to get someone to really listen and pick it up. Anyone who presents with self-harm and suicidal thoughts, that person should never be turned away. To have a doctor say that because my context was trauma so I can't be admitted into any service… it took me years to actually get any support. So I think it's really important that the senior clinicians and psychiatrists who are making these decisions actually engage more around ideas about adversity in trauma. Because I think that people like me can fall through the net

It has service users involved in service design

Trauma informed understanding needs to be embedded across the whole of services.

Training should be right across the board and it should be involving and co-designed with people with lived experience of trauma.

Those of us who have experienced good therapy and know what it should look like, involve us in the training. Use our breadth of knowledge and breath of use of people, so that a lot of perspectives are heard. Not just one or two people but a wide range. So every practitioner at least gets to hear from a range of service users who know about trauma-informed therapy.

In actual fact the actual power should be with the service users, not the providers. If you are going to put money towards the services, then users have to have a voice in the forums in which those decisions are taken and what particular outcomes or recovery objectives. There used to be performance monitoring meetings with service commissioners, providers and users but that seems to have fallen by the wayside. We need to have an ongoing voice to ensure the outcomes are meeting what patients are looking for.

It has staff at all levels of the NHS trained in trauma awareness

I think that a trauma informed service would be something where receptionists to senior managers have all received appropriate training in trauma and how to work with people who have experienced trauma at whatever stage of their lives. It's not just the practitioners who need that training. It should be a whole seamless service that is trauma informed, including the supporting structure for the service, rather than it being an add-on where you add on a bit of trauma-informed to make it better.

I've gone and done presentations to Women's Services and I'm really shocked by how many services don't know anything about trauma. I think my gosh, as a service user, I am coming to you but I'm having to teach you what trauma is. It's really sad to think that services regard it as just another label. We need that help from these professionals.

Treating trauma as a label also really impacts self-esteem, engraining feelings of helplessness and worthlessness even more.

I personally would really like to see not just receptionists or managers or care co-ordinators be more informed, I'd actually like to see the people actually making decisions about these diagnoses being more trauma informed.

It has staff at all levels of the NHS skilled in trauma sensitivity

At times there have been receptionists in some services who, when I've been falling to bits, have been asking me to leave buildings because it's disruptive to the waiting room if I am sat there sobbing. It doesn't seem to happen as much now, but it's certainly happened in two recent times. I have seen people come in for personality

disorder groups who have been quite noisy and receptionists have been quite stiff with them, treating them as people who are too boisterous. Receptionists need training because it's the first point of contact with a service, and it can make all the difference to your day.

There should be a lot more training around it, receptionists and practice managers, about the dynamics of it.

Bridging Gaps is working with GPs, to say that there should be flags on their notes so that if you are traumatised, when you ring in, you don't have to go through your story or explain your condition. There is a flag so that receptionists and staff know it's a person who suffers from trauma. A lot of people who suffer from complex trauma have said that the one thing that they feel quite put off from is having to tell a receptionist who they feel is not qualified. And that can be a barrier to people coming forward to actually even use services. With this sort of flag, receptionists will know that they don't have to ask questions.

It's really important to me to not belittle anybody's trauma. Because that trauma is that person's trauma. Whatever it may be that person has felt it and gone through it. And so it's making sure that there is that sympathy and empathy or a willingness to listen to what that person is saying.

It addresses concerns about SCM

When I completed the SCM program and told my care coordinator it hadn't helped I was made to feel that I had failed not that Services had failed me.

PD can be a lifelong issue. If someone is asthmatic we don't say you've had another attack, we won't treat you. SCM is going to be rolled out and I am deeply worried that it will be an intensive intervention but will further embed the culture of you've had all the treatment we can give you, it's your problem now, not ours. So I would absolutely beg the CMHF to include something to bridge that gap and allow for the fact that people will have good times, bad times, multiple crises, but there is something that can meet them in the moment. Not based on their history, or anything like that. The CMHF is going to be fundamental in making a meaningful change in the care pathways that exist. The culture and the staff that you get to do that is what will make or break this service.

Question 2: What are the main stigmatisation issues with regard to personality disorder diagnoses?

An over-arching label

I experience voices, mood swings, what I understand to be complex trauma. It's not one label plastered across my forehead, because that is extremely stigmatising. That diagnosis is hugely stigmatising.

I was given that diagnosis by a psychiatrist who had seen me for 3 minutes and had never reviewed my notes. To have 'personality disorder' plastered across your

forehead as a diagnosis, was so pejorative, that I attempted to take my own life. The Social Care Agency know me and said that that is not a correct diagnosis, they know me better than that. How can people be given so much power to make such stigmatising diagnoses without looking at a person's broader, longer life.

The label keeps the illness under the table.

Misuse of the label

In the news and media, particularly regarding an assault, the person is said to have a mental health problem. With normal mental health problems, you don't want to go around killing people. So I get cross with that label being misused.

The label becomes a self-fulfilling prophesy

The label can be demoralising and shameful. It can make you be a bit introvert around stuff, or start taking on the traits of personality disorder. You buy into it, that you've got a personality disorder.

The label keeps you in an inappropriate care pathway.

You get medicated and then you stay in that syndrome. It's not your fault. You just don't know what you're doing.

The label remains with you

That label has haunted me for the last 15 years. It has prejudiced my treatment, it has been a barrier to getting appropriate and timely treatment. It took me 10 years to get my true diagnosis of an severe mental illness (SMI). When it comes to it, PD trumps other diagnoses. I am a label. I needed to put in a subject access request to see my records, to see the prevalence and assumptions that were made about me around PD. It was sadly not surprising, but it was also very profound. I was lucky, I had mentalisation-based therapy, the treatment of choice. It absolutely changed my life in terms of my ability to cope. Now, diagnostically, I probably don't meet the criteria of PD. But I will never, ever lose that label.

PD will always prejudise and limit my care. And potentially that could mean life or death for me and for many people.

The label allows for stigma within services

And the stigma and discrimination that comes from that label by people in the mental health workforce is absolutely unacceptable.

Language is so, so important as are judgemental attitudes and these are sadly prevalent in mental health services.

People who come into the services for help need to be respected and cared for. This is something that mental health services consistently screw up on. We are not animals and we are treated less than that sometimes.

The lack of power to challenge to label

It's almost impossible to get that thing taken off your notes.

Jargon that is demeaning

Having a diagnosis of personality disorder and being in secondary mental services for long enough, you hear certain phrases and terms constantly used. It's shortened to PD and used too often and too casually; oh they're a PD! Oh, another PD. That is significantly more inflammatory than personality disorder.

PD does seem to be used increasingly as a throwaway line of abuse.

If someone doesn't have lived experience, they can start using flippant remarks. Like you are just trying to manipulate the situation or you are just looking for attention. But in reality you are just trying to get your needs to be met, but you don't know how to express yourself.

A barrier to accessing services

The shame and the guilt can prevent people accessing help, even if they knew that help might be there.

Question 3: how to reduce stigmatisation?

The need for a new model

That umbrella term of serious mental illness needs to be deconstructed and used in a better way, because it's excluding people from getting the support that they need. Any mental illness is serious, because nobody should have a mental illness. We can't grade mental illness based on arbitrary criteria, we need to look at how people are doing and then support them in an appropriate way.

We need to move away from diagnosis altogether to formulation to try and stop the pejorative stuff. I went round in circles regarding PD with the psychologist I worked with as it massively limited my ability to trust them until they explained formulation.

The need for a correct treatment

Guilt is about something you've done; shame is about something you are. I think services need to work on that. If my whole identity is one of shame, I am never going to recover from that. I can work through this, but if services don't provide the right support, how many people will take their lives? That is the bottom line. I've worked in mental health services for 25 years, I get so frustrated with myself because I know rationally I am not to blame for my childhood trauma but the shame is so ingrained in me that's the key for me and what I need services to support me to work through.

It's about identification, if you have someone who is not going to listen and identify with it, it can be a revolving door. How someone could treat you in the moment could

take you right back to that traumatic experience if it's not being dealt with from a professional, experienced and astute level.

The importance of trust

Trust is a big thing; people don't want to open themselves up to just any individual. You need that rapport and trust factor to build up. And that stems back to the inner child and the traumatic experience, putting barriers up, personas on, putting masks on.

You have to trust someone to start opening up because of the shame.

The need for services to focus on the issues not the label

We need to foster the understanding and belief that people can and do recover from PD. They can recover or get to a point where those difficulties can be handled with self-management. Mental health services need to be able to look at somebody on the basis of their difficulties and not put every single thing about a person down to those two little letters of PD. Of all the things, this is the area I feel most strongly about.

They need the right people on the ground who actually understand trauma.

The need for services to acknowledge poor performance in use of jargon.

My diagnosis was borderline personality disorder. It's a horrible label, but I accepted it because I thought that it would give me the treatment that I needed to recover. It's so important that we have that hope, because without it it's life or death. The difficulty is that I've been labelled as manipulative, attention-seeking. These words need to be challenged within mental health services. Whether they do it overtly or covertly, I have heard colleagues say these things over and over again. I've worked in mental health services and it's made me so angry, I've literally got into shouting matches. Attention- seeking is actually reaching out. We all requite attention at times. And manipulation… I never learned healthy coping strategies or healthy ways to ask for what I wanted and needed, because of my dysfunctional childhood. These are things that need to be taken on board.

I am concerned about staff using flippant words and things like that. The amount of time I've had to check my colleagues on the words they use or assumptions they make, it's very eye-opening. Services need more people with lived experience joining teams and working with teams, that is how we can change the culture. This needs to be included in funding.

It's not just about services realising they need to change they need to acknowledge and apologise to those people who have been re-traumatised by the very services who are there to help.

The need for better trained and supported staff

There's a real need for humour based responses and appropriate safeguarding, not just for service users, but also for staff as well. We must recognise that staff are not getting the support they need, so as service users, we are not getting the support we need. There is a real sense of service fatigue in services. We can't get better if the staff who are supporting us are struggling just as much as we are. So they often end up stepping back and not supporting us, or blame us basically for our own behaviours. It's happening everyday in mental health services.

This has got to stop. We need to address the relationship between service users, practitioners, front line staff, desk staff, anyone in the service, and have a solid conversation about how this can be addressed.

Transitions of adult care to older adult care

Tuesday 15 December 2020

Framing question: What matters most to you, as people with lived experience (either personal, professional or both), about supporting people with their mental/physical/both needs as they move through their life course?

A: Fears and worries

Changes can destabilise

In the future, things might change that might mean that I have to have more help than I am having at the moment. I have two grown up children who are supportive. But changes in your life mean that things can go from being stable for a long time to you actually needing more help and support.

People with mental health problems, when they get out of prison, they can deteriorate very quickly. Look at the extent of alcohol and drug addiction. And how many people have been incarcerated because of mental health problems, often they have to be detained before an intervention can be put in place. There needs to be procedures put in place before it can progress onto that.

Users not being listened to

With regard to older friends in the community that we support with low level mental health needs, they have expressed they are not listened to and they are digitally excluded, and this has been worsened by COVID.

Being dealt with by services with little or no training in SMI

My son, now 22, has also been detained many times. The police doing their best but not having full mental health training and A&E staff sadly passing him from one to another, often out of area.

Reductions in service provision

The later life psychology specialist provision is decreasing more and more in Bristol. It's been significantly diluted in the last 5 years. And that needs to be addressed.

No psychology provision in plan for CHL in North Somerset.

Unfortunately, there isn't a specialist later life mental health service in Bristol through AWP. I'd love people to be able to access support for their mental health between "serious" episodes of illness that meet recovery risk criteria.

In North Somerset there isn't a care home liaison service in AWP, and in South Gloucester, funding is limited and may not be enough.

The reduction of services in North Somerset is a deeper issue than just making sure mental health issues are addressed. North Somerset has difficulty with integrating with the other areas and working in a collaborative way. Services have lost funding. There needs to be some real conversation around how North Somerset can catch up with Bristol and South Gloucester.

If the services are not there, or there is a lack of specialist expertise already for adults with serious mental illness, how can that be developed for later life? As people get older, they become more resigned to not receiving the services they need, they become fatalistic. So what's to stop them getting lost in the system in later life? How can you get people back into the system when there is a shortage of specialist expertise?

Concerns about how any new funding will be spent

Given that there has been a reduction in later life services, what is the balance of how the new funding monies will be spent?

Answer from CCG colleague: we are aware that there are differences in provision of later life care between regions, especially with the response to COVID. This work is aimed at clarifying where there are particular gaps and, even where there is provision, how can the model be re-designed to make it better and more integrated with the wider service provision. NHS England wish the new investment to improve support for adults with severe mental illness. The BNSSG mandate is slightly broader to cover adults who may not have that specific diagnosis of SMI but their need is the same.

Improvement in standards of service

It's difficult to improve on services when the mental health providers are not good at making progress which is demonstrated by the CQC rating. AWP since 2012 has been rated as 'requires improvement' on it's four focus/comprehensive inspections. Is this really OK for BNSSG population?

Barriers to access services

I know that Learning Disability Services have kind of closed down their criteria for how learning disabled you need to be; how able you are for them to work with you. I think that can be a bit of a tricky area sometimes. The vast majority of my referrals are for white heterosexual people. I am not aware of why I don't see more people from LBGTQ+ communities or what the barriers to referral are exactly.

B: Requirements of a mental health service that addresses the needs of adults with SMI in transition

Maintains access to services

Not recognising that once someone reaches a certain threshold age, the way in which they are supported changes or is different in terms of range of support or teams of people.

Psychotherapy and counselling and people falling through the massive gap is really important.

There is also the issue of how older people access primary care psychology in the first place.

Provides services that are appropriate and integrated

In Bristol dementia and mental health services are held with different organisations. There is a lot of overlap and referrals can sometimes be bounced back and forth. It isn't helpful sometimes that the services aren't joined up anymore.

Dementia/mental health/social services aren't integrated in any way and it makes things really challenging for patients, families, GP's and secondary care.

I would be especially keen to hear how mental health and wider support services (e.g. frailty services) can better link up.

Provides support programs that are community-based

People going in and being around older people. Because my dad is still in denial about his mental health, he is going through the 12-year bereavement and will not access mental health services. He is lonely and bored, but also independent. So we need community involvement, to help people be more social and work through issues with their mental health through activities like gardening or craft. My dad doesn't have anything to do, and that impacts his mental health. That is something that could be worked into the framework to recognise and support mental health.

At BS3 (local community organisation) we have a huge focus on working to reduce isolation and loneliness. Community connections are so important to support the early intervention and prevention agenda and look at the wider determinants of health and wellbeing.

Provides good access to information about support during and after transitions

If I am unwell, there is no-one there to support my dad. If he were unwell, and he has been in the past, I wouldn't know where to begin. I don't know who to call. I don't know how to arrange help and support for him in this situation. So if something does happen, I need to know who to turn to.

Information and advice has always been a challenge. The Care Act says that Councils should provide information and advice about who to go to and for what when these transitions occur. But things change fast and it's never easy to keep things up to date. And things are so complex. There is a system called Connecting

Care which allows information to be shared from GPs and Sirona, case by case, but we need better systems to underpin this kind of transition stuff.

Maintains the involvement and support of GPs

I am very lucky, I have a very good and supportive GP. But a lot of people haven't got that. The GPs should be picking up on changes in people's lives and whether that is affecting their mental health.

Active signposting, also known as care navigation, is a win-win for the entire practice community. It offers the potential to free up a quarter of GPs consultation time each time by referring patients with need to the appropriate member.

Uses other pathways such as social prescribing

I know that services are overwhelmed but I do believe that there could be different pathways, things like social prescribing services. There's a lot more that could be done in that transitional period. So interventions could come in sooner.

Social prescribers hope to offer help with this sort of thing and Age UK. It is hard for service providers to keep track of what is about so I think it must be bewildering for carers.

All roads can lead to social prescribing, to advice, support, guide and signpost. Information is power!

Social prescribers are very important. In North Somerset there is a patchwork type of service, some GPs have them and others don't.

In BS3, we run the social prescribing service. The link workers have some knowledge of mental health issues but they are not specialists. They are also holding people for longer as services and activities are limited.

Involves those with lived experience

Lived experience is a really fundament cornerstone of so much of what we need to do going forward. Hearing your experience and insights is really powerful in thinking how we can do things differently in the future. It's not always about more resource, but how we structure ourselves better. From my own experience with my father, I understand the system better than a lot of people. But even for me it can be enormously confusing. So for people who are trying to manage their own condition, and also find the right service for their needs, it can be really hard. So disseminating knowledge and structuring services in a way that makes sense to service users and communities is so important.

We need to quality assure providers via lived experience or Experts by Experience Peer Reviewers, similar to what I do with Royal College of Psychiatrists.

With the NHS' Five Year Forward View, and the CMHF, all inform how lived experience/Experts by Experience along with co-production should be the new

normal. We are yet to see this in BNSSG. We see plenty of voluntary, community and social enterprise sector (VCSE) involvement but not lived experience coming to the forward.

Provides good training across all support services

There is a lot more that could change the dynamic of the transition. People that are social prescribing, and even doctors are not trained to work with mental health patients. The training is very imperative in the dynamic. Especially in the care homes. Because if someone is untrained, they don't know how to deal with a situation, that leaves the patient or the resident in jeopardy.

More training for link workers in mental health support is required but has been difficult with COVID.

Identifies the gaps in support services

One of the priorities with this work is to be really clear about what the gaps are and how we can go about trying to fill them. And then once that level of support is in place, then we can start to think about how to ensure that everyone who needs that support is effectively engaged and that the support is appropriate and the sort of service that they would want to benefit from. It almost feels like that there is that order of things, to really fill the gaps as quickly as possible first. Professional colleagues need to be able to succinctly identify what is working well and where the gaps and priorities are.

Takes learning from the Dementia Model

We have got to a place in the mental health care system where dementia is better understood and recognised by colleagues, especially in acute hospitals. Services are designed to meet the needs of people with dementia in dementia-friendly environments. But we need to think about how to encourage that same sense of mental health awareness in older adult services and acute hospitals and beyond. When people with lifelong severe mental illness who are elderly are discharged for hospital, do they have the same access to specialist support? And familial and carer support that wraps around the family. I think it is something that we need to be mindful of. When people are discharged, it's not always easy for the families to navigate access back to services, and it can feel like falling off a cliff for families and carers. When people come out of acute care, it should be a continuum of care, not these cliff edges that people fall off. Specialist later life liaisons would be very helpful in joining things up. There is something for me about staff working on those wards and seeing it as part of their responsibilities in the same way as they do with dementia care. This is something that we need to bear in mind.

Uses the same terminology

I think that the language we use needs to be common - 'frailty' is perceived as very different things to different people, and that can lead to confusion and omission when we are looking at what our populations need.

Adopts a Personalised Care Plan Approach

What is running in parallel is around Section 1 and personalised care. The 21 enablers, some of it can cross reference towards mental health. In the South West we have the South West Integrated Personal Commissioning Team. They are based in Taunton. If I looked at their efficacy in terms of what they have achieved, I don't think it would be something that would stand out, but they have been plodding on. But now is the opportunity with the NHS Long Term Plan is to look at what they can do for us in BNSSG. They are looking to re-launch themselves. We could make use of them in terms of what does a good first-class support plan look like. We need to learn about what other people are doing and how they can support us. There is also the Personalised Care Group at NHS England. These plans are for both physical long term conditions and for long term mental health conditions. Is there a discussion to be had about how we embrace what is out there that can support the ambitions across BNSSG?

There are other colleagues in the CCG who are linked into this concept. They help us understand this and can give us a better idea of how this can all be linked together.

We need in BNSSG to engage with South West IPC to develop Personalised Care, Personalised Care Support Plans & Personal Health Budgets. And maybe have social prescribers for Personalised Care. It would not take much to have this discussion.

Invests in Staff Resource

It's difficult to know where to start sometimes. There are some good things about being part of an ageless recovery service. The transition between one part of the team and the other is easy. It's just me seeing somebody rather than the other doctor. But in other ways we just don't have enough people to be able to do all the things that I'd like to be able to do. There are only 3 part-time doctors in Bristol working with older people. And there's no specialist OT. We don't get much specialist psychology time or physio. The wider, multi-disciplinary team is gone. I've been asked to work with frailty in a joined up approach with GPs, but there is just me. It's difficult for me to even get to meetings to talk with the GPs about frailty. It just feels completely overwhelming, seeing the need that people have. And seeing people via referrals, but not having the service to be able to give them.

Adopts new models of inter-disciplinary working

Each primary care network should have a mental health lead who is responsible. There needs to be more dialogue to improve knowledge of available services and encourage integration of services.

It's not always about getting more resources, it can be how to work more effectively with the resources we have e.g. more linked up, dissemination of knowledge, restructuring.

When I was in Wiltshire, GPs would meet with care homes and psychologists to develop non-pharmacological education and interventions. We would meet regularly. It's really important for Later Life Services to have a seat at the table in those discussions. If there aren't enough people to do that, then services aren't linked up, and we don't have a holistic look at how people are managed outside of medication. That is so important in terms of later life.

There is a need for stronger, multi-disciplinary ways of working. People who are working in mental health have much more opportunity to be thinking about a patients' needs and linking in with Social Care, social prescribers, the voluntary sector and others. One of the ideas we have is a locality strategy. At that level it would be a much more joined up way of working. All different professionals, with people with lived experience, could have a much stronger way of working. Then it would be easier to identify the sort of support somebody needs as quickly as possible and any real gaps in provision. They then can be highlighted more easily across the range of professionals. It's then easier across the whole system to know where to invest in more resource.

Localities and how we work with other professionals is really critical for the future. We've all got such a big role to play. So how do we join ourselves together in a really meaningful way so that people who don't know where to turn to…actually it's about how we hold people in a much more supportive and structured way together across the whole range of health and care services. That's quite a big ask, but it's something that we've got to really strive towards. I'd rather be ambitious and try and do something really different, to reach for the stars.

There is a lot to think about for different groups and conditions which goes beyond Neuroses & Psychoses definitions.

Ensures access to support for marginalised groups

You need to pay attention to your marginalised communities. I know from conversations with older people in the LGBTQ+ community, they have a really hard time accessing mental health services, issues with isolation, issues with discrimination, loss of partners, loss of friends. It's not great. The CMHF needs to help support older people in the LGBTQ+ community. I would like to think that when I reach that point I won't need to have to worry about exclusion or isolation, because services are in place to tackle discrimination and allow me to have a good old age. It is important that this is addressed. And the same issues are in ethnic communities as well, that really needs to be picked up on. You need to break down the barriers and discrimination around marginalised groups.

We also need to consider learning disabilities and Autism across this transition pathway. I don't think that anybody has mentioned these. I just want to throw that in because those people need to be considered as well.

People who have grown up in a dysfunctional home may feel socially excluded, and this may materialise as mental health problems. And learning disability issues can go into middle and later age. For me it's about basic human rights of what people should be entitled to.

We need to consider localities and the populations within those localities. Because they can get additional uplifts or funding if they have hard to reach communities.

C. Adopt an age-less model with multi-disciplinary teams

The benefits

For older adult transition, we need to be mindful and have an ageless or age-inclusive attitude to integrated services. Because there can be that sharing. But it's really important to note to note that when you move from adult to older adult in terms of services, that there isn't that dilution to keep thinking about that as a specialism. Because it's about keeping older adults in focus.

Given that we have different approaches across the area, do we want a more uniform approach to being either age inclusive or having specialisms in each? Is that something that is being discussed?

There are pros and cons to both situations, and I don't know that that has been talked about. All the old adult CMHTs being separate from adults of working age or adult CMHTs. If it were to happen that it becomes and age inclusive CMHT, we need to be mindful to keep the pros but really keep the cons at bay. This is in terms of making sure that within that team there are people who specialise and that is valued, and it isn't diluted. In Bristol, when later life psychologists leave, they are replaced by psychologists who specialise in adults. And then slowly, slowly, the specialism in terms of thinking about older adults and their non-medical, psychological wellbeing is getting more and more diluted. That is happening in South Gloucestershire as well. That hasn't happened in North Somerset! There is still a really strong focus in the team thinking about the psychological models of care. So it's about keeping that in focus.

Yes, this focus on psychological wellbeing in older adult care is really important, it's something that you don't want to lose.

I don't want CIT teams back again, but if there isn't that age-less model in the other two areas, we still need to keep those specialisms in focus. It's an expertise and that has to be valued and validated.

Yes, it needs an multi-disciplinary team style of working and you need the expertise. Because people present with such different problems.

Potential issues

I think the other thing, in terms of adults services, is that trusting relationship. A lot of the network we are talking about needs to wrap around older adults with severe mental illness is established through those trust relationships between professionals and colleagues who ned to work together in a consistent way. And that's a really important dynamic that we need to think about. Combining people into one CMHT, it's very hard for professionals to maintain the breadth and scale of relationships with the multiple providers that they need to engage with. So having the older adult focus

is critical, because there are different services available for older adults. BS3 is a really good example of how the third sector can be a rich source of support for older adults, but that would be different with adults of working age. So how do you maintain those relationships? So it's really important to keep the focus and the sense of older adults and supported transitions, helping people access the right care for their needs, as and when it comes about through those trusted relationships with partners.

Mental health rehabilitation

Tuesday 15 December 2020

Question 1: Mental health community rehabilitation - what matters to you, what is working well, what is not working well?

a. What matters to you

Supervised safe spaces

Safe spaces, at a variety of levels, in the key issue for me. DHI used to run a safe space where you could go to get away from the playground as it were. To just sit there and be supervised at a distance, and stop things escalating. There were no mental health professionals there. So there needs to be a supervised safe space with mental health professionals, in the vicinity. At the moment the only places that are used for this are police cells and A&E. this could diffuse a lot of stuff before it got any further.

b. What is working

Support groups

I think that group work like SMART stops life problems getting out of hand by solving them as a group, before they start to escalate.

Peer support

There are peers working within the Bristol rehabilitation services which includes peers going out into the community, and to Well Bridge accommodations services. That was part of the rehabilitation before and it's working well. They work as part of a multi-disciplinary team and bring a strong skillset into the service. They are an integral part of the way the service operates.

Longer, fixed commitments of Community Rehabilitation

The initial 15 months that I had with community rehabilitation was profoundly life changing. Community rehabilitation was profoundly different to Assessment & Recovery for me. One of the things that is absolutely crucial to the model of the service that supported me was knowing right up front that I had 12 months with the team, that was what made a massive difference. And knowing that I had a peer recovery navigator and I also had a recovery navigator. And we were able to take the time to build those relationships, to build that trust. I didn't know what my goals were coming into the service except that I wanted things to be fundamentally different. But there was time to explore that and try things and to learn to grow.

Meaningful activity in community rehabilitation

There are opportunities that the team had to provide meaningful activities was great. There were numerous activity groups. And I am thinking particularly of the Forest Friday program. It's a wellbeing project in nature. And I think again this is something that is really unique, and not something that A&R services have the time or staff to facilitate. The creativity of providing those spaces for someone who is acutely socially anxious and needed a huge number of weeks to be coached to go along, it offered a huge number of opportunities to be with peers, to engage or to be with workers. You can go off on your own for a bit or take part in the activities. Alongside that they had a cooking group and an allotment group.

I wanted to say how helpful activities such as swimming, art, writing, book club, gardening and walking have been to me. And also some of the educational opportunities I have taken part in with the Carlton Centre in Weston-super-Mare. Those activities are wonderful. Activities which could perhaps be outdoors or in a sports centre or just walking are very helpful. You get help and interaction with friends, and you can also access peer support and find out what is available. I want to emphasize how important these activities or things are.

c. What is not working

An inflexible service

The service needs to be organic. For some, the first step has to be instigated by the person who needs the help. But if they're not, the service has to be brought to the people who you are trying to serve. Equality, diversity and inclusivity measures are really unrepresentative. To engage with a diverse community, it's the same tools. You need to go to their place, to come out of your comfort zone and take it out to the community, rather than people coming to a structured place.

Services do not go out to communities. There are a lot of small scale examples of outreach, for example the IMHN has gone out into the Somali community. But it's how do we ensure that we really learn from that and broaden it.

Recognition of the value of peers

What is a peer? They normally come from the organisation providing the resource as part of a multi-disciplinary team. They bring a very strong skill set into the service. Is it a resource to be tapped into because it's cheap and easily accessible from the organisation? Or should they be viewed like consultants or trainers in equality/diversity/inclusivity or whatever. Are they valued like that? I am going to say that they are not.

Barriers to access for community rehabilitation services

I wanted to talk about the requirement for people to be willing to work to take part in the schemes. I wanted to stress that somebody who has had a mental health crisis, they probably have very low self-esteem and self-confidence. If you make the bar too high, it will be off-putting for people to try to access or join in.

Lack of services

I know that in my experience, working with people at different points of their pathway, there are points where you really notice that someone needs that kind of intensive service. And people come back into services in crisis because that wasn't that kind of intensive service available to them in the community. So they end up in out of area placements, sometimes for years.

People not having access to focused rehabilitation services is often the difference between successful recovery and repeated periods of crisis of whatever kind. In BNSSG, there are no community rehabilitation services in North Somerset and South Gloucestershire, so there isn't equal access across the patch.

Previously in 2007-2012, in South Gloucestershire we had the Assertive Outreach Team, although we didn't have community rehabilitation. Since we lost that team, I can see that we are finding difficulties in supporting patients in need. That team had a wide range of services to enable the person to get back on track, but now we have lost that Assertive Outreach Team. So establishing a Community Rehabilitation Team in South Gloucestershire, I would strongly support that.

Years ago I used to have a support worker who came to my house, but with all the funding cuts, things like that have been cut.

Limited Focus of Assessment & Recovery service

I'd been in a ten-year cycle of assessment and recovery via the GP, crisis after crisis. Assessment & Recovery teams are fire-fighting. The caseloads, the pressures on staff, means that people can be held until they reach a point of low-enough risk to be discharged. From the minute you're taken on by Assessment & Recovery, you know they are trying to discharge you as quickly as possible, as soon as you at that low-enough risk. But there isn't necessarily any meaningful recovery or any onward recovery pathway. So people get stuck in that cycle of living from one crisis to the next.

In terms of the CMHF and rehab, the really positive thing is redesigning all services for a better patient service. The CMHF talks about 'no wrong door'. And also having access to the right services at the right time. Sometimes there isn't that length of engagement or access to the right services.

I wanted to make a point about the term 'rehabilitation'. With pathways into the service, we often see people coming in from Assessment & Recovery Teams and In-patient. Through the intensity of that work, quite often people get discharged from the service, not back into community mental health teams, but back to the GP. But one of the limitations of the term is that it implies that something has been done and it's finished, or gone back to a previous state. But that is not the case. It's about quality of life and life skills and all that part of the work. You want community rehabilitation services to leave people with a good quality of life and high levels of independence.

d. What is needed – the parameters of success

Training in basic life skills

I kind of think that in this sector, having lived experience and using services, I look at the prison system. 98% of that is drink or drug related. There have been a lot of cutbacks in this sector, but in Bristol, people get out of prisons or institutions and things like SMART groups can be a stepping-stone. Maybe as a first stage. Some people just have no life skills, it's as simple as that. That comes under the mental health spectrum. Instead of medicating, people could be taught these skills in a rehabilitation centre as part of their recovery program. It could be a formal 12 step program or just to expand on their education, because a lot of drug addicts and alcoholics don't have any life skills and limited education. They just don't know how to live.

Timely, properly-financed peer support

There needs to be more peer support for people leaving prisons, where people can step in. As long as there is something available, then people can be signposted and properly supported. For me, education and accommodation are part of peer support. To be able to signpost where people can get this sort of help, and to be shown clearly where they can get it early on when people come out of prison or addiction. So people don't get discouraged. If it's intervened at the right stage, then people can have that second chance. And peer support can encourage them to do this.

Peer support for people who have experienced traumatic sport injuries can be very helpful. It needs to be properly recognised. It takes a lot of financial investment and time because it is very important. Peers are the bridge between the system and the people who receive the help, the bridge that kind of makes sense. Everybody recognises the value of peer support at the beginning during consultation, but when it comes to actually financially backing it, it becomes less important. And mentoring as well.

Peer support is coming up in each of these conversations. The evidence indicates that unless you have a robust peer support system in place, you set yourself up to fail. So the money needs to follow the intention.

Great Peers end up being employed by providers, because their career path in the NHS is not financially attractive enough to stay. There is a need to really change this, because once contracted, your ability to challenge bad practice carries risk.

Last year in South Gloucester we started a cycle education group. Those patients who attended the group wanted to start up a peer support group. We supported them to enable them to have continued peer support after that group. They are now meeting separately. We did provide some initial support and supervision, and then allowed them to grow as an independent group. So I am in favour of peer support groups.

Improved inclusion with under-represented communities

People from BME groups are still under-represented in rehabilitation services. We should think about that more.

Lower caseloads with person-centred focus

And I think that lower case loads are absolutely crucial in the commissioning of community rehabilitation services. For me, that meant that staff could do things for me that mattered as a person. To give you a really unique example, I was terrified of making a train journey, but they took the time to do a practice run with me. That was so person centred in terms of what my needs were at that time. That is the advantage of community rehabilitation services. It was the most person centred support that I have ever been able to receive.

Longer time frames for support

For me, not having that constant fear of imminent discharge, I was able to grow and develop more as a person, develop my own resilience. It is really sad where people are in situations where it takes years of revolving door access of other services before this kind of support is there. But when it is, it can absolutely transform a life.

I think time is critical. Each person's journey is unique and these services need to ensure that they can stay the course with someone until their goals are met.

Person-centred and place-based services

There will be a re-evaluation and re-design of all mental health services. There needs to be point early on in the service where the right treatment can be accessed and that there isn't a wrong door. It needs to be set in a wider context as well. When thinking about rehabilitation services we have to think about the whole new CMHF and how services will be person-centred and access will be place-based.

Physical health issues and disabilities need to be properly considered when it comes to willingness and engagement. I'm keen to take part in things but I've got physical health problems which means that engagement can impact that condition.

What we have spoken about is the intensity of work. It's going to take time to build relationships and ensure that the work is person-centred.

Wider, meaningful activity based programs

There needs to be more of those kinds of opportunities. Because they're things that take the focus off the actual mental health difficulties and provide environments in which people can, almost unknowingly, flourish and really overcome the mental health difficulties that they feel. I think that is another thing that really distinguishes this model of working. Services should really be encouraged to provide more of these types of activities as part of rehabilitation.

Improved outreach

Through the COVID response a number of areas for investment were identified. And assertive outreach was identified as one the top priorities through that funding.

Improved criteria and systems for identifying those needing rehab

Regarding the difficulty of accessing services, often we don't get it right in finding people who might need rehabilitation and offering services to them. We rely on our quite haphazard referral system across services, and I think that means that there are a lot of people who miss out on rehabilitation who could and should have it. I don't think that there are easy answers to it, but it is something that we could focus on more and get better I'm sure.

Currently most referrals come from RiO via care co-ordinators, in-patient, or from rehabilitation pathways. Rather than waiting for care co-ordinators to make referrals we try to identify people who meet a range of criteria which might indicate some benefit from the rehabilitation service. So in thinking about this kind of review, building that in from the start could be really helpful. So thinking very clearly what are the criteria, who might rehabilitations service be helpful for? And then building in a mechanism and systems for identifying people, rather than relying purely on care co-ordinators.

I know from my experience that because I look alright, I sound alright, I have a good educational background and I'm generally pretty well presented, I don't meet the criteria for any support. But I know that I would benefit from the support that I'm asking for. So when it comes to looking at how you get people into rehabilitation courses, special attention needs to be paid to the criteria for accessibility. Because there's potential for a lot of barriers to access. I know that for me, any request for referral would get turned down because my clinical history doesn't show any major events or trauma, but in reality of have difficulties in participating in normal life stuff, like relationships. So I will fall through the net. So special attention needs to be paid to the criteria for people accessing rehabilitation services.

Earlier identification of those needing rehab

Timely intervention is a crucial thing that needs to be considered. There are many people who only get to the point of being offered or referred on to rehabilitation because existing Assessment & Recovery Teams feel that they've exhausted their opportunities. One of the things is really important is about identifying who would benefit from an intensive rehabilitation service. I am very aware of the fact that there is an expectation that you will work, your willingness and motivation is part of the assessment criteria. We need to find a way to capture that earlier, so people who do have that willingness and motivation, that untapped potential that they've not been able to reach because of their mental health difficulties, that that can be identified and engaged with earlier. Because the earlier that someone can have a positive rehabilitation experience then the less suffering that that is going to occur prior to it. And then the more potential there is for someone to live a truly independent, fulfilling life.

Rehabilitation to be viewed as a journey

Thinking through to the CMHF and the opportunity that brings, there is something about the idea that rehabilitation isn't always finished. People might have future difficulties; people might need to re-access back to services again in the future. So we need to think not just about the pathway in to services from hospital or Assessment & Recovery teams, but it's also about what on-going support people might need into the future as well. And the way that can be supported in the community. How can we provide the right level of support in the community into the future?

We need to think about what is not working so well. The current model of the service is that for the initial 6 months, post discharge, you have rapid access. So if your GP needs to refer you back to secondary care, you go back to rapid access to rehabilitation for a short term intervention. I think that this for me is an area where the model didn't work. What should have been a short intervention turned into almost 2 years of cycling from crisis to crisis. Of feeling that I was on the Community Rehabilitation caseload, but not really a proper patient in terms of the CPA or things like that. I think we need to make a decision about rehabilitation services. Are they something that someone has one shot at, and that's what we can do. Or can rehabilitation in terms of the CMHF be viewed more as something that might be a progressive, staged journey.

My second rehabilitation experience was something that felt to me to close the door to mental health services and closed the door to my relationship with my GP. In terms of something that feels like it's not working is that in spite of all that positivity in my recovery, I am now in a situation where… the CMHF talks about a cliff edge, and I describe it that way. But at the end of the day, having twice been through the rehabilitation service, it's not been a cliff edge this time, it's been an ice ravine and those crampons I spent 10 years perfecting that art of using, have been taken off me. And I think that what we need to do is make sure that there is a clearer pathway. My experience was that the second lot of rehabilitation work actually got in the way of me achieving appropriate and timely crisis support. It's absolutely fundamental that we use the rehabilitation services for their immense strengths that they have and not let them get in the way of other service options if they are more appropriate.

Integration of service within the wider mental health framework

What do people think about the bigger system that community rehabilitation is part of? My experience of working with people is that other parts of that system being 'rehab-friendly' is really important to recovery and success. A lot of it is just good practice, but basically there is a need for an understanding that people need an intensive focus on how they find their way to where they want to get to, how they find what their goals are and find a way to get to them. This is different to a service which focuses on crisis and treatment. It can be done, but often the barrier is the intensity of support and having the right range of people. Peer workers are a crucial part of that. Not all services have the ability to deliver it.

One thought that seems to run through as we run through the series of focus groups is integration. Integration of different services that make up the wider system linking with each other.

A person-centred partnership model

The partnership with AWP and the VCSE way of working together, that's what brings strength to the model that we have at the moment. It's the combination of lots of what has been spoken today, the high aspirations, the meaningful activities, the community connections, all of that linked together with the big, recognised interventions that really work for people. And part of that partnership is the individual at the centre, driving that. We need to keep in mind the need for and strength of that partnership.

Parity of services in North Somerset and South Gloucestershire

I'd like to see the expansion of community rehabilitation to cover both North Somerset and South Gloucestershire. It's a service that is desperately needed by some people in these areas and it's not available at this time.

From the focus groups [that took place as part of a separate project looking at the current community rehabilitation service in 2019], there were people who had benefited from community rehabilitation who wanted to know how their relatives could access Community Rehabilitation. When is community rehabilitation going to be available in North Somerset and South Gloucestershire?

Easy access to information about services

Consistency and branding to allow desperate people to find and recognise framework services easily, and trust that they are pieces of the same jigsaw.

Concerns about Change

We need to be able to reflect on what is right and wrong, and then improve it. For me, silo thinking is a problem with organisations. Sometimes we have to be honest if systems don't work and give each other the 'shit sandwich'. We need to recognise what can be done better.

I'm scared that what will happen is we move chess pieces about without meaningful lasting change.

Eating disorders

Wednesday 16 December

Question 1: What has been your experience of accessing support for eating disorders?

Experiences of stereotyping

I was lucky with the support that I got when I was first unwell. I was put straight into services and diagnosed with anorexia within a month. And then offered day patient, community outpatient or inpatient. The reason for that was that I fitted the bill of a typical anorexic. White and slim, a text-book anorexic. So I was given that treatment very early on. I did everything I could to disengage from that, but I still was getting offered it.

I've never been able to access any proper support because I'm not underweight, I'm not grossly overweight, I'm not vomiting or using laxatives. And also I'm a guy. I have complex eating problems and that is just my experience with it.

We did some research funding at STEPS to look at Primary Care and about early identifications of people going to their GP and how we can support GPs so that they don't fall into stereotypes. For example, we see less people from BAME communities, even though there are eating disorders there, because they don't get identified in the same way. And the same is true for gender. We see less men than we should be seeing in services, they just don't come through to services.

A service that is not timely

Resources are pulled into people who fit the bill and have the weight and BMI that justifies treatment. But that may not be the best time to support someone. And it shouldn't be the basis for support. I was better mentally when I was at a lower weight and worse mentally at a higher weight. There is not necessarily a correlation between the two.

I got well and now I want the opportunity to have support from the perspective of dealing with the trauma of my disorder. But I can't get any access to that. I am having therapy from SWEDA, which is incredible, but that was my only option. I was very unwell, and I had to get to a very bad point. I feel sad because the time that you are unwell with an eating disorder is significant, but it's the times before and after that get missed.

A service that has barriers to access

I am fortunate in having repeated access to support for eating orders. But it really is about severity. The threshold is incredibly high. My onward referrals came from admissions to a general hospital for treatment. A dietician who had eating order expertise was the bridge in getting me access to dedicated services.

I have never been able to get support for the issues I have around food. And the main reason that I have been told that is around my weight issues, because it's usually stable and normal. I don't have patterns or methods, I can be quite varied, sometimes it can be binge behaviour or purging. Or I will go through periods of barely eating at all, then suddenly eat normally. My GP and care co-ordinator have been upfront and have said that unless I am presenting as anorexic or bulimic, I won't get the support that I need. I might get some other mental health support but my eating order is not really being specifically addressed.

Most people think that you have to go through a GP to access eating order support. But at SWEDA, we are a charity, so we love self-referrals. We work with people who have severe eating disorders, who perhaps the NHS hasn't worked for them. But we also work in the disordered eating line. We also work with people with poor body image, because that can be a precursor to an eating disorder. We don't work with rigid criteria; we are open with what we do.

The gap between primary and secondary services: too severe for primary care and not severe enough for secondary services.

Mixed experience of peer support

I have mixed experience of peer support. When I was first diagnosed at 19, I was massively in denial. I knew very little about eating disorders or available services. I went to a day patient hospital, but being surrounded by people with a variety of eating disorders, I learnt most of my eating disorder. I picked up traits which took me years to recover from, because I was like a sponge. I just learned and learned and learned, but I knew it was not what I needed. I was just picking up traits. Eating orders are incredibly competitive and you just learn from each other, copy from each other, compare. Most people who have eating disorders are plagued by comparison. So to put them all in a fishbowl together, for me, added years to my recovery. So the peer element is very difficult.

When I was an in-patient, those peers really got me through. I laughed the most I have ever laughed in my life when I was in the in-patient unit. It was the best time I'd had in years. It was the other people around me that got me through. Someone I met in hospital is my best friend now. But the nature of eating disorders means that peer support can be really dangerous as well in that environment.

With regard to peer support, at SWEDA 75% of our staff and volunteers have had an eating disorder. As a charity we find that quite a valuable experience. They have a real understanding of what it's like to live with an eating disorder that perhaps other clinicians do not understand. We feel it's important for our peer supporters to have that lived experience.

The other thing I wanted to say about peer support is that whilst eating disorders are incredibly competitive within a group of individuals, certainly for me, eating disorder comes with an abundance of shame as well. I didn't tell my care co-ordinator for two years that I was having difficulties.

For in-patients, I don't know if it resonates, but just seeing someone who actually is recovered and holding that kind of hope for patients, that is really fundamental. Being able to see somebody who has gone through the same things as you have. Being able to say yeah, I've gone through that and come out the other side.

On the community team, it's been helpful having somebody else that patients can talk to that isn't a therapist, who takes a different approach. That is really nice. But the peer supporter needs to have the right training to be able to manage that.

Question 2: What has worked well with eating disorder services?

Effective community support

What has helped me is the right support in the community.

Open access referral

Within CAMHS there is a national guidance for eating disorders. There are eating disorders teams in CAMHS that accept direct referral, and the school and educators can refer direct to them. That is going well. I am not quite sure if they have moved on to self-referral yet.

Yes, I am not sure if CAMHS have moved to self-referral yet but what they are doing is rolling metal health in schools teams across BNSSG. Those are intended as a mechanism to support early referral as well as CAMHS services. There is a 4 week waiting time standard for eating disorders in CAMHS. Obviously if you have a laborious referral process, that doesn't achieve that standard. So it was all designed around a process of easy and early access. For all forms of eating disorders and disorderly eating, anything that causes concern or anxiety to professionals or individuals who wish to be seen or treated, it comes via that route. So it's a very open access to services to get early support and help.

CAMHS now works on a 0-25 years bracket. It's that older age range of 16-25 years that is really important to think about. And it doesn't mean that CAMHS services are going to cover all the way up to 25, but this is a specific service targeted at 16-25 year olds of some form.

Question 3: What hasn't worked well with eating disorder services?

Lack of Knowledge by GPs/Primary Care

For someone to step through the doors of a GP is huge, but actually, what's the point? In my whole time with this eating disorder, I never really had a GP that had any understanding. When I was admitted as an in-patient I was very, very unwell. And the consultant said that it was a life-saving admission. Previously I had been going to the GP and being weighed every single week. People with eating disorders are very good at what they do, so it wasn't hard for me to see the GP, be weighed and then sent home every single time. I think that is where there are huge issues. When I was first unwell, my mum took me to the GP because she thought it was the

right thing to do. And every GP since has the understanding of someone who has just read 5 pages of a book, and not really absorbed it. If the GP is the first point of call for someone in a really critical condition, regardless of weight or duration, if they come to the GP with such a critical condition. And the GP has such little knowledge, that is so dangerous. Because not only do they have the potential to trigger them, but also the potential to send them home without any support, or in an actual worse position. The GP or nurse would weigh me every week, and say it's brilliant if I had put on a bit of weight. It's not that they are not good GPs or nurses, it's that they didn't have the training or knowledge to really understand the condition.

It is very hard for the GPs in a ten-minute consultation. My wonderful GP's very maternal response when my eating disorder is at its worse is to give me eggs and cheese from her farm, because I'm not getting any protein! On the one hand, it's a human, compassionate response. But it over-simplifies it. Any form of eating disorder is not as simple as mind over matter. There are massive complexities around it. One of the difficulties for GPs is that they are very limited at the moment. They can make an onwards referral, but there are waiting lists and there isn't enough availability. So all they can do is monitor bloods and weight.

I would totally agree; I think that a lot of them don't understand eating disorders enough.

We at STEPS went out to the GPs and gave them talks about eating disorders and how important it is to understand eating disorders. Again, it was a bit of a mixed bag. Some leapt at the chance to have a talk, others didn't want to know. We have been able to save so many people that the GP has missed completely, they were very low weight. But the GPs just don't recognise things, they are a bit lost. And some GPs send people away because they think that they are not of a low enough weight, which is so dangerous.

Linear rather than multi-faceted support pathway

I am going to a psychiatrist right now. I have been struggling with depression and mental health as well. But when I try to access details about eating disorders and bulimia, what kind of treatments would focus on my issue, the psychiatrist said I should focus on my mental health issues first, then work on the eating disorder. This was not helpful to me. It made me feel frustrated.

We have heard in a previous group about a person seeking support for multiple conditions and clinicians wanting to treat physical issues like substance abuse first before they address mental health issues. This can be very dangerous. It's unanimously recognised that this attitude does not help and actually makes things so much worse. So it's so sobering to hear that this is happening in this context as well.

Lack of eating order expertise in community rehab services

In my perspective of lived-experience, having been supported by 'comm-re' over two periods during the best part of three years, there was no expertise in terms of eating disorders. When I finally opened up to my care co-ordinator, she was really honest

and admitted that it was an area that she didn't really know about, or the team were experts in. They had to reach out to STEPS for this expertise.

Question 4: What does a good eating disorder service look like?

A much broader approach to defining and referring eating disorders

My question would be around how wide to we need to go with eating disorders and disorderly eating? We want to be as broad as possible and I wouldn't want to be contained by any label that said eating disorder, because that's what it says in the CMHF. I think actually, it's such an all-encompassing thing. Sometimes the CMHF can be a bit reductionist in want it says, but actually listening to what has been shared today, I just want to appeal to everybody to 'go big', to think as widely as we can around this topic. Because this feels like it's really fundamental and important for so many reasons. And not pigeon-hole people into a 'eating disorders' box, which is the way that the CMHF might imply.

I think that it's absolutely crucial that whatever is done going forward in this, that it is about thinking big. Because there are so many people that won't necessarily have a diagnosis for this. They are having their difficulties with eating disorders or disorderly eating and they don't have that diagnostic tick that their lives would be so much the better for.

I think that points of entry for accessing support with eating disorders need to be sort of spruced up a bit. So at first point of contact, like GPs or care co-ordinators, as opposed to charities, need to step back from their very criteria-locked view of eating disorders and broaden their scope a bit. If someone like a family member or friend goes to them with concerns, those concerns need to actually be taken seriously by the person who is listening to them, whether or not they fit the criteria they think of what eating disorder is. I think it's around awareness and education for people who are at the points of entry for access, and not dismissing people if they don't fit the classic picture of this is an eating disorder. Then that will immediately improve access for a lot of people to be able to sit down and talk though the issues that are being experience and get the help that they need.

It's about being able to address those things in a safe space without being turned away because I don't have the traditional habits associated with binge eating or bulimia or anything like that. It is really about broadening the perspective. And understanding what eating disorders actually are, how they affect people, and what people actually need to manage the issues that they are experiencing.

It's about how you present as well. And how people can see you and therefore aren't maybe looking deeper than how you are presenting. We all know about the importance of the first time; the second time someone presents. And in some cases how difficult it has been for them to do that. And therefore that is very much key to catching them and seeing what their needs are.

A more accessible and faster referral model

There has been some research by BEAT about GPs and their training. I think it's gone up to the medical Council, in that GPs have not had enough information. Hopefully with this new mental health, it will be about self-referral. If we can educate people to self-refer. At SWEDA, we prefer a self-referral because sometime people become known to the GP by family members, and perhaps they're not ready themselves.

In terms of the GP, there's definitely a move in CAMHS to go to self-referrals and also to have other be able to refer, for example school nurses. So lots of people, even in adult services, they are still in education. Often people are much better placed in education to refer people or to notice that something is going on. Or have someone to support you to do a self-referral. It would bring down the lead times. In eating disorders, we know that the longer the delay between searching for help and getting help, the worse the outcome for the person. So it's about trying to bring down those times from when you self-refer to coming through to specialist services, rather than jumping through loads of hoops. In Bristol, patients go to eating orders straight away, but in other areas they go via the general mental health services. So people have to wait for that assessment before they then go for another assessment, which is really hard.

In Bristol, STEPS has now had a primary care eating disorder service so that GPs can directly refer candidates. And we are seeing people who still fulfil diagnostic criteria, because that is how the commissioning works, but they can be seen quicker because they clearly need some CBT, but they don't need to come through to a tertiary service.

Earlier and more timely intervention

It occurs to me that we tend to package things neatly in health services and offer them. And for good quality care, these are the boxes to be ticked. Peer support, tick! Actually what is more important is the point in time that that intervention or support is offered. That feels like the fundamental thing I am hearing. Being offered a service might not be the right thing at that time because of the needs of the condition that you are experiencing at the time. But having professionals with the right ability to recognise the point at which that offer might be the best point to put that in is really important. That is a really interesting reflection to keep in mind.

Key to improved lives is early intervention with an eating disorder. I can say proudly that in the last couple of years, I have made massive steps with various behaviours. But at the same time, it's one of those things that the longer it goes on unresolved, the harder it is and the more it can escalate.

No eating disorder is not serious at any level. Whether it's life or death or daily difficulties. It's absolutely crucial that different levels of appropriate treatment are available. Because I am very aware that the link between mood and food, and food and mental health is absolutely massive. So we need to find a way of making sure that services don't just treat the most extreme of cases.

In terms or early intervention there are good things nationally going on. One of them is called FREED, it's about getting young people seen earlier. And I know that is Somerset they have had lots of funding to do that. We have been trying to do it without any funding, which is pretty much impossible.

We see that parents know there is something wrong and bring it up. Teachers will know that is something wrong, but they don't feel that they are the right channel to be heard. So if people can come through to a specialist straight away and getting the right information, which would be the right way to go with adult eating disorders.

Person-centred, holistic support that is tailored to the individual's needs

The need for a person-centred rather than diagnosis centred approach is very important. That is coming out loud and clear.

I was doing group work with STEPs. And I was advised by my therapist and to have psychotherapy as that would fix all my problems, and that I didn't need dedicated eating order treatment. I feel very strongly that it's important to take holistic approaches to this and not segregate difficulties. Eating disorders is a particular area where specific work needs to be done; in parallel or as well as. It's not OK to say that if you fix your mental health problems, you will fix the eating disorder difficulties as well.

There needs to be more awareness around body image issues. You only have to look outside and we are bombarded by images of ideals and how we should achieve it. It's the influences right outside our front doors, all the time. Services need to pay attention to that because body image is something that is really important. I was very badly bullied because of weight issues and even now, as an adult, that really impacts me and influences my eating habits. Services need to be able to challenge those ideals that we are fed on a daily basis through every type of medium.

The issue of body image is becoming very much on the rise with COVID and people being exposed to more media during the day. More and more it is becoming a pressing issue. There is a real concern now with this issue.

It's really important to think about psychiatric medications have side effects that include increase in weight. I am someone who just has to look at an anti-psychotic to pile on weight. I think that this is an issue to bear in mind. Sometimes treatment by meds can sometimes make an eating disorder more difficult, because there is the inevitable weight gain. And equally, when an eating order is particularly bad, that can lead to lack of compliance in terms of taking the medication which improves your mental health!

Support that is culturally sensitive

When we are facing the holiday season, it's going to be a real struggle for me. It's all about food. We can't tell the difference between different meals. And I am from an Asian background, so the whole cultural thing forces me to say yes instead of refusing. In the holiday season, we need a lot of support.

There is a need to recognise the cultural diversity in the region, particularly around holidays, periods of celebration and food. And these may fall at different times of the year. So we need to make sure that that's acknowledged and recognised in supporting individuals with this type of condition.

Treatment without exclusions

One of the most helpful things was the psych education program that we had to complete. Educating us about the human body and things about what I was doing to myself. Sadly, that input from services ended horrendously with me being kicked off the program because I was self-harming, although I think that NICE guidelines now say that that should not be a exclusionary criteria for services. And I think that this is very important in terms of services approach.

Continuity of care through support systems

Eating disorders are an ageless problem. In this area it's really unfortunate because just as people are often doing their A Levels when they are 18, they also go transferred into Adult Services and family support stops. Because we haven't got family therapists and that kind of thing. So we need to try to think about commissioning services so that those kind of transitions are seamless and are based on clinical need, not on age.

When I was discharged from in-patient care, it was to pretty much nothing. So I pretty quickly went backwards. I felt that I couldn't return to exercise because it was a big trigger for me. I did start an exercise class but I was worried because it was such a trigger and I was risking going backwards. I spoke to the trainer and asked her to hold my issues with me. Since then, she has learned so much and completely changed her ideas about eating disorders. So it's the people who we are going to be with outside of service clinicians, like fitness providers, GPs, they need better understanding. Because you can only get better when you're ready. So it's better to spend time and resources on the people who are in the positions to help when the person that is suffering is capable of reaching out for help. When they reach out, that is the most crucial point. And if they reach out to someone who doesn't understand or have the education and knowledge, then that's when the issues arise.

One of the things we know is there is something about having support when you're transitioning from intensive support like in-patient admission into the community. We had a day therapy service and when we asked people what they wanted, they said they really wanted to go back. Because there is a step down from in-patient to the community service where we can only offer one session a week and maybe something else alongside that. But there is no real support to get back into real living.

Improved GP awareness and knowledge of eating disorders

It's a basic thing that needs to change, it's just education. So that those who are in that position can do more. I was never out of contact of my GP. It's not like I fell off the radar. I was very much on the radar, but I still managed to get very near death.

There needs to be more for GPs because they're not experts, they need to have more options to refer people on.

The need for and importance of advocates

if I think back to all of those moments, when I first was admitted to a new habit, a new way fuelling my eating disorder, had there been more pro-active help to pick up on that and to actually challenge me to address it, that would have perhaps meant that I didn't eventually get to a point 12 years later where I had finally broken that habit. For me, the Holy Grail of eating disorder treatment would be able to be pro-active. I am not someone who has friends and family carers, but I do think that whatever work is done in this area, people who can fight your corner need to be listened to. And when individuals like myself who don't have these people, it's crucial that services themselves like GPs can be the ones to take on that role of fighting for someone who isn't ready to fight for themselves. Until your commitment to change is high enough, there will be periods where the so-called benefits of the eating disorder are far more important than changing behaviours.

That is a valid point, about supporting people when they are not ready to make changes but still need support. How do we do that? With lots of people, it's really about relationships that build up over years, and knowing somebody really well. Then they can pick up when someone is ready to make changes or just have a better quality of life. For some people, they will have this illness for a long period of time and how can we support them in the best possible way until they are ready to recover fully?

The need for eating disorder champions within all mental health services

Mental Health services themselves need more awareness and more training. Whether that's the need for 'champions' where teams each have an eating order champion. But there is definitely scope for that because (and I say this with no criticism at all because it's me that hid it) but I hid my substantial difficulties for two years from my care co-ordinator. Teams and staff need to be more on the lookout for all the issues around mental health and eating disorders.

A role for peer support

Peer support is an interesting one, and is something that would need to be done incredibly carefully. I learned and developed the majority of my eating disorder difficulties as a result of things that I learned and soaked up from others around me. I think that there is a place for peer support and it's very interesting to hear about the SWEDA service. But there are different elements of peer support. Some things can be very informal, or some can be very structured, supervised, either paid workers or volunteers. And I can imagine that one-to-one peer support could be exceptional with someone that's in a place of recovery themselves; and they're stable enough to be able to commit to that. I can see a place for group peer support but I can also have a lot of fear around the dangers of that. Even if you put in things like group boundaries and things like that, it's such a competitive illness. Even with all the group rules in the world, things will go on amongst peers.

So there may be peer support opportunities to overcome shame and maybe make things less hidden. And I guess it could give acceptance and acknowledgment to overcome the shame. That would be crucial to engaging in professional treatment or even committing to want to move past your difficulties on your own.

Effective community outreach to vulnerable groups.

We at SWEDA have seen the need for a person centred approach very much over the years. We have had people come to us who have had the condition for over 10 years without being seen. Now, we find that people who come to us are getting younger, because we are seeing the earlier. That is because we are actively going out to colleges with the younger people. So if we can get them earlier, raise awareness and talk to people earlier, they may come forward. And now we are going even younger using a Children in Need grant to children 4 to 14 years. There are more young people presenting themselves. And they are quite happy to talk about it, at things like Fresher Fairs. Things have changed regarding eating disorders hugely, but the problem is massive. The money needed to support all those young people is huge. And with COVID, our services have increased by 95%.

One of the challenges as well is anti-mental health stigma campaigns. Yes, attitudes have changed recently. In past years eating disorders would not have ben normalised enough for people to approach and talk. But there will always be some people who remain hidden.

Transitions of children and young people to adult care

<u>**Thursday 17 December 2020**</u>

Framing question: As people with lived experience, what are your experiences regarding transitions and support for children and adolescents with mental health issues?

Diagnosis difficulties lead to inflexible care pathways

We have problems with irresponsible prescribing of medication in the hospital and with CAMHS. It felt like a game of Russian roulette. My son is autistic, but he was diagnosed with anorexia and depression. The psychiatrist gave him anti-depressants and said that they were very safe. But they weren't safe in the condition he was in. It was actually very dangerous and had adverse effects on him. And what went wrong with medications has not been documented and shared from the hospital into the community. There have been a lot of problems where the professional gets it wrong and the other professionals will just back them up rather than saying there is something wrong and let's investigate and set it right. They didn't document or assess the medication that they were giving my son, and he had adverse effects that meant he could have died if they had continued. And the record of that medication is still not on his medical records.

My son has learning disabilities, but he was ill with malnutrition and neurological problems. He was mismanaged in the hospital and diagnosed with anorexia. When he came out he was assigned to CAMHS. He should have been assigned to the Learning Disabilities Team. There was not a significant effort to get him with the correct team. I didn't even know that the team existed, I had to learn that from another parent. I asked my GP for a referral but it was bounced because my GP didn't have all the necessary information. The Learning Disability Team is even in the same building as the CAMHS team he was seeing. His situation could have been radically and drastically improved if there had been a discussion at the beginning about the most appropriate team for my son.

I had 6 sessions of CBT and then I got given 12 sessions of high-intensive CBT. The first 6 sessions were vaguely helpful but it kind of became clear that it wasn't really what I needed, which is why I was given the 12 sessions. But it may have been helpful to have the discussion earlier, because the 6 sessions were kind of fruitless, and I wasn't hitting the kind of marks I was meant to be.

Perceived lack of continuity of care

I would say that it might have been helpful to have a plan for going forward, because once that period ended how could I access support in the future if my mental health declined for whatever reason, or were there groups that I could access or online forums? I think that would be helpful.

Over-reliance on CBT

I will say I've encountered people with very strong feelings against CBT because it just wasn't right for them.

It's one of the few therapies that has conclusive evidence as to it's effectiveness, so it is tempting to fund it heavily, but there should be more options for people ideally.

Services did not listen to me or support me

My son was on about 7 different medications, and I still don't know why, but his behaviour deteriorated, to the point where he was smashing things up at home and going berserk. He was taken to hospital but they wouldn't do anything. Social services Children's Team were extremely horrible to me. I started talking to all sorts of people but no-one listened and no help was given to me. He kept having these berserk episodes. We lived on buses and at take-away outlets, as these were the only things that kept him calm. Our home was destroyed. I was trying to go through a formal complaint system. I was trying to get him into the Learning Disability Team. Finally, after he assaulted a learning support assistant and was excluded from school, we went to CAMHS, but we were told that we had to leave because my son was disruptive and they would call the police. He was excluded from coming to CAMHS or seeing the staff. He was nearly sent to a mental hospital in Northampton for assessment, and that was the first time that someone from the outside was involved and took control.

I was not treated very well. When I said that I was self-harming, they said it was superficial and doesn't matter. When I said that I had eating issues, they said that I looked a normal weight, so you don't have eating issues. And I've also had experience with the crisis team when I was experiencing psychosis, and it was almost impossible to get a referral to the early intervention team.

Perceived difficulties in accessing CAMHS services

An issue that's raised quite a lot in discussions with the young people I have worked with is accessing services. They often report that although referrals go from GP, school or family to CAMHS, the referrals are often 'bounced back' as they don't meet thresholds. By the time the children meet these thresholds, it's often at full crisis point. This means that they will probably have quite lengthy and traumatic experiences. So some of the issues around transitioning into the CAMHS services needs to be looked at.

I did not know there was a crisis service in CAMHS. Our difficult times were going on with absolutely no support. I was told to dial 999, call the police or go to A&E.

Clarification by CAMHS colleague: CAMHS Services work 9am to 5pm. But there is a crisis service up to 10pm for Bristol and South Glos. There is a hospital admission function that has been running for years, and a preventative team to stop hospital admissions. There intention is to create a 24-hour crisis service across the whole region.

Transitions is something that has been spoken about both in terms of getting into CAMHS and then from CAMHS to adult services. I have had a quite difficult time with that. I first tried to get help when I was 13, and I was told to go home and have a hot chocolate. I was in crisis and admitted a year later, but I was sent home because the CAMHS service was not available after hours. It took a year and a half to get the initial appointment with CAMHS, because they said that my paperwork had got lost.

An observation from the sector regarding waiting lists is that families' expectations are raised. They then sit on a list to be seen, which can be lengthy. Then they get to the top of list, only to be told that they don't fit criteria. Then there is no signposting to other services or support.

Poor care delivery, which can further traumatise

There was clearly something wrong with my son. It's not an issue with funding, it's about inappropriate people and activities. Everything in our sad history was about mistakes by people who didn't do their jobs, and did the wrong thing.

There is a complexity in diagnosing under 18s. It can vary from doctor to doctor, and there could be three or four diagnoses. So there is an inconsistency in diagnosing which leads to differences in approach and treatment.

At my first initial appointment with CAMHS, I was told by the assessor that if I wanted to be taken seriously, then I probably shouldn't be showing my self-harm, because it wasn't deep enough to be a serious problem. So I went away and did something drastic so that I could be taken seriously. And there are quite a lot of young people that have been told that. That if you want to meet the criteria for support you have to do something drastic. And people do, because it's taken so many years to get there and you're at crisis point.

It's really important to remember that when you have accessed CAMHS, that is setting up you're experience for what mental health services are going to be like. I'm terrified of mental health services because of my experience. I don't want to engage with them. People forget that your first experience of services and support is what sticks with you for the rest of your life.

Lack of crisis provision such as safe spaces/sanctuaries (Non-parity of support between adults and young people)

In adult care there are spaces you can go when you're feeling distressed. I feel that there needs to be somewhere that isn't hospital for young people.

The majority of young people that I deal with have had lengthy admissions to CAMHS units. The stories that they tell me, I am absolutely horrified and I'm haunted by their experiences in hospital. In adult mental health services, we do have crisis houses that we can access as an alternative to admissions. There are safe places to go. And adult services gate-keep into crisis houses and psychiatric hospitals. But CAMHS don't have that kind of provision, and I have never understood why they don't.

It has been acknowledged that the lack of this sort of service is a significant gap. Funding has now been found to provide the equivalent crisis team for children and young people

Lack of provision for local specialist hospitals (non-parity of support between adults and young people)

A lot of the hospitals that young people are being admitted to are private hospitals. They're miles away from people's homes. Young people go into hospital traumatised and come out even more traumatised. And that is heart-breaking. It is really difficult when these young people when these young people get admitted to out-of-area, private-run psychiatric hospitals.

Yes, this is absolutely something that is absolutely insane. My son was at risk of being sent to St Andrews in Northampton where he would have been put in a unit that had just been slated as inadequate by the CQC. I absolutely refused to allow my son to be sent there.

There seems to be a big barrier to getting intensive support, either in people's own homes or hospital. Around the country there is a reduction in funding for social care and respite, so early help and intervention is less available.

CAMHS is not integrated or dialoguing with children's services or adult services

A lot of people using CAMHS say that there is a problem with CAMHS and children' services not being integrated in any shape or form. And often they don't have any communication. Services work quite effectively for adults, the crisis teams gate-keep everything, there are alternatives to admission, they work closely with care co-ordinators. And there is a joined up service, that is quite effective. So you already have a model of services that you could actually mirror.

Even though CAMHS now use computerised notes, they still have systems that don't talk to each other. Even though they are both run by AWP. And that's a different system from adult mental health services. So when I first see people from CAMHS in adult services, I don't have anything at all. Sometimes that is a good thing, because that first story is relevant, not what somebody else thinks of them. But generally, adult services having access to the electronic CAMHS systems is something that would be quite helpful.

Taking the information off CAMHS and onto adult services systems is possible, but it's very time consuming.

If you are moving in and out of services, and at a point in time, you want to again access secondary services, one of the basic things that you want is not to have to tell your story all over again. It's not an easy thing to overcome with paper notes and systems that don't talk to each other. But it's really important that that information is there and available to be accessed.

A shared platform, that allows much more seamless sharing of information, should be accomplished.

No seamless CAMHS to AMHS Pathway

I didn't know that you had to leave CAMHS when you were 18. I tuned up to an appointment just before my 18th birthday and my worker told me it was my last appointment. She said that sometimes people are transitioned, but she was not sure that I needed adult services. So that was that! I was discharged without a plan. It's taken two years of being passed between my doctor and adult services to finally be seen by them. And to top it off they can't find any of my notes from CAMHS! So for me, it's not the best experience, but it's not as bad as some people that I have spoken to.

Not having a transition or not being aware that there could be a transition is quite common. If you're in CAMHS for eating disorders, the transition is better and there is a crossover between support groups, but it's not consistent. It's a bit of a lottery about whether or not you're going to get a transition. And that is shocking that it's normal to have these kinds of experience.

Everyone does need to have a good transition and the attitude that practitioners take to young people under 18 is significantly different to over 18s. As an organisation we do our patients a disservice if we don't help address that. Both amongst ourselves as practitioners but also for the young people that we are supporting.

In Bristol, we at AWP are responsible for transitioning people from CAMHS to adult services. But we are dependent on CAMHS to flag up these people coming up to 17½. CAMHS tell us if they think these people will need adult mental health services. The transition should be seem-less. There is supposed to be the same sort of service in North Somerset, but they are located in the Recovery Team and they work in different ways.

CAMHS is described as the Cinderella Service. It's difficult to get into. And then there's a cliff edge at 18 and transition to adult services, because that's even more difficult to get into. Access rates are improving, getting up to the 35% target set by the NHS England. More money will mean more parity of service.

There is a statistic that says that 75% of people who come through CAMHS don't meet the threshold for adult secondary mental health services. In generalised transitions for people who are on journeys regarding managing their mental health, they experience real difficulties in transitions. The pathway is really unclear. It should be a CAMHS to AMHS pathway, looking at people approaching 18 and working them into adult services.

Voluntary & non-profit sector not utilised

Even if it's not a transition out of CAMHS, it's still ridiculous that no information or support from the voluntary sector support was signposted. Hopefully it's different now.

Bristol is a big area and there is just me at AWP to cover the three CAMHS teams and three Recovery services as well as a few other ones like substance abuse.

North Somerset is now moving to electronic records, and the transition regarding paper records has been difficult, but hopefully that will improve. But within the CCG contracts for services, it would be nice to see that other non-profit providers like Sirona Care & Health have the same roles that AWP have.

Lack of child-centred, compassionate support, tailored to the individual's needs

So many other services are under 25 years these days. It seems ridiculous that NHS services aren't. Having things like flexible transition services are going to be so important. It's impossible to decide when people are ready to transition into adult services. It needs to be a more unique personalised service. That would be a good way going forward.

And a change of approach to look at under 25s should be something that goes on on the GP side as well.

One of the words that has come out is 'compassionate'. That is a word that we should really hold on to. We need to create a culture in services that is caring and compassionate. That must come through to people in their experiences.

When I was with Early Intervention Psychosis Services (EIP), I was always treated as a human. My whole treatment was entirely respected on my opinions. And I felt very valued with my opinions. Before that, I had had counselling and I didn't feel for a moment that my opinions were valued. It was very much the counsellor's opinions. And that wasn't helpful at all, because his opinions we all so entirely wrong. He didn't think that I had psychosis. For me, EIP and Off the Record (OTR) are very good at understanding that we are still humans, and valuing our opinions is vital to our care. And respecting how we want to be treated and want to improve ourselves is vital.

And to acknowledge that it's not on the parents' basis, the child has to be up for it themselves. It's entirely up to the child how they want to experience that care. You have to consider the service user's opinion, no matter what their age or difficulty.

Recognising where a person is almost part of the respect that I would anticipate as being part of a compassionate approach. Even small choices you get to make in services make it so much easier to engage as a user.

Humans are organic beings. Solution needs to be organic also. Mental health is not a one size fits all.

A need for good peer support – learning from the voluntary sector

I received my peer support through EIP. As soon as I came into the service, I was given a peer supporter. The first thing which peer support does is to give you that kind of feeling that you're not alone. The second thing is the feeling of community and the feeling of understanding through people. Eventually that has built up to me

doing some peer support myself. I can't speak highly enough for peer support for adolescents.

With peer support, more in terms of what is existing, it is important to say that OTR has been a lifeline. I can get peer support without having to prove that I deserve that help. Imagine what it would be like if there were more things like OTR that aren't scary and intimidating to use. And we can learn a lot from what they do with peer support and how they go about that.

Poor support for carers

From my experience there are a lot of similar feelings of struggling by carers. I almost feel like it would be helpful to have some sort of support worker figure who is more readily provided. The person I was looking after was prescribed anti-depressants. And it can be quite tricky getting used to these. I was left entirely responsible until the next GP appointment, overseeing some really scary situations that I didn't feel at all emotionally prepared for.

The negative impacts of mental health can ripple through families, friends and society.

A lot of (unclear) could do with a buddy in a lot of situations. I could have certainly done with one during the awfulness that we went through. It would have helped to have a buddy much earlier on. As a parent trying to look after a child with a disability, it might have helped to keep us out of trouble. There needs to be a lot more networking and support and people encouraged by the (unclear), in getting to know other people who are facing the same difficulties. Some of the most supportive helpful people that I've encountered have been the other parents of children with disabilities. We can help each other.

EIP had a Friends & Family group, just for parents and friends of people who are struggling, to be able to go and meet other people who were also struggling with those issues. My family found it helpful in understanding the condition I was going through at that time.

Difficulty with early access

There is a positivity in not having to wait a long time for a service. That seems to equal better outcomes. That is something that we need to think about

There seems to be a 'remedy culture' for when things have gone wrong, rather than early-stage assistance to help somebody navigate the system, especially if they've had experience with social care and feel 'bounced around'.

I think that there is a need for system of quick entry and quick assessment, one or two meetings, then get the right things done. That is much better than a dozen appointments which are really missing the point. That has been part of my experience.

I want to express just how important it is to be treated seriously early on. If you're not at an early stage it can get so much worse before it gets better.

Poor communications

Even being told 'hi yes you're on the waiting list' would be good. Anything other than radio silence! Radio silence is the worst. Even though it took a long time, IAPT were very on it with sending me a letter every time something changed in availability and it was really appreciated.

Is there a genogram outlining all these services and what they are?

Lack of staffing resource

It is quite difficult in terms of service responsiveness because sometimes enough resources are not really put into how staff can be more responsive in terms of access to the right services. It's a bit of a challenge and balance as well. It's important to recognise some of the pressures within the system that can also stand in the way of services being responsive. I have heard people have long waiting times and that is really something to do with resources and the availability of people to be able to respond in a timely fashion.

Trauma-informed approaches and personality disorders (session two)

Monday 21 December 2020

Question 1: Respondents' experience of support for individuals with personality disorders?

Failure to recognise the link between trauma and addiction and substance abuse

My history is one of anxiety and addiction, centred on childhood trauma. This has meant that they won't give me any support or counselling until I'm sober or clean. Its almost as if they recognise that there might be some kind of a link between the trauma and that, but they can't deal with it now. That meant loads of difficulties in trying to access help. I've also had suicidal thoughts and suicide attempts.

I find it hard to understand why trauma support and drug and alcohol support are not embedded together.

Interventions that are too late (thresholds)

You have to be in crisis for somebody to actually even recognise something is going on. That is appalling. I have been sober for 10 years now, but have had periods of homelessness.

Negative staff attitudes

I went from being a teacher to being too unwell to work at all, because of my personality disorder. In this area there is such them-and-us attitude. If you're a person with mental health difficulties, you are nowhere near the same sort of person. It's not equal. And its not necessarily like that elsewhere. It is partly finances, but everywhere struggles with finances. It's as much about attitudes, we are not actually seen as equal people. So how are things ever going to be changed if people with mental health difficulties are not seen as equal people? Attitudes need to change. Some mental health services work with people in a good way.

Having to fight for the support needed

The borderline personality course that I did, it was in Bristol, but it wasn't enough for me. But I only then got further support by making a fuss. Again, there was no on-going support at all. When I finished, that was that. It was only when for the first time that I had a psychiatrist and a support worker, that I was able to push for more intensive group intervention support.

Unless you leap up and down and make a fuss, then you just don't get heard. And when you have been brought up with a trauma history its very hard to do that. You take what you're told as fact, and then end up feeling like you don't matter, that you're never going to be heard. It just makes it really hard to reach out, then keep reaching out.

The legacy of poor trauma-informed support within the health authority

Bearing in mind that there has been a history of poor support for people with personality disorders in this area, the is a big legacy of people not having good support. Services in this area are poor, compared to many other parts of England. So it is good that services are planned to be improved, but we must remember the context of where that is.

The slide into questioning your own self-worth

I wasn't given a diagnosis until later on in life. I didn't know anything about BPD, what the hell it was. But I was presented with all these negative things. You self harm, you have suicidal thoughts, you can't maintain relationships. As an approach, an introduction from professionals, it was hard to hear that. It makes you doubt if you have any self-worth left.

The experience of a diagnosis and being left questioning your self-worth around that diagnosis, and all that goes with it… being unfamiliar with it and then all the baggage that goes with that, is something that a lot of people have experienced.

The lack of understanding of the impact of shame

Shame has always been part of early childhood experiences, which meant that I couldn't talk to anybody because I was too ashamed. It's a big part of trauma.

My interest in trauma led me to look at the issue of shame, as a social emotion with trauma. I have recently taken part in training about shame. Shame makes you actually hide and not talk about it. When people mention the inability to talk, I think that shame is a huge part of it. When I was considering my own shame and experiences as part of my research, I found out about therapies such as EMDR, a very expensive rapid eye movement therapy and compassion-focussed therapy. When I was put through to Bristol Wellbeing Therapies (former IAPT service), I looked for that specific support. Someone who isn't as in-the-know would really get lost in that. Shame is a huge part of trauma and early adversity in childhood, but would those therapies be available? From my professional experience, I like to look at the source and not just at the symptoms.

The lack of understanding of the effects of trauma

An important point that is often not considered is around speech. When you're already traumatised and distressed, you often can't speak. And most of the services rely on you being able to speak. A lot of clinicians have said that if you don't speak, we can't help you. There is no recognition of what trauma does to you, if its come to the surface. I suffered badly from services just not taking any acknowledgement that when you're traumatised, your speech goes. So they would put the phone down and things like that. It all relies on you being able to speak in some way.

I wasn't prepared or even ready to speak about my trauma. Because I wasn't engaging, I was told that there was not help for me. The time I spent with services was therefore traumatic in itself, because I felt that people were disregarding me and

not listening to the things that I wanted and needed. They denied me complex psychological intervention, something that is key to understanding trauma. As soon as I tried to ask for that I was labelled demanding and difficult.

Peers are not acknowledged and recognised.

One of the hardest things is to hold onto a peer. Being a peer is not rewarding. My experience is it's a cheap resource to gain experts in. It was acknowledged when it was given, peers were told how well they were doing, but they are not rewarded. And you need to keep peers. Because its about relationship building. Its OK to say peers are valuable with things like stigma busting and carrying the message to vulnerable communities, but its about rewarding people.

Borderline personality disorder (BPD) as a catch-all diagnosis to exit

It's really important to understand that all ten personality disorder types are thought about, not just focussing on one. There's a very narrow view that everyone has Borderline EUPD. People don't look at anything else. There's loads of different types of difficulties, different types of personality disorders. In the mental health classification system there are 9 very specific criteria for BPD. So are the people diagnosing actually following these criteria? It should be specific, but it is being used as a catch-all, which it shouldn't be.

I had a series of traumas later in life which led to a diagnosis of PTSD. I struggled a lot to get the right help. And I was often tarnished with the brush of BPD. Simply because of some of the things that were happening to me, such as suicide attempts and self harm, are symptomatic of something else. I found it challenging with services. They use the BPD diagnosis for those people that they almost don't have time for, and it feels like people are then brushed aside. Then doors are often shut to you and you have no access to real help. When I was labelled BPD, nothing was happening for me. I had to withdraw from services because I felt that I was being ostracised by them.

The term BPD is used far too much to sweep up the dregs. The ones who they feel don't fit into any other diagnosis box. They rush to give that diagnosis because then they don't have to do anything about it. Because BPD is difficult and they are not going to try to help those people. The diagnosis then just moves them along so they can then go and treat those people who are 'truly unwell'. A lot of people talk about BPD because the term is so freely used by professionals, and that's a issue, in my opinion

Services that fail to understand cultural issues or use culture-appropriate language.

This is a theme that runs through everything that we do. Its often not understood in a professional context. We have initiatives, but there are some foundations that are taken for granted. Sometimes the language of these initiatives is so far removed from an emotional and stressed-out person, its almost alien. Professional use language to make themselves feel better, but they are not addressing the foundations of good service, such as including communities of colour and using

language appropriate for them. The language sometimes used in these services is almost scary to some communities. To some, it's just talking. If there is no recognition that what went on before didn't work because it did not understand cultural differences, then it's just another initiative.

Question 2: What should a good trauma-informed service look like?

A joined-up approach for people with trauma-based issues

Suicide prevention training certainly needs to have a place within a much wider cultural approach to the issues of personality disorders. Depression, anxiety and suicidal thoughts come into that. The current approach in my experience is totally disjointed. My experience with services has not been all bad. But this thing about addiction as a coping mechanism, to try and cope with the world. Why the bloody hell would you give that up without knowing enough about any support that you could be given to help you cope?

Addresses the link between trauma and personality disorders

I am involved in the national training for personality disorders. It's all completely interlinked, trauma and trauma-informed practice and personality disorders. National good practice, whether its services or training is trauma-informed, its completely inter-linked. 85% of people with personality disorders have had trauma in childhood.

Provides a range of levels of support for as many as possible

Structured models are fine, as long as they are the correct model. There is a need for a range of things, different pathways, so it's not all or nothing. We know that there are thousands of people in this area, but most will never get near specialist therapy, its only for tens of people at a time. So its important to have a gradual pathway for people, which a lot of other areas around the country have. So it's not just all or nothing. There are lots of other things that can be done in between to help people without it being nothing.

Follows best practice right from first contact

People diagnosed with PDs need advice early on and someone to hold you through it, that guidance piece, by someone who understands where you're at and where to go next. This is something that is really coming through as important.

You need to find a way of working that acknowledges and takes account of people presenting who may not be able to speak when they first present. People communicate through a whole host of ways; verbal is just one method that is easier to pick up in. But eye contact and posture, or even writing something down are important. It is well acknowledged that when you are traumatised and really distressed, your speech will go. Whenever changes are made, the fact that people may not necessarily be able to speak when they first present must be considered.

Understands that personality disorder is multi-faceted

Please, please consider all ten types of personality order, because there are a range of difficulties and problems. And not just the umbrella term of borderline personality disorder to label everyone.

When considering awareness and training, its often not a simple diagnosis of BPD. And its important to have the information about all of them.

A culturally sensitive and proficient service

A big problem with some services is they can be perceived as all just words. One of the particular concerns at the moment, as we talk about psychologically responsive environments, is that it's great that people have this on their agenda, but what does it mean? Are these just more words? Where does it all land? How does it make a difference? Change started when Bristol systems and institutions, police and the council, acknowledge that they were racist, and were open about it. Then there was nowhere to hide. Saying this was very helpful to all of us. So what do we do about that? We have to cut through all the words and be really clear about what is going to change? What will be different? Being specific about what the problem is and what does the change look like.

Following on from discussions with the Somali community, for them the first, point of contact was not the GP and the Primary Care system. So how do we reach out to those communities and think of different ways to allow that support to reach them? This is something important to explore.

There are cultural issues with staff in mental health generally, but there are particular issues with personality disorders on top of that. Its partly stigma, its partly lack of understanding. They come to training and they learn, but what happens when they go back into teams is the issue. Some trusts have personality disorder specific training for starters. In others, all staff have training in cultural sensitivity from the word go. They have realised that these are difficulties that many people with personality disorders experience. So all services are geared to meet the needs of those people. Everyone has the basic level, then certain staff get more tiers, depending on their role. And some have specialist locality people for personality disorders. SCM as a first level, then therapeutic communities for complex trauma.

Adopts real transparency

If we say that we are going to do X, did we do it? What difference did it make? Having that continuous circle of improvement to try and make sure that problems are addressed.

Has a unified service model

The best services have a unified model. It's what happens one-to-one, the service user and the staff member.

It's how teams work together to support each other, the culture of the team. It permeates the organisation, how they support staff so that caseloads are not too big and they are able to have good supervision and support. Turn around rates are

massive in PD services for staff as well as people with personality disorder difficulties. So you have to support staff. Here in Bristol, we have some failing organisations. Not all but some have been failing service users for years and years. And they are still there. We might come up with a beautiful model, but who is going to run it? If they don't improve, however good the model is going to be, it won't help the people of Bristol.

Management prioritises good organisational development practices

We don't have the levels of workforce that we need locally, so a big part of developing the model is thinking creatively about we can ensure that we have the right people in place to support the desired outcomes. This may involve looking at models from elsewhere to see how successful organisations achieve this. Organisational development is one of the big pieces. How can we invest in support for our staff who are working in a whole range of different organisations? One individual might have professionals working from different organisations. How can we achieve a shared culture and way of working between them? And to include supervision and reflective learning and all of those things. We know that there is a strong evidence base for that, enabling staff to not get burnt out but to deliver care that they need to. There is a long way to go to embed that, at scale, in our local area.

A service which is listening, person-centred and compassionate

If you are a staff member you need to stand back and really hear the person. Allow the person to speak and say things in their own words. Give them space. And the staff member should encourage the person, at the same time making sure that they understand what the person is trying to say. Then the next stage is about trying to help the person communicate what is really going on for them, help them to start putting into words some history of their story, and then gradually little things coming out bit by bit. And helping the person, not just with information, but encouraging them emotionally, not putting words in their mouth, but helping them to vocalise some things. Its about those things, and reflecting, being with people and giving them space and supporting them to move at their own pace. It's called 'curious stance' or 'available mind', various buzz words like that, but that is essentially what it is.

Not building expectations, allowing time for the building of relationships.

Not making assumptions about people.

It all should be person-centred. It's not even diagnosis centred, it's person centred. So it's all around formulation, the work we do. It doesn't even have to mention diagnosis. What formulation means is the staff member should always work alongside the person they're working with. It follows what is commonly called the 5Ps:

- The first P is the person sharing what their problems are now.
- The next P is what in a person's past life may have lead to trauma, if they're able and willing to share it. Its also about triggers, what are the triggers for the person now that will help (unclear).

- The next P is perpetuating factors, what keeps those issues going round and round.
- The next P is what positives and resilience does the person bring themselves, what do they already have, which to me is often ignored.
- The last P is plan. So then you do a sort of narrative around that, and then it gets into a plan.

The important thing about formulation is that it should be constantly updated as the person gets more insight about themselves. It shouldn't be a still document. Formulation used so much because a. its individual and b. it looks at the person and hopefully the future of the person. And it's completely and absolutely individual and person centred, and not diagnosis driven.

A passion-focussed therapy will always be helpful.

Compassionate formulation therapy, you hope, would be integral to all person-centred approaches.

And reflective practice should be stressed as well.

From my experience, I didn't feel that I was treated with compassion. I didn't feel that people were listening. I didn't feel valued or validated, I didn't feel encouraged. Nothing. Like we've mentioned, compassionate care is the very centre of this. You need to feel that you are being listened to. You need to feel that your story is able to be told. You need to feel that you're not being judged.

We have some very significant external, cultural blockages to improving outcomes around societal pressures such as success, money, and personal happiness. To me, that emphasises the importance of a holistic person centred approach which can recognise those pressures.

Has therapy as the core of the service

Services are very good at the moment at treating symptoms of an illness, be that self-harm or suicide. You need to get to your crisis point before you actually manage to access any services. But then, on the other side of that, you get to a crisis point and access services in that tiny acute period, but then you're told that you're too unwell to begin therapy. I think that therapy is the key for trauma informed approaches. You need to have that space, that non-judgemental and open and honest space where you can begin to process those traumas. It's about processing. And that's what services are, for whatever reason, unable to provide at the moment. Whether its short staff or lack of money. There is a reason why therapies are good, and that's where it all lies, that's where the future is.

The national evidence shows that people with personality disorder difficulties move forward by learning coping mechanisms. The trauma doesn't necessarily go. What happens is that a lot of trauma is in your unconscious. It's fine to get support to get some of it into your conscious to get more insight. Once it's in your conscious you can try to learn some coping mechanisms. That's what all the data shows. That is how people move forward in this field. Sadly, life expectancy is 18.7 years lower for

people with personality disorders, due to massive suicide rates and also physical difficulties. That is what the evidence shows. It's insight leading to coping mechanisms. Whatever is done in any new service needs to replicate and show that on different levels, because that is how people move forward.

Yes, we need to acknowledge the existence of co-morbidities and linking that into coping mechanisms, issues around substance abuse and alcohol use.

Accepts longer time-frames for care pathways

And building coping mechanisms needs time. You can't do it in a short amount of time.

Rewards and values staff

There is evidence in other areas to show that mental health teams understand that there is a relationship between the way you treat your staff and outcomes for the people they're there to support. They are 100% completely inter-linked.

Values and supports peers

If you want to retain peers and for them to be willing to pass on their skills, you need to recognise and acknowledge them and reward them.

Yes, we don't want to undermine the value of peers by institutionalising them. By installing peer support workers in institutions, but then leaving it to them. This is particularly important if they are to be part of meeting long term need, rather than just short-term reactive support that the NHS provides currently. We need to think about what we should be doing, not just what we could do, to meet people's needs.

Learns from the experience of other trusts/services

In BNSSG, through AWP, we recognise that we haven't got the levels of support that other areas have and we need to strengthen what we have available. We need to bring together people with lived experience and professionals. We need to come together to really look elsewhere around the country at what is working well and what can be built on, and what is the recipe for that. It may not be just funding, it could be cultural shifts and more inclusive approaches to services offered. Then it's a matter of getting the funding in, testing ideas and evaluating them to make sure any changes have the impacts we want them to have.

We need to improve in our area. We are at a very back level. So we need to work together to move forward. Because we can make a difference, as long as we are all working together, and everybody is an equal human being and treated as an equal human being, and we all lend out expertise from whatever perspective we come from.

Peer support approaches (session two of two)

Tuesday 12 January 2021

Question 1: How do these general themes and principles sit with you as people who either deliver peer support or a passionate about it?

1. **General agreement to the overall principles**

Validation of the principal of equality in the space

They sat well with me, the general outline. I took on board most of what you said. I really picked up on equality, non-professionalism and the physical activity. As a Forest School leader I am particularly interested in seeing people develop skills, but not under a hierarchy. It's more about the feeling of being in a circle. In Forest School we sit in a circle and the fire is the main focal point, there is no kind of repressive hierarchy. It's brilliant in bringing out people's confidence. With people who suffer from mental health problems, the last thing that they want is to be under a regime. They want to be brought out and nurtured, give the opportunities to flourish in a peer support environment.

Peer Support should not be over-professionalised.

Over professionalization is when mental health services or organisations come in and start hijacking the group and applying a load of arbitrary rules that create barriers for users. That is the worst-case scenario.

And when peer support is tied to funding sources that detract from the actual purpose of the support group as well. So don't let capitalism get in bed with peer support.

Peer support is more about a shared space, then professional guidance.

Peer support is spontaneous and normal behaviour amongst people. To centralise and manage peer support via a hub-and-spoke model is necessary for an organisation's ability to safeguard and supervise, but that is counter-productive to peer support, which then becomes indistinguishable from peer support workers. A way to counter this is to allow as much control as possible to the peer mentor and mentee in deciding where to go and what to do, taking care of necessary risk management but not intruding on their relationship. It takes courage and good quality training as well as good knowledge of the peer mentor's strengths and weaknesses.

Peer support should be flexible

Yes, it should be super flexible. What will happen naturally through that relationship will be that someone will say oh do you know, I really want to get outdoors more, and then you start to plan an outdoor activity. Or they will say they are bored and they really want a job, and then you look into jobs. But to start with it needs to be about building the relationship, rather than an agenda with star outcomes, that sort of stuff. I think that it comes naturally. Supportees will sense and know if the supporter is

pushing for particular goals. But if the supporter knows that their role is just to build relationships, all the added stuff on top, like starting people on their recovery journey, that will come as an added extra.

2. Some further thoughts

The importance of support for peer supporters

Spontaneous peer support is a mutually supportive relationship. This is not the case in peer support managed by an agency, where the mentee gets support by the peer mentor and the peer mentor is supported by the agency. The benefits to the peer mentor come in the form of professional development and confidence building and occasionally confidence in one's own recovery

Peer Supporter: fellow traveller or guide? What is the balance?

Do you lose that unique position that a peer holds if peer supporters become support workers? Is that relationship lost? There is a dichotomy between protecting people in a peer support setting and recognising the intrinsic value of a peer on a mutual, inter-personal level.

I am a client and a support worker at the same time. I am in-between. I just realised that it is hard to get that balance between standing back and observing and identifying enough to build the relationship, but not so much that you lose your objectivity in safeguarding and issues of that type. It's quite a hard balance.

It is clear that protecting the shared space is important; it must be protected at all costs.

For me, peer support mustn't have an agenda as such. So not having to reach certain outcomes, not having to work to a deadline. But it should just surely be about the relationship. And about building relationships with people. And less about getting people into work or getting people back on their medication or whatever.

There may be outcomes from a peer support relationship, but those outcomes don't necessarily need to dominate the actual way in which the peer support is run.

The need to prioritise the relationship in peer support

But what is key at first is the relationship and the humanness of meeting up, chatting and hearing people. This is important and something that is completely lost in the mental health system. There is no humanity in it at all. That is what peer support people should do, come in and be a person with the person that is being supported, to build the relationship together and see where it goes.

Outcomes might be something that people should work towards, but that is not going to happen without a fundamental approach to basic human relationships.

It might be worth quoting the literature around the importance of basic needs and how relationships actually work.

The building of relationships is the primary thing, but how do we persuade the people with money that everything else will come out of it naturally. How do we make them see that it will come?

Peer Support must be rewarded commensurate with its role and responsibilities

Peer support roles should not be over professionalised. I agree with this. But they do need to be financially compensated. Peer support roles are advertised as Band 2 and 3. So they are a relatively poorly paid. Its only when you get to Bands 4, 5, 6 or 7 that you get better money. I think that if you are going to have peer support, you should acknowledge it as worthy of payment as any other type of support. If there is an equivalent job, peer support should have the same banding.

The value of peers and subsequent recompense for people who work in a peer support setting can't be ignored.

There are added benefits of peer support

Peer support can prevent the use of other services and hospitalisations as well.

There is the issue of community projects as well. There are successful community projects where people have been supported and developed, plus there has been a tangible outcome in terms of community benefit. The important thing is not to get too defensive about justifying projects. Can we illustrate benefit with community projects that have succeeded in BNSSG?

Peer support will have longer timescales than other support programs

There are massive pieces of information on the importance of relationship building. That is what therapists and support workers will often say, but what is lost is the timescale really. And the bit that we need to focus on to try and persuade people is that people need time for relationships to build. As soon as you say you've got 6 weeks with a person, it's all about what can be done in 6 weeks. Relationships take time, but it will save money in crisis services and it's going to save money elsewhere.

It's about recognising that standard mental health programs such as those within AWP don't necessarily achieve recovery in 6 weeks. Peer support workers have to justify achievements after 6 weeks, but AWP don't have to justify it. They carefully avoid any report on patient experiences when they talk about outcomes, because that is subjective. That can misrepresent people's satisfaction with existing mainstream services. What people want is a good experience, and good peer support gives that. Show me how the mainstream support sector provides a good user experience from the standard 6 week CBT or whatever. We need to go on the offensive and prove that peer support does improve patient experience and produce benefits for users and the community. If we can improve the patient experience, that will lead to some form of recovery.

It is important to reconcile the benefits of peer support with the current way that support is commissioned. It's the case of qualitative versus quantitative results. Qualitative results are equally as important.

Question 2: What guidance would you give to an organisation that has been tasked with providing peer support to help them decide their service specification?

Breakout Group 1

Respect and peer support workers

- Involve peer supporters in all decision making.
- Actions speak louder than words - there are barriers in place that do not allow you to be a good supporter and be the best peer that you can be.
- Training is important, particularly around interpersonal skills (Expressed as 'Train the empathetic part of your brain, don't allow the system to tell you that you are not able to prioritise empathy')
- People with lived experience should be seen as no less valuable as a peer or a lesser person.

Define and respect the role

- Ensure that mental health workers don't dump their unwanted work onto peer support because it doesn't fit in with what they consider to be worthy of support in their remit. Mental health services need to clearly understand that they cannot turn round to peer supporters and expect us to take them because they don't fit the diagnosis of eating disorders or bipolar. Otherwise peer support will be loaded with issues that they are not equipped to actually help in the ways that people really need.

Recognise and value peer supporter expertise

- Allow peer supporters to educate up the organisation, recognising the importance of lived experience. Because sometimes organisational hierarchy can lose touch with service users. So transform the service by empowering peer supporters to become educators, to be able to confidently share their knowledge with other mental health professionals. I have always been begging to share how good and beneficial peer support can be.

Reverse the balance of influence

- Move to a model based on the Plateau of Mutual Power:

Instead of being a pyramid, it's a trapezoid. You cut the top off the pyramid and make space for many people on the summit. In the LGBT steering group, we have a lead panel that takes collective responsibility for driving the group, supporting from the bottom up. This moves away from the idea of a few at the top dictating what

everyone else is doing below them, which is the problem that we have in many mental health services. Decision makers are disconnected from the reality of the services they are providing. The goal of leadership isn't one of authoritarian control but rather support; leadership on the plateau drives from the bottom, developing roots, and helping members to step up onto the plateau, and off of it, as and how they need.

Consider New ways of thinking

- Instead of treating clients as individual units (client syndrome), and justifying service provision on the number of units, look at the overall value of what is in place.
- Mental health professionals look for a diagnosis, they look at you pathologically, as an object. Its about how can they categorise you within a certain group and then work out a treatment plan based on the category. But peer supporters look at people as individuals, working one to one, understanding them as people rather than as a condition or category.
- The mental health medical model is a deficit model; its about getting people up to 'normal'. It says that you are deficient of a certain kind of normal characteristic that most people have. You are disordered and dysfunctional. But a peer support led model asks what potential does this person have to grow and develop through experiences with peer support.
- The system is the ill one, not the individual people. We are not actually ill. So the support system should be well.
- But don't overburden peer support workers, its not their responsibility to fix or make the system better.

Understand, acknowledge and accommodate that peer support workers may still have mental health issues

- Peer support workers have lived experience, so they have had or are still going through difficulties with their mental health. What support should be put in place to ensure that this doesn't mean that they are less of a person? They must be supported well within a new role that may trigger things and bring up old emotions. Or the grief of knowing they didn't have the support themselves that they are now providing for another person. *(Question: Should AWP provide peer support to all their staff so they feel well supported and therefore reduce staff turnover?)*

Breakout Group 2

Recognise and reward peer support skills

- I do like the HEE Competency Framework, because if we want to pay people more in the NHS, that is the kind of thing that helps us do that. I have a lot of volunteers and I really want to pay people. But this is one of the problems with the NHS. You have to be quite defined. In doing that you lose a little bit of purist peer support, but you also change the NHS because these people who work in it are not being 'medicalised', there is the characteristic of

'alongsidedness'. The Competency Framework does have it's issues, but it is starting to treat people more equitably, getting people in the door and into jobs. So then we can start to make more peer posts from that.

- It would be good if some of the competencies of peer support workers could be picked up on and linked to grades. So, through appraisal, no-one starts on a Band 1. Or maybe look at apprenticeships at Band 2 or split grades. Primary Care Wellbeing Coaches, Social prescribers and Care Co-ordinators have salaries set outside NHS grades because they are sub-contractors. They need to be able to say what people are worth. Social Subscribers are new occupations; where is the long term memory and experience of what they did in the past, yet they start on £25K. But peer support workers start at the beginning of Band 2 or 3. And they bring a lot of lived experience relevant to the role, and that should be recognised.

Define and respect the role

- Organisations that use peer support workers need to acknowledge that they have a lot of experience and it's not an entry level post. And there should be career progression. It shouldn't be a role that people never have an opportunity to develop their career in and go up the bands. That is really important for the self–esteem of the people who take on that role. A number of NHS Trusts have done this successfully. And Second Steps have also done it successfully. But in this case, because the job descriptions were not clear initially, the roles were not well defined initially. That is an important lesson. Teams must be educated in peer support and the value of peer support. Because some staff have said that peer support workers are not qualified and have not valued the lived experience. And peers have felt almost bullied in that respect.

- We have often talked about peers getting seen as 'staff on the cheap', and it's really not. So whatever we want the CCG to specify, it's really important that peer supporters are not just seen from an NHS point of view as Band 3, 4 or 5 staff. But there is money available so they can be properly supported. This might mean what could be called increased supervision, but it should be meetings or ways to help supporters to think through the work that they are doing. If you need lots of people with lived experience, there needs to be realistic adjustments around their mental health problems, and the proper costs for these need to be built in. They need to understand and provide for the real costs of providing support from lived experience. You wouldn't employ somebody because they are in a wheelchair, and then fuss about the price of a wheelchair ramp, would you? So this needs to be thought about and provided for from the start, because otherwise they become a really easy cost saving – we won't have them because of the added costs.

- We need to be mindful that funding limitations, especially in organisations such as AWP, mean that there are fixed term contracts of say just one year. So we need to try and see what is the best commissioners can do to ensure there is reasonable settlement for delivery of services. And midpoint quality assurance monitoring and checking.

Build in clarity and flexibility to the role

- At Second Steps, I wanted to move from a part-time or full-time volunteer to staff. And there was a clear path for that. And if I was unwell, it wasn't that I could not take the role, it was how can they adjust around me. With other organisations, there was no clear path from volunteering to working. This can cause problems with benefit claims, because the benefit agencies need to clearly see the path that you are on. So paths should be built around what people actually want.
- With these new roles of peer support all organisations, NHS and voluntary, need to take on board and support peer workers and acknowledge that they are coming into the role because they have lived experience which they bring to the role. But they also need to understand that they can become quite unwell at times and may also need support with that. So that needs to be taken on board from the start.
- There have been times when organisations have taken over services and told peer supporters that they can't be a peer if they are still using services, sometimes saying they have to have been recovered for more than 6 months. Why is that? It seems wrong.

Ensure continuity of care

- Recovery looks different for everybody. You might be really struggling but no longer meet the symptom threshold for access to services. So if we are talking about recovery, which is where peers come in (not about control of symptoms) you lose out if all the peer support workers sit with AWP. So you do need peer support workers across both sides. That would be my ideal situation. Knowing that no matter where I am in my mental health journey, I have that option open to me.

'Must-have' principles of a Peer Support service specification

Realistic expectations embodied in specific job specifications

- When you look at most jobs, there is a specification of knowledge, skills and experience. But this job is different because people bring lived experience in lieu of academic qualification. This needs to be reflected. If you look at a range of services like crisis care, community care, perinatal services, the principles and values will predominantly be the same. It's the client groups will be different as well as people's experience. So it's kind of like keeping it real in terms of what actually people are actually able to offer and what the requirements of the job are. It has to recognise that people are individuals. People in the NHS have the same terms and conditions through Agenda for Change, so we need to know how peer support fits into this. And what services will peer support be embedded in?
- And realising that distinction that peer support is not therapy, whilst there is huge value in sharing experiences.
- I am not sure how you incorporate the 'boundaries' thing in, but I think that it's a massive issue. What I would like to see is that it is a discussion that

continues to be had, not just rigid boundaries put in place that are not flexible. It's important for peers to have flexibility within their roles to be able to work, both in NHS Trusts, but also in other providers. Sometimes boundaries can be a difficult issue both for peers and people receiving support. I think that it needs to be an on-going discussion.

- I would expect that if you are applying for a peer supporter role, then lived experience is the peer bit, and I would expect there to be a budgeted purpose in support. Then to have that money available from the start so that people can thrive in their roles. Otherwise we miss the point about employing people. It's like that diagram of the three people looking over the fence and equity vs. equality. We need to arrange our resources to support people to be at the same level from the start.
- Regarding Recovery Navigators, staff turnover was really high in the beginning, I think its better now. One major contributory factor in high turnover was caseload

Job security and career progression

- Another lesson that we learned at Second Steps was that the first three peer supporters who were recruited were all people who had not been working before, they'd been on benefits. So they came into the role from being on Incapacity Benefit. Short term contracts are common in the voluntary sector, so there may be an issue around job security. Because coming off benefits is a massive step for people, moving into paid employment. Coming in at Band 2 or 3 will mean that they are likely to be worse off financially to start. That is why job security and career progression are really important. Organisations need to be aware of that anxiety, especially if people are only on a year's fixed term contract. Will they be able to go back onto benefits if the job ends or fails? It's a dramatic decision for people. We need to be mindful that this is a situation that could re-traumatise people.

Continuity of care

- Understanding that peer support workers will have their own lived experience, and therefore may have their own periods of difficulty. So having systems where there is reliability, if an individual worker needs to step back from individual or group work, there is something in the set up which means that there will be consistency for the person receiving the peer support, so they aren't left in limbo.
- Services that work need to be there all the time. So if there are changes, they must be changes that improve the service, not things like stopping services, cut backs or changing days. So people will not be distressed.

Safeguarding

- I am thinking about the safety of the person receiving the peer support, but also the person delivering it.
- Part of the role of a peer is to be able to share their journey. People need to be able to feel really confident about being able to do that. And they need training, supervision and support to do that. That is both for their own

protection, because things once said are out in the room, and they can sometimes be used against them by some people. But also you need to make sure that the person is aware of where disclosure and the detail around it is appropriate. The peer role is all about lived experience, you can't be a peer without lived experience, so everyone knows that you have lived experience. And that can sometimes cause some team members to be quite prejudiced around people. So knowing what to share and when it's appropriate to share, if it's a paid role, is complicated and needs to be considered.

Culture of optimism

- There is something about a culture that is hopeful and forward looking, but in a non-pressured way. And recognising that things can take time, but the building of relationships is absolutely fundamental.

Training

- For me its really important that there is really robust training and supervision package in place, to keep not just the peers safe, but to keep the people who are receiving the support safe as well.

Reconvened full group: Summarising key points from two breakout groups

Group 1 General reflections

Respect your peer support workers:
- Ensure peer support workers are involved in decision making
- Ensure peer support workers are listened to.
- Ensure peer support workers are recognised and their contributions are valued.
- Recognise and use their expertise

Train support workers well:
- Regard training as essential
- Ensure that peer support workers can also train other staff in key issues.
- Make sure that training does not diminish the benefit of empathy and human nature and avoids over-professionalisation.

Address cultural barriers to peer support:
- Busting the hierarchy
- Building the Plateau of Mutual Power
- Promoting attitudes of 'Alongsidedness', working with the person, not medicalising them
- Flipping attitudes – not a deficit model, but looking at potential, what a person can bring to peer support

Organisations should learn from good peer support practice:

- Practice what you preach
- Lessons learned and implemented in practice regarding peer support can help staff turnover in organisations

Be realistic about job specs:
- Make sure that the peer support worker is not tasked with supporting those who formal health services regard as not worthy of their involvement.
- Accommodate reasonable adjustments to the job.
- Ensure realistic, manageable case loads. That needs to be a consideration. Excessive case loads just set people up to fail.

Group 2 General reflections

- Crossover for children and young people support, and peer support groups
- Peer mentors and psychologically informed environments
- Equalities issues and accessibility (e.g. posters, literature, built environment)
- Barriers to peer support should be removed from the start
- Clear framework for doing it
- Reference to national peer worker framework
- Agenda for change and banding of pay scales

Other issues highlighted:

- Employment structure & progression – people must be supported through this and not set up to fail.
- Proper structures need to be put in place.
- How will grading, specs and career progression fit in with Agenda for Change?
- How will transition from benefits to paid employment work? Consider how the organisation will facilitate people who haven't worked for a long time coming into the routine of work.
- If contracts are one year, fixed term, will people have job security? People need to be supported to feel secure in those jobs.
- Poor structures and employment journeys could impact significantly on peer supporters' mental health. Organisations need to own the responsibility for getting it right.
- Diversity - When peers are recruited from diverse communities, communication is so much easier, because language and the way professionals talk rarely represents who their clients are.
- Reflection - another lesson learned is the importance of peers to have reflective practice with non-peers so concerns/challenges can be discussed without fear of repercussions. Reflective practices are a great tool for peer supporters to judge where they are in their journey.

Appendix 2: Writeup of the *Mental Health Conversations* event

This event took place on Tuesday 5 January 2021 and revisited the discussions that had taken place at the focus groups. The outcomes were sense checked, and principles for future work ('I' statements) were also discussed.

Mental Health Conversations
5 January 2021

Bringing together our lived experience as part of the next phase of the Community Mental Health Framework programme in Bristol, North Somerset and South Gloucestershire (BNSSG).

1. **Background to the Community Mental Health Framework and the approach so far**

Victoria Bleazard and Nick Goff, BNSSG Clinical Commissioning Group

Background to the programme

- This is our opportunity to transform community mental health services, building on healthy communities, supporting people to live happy and healthy lives

- National funding is available from NHS England (£12 million over three years) to support this transformation

- Looking to create integrated local approaches to support people's needs, aligning with localities and primary care networks and existing community approaches

- This will build on work already ongoing that started in response to the coronavirus, and developments via the Healthier Together project

- Looking at a co-produced approach with people who use mental health services, and professionals across the local mental health system; and in voluntary, community and social enterprise (VCSE) sector organisations

The current approach

- We are in the 'discovery phase' of this project, engaging with groups and individuals

- All this engagement will come together to develop the core components of a specification that we can engage with people about how to deliver

The scope of the programme

- The focus is people with severe mental health problems, and wrapping care around the more 'preventative' model to allow people with mental health problem experience care with no gaps

- Flexibly stepping up and stepping down care to meet people's needs

- Good quality assessment wherever a person needs support

- Thinking how a person is fully involved in their care, as well as carers and support networks

- Ensuring that the offer is sustainable, equitable, and reaches the needs of diverse communities locally

- Coupling national work with local requirements, e.g. existing mental health contract re-design; and integrated care systems/partnerships

- The building blocks of the work include prevention, service accessibility, communication, leadership in services (e.g. including trauma-informed) and how we bring key organisations along

- Digital infrastructure and outcomes are also key elements, to allow staff and people delivering support to connect

2. 'I' statements – setting out principles for the project

Tom Renhard, Independent Mental Health Network

- The development of the statements, reproduced below, started with some national statements that were used as a template to develop local statements
- Via the engagement process so far, these have been re-written to be more specific to our local area
- These will act as principles for the next steps in this work
- These continue to be refined, but we want to sense-check them today
- The statements presented to the event were:

Experts by Experience

- *I want to be listened to, be seen and respected, and have choice.*
- *I want to be assessed once.*
- *I want to know who to call when I need support, and be helped to access care when I need it.*
- *I want care that is tailored to my needs – from both clinicians and my community.*
- *I want care that is sensitive to my experiences and trauma, from people who understand.*
- *I want care to be joined up and accessible, available as I move through different stages of my life.*

Carers

- *I want someone else to share the load.*

Workforce

- *I want to see people recover.*
- *I want to feel part of "one team" providing care that wraps around people when they need it (no more "wrong doors"; primary/secondary gaps; "crisis before care"; "referral cliff edges").*
- *I want us to move from talking about health inequalities to addressing them.*
- *I want us to have trusted relationships to proactively manage risk across our organisations.*
- *I want IT systems that will allow me to do my job.*

3. 'I' statements – discussion

Note – the statements were discussed in breakout rooms. The notes and comments from each discussion are presented below by category of statements.

Experts by experience statements

- *"I want to see people recover":* this statement is lacking in nuance. Puts immense pressure on people to 'recover', get 'better' and get out of the system
  - *'recovery'* looks different to everyone, it's unique, and is about what the individual needs
  - Getting away from the language implying that recovery has a 'start and finish point'. Some people take time to recover, some longer than others, and 'that's fine'
- mixed views about *"I want to be assessed once"* – is assessed the right word? Formal power imbalance.
  - One group suggested *"I want to tell my story once"* as an alternative, but another group felt *'assess'* gave more a sense of telling the story leading to action. Another group agreed that the statement needs to convey a continuity of care, but *'assess'* is the wrong word to use in order to convey this
  - Telling a story only once of course is important. Ensuring that this info is shared between services, to prevent inadequate info being shared between professionals carrying out referrals
  - One group felt this not to be relevant if an individual doesn't agree with their diagnosis or wants a re-assessment.
  - One group felt that it is important that the story that is shared onwards with professionals is relayed accurately each time so that the individual recognises it as theirs
- One group suggested *"I want the people affecting my life to all be connected"*
- regarding independence, having enough information and knowledge to do this to empower people to make decisions about what they want to do
- one group suggested *"I want continuity of care"* to be added as this was felt to be crucial

- particular support showed for *"I want services sensitive to my trauma"*; clinicians/workforce need to understand this area more
- One group suggested *"I don't want to be baffled by the amount of people involved in my care"* to be added
- Regarding *"I want care that is tailored to my needs"* and *"I want care that is sensitive to my experiences and trauma"*;
  - One group raised that the stigma and shame particularly in BAME communities needs to be incorporated this as well

Workforce statements

- One group felt that the workforce needs to accept people with mental health experience
- In response to "*I want IT systems that will allow me to do my job",* one group responded that IT has been an issue for years – is it now time to move forward
  - building on this point; making sure people read things but having a summary of key points so people don't have to explain things over and over
- there was widespread recognition that the use of the term *"recover"* put pressure on people to 'get better'

Carers statements

- it was felt that more statements are needed around carers supporting people with trauma; how it impacts on carers' wellbeing; and the support needed
- carers often don't put their needs forward and don't look after themselves
- carers will need knowledge and information about what to do
- *"I want carers to have more rights"* was suggested
- Two groups felt that *"I want someone else to share the load"* was negative and implied a burden; but the sentiment of the original statement was agreed with

- One group felt that this section of statements was quite light, and suggested *"I want to be listened to when I have a concern"* for inclusion

Overall

"How can we ensure these statements are not just words…"

4. **Themes of the model**

Tom Renhard, Independent Mental Health Network

- Published in advance were the key points extracted from a range of focus groups run in December 2020
- Each focus group looked at a different component of the Community Mental Health Framework programme:
  - Trauma-informed approaches
  - Personality disorder support
  - Eating disorder support
  - Community mental health rehabilitation
  - Transitions of adults to older adult care
  - Transitions of children and young people to adult care
  - Peer support
- A selection of distilled points where shared for each topic

5. **Themes of the model – discussion and reflection**

Note – the themes and outcomes of focus groups were discussed in breakout rooms. The notes and comments from each discussion are presented below by theme.

<u>Overarching comments across the themes</u>

- people are not often listened to or really heard by staff, with the example of wrong medication given - sometimes good outcomes appear to come by trial and error or pure chance
- it is difficult to use system knowledge well from specialists
- services are hard to access – often won't take people who don't meet/have sufficient 'need'
- often medication is the first answer – difficult to get actual 'treatments'
- Services don't reach out – and therefore don't reach most vulnerable
- An observation was shared about the trend of people needing to resort to private therapies because they feel they are 'out of options'; e.g. GPs not referring onwards as they didn't believe a person needed further specialist counselling
- Supporting the workforce better, so they aren't overloaded, was felt to be important
- Treating people as individuals e.g. considering what the best way is to contact them, is also important
  - Some staff don't listen to patients; how can that be fed back by patients to improve practice
- complaints may not be taken seriously, resulting a lack of confidence in the process
- Open and transparent communication is vital
- Who decides what 'recovery' means and when you're 'functioning'?
  - lack of onward pathways or options once a finite treatment is completed
- GPs felt to not be able to provide adequate support or onward pathways
- Continual assessments result in people not being properly heard

- co-existing difficulties e.g. drugs or alcohol – *'why would you give up a crutch to access a service when you don't immediately get something / the skills to replace it [the crutch]'*
  - Need to ensure such difficulties are not used as barriers to accessing services, but addressed holistically
- There was a common view that the framework needs to empower individuals to just be honest about their symptoms and not feel like they have to exaggerate or present as worst case, or wait until crisis etc, in order to access support
- There was also a common view that recovery should not be viewed as a 'journey' – implies there is a destination anticipated, and therefore failure if it's not reached
  - 'recovery' might start in one direction and lead off in many different ones.
  - group felt this point should be altered in language to move away from the cliched 'journey' word
- Accountability amidst multiple multi-agency meetings; who is responsible.
  - A question was posed: is there a key person in each organisation that is accountable for saying 'I will embed this within my organisation' and 'I will ensure that my team are encouraged in embedding these principles'?
- Co-production cannot be a 'tick-box'; lived experience should run through the whole programme
- One group gave an example of good practice when accessing private sector services as the provision of a "key worker" type role throughout the patient journey. This role would have responsibility for the care from beginning to end and also act as the main point of contact all the way through.
- One group felt that there was a medical aspect where an acute condition requires treatment but also a social care side where the person still needs support. It was discussed that a flexible model where individuals could "dip in and out" as needed would be helpful.

- services being provided must meet the needs of the individual and there were examples given of people not being able to access treatments that they felt would help them and going to the private sector because the evidence base didn't suggest that it would be beneficial for the NHS to provide

Peer support

- Peer support doesn't just have to be 'done right'; it needs to be resourced and supported right. It cannot be mental health done 'on the cheap', with proper provision for supervision for people across all roles
- Ensuring tokenism is minimised
- The peer support role is critical
- Recognising that the value placed on peer support is not a 'flash in the pan; it's become so relevant in the last six months of course
- Cutting through a feeling of 'too many voices and too little action'
- Agreed with the point about peer support not being used to 'fix things' – the relationship between people going through something together is more important
- Look at Off the Record for inspiration about peer support
- Negative experiences can indicate individual problems and problems with the service; we mustn't forget this
- One group felt that can be useful if the person has the right relevant experience and can use it properly.
- The 'value of having some one walk a mile in your shoes' that peer support can provide was recognised
- Need to ensure people are aware of services that can support – especially for carers
- Need to take time to build relationships and trust
- Must not overlook the VCSE sector's role

Trauma-informed approaches

- Support being trauma-responsive not just informed

- Remembering that people often have trauma from being in health services
  - Services need to acknowledge and correct this where appropriate
- Before we talk about trauma-informed services we need understand what that means, rather than it just being a 'slogan'
- organisations need to be trauma-informed, not just trauma-informed practitioners
- a culture of compassion and kindness in organisations from top to bottom is essential
  - training alone is potentially tick box, this approach needs to be understood and championed by all staff at all levels in a service
  - Suggestion made about e-learning options being available to the wider public beyond just staff / service users so that society itself can become more educated and confident in mental health
  - Co-designing training in services, and also co-defining
- Basics such as how we interact in relationships with people are key to strong services - empathy, compassion, acceptance

Personality disorder support

- We must ensure that a diagnosis of Emotionally unstable personality disorder (EUPD) is not solely considered, with diagnoses beyond this being considered
  - this of course can lead to inappropriate care pathways
- a trend of the overall 'label' being often misused was discussed… *'oh, X has a personality disorder'* without any further consideration; can definitely contribute to getting people onto the wrong pathway
- If people are presenting with symptoms or behaviours associated with another condition, there is a culture of it being a given that symptoms/behaviour associated with a personality disorder means a person will be in services for the long term
- First-hand experience was shared of treatment someone is receiving changing abruptly when a diagnosis changes from/to personality disorder

- A personality disorder diagnosis can present a real challenge when accessing support
- Clear and timely diagnosis is important to prevent inappropriate pathways

Transitions through the life course

- Treatment during the different stages of the life course is definitely not a 'one size fits all' situation – not assessing solely based on age boundaries
- Transitioning when you're ready, not when the service says your ready
- *'it seems archaic that we aren't looking at ageless models after having been talking about it for so long!'*
- Not forgetting that leaving services (e.g. secure services) is a transition in itself; not losing the inpatient support structure could be key
- the transition to older adult services was discussed – this should be based on life events and personal circumstances, not just on a certain age number
- people will need different responses at different times in their life.
- For children and young people, we need to consider the transition from Education, Health and Care Plan (EHCP) plans to adult services, and how personal budgets could help to support this transition
- For children and young people, the voice of young people needs to be heard in conversations
- Considering, for children and young people, body dysmorphia, intersectional approaches, working with and delivering intervention in schools/colleges and universities

Mental health rehabilitation

- A designated care co-ordinator that supports a person through their whole journey would solve some problems
- For some people living with mental health as a long term condition is a reality, and this needs to be through of as rehabilitation; i.e. if life is liveable, that is rehabilitation

- Move away from looking at discharge as soon as possible in a service, or at least provide a substantial time period for which to have proposed discharge

- Time and flexibility key so that individuals can meet their personal needs rather than the limitations of what a service considers 'recovered / functioning' – services can currently hold a prejudice about what they perceive this to be of service users – surviving / thriving

- This service was considered to historically have been used as maintenance for those that would never get better – hope and aspiration for individuals must be at the heart of rehabilitation services

- Acceptance within services that some individuals will get to a level they are happy with and want to stay there rather than be pushed to go further – but services felt too often not be prepared to help if service users don't want to continue developing

- The finding that rehabilitation should be viewed as a 'journey not a destination' was discussed; one group felt that this could make individuals feel as if they'd failed if they didn't reach the destination – needs to be flexible and acknowledge that the destination can change.

- One group particularly felt that rehabilitation services are planning for discharge as soon as the individual begins treatment

- Services must promote hope and create an environment where people can recover, whatever 'recover' means to an individual

Eating disorders

- In CAMHS, experiences were shared of being turned away because people were too underweight – with no support being offered in the meantime!

- *'If people are asking for help, they are asking for a reason'*

- Bristol does not have a day-patient service for eating disorders; there is no 'step down' from hospital to home

- CBT-E has been proven (by Oxford Health) to improve outcomes in a hospital setting; Bristol does not currently offer this

- STEPS have not been in communication with carers since March – causing a significant gap
- STEPS do not provide clear health monitoring guidance to GPs; one participant reported being discharged from an acute hospital and their GP had no guidance from about ongoing checks
- Looking at initiatives (e.g. Maudsley's Peace Pathway) for autistic people suffering from eating disorders
- No out of hours support for people with eating disorders experiencing a crisis; an experience was shared of the Crisis team 'shying away' from people with eating disorders in crisis; it was noted that people with eating disorders have the highest risk of suicide

"If you know you're in need of a service, you often don't receive it."

6. <u>Next steps of the programme</u>

Tom Renhard, Independent Mental Health Network

- The engagement process of the programme is nearing completion – final sessions will be held over the first two weeks of January
- The CCG submission to NHS England, setting out how we mobilise the project, is due to be sent on 20 January 2021 (*note: the deadline has been extended to March 2021)*
- Outcome of discussions will shape the framework (bearing in mind that the next submission is incredibly limited in word count, meaning care will have to be taken to emphasise the points known to be important in the submission)
- These conversations will be ongoing, as we move past the submission into the next steps of the programme; looking at the specification, implementation stage, and working to ensure co-production is embedded throughout.