Mental Health Conversations – 5 January 2021

Part of the Community Mental Health Framework Discovery phase

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).

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This version: v1.3

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

[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
Chief Executive Officer
Independent Mental Health Network
February 2021

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

2. 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

3. ‘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.*

4. ‘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

<u>Workforce statements</u>

- 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'

<u>Carers statements</u>

- 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…"

5. 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

6. 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.

Overarching comments across the themes

- 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

<u>Personality disorder support</u>

- 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

<u>Eating disorders</u>

- 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."

7. Next steps of the programme

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.