

Lived experience of adult mental health and wellbeing Services in BANES

Survey and focus group feedback (during the period 11th Aug - 31st Oct 2021)

Having a voice in shaping services

We listened to **91 local people**, who **shared their personal views, experiences and ideas on accessing mental health and wellbeing services in Bath & North East Somerset (BANES)**. We captured both the experiences of service users and carers, and our vision was to have people's voices from all backgrounds and communities within BANES.

**33 people attended
local focus groups**

(In collaboration with KS2, St Mungo's
Mulberry House, Bath Mind and AWP)

**58 people completed an
online or paper-based
survey**

At each focus group we asked 3 key questions:

- What's working well?
- Where do health inequalities exist?
- What are the barriers/gaps in mental health services?

The survey allowed us to ask a broader range of questions and gain feedback from a wider range of people.

Key Themes

Through this feedback, we have identified a number of key themes:

1. **Access to mental health services (GP, talking therapies, PCLS, secondary services) - both in terms of first time access or re-accessing services** - Many people's first point of call is their GP. Delays in appointments and inefficient referral systems can increase emotional distress and reduce the benefits associated with early intervention. The relationship between patients and their own GPs is crucial to continuity and quality of care. Access into mental health services can often be difficult, with long waiting lists. Promotion of self-referral (i.e. Talking Therapies) and signposting to wellbeing groups and services (i.e. Virgin Care, DHI, St Mungo's, Bath Mind) in their community is crucial to enabling people to feel empowered. Covid-19 has made access to support more challenging.
2. **Collaboration of organisations, including supporting transitions and information sharing** - People want services to offer greater transparency and be less fragmented. People want to feel supported holistically. For example, mental health and physical health coexists and these services should therefore work together, rather than in isolation. People don't want to keep repeating their story or be bounced around services, they just want organisations to working together and be able to trust them. People who have complex mental health needs want organisations to collaborative, in order to help meet their needs, rather than focusing on their own service thresholds. During transitions, i.e. from one service (i.e. CAMHS) to another (adult services) people want to feel that there is seamless support, without falling through gaps in the system or having to carry out multiple reassessments.
3. **Managing own mental health and wellbeing in the community (GPs, AWP, Virgin Care, Bath Mind and other wellbeing services/groups)** - People want to be able to manage their own mental health and wellbeing in the community, with a variety of both peer support groups and professional support, available locally. A key focus is the right support at the right time, for the right length of time. Access to activities that provide focus, structure, social interaction and peer support, aid wellbeing in the community. Psychoeducation and carers' training has also proved beneficial for those taking part.
4. **The value of involvement / co-production in services, utilising those with mental health lived experience** - People want to be involved in their own care, and carers want to be recognised and part of the process. Both service users and carers are interested in involvement and coproduction activities in order to help improve and shape services, on an equal level with appropriate support.

Lived experience of adult mental health and wellbeing Services in BANES

Survey and focus group feedback (during the period 11th Aug - 31st Oct 2021)

5. **Equal access to services and meeting the needs of person-centred care** - People prefer to access services and wellbeing activities in their local communities, but there is a disparity between rural vs city provision. Other issues of inequality include digital poverty, cultural understanding, and being a part of a marginalised group.
6. **Crisis support, inpatient care and discharge planning** - Crisis prevention is important. Service users want to be involved in decisions about their care, such as changes in medication, and helped to understand more about what is happening in times of crisis (i.e. being sectioned under 136). When coping with a loved one in crisis, carers feel there is a lack of support for them, they want to be listened to and better supported. Those in crisis without a carer/supporter/friend involved, are disadvantaged.

Feedback quotes

Some feedback quotes have been edited, in order to protect the names and identity of those who participated.

1. Access to mental health services (GP, talking therapies, PCLS, secondary services) - both in terms of first time access or re-accessing services

“In BANES you can self-refer to Avon & Wiltshire Mental Health Partnership NHS Trust (AWP) Talking Therapies, but this is not known enough, needs to be promoted more”.

“A friend was unwell but not so unwell to actually get support. Consequently, my friend ended up missing out on access to AWP’s Early Intervention (EI) team as he was past his first episode when he got help”.

“Referred by GP to AWP for reassessment, I was contacted same day and seen two days later. I had my medication changed. A very pleasant and efficient service”.

“I tried to get support from Cruse bereavement service in both Bristol and Bath area but their waiting lists are closed, and have been for a while”.

“There are a lot of people who don’t believe they need support, or aren’t ready, how can we make it easier for them to access services?”

“Social prescribers - makes so much sense. Friend is a GP and they say they use it as a viable alternative to medication, or to compliment medication”.

“The pandemic has blighted appointments, definitely harder to see a GP and get other appointments. Trying to speak to the GP in the day, you just end up hearing ‘we’re all booked up until xxxx’”.

“GP has been absolutely brilliant - rings me every two weeks, consistent throughout Covid-19. Mental health is all about listening”.

“If you’re too ill for Improving Access to Psychological Therapies (IAPT), you’re on a waiting list (10 months for a therapy service)”.

“For individuals who are bed bound due to mental health issues (chronic anxiety) or other conditions - they need visits by mental health services at home”.

“Found it valuable to meet other people in the EI (Early Intervention, AWP) group, people further down the road of recovery. You then provide the same when further along recovery yourself”.

Lived experience of adult mental health and wellbeing Services in BANES

Survey and focus group feedback (during the period 11th Aug - 31st Oct 2021)

"I had 24 counselling sessions with Bath Mind at a cheap rate. I'd like some more sessions, but I can't get back on the waiting list, as there's too many on the list".

"AWP Talking Therapies services offers short-term 6-12 week support, but often patching up the problem".

"Initially bounced around between Primary Care Liaison Service (PCLS), Intensive Support (IS) and Talking Therapies, but only referred after numerous A&E presentations with self-harm injuries and suicidal behaviour".

"For those with a history of mental health, they need someone they can trust to go to if they start to struggle, someone they already know. Not necessarily a mental health professional but someone local who can help signpost and help them get more support, i.e. volunteers, community connectors, peer mentors. Also an easy access back into services".

"Access to clear information with contact numbers through GP's and leaflets in pharmacies is important".

Case study: Experience of being in and out the GPs for mental health stuff (mild and moderate), but never feeling it went anywhere apart from SSRIs. Had to get to a point of getting very unwell before getting help. Every time I saw a different GP, so they all individually focused on the short-term, rather than noticing and identifying cycles of being in low and high moods. If the cycles could have been noticed earlier, maybe I wouldn't have needed SSRIs.

2. Collaboration of organisations including supporting transitions and information sharing

"GPs and mental health services are not joined up enough. There's a gap between access to Talking Therapies and being too unwell to manage in the community".

"CAMHS Oxford Health NHS Foundation Trust transition to AWP adult BANES services was OK for us, but I know not the case for others".

"I found myself always being bounced back to the GP or from one service to another".

"Coping with a recent bereavement and a complicated housing situation, I wanted a referral for a support worker to help with both my emotional and practical support needs. My GP said "I don't know how to do that". It left me feeling like "I don't matter", "I'm not important". I would've liked my GP to ask someone and get back to me with how to help, rather than not help at all".

"Continuation of care plans after 18 and shared data, so as no need to restart painful memories every new support worker starts".

"Once a Care Co-ordinator is appointed it is good but having to tell the same story to the help desk all the time before that is very laborious. We were referred to the befriending service but have not heard anything back. Also there is no follow-up done by the team once something is recommended. If the service user is low, nobody does anything!"

Case study: Dealing with two different NHS Trusts is "a nightmare" (as a carer). Who do I speak to? Who is responsible for decisions? Where is a hospital bed? When things are settled it is OK. But when things go wrong and escalate, I don't know who to be in touch with. People (mental health professionals) in the background might know what they're doing, but I've learnt not to trust people. People change all the time and the chain of command is hard to get to grips with. It's the communication that is lacking and the decision making behind the scenes by professionals might be OK, but suspect that it is not. I want a security blanket of how things should

Lived experience of adult mental health and wellbeing Services in BANES

Survey and focus group feedback (during the period 11th Aug - 31st Oct 2021)

happen - i.e. I can trust what needs to be done is being done. This is often not the case and causes me sleepless nights.

3. Managing own mental health and wellbeing in the community (groups, GP, talking therapies, 3rd sector, etc.)

“Psychoeducational workshops explaining mental health issues such as bipolar, hearing voices, etc would be helpful. Would help to understand your (or your loved ones) own diagnosis. In the past AWP Recovery team used to hold a group for carers about specific monthly topics such as medication and personality disorders. Carers found it really helpful, alongside sharing information”.

“KS2 & St Mungo’s carers training helped a friend. It helps carers understand their feelings (i.e. guilt, feeling angry and then bad, upset). Also helps others understand things such as hearing voices through role play. Would like to see it delivered face-to-face again, as currently on Zoom”.

“Hope Guide has lots of groups in it, but promotion of it needs improvement”.

“Groups have been amazing, gives me a focus - Bath Mind open opportunities, Creativity Works writing group, wellbeing walks, Carer’s Centre groups. If at home in four walls, it would be different”.

“Bath Mind phone calls (during Covid-19 when groups were unable to meet) - really helpful during lockdown, listened to. It’s not always about talking, but listening”.

“Care in the community means that much less support is available than used to be. This has put a great emphasis on people’s loved ones doing much more and therefore more respite is needed to give carers a break”.

“Bristol Autism Spectrum Service (BASS) have been useful as they run social and psychoeducational groups, understanding your diagnosis, dating workshops which have been really useful in helping me progress. Something similar in mental health would be useful. It took me a really long time to understand my mental health diagnosis”.

“Bath City Farm enabled me to feel useful, meet others and do an animal welfare course”.

“KS2 (carers peer support group) has been really supportive and AWP are improving the way they work with carers”.

“If I feel upset I know I can speak to someone. The groups are a great leveller, we all help each other if feeling down - how society should be. Groups have all age groups, people of all sorts of jobs”.

“Befriending service has been a lifeline, weekly call at a set time”.

“I’m comfortable in support groups with people with mental health but I would like to build up a network of support groups outside of mental health (i.e. meet new people, church, activities), but find it difficult about what to say to people”.

“Mum’s mental health issues has taken a toll on my mental health” (as a carer).

“Attending groups outside of mental health such as church and tennis has been positive for me”.

Lived experience of adult mental health and wellbeing Services in BANES

Survey and focus group feedback (during the period 11th Aug - 31st Oct 2021)

“Support wasn't long enough. 6 weeks, 1 hour sessions. The first 2 weeks is spent getting to know the sufferer, then 2 weeks talking then 2 weeks ending the support. It's just not long enough.

Case study: Case study: To support me during the process of tapering off medication (benzodiazepine), I asked for a phone check-in from a Consultant regarding my mental health, i.e., a call every 3 weeks over a period of a couple of months. This was refused. Maybe I didn't meet their high criteria for offering support. I used the response as motivation to come off, but this rejection means “I wouldn't want to go anywhere near AWP again”. I also feel I came up against services, rather than people, and that I needed to be worse than I was to access support. I would've liked to have attended a mental health support group that focused on talking about mental health, sharing what works, to help me better understand my own mental health and develop better coping strategies.

4. The value of involvement / co-production in services, utilising those with mental health lived experience

“AWP service user involvement online is helpful for those that aren't able to go out to involvement meetings, allowing them to - ‘still have a voice from own homes’. This helps those with mental health needs as well as and physical health needs. Combining face-to-face and online opportunities is preferred”.

“Would like a more holistic, person-centered approach from Psychiatrists, i.e. less medication (because of the side effects and the positives being over stated) and more emphasis on other outcomes - work, housing, peer support etc”.

“Confidentiality is an issue at AWP, both in the past and recently. Rules never exclude carers being listened to, not spoken to and not included”.

“Can phone AWP psychiatrist up (as a carer) and they would call me straight back, and be very reactive with support and change medication (with the service user). That clinical input has really helped. Feel that I've been listened to and believed, it hasn't always felt like this”.

“Too many services say “we're not commissioned to work with carers”, often said by 3rd sector groups”.

“Only 1 in 8 of AWP service users have a clearly designated carer. These figures seem very low, more carers need to be identified. More work needs to be done to identify carers”.

“I think the most important people in the system are the Care-Coordinators and engagement and training is vital. Firm up triangle of care”.

“AWP are really trying to include carers and service users in developing services, and starting to recognise carers more - when AWP find a carer they've struck gold”.

Case study: Having my Mum (carer/supporter) involved is really useful as she knows me so well. A doctor wanted to change the dose of medication I was on. My mum was really concerned about this and the potential negative impact, so she spoke to the Consultant Psychiatrist, who then agreed with my mum. My medication was kept the same. My mum knows me better than I know myself (highlights the importance of carer/supporter involvement).

Lived experience of adult mental health and wellbeing Services in BANES

Survey and focus group feedback (during the period 11th Aug - 31st Oct 2021)

5. Equal access to services and meeting the needs of person-centred care

“Keynsham nothing there - a lot of groups are based in central Bath. Hard for groups to be set up in Keynsham. I’m involved with the local church and Creativity Works photography group. Everyone says there’s loads going on in Keynsham but there isn’t. I’d like a cooking group in Keynsham and things like Breathing Space as well as a Bath Mind open opportunities group in Keynsham”.

“Breathing Space isn’t as accessible to those that live in Keynsham. There is only one bus an hour from Keynsham to Bath (used to be three an hour) and there’s hardly any free seats downstairs which is quite difficult for me (mobility needs)”.

“For those individuals with mental health difficulties that are hard to engage, they are left to their own devices. Service provider’s mentality of ‘if they don’t come to us, they don’t want to engage’. Services however have to go outside and engage with them (i.e. gypsy, travelling community)”.

“St Mungo’s Mulberry House is a great service with a supportive environment, has helped my mental health and ability to be more independent. Treats everyone as a person, lots of great discussions not just about a diagnosis. Really accepting environment where anything can be discussed”.

“Prior to Covid-19 restrictions, the Care and Share café had 15 regular carers attending. Now it’s online, attendance has dropped to 3. Vibe feels better face-to-face, carers prefer it”.

“Multi-faith room available for inpatient prayer and reflection time whilst at Hillview Lodge. Hillview Lodge has a chaplain (who also attends the BANES acute care forum), what other faiths are included?”.

“Transgender more visible in society, people need to be aware about how to be more accepting and use the right terminology. Services need to ensure they are as aware and accepting of difference as possible”.

“It would be helpful if my Psychiatrist spoke to me about my race (Mixed British and Indian) and was aware how it was part of my identity, alongside my mental health”.

“Everyone says ‘go online’ to access things, but I’m not great at IT”.

“For those with no access to the internet - more public awareness of mental health support is needed, i.e. leaflets through the door, articles in free newspapers, on the radio, public events/walks with mental health organisations speaking to people”.

“Zoom has been a great help to get into groups”.

“I need support and some of this is only available online. Internet speed is an issue for me, plus I don’t have a phone that I can use to access the internet (small phone with minimal screen) and cannot afford to pay £40 a month to make this happen”.

“Would rather have phone calls than Zoom, as there’s less things to go wrong (concern around confidence with technology)”.

“For young people with emerging serious mental health difficulties they aren’t getting enough support. If you’re psychotic you get the ‘Early Intervention’ team. If you have another serious mental health issue, you just don’t hit the criteria for a similar wraparound service”.

Lived experience of adult mental health and wellbeing Services in BANES

Survey and focus group feedback (during the period 11th Aug - 31st Oct 2021)

6. Crisis support, inpatient care and discharge planning

“My loved one goes into Hillview Lodge acute ward, they keep him for one night and give him 1 tablet of medication. Next day he is very convincing that he’s OK and says he’ll call if needed, but he never does. He therefore gets discharged. I’d like AWP to be more realistic”.

“Sometimes no-one’s there for carers, carers often don’t look for support until there is a crisis”.

“For individuals with deep rooted trauma, more trauma informed-care is needed”.

“During lockdown my son came to live with me. I could phone the psychiatrist and she would phone me back and moderate his medication or make an appointment (if a cancellation in her diary arose), and things have started to improve. Having a close rapport and communication, being listened to and believed = stuck gold during the pandemic”.

“Having autism it can be really difficult to understand what is happening when being sectioned and very unwell. This can feel dehumanizing. Maybe a laminated card with basic information on what is going to happen could be used and clearer communication about why things are happening - when and how (the process). Can be hard for staff to do this at the time as they are also maybe stressed by the situation”.

“I didn’t have an idea about where I could go on leaving Sycamore (Hillview Lodge acute inpatient ward). The Move On Worker suggested Mulberry House and supported me with attending the interview”.

“I self-harmed and ended up in A&E, RUH. The mental health staff were very helpful. They said they’d inform Social Services about my needs and I was referred to the Wellbeing Service. It took 5 months, but they helped me to find the Bath Mind open opportunities group”.

“People go from one crisis to the next. Can only get in hospital now if you’re sectioned”.

“Lack of provision/road map for 18-25yr olds. No regional provision to meet daughter’s specific needs (eating disorder diagnosis). Other people’s crisis’s trump her needs”.

Case study: When people really need help, they are very often not well enough to ask for it or look for it - how do you fill that gap? I’ve had to speak for my loved one, as she’s not always well enough to speak for herself. For example, her Care-Coordinator went off on long-term sick, but my loved one still needed help, so I had to speak for her to get extra help, as she wasn’t well enough to say she still needed support. What happens to people who don’t have someone to advocate on their behalf, when they’re not able themselves to phone and ask for help?
