Community Mental Health Framework

Discovery phase

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

Executive report

February 2021

This version v1.1

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A full report, including complete write-ups of each focus group and the Mental Health Conversations event is separately available.

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

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 captured the themes and experiences that people raised, without being verbatim transcripts. The *Mental Health Conversations* event took place on Monday 5 January 2021.[3]

[3] Full writeups of focus groups and the *Mental Health Conversations* event can be found as appendices in the full report, available separately.

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. 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.

Themes present across all topics

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.