Co-occurring mental health and substance use (MHSU): Voices of service users and carers

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Summary

People with lived experience of co-occurring mental ill health and substance use shared their stories of trying to access support, and how drug and alcohol services and mental health services can work better together to improve the care people receive.

Substance use and mental health go "hand in hand" with one another. For some, substances were used as an escape from their ill mental health and/or trauma. For others, their substance use predated their ill mental health, and found their mental health deteriorated due to their overconsumption of substances.

Accessing support for mental health and substance use at the same time is challenging. Many were not given mental health support until they had stopped using substances. Participants called for mental health services to allow people using substances to access support for their mental health.

Communication between drug and alcohol and mental health services needs to be improved. The majority found that drug and alcohol services and mental health services are fragmented and do not communicate with patients or with each other. Many were passed "back and forth" between the services.

Care and support need to be holistic. Many felt the care they received looked at their substance and ill mental health in isolation, meaning their issues were treated individually despite being related to one another.

Mental health and drug and alcohol services work well individually. Participants shared that they received high-quality care from services when they accessed either mental health services or drug and alcohol services separately and generally had positive experiences.

Recommendations

The findings draw attention to many positive experiences of people with co-occurring mental health and substance use. However, many faced significant challenges in getting support for their mental health whilst using substances. They found that drug and alcohol services and mental health services often do not collaborate or communicate effectively. To help improve services, the following recommendations have been proposed:

Recommendations for the Co-occurring mental health and substance use programme:

Address stigma and misinformation:

- Improving awareness of the intersection between mental health and substance use amongst all health and care professionals
- Reducing and addressing stigma associated with ill mental health and/or substance use, ensuring people feel able and comfortable to access the care they need
- Introducing drug and alcohol training for mental health services

Increase awareness of drug and alcohol and mental health services:

- Raising awareness of drug and alcohol and mental health services available amongst professionals
- Encouraging GP practices to play a more proactive role in referring patients to drug and alcohol services

Recommendations for mental health and drug and alcohol services:

Improve collaboration between services:

- Ensuring feedback is shared between mental health and drug and alcohol services
- Improving joint-working between mental health and drug and alcohol services, in particular between the two key service providers, HPFT and CGL
- Establishing multi-disciplinary meetings between mental health and drug and alcohol services to discuss an individual's care and needs
- Ensuring the co-occurring mental health and substance use protocol (previously named the dual diagnosis protocol[1]) is effectively recognised and acted upon. Once complete, review and update the associated leaflet.

Provide holistic care to people with co-occurring mental health and substance use:

- Adopting a personalised, holistic approach to care, ensuring substance use and ill mental health are not looked at in isolation.

[1] Dual diagnosis protocol is a set of procedures used to support those with poor mental health and substance use (Dual diagnosis - Spectrum Drug and Alcohol Recovery Services)

Ensuring carers are appropriately involved and communicated with:

- Improving carer involvement in their loved one's care (taking into consideration confidentiality).

Recommendations mental health services:

Improve mental health support for people with co-occurring mental health and substance use:

- Improving access to mental health services for people using substances, ensuring they are not denied care and support because of their substance use
- Ensuring healthcare professionals working in mental health services have drug and alcohol training

Suggestions were made by respondents regarding improving access to drug and alcohol services and the support provided by these services. These recommendations have been incorporated into our other reports, with action plans put in place by Public Health. You can read the reports and recommendations on our website.

"I'd like to thank everyone who took part in the focus groups and interviews and the organisations involved for their support.

"Public Health is leading a multi-agency programme of work with health and care organisations to improve access, pathways and outcomes for people with co-occurring mental health and substance use (MHSU) needs. This engagement report is a key part of that programme to ensure that we are focusing on the right areas. The focus groups identified areas of improvement, linked to, stigma and misinformation, increasing awareness of mental health and substance use services, improving joint working between services, carer involvement and improving mental health support for people with co-occurring mental health and substance use.

"The findings from this report will help inform our ongoing co-occurring MHSU programme of work which is aligned to the Drug and Alcohol strategy."

Sarah Perman, Director of Public Health, Hertfordshire County Council

1. Background

Mental illness and substance use disorders often have similar causes such as trauma, genetics, brain composition, and stress. The co-occurrence of ill mental health and substance use is often bi-directional, with some individuals turning to substances as a way of coping with ill mental health, while others may develop mental health issues as a consequence of long-term substance use.

Co-occurring MHSU is more common than many might think. Research shows that up to 50% of people with severe mental illness (SMI) also use substances, and that the majority of drug (70%) and alcohol (86%) users in community substance use treatment in England experience mental ill health[2].

In Hertfordshire, we know that adults in treatment for non-opiates and alcohol and non-opiates had a high prevalence of mental health need in 2023/24 (73% and 76% respectively)[3].

In addition, the 2021-23 Hertfordshire Suicide Audit identified that drug and/or alcohol problems were the second most common cited risk factor (33%) following mental health issues[3]. Mental health was also cited as a risk factor in 67% of deaths concluded to be caused by drugs and/or alcohol in Hertfordshire in 2023 (Hertfordshire Drugs and Alcohol Death Audit)[3].

In 2023, Public Health at Hertfordshire County Council, Healthwatch Hertfordshire, Viewpoint, and Carers in Hertfordshire explored recovery and reintegration amongst service users and carers using drug and alcohol services. This engagement found that mental health support was a key issue and this project aims to explore this in greater depth.

In July 2024, a multi-agency mental health and substance use (MHSU) steering group was established, chaired by the Director of Public Health, with the Development Director of the Mental Health, Learning Disability and Neurodiversity Health and Care Partnership (MHLDN HCP) as co-chair. The MHSU steering group oversees a programme of work to improve pathways and outcomes for people affected by both mental ill health and substance use at the same time, known as co-occurring MHSU. In October 2024, a Strategic Lead Co-occurring MHSU started at Public Health to lead the programme of work.

By hearing directly from people with lived experience of using both mental health and drug and alcohol services, partner organisations across Hertfordshire plan to shape the co-occurring mental health and substance use programme of work to create positive change and influence wider decisions.

[2] Better care for people with co-occurring mental health, and alcohol and drug use conditions

[3] co-occurring-mental-health-and-substance-use-jsna-briefing.pdf

2. Methodology

A collaborative approach was undertaken with Public Health at Hertfordshire County Council, Healthwatch Hertfordshire, Viewpoint and Carers in Hertfordshire working in partnership to hear from people with a lived experience of using both mental health and drug and alcohol services.

Focus groups were conducted and facilitated by independent representatives from Viewpoint and Carers in Hertfordshire. This engagement was transcribed and thematically analysed by Healthwatch Hertfordshire to identify key themes.

Between January and April 2025, we engaged with 29 service users through four focus groups and one one-to-one interview, and engaged with 10 carers through two focus groups. It is important to note that whilst it was important to hear about the support needed as a carer, the primary focus was to understand from carers about their experiences of accessing support for the person they care for.

Given the sensitivity of the topic and the importance of retaining anonymity, demographics were not collected from participants. We would like to extend our thanks to the organisations and people involved in supporting this report.

We know that there are many residents using drug and alcohol services and mental health services simultaneously, and this sample is a good starting point for understanding their experiences. Although the findings may not be representative of the county, it is important that we still recognise, value and listen to these stories and experiences.

3. Key findings

3.1. Substance use and mental health go "hand-in-hand"

Participants shared their stories and the relationship between their substance use and ill mental health, and how the two conditions have interplayed throughout their lives.

Many described using substances as an escape from their ill mental health and/or trauma.

"Alcohol has always had a grip on my life, it escalated in COVID when I was in an abusive and violent relationship, I started drinking more and more. I've been diagnosed with Post-Traumatic Stress Disorder [PTSD] as well."

"I was diagnosed with anxiety in CAMHS [Children and Adolescent Mental Health Services] when I was 13/14. When I was 16 I discovered alcohol…it's a good aid for knocking yourself out. So I did that for the next 16 years."

Some participants said they were initially diagnosed with a mental health condition and used drugs and/or alcohol to help relieve their symptoms. They shared that their decision to start using substances was a byproduct of having ill mental health. However, for others, their substance use predated their ill mental health, and they found that their mental health deteriorated due to their overconsumption of substances.

"My things were ketamine [ket] and alcohol and I started using when I was about 12. I used it because I was diagnosed with anxiety and it helped me get through the anxiety."

"I started taking drugs at 14 and drinking at 18 and I was a serious cocaine addict. I had a serious alcohol issue and using a lot of drugs. It spiralled out of control recently due to divorce and I'm currently in therapy to understand who I am because I've been under the influence for 36 years."

Ultimately, the vast majority of participants acknowledged that substance use and mental health issues go "hand-in-hand" with one another.

"I suppose, I've had a hand- in-hand relationship with substance and mental health. I was first diagnosed with psychosis when I was 21 and then I was diagnosed with depression about 2 years later. For as long as I remember, I've had a hand-in-hand in between the two."

"I've been a binge drinker since I was 17 which goes hand in hand with depression. When I did start drinking I couldn't stop and that started to really affect my life."

3.2. Accessing support for both mental health and substance misuse is challenging

Participants described the difficulties they have faced in trying to access mental health support alongside help for their substance use.

Many shared that mental health services refused to support them until they had stopped using drugs and/or alcohol. Participants felt that services were putting barriers in place rather than providing constructive support, and described trying to receive help as a "battle."

Participants also emphasised that not receiving support for their mental health would only prolong and potentially exacerbate their substance use.

> *"Alcohol is my issue, I have had brief things with my mental health, but it's one of those ones where they won't touch it when I'm using. I think that's wrong. I think it should be changed, as it's a bit of a chicken and egg situation. I think that's a problem that needs to be addressed because it is very frustrating because people get batted post to post and it's very frustrating."*
>
> *"I've been told in the past that I couldn't get counselling unless I was 3 months sober. Well, I'm going to keep drinking until you help me!"*
>
> *"We'd been to the GP numerous times and we went 4-5 years ago because my son was suicidal and the GP said 'Oh well there's no point in me referring you anywhere because you use substances so nobody will see you.'"*

A couple of participants shared that they had been in hospital because their substance use and/or mental health had deteriorated. However, when hospital staff made referrals to the mental health crisis teams, referrals were denied due to their substance use.

> *"I literally lived in hospital pretty much because obviously when I was intoxicated my mental health was even worse and I'd be taken in. I remember I would go in and they'd say 'Oh you need to wait for the mental health team to see you'".*
>
> *This was when I was having suicidal thoughts and obviously the alcohol makes it worse, and they just discharge me and say they can't do anything because I'm drinking."*

One participant felt that they had no choice but pay for themselves to access private rehabilitation.

> *"I tried (substance user service), mental health team over the course of six years and by the end I felt so abandoned and despondent by it all, I pretty much solved everything on my own and spent £14k going to a private rehab."*

A few other participants suggested that mental health services may only provide support to people with co-occurring needs if they are suicidal and/or have attempted to end their life. However, some participants have unfortunately experienced this circumstance themselves and have still not been able to access care for their mental health.

> *"The paradox here is that medical substance use is defined as a complex medical condition but mental health services don't recognise it unless you get three months sobriety, then they're not going to work with you. The only way they're going to work with you is if you're suicidal."*

Katy's story about being turned away from hospital

Katy* has struggled with substance use and on one occasion, the police asked if she would like to be taken to hospital. She told the police officer that she would be discharged by the mental health team at the hospital and sent home.

"Couple of years ago now I got myself into a situation might we say and I hadn't committed any crime and the police turned up and they were talking to me and they said 'Do you want us to take you to hospital' and I was like 'No because what will happen is we'll wait eight hours in A&E, I'll see psychiatrist and they'll say you're an alcoholic and send me home. I don't think the police, I mean why would they, fully understand what a massive wedge or wall there is between addiction and mental health."

**Please note a pseudonym has been used to protect their identity.*

However, a couple of participants recognised that it could be difficult for mental health services to treat someone who is using drugs and/or alcohol, and for drug and alcohol services to know whether someone needs support with their mental health. Despite this, the majority felt that mental health services should still try to provide care to people using substances.

"I am the worst drunk I've ever come across, just awful and nasty. So then again I do understand the services, because how are you going to counsel me if I'm in that sort of state?"

"I can see the immense challenge there must be for drug and alcohol services to actually recognise that people might have mental health issues because it can't be assumed that just because you're a user, you have mental health issues."

3.3. Integration between drug and alcohol and mental health services needs to be improved

Participants shared their frustrations around the lack of integration, communication and collaboration between drug and alcohol services and mental health services to support people with co-occurring needs.

When asked whether drug and alcohol services and mental health services work together, the majority of respondents expressed negative sentiments, commenting that services are fragmented and do not communicate or collaborate.

Some participants shared that they were passed "back and forth" between drug and alcohol services and mental health services, meaning they often received very little care and support.

"I don't think that they work together at all. It's either one or the other. It's having a mental health problem or a drug/alcohol problem."

"Individually it's great, but I've been the go-between and they don't seem to share information and that's the biggest frustration."

Mark's story about transition from child to adult services

Mark* has a 19 year old child who has experienced mental health problems for a number of years and also has ADHD. His child has co-occurring needs and has found that now his child is an adult, accessing services is even more difficult.

"The services they accessed I understood up to the age of 18. Then at 18 we were kind of left at sea all of a sudden, they're 18, they're a grown up, they could just automatically access these services on their own. We've always found since they've turned 18 that it's a real struggle."

Mark been trying to work with services to get his child the care they need.

"They know they've got issues but they keep saying it's not their mental health issue, it's their addiction. So they need to get their addiction sorted out but they're not really dealing with both. It's like we're playing tennis with the two departments and they really aren't working together in our experience."

**Please note a pseudonym has been used to protect their identity.*

Similarly, carers shared they had to perform the role of helping their loved one to access services, and recounted having to be the go-between for the person they care for and the two services. Carers also noted that getting support for their loved one was challenging and that they often had to "fight" for it. They suggested that drug and alcohol and mental health services should communicate and share information with carers (in line with confidentiality) more effectively.

"The amount of notebooks and paperwork I take to appointments so I can say 'No this is this' and take copies with me. I feel like an admin function just to keep my husband safe."

"I've been fighting for 10-15 years…and if you don't know to fight it, it's incredibly difficult."

Participants with co-occurring needs also said that their care is not holistic or personalised, and that their substance use and ill mental health are looked at in isolation, meaning their issues are treated separately despite being related to one another. As such, participants, particularly carers, emphasised that the dual diagnosis protocol[4][5] is not effectively recognised by mental health services.

"They need to look at the whole person, you can't just deal with one problem because there's so many things going on. They don't look at the root cause, and I think it's that whole thing about not addressing the mental health side of it, and it's so linked that you can't ignore it."

"I have a concern that some of XXX"s senior staff don't give as much serious thought to this dual diagnosis as they should. I think that in my experience it's been glossed over a lot."

[4] Dual diagnosis protocol is a set of procedures used to support those with poor mental health and substance use (Dual diagnosis - Spectrum Drug and Alcohol Recovery Services)

[5] Find out more here: cgl-dual-diagnosis-leaflet.pdf

"The protocol is not being applied if the GP says she cannot have a mental health assessment or a psychiatrist because of the alcohol problem. That is the whole problem that has been going on for so many years."

Positively, a few participants shared that drug and alcohol services and mental health services did work together to support them, showing signs of progress being made.

"We got someone else and he seemed to know a bit more and yeah it calmed me down a bit and they seemed to sort of work together a bit better. It took a while but they got there in the end."

Jacob's story about a positive experience with support for PTSD and alcohol

Jacob* uses alcohol and this worsened during COVID when they were in an abusive relationship. Since then Jacob has been diagnosed with Post Traumatic Stress Disorder [PTSD].

"I've had different things but alcohol has always had a grip on my life and what not. It escalated in COVID when I was in an abusive and violent relationship, I started drinking more and more. I can go quite a long time but when I start to drink if I'm in a low mood, it escalates. I've been diagnosed with PTSD as well."

Jacob was able to get support with their mental health, alongside their substance use, which has helped them to start drinking less.

"I think if you get the right treatment for your mental health problems, that will hopefully help you to drink less anyway. I have the right medication and I think I'm much better up there."

**Please note a pseudonym has been used to protect their identity.*

3.3.1. Broadening access criteria for people with co-occurring substance use and mental health

To improve service provision, most participants suggested that mental health services should allow people who are using substances to access support for their mental health. This is particularly important because, in the majority of cases, their substance use is a result and consequence of their deteriorating mental health and needs the root cause to be addressed.

"I do not understand why the mental health services will not assess somebody if they are using substances. XXX say 'we can't treat somebody if they're using substances'. Royal College of Psychiatrists actually say you can and they should. NICE guidelines say the same thing."

"You would save money if you ran services in a different way because people wouldn't become so sick and people that I've spoken to – even the staff at XXX – have said that most people that go there have mental health problems."

From the conversations with carers, we heard suggestions that drug and alcohol services and mental health services should set up multidisciplinary meetings to bring services and professionals together to discuss an individual's care and needs.

"Talking to each other so there's some consistency, so they all know what's happening with the patient."

"It really has to be a kind of multidisciplinary approach to it. Otherwise you're having to fight a system that you don't really understand. They don't work together as a team, they don't talk to each other."

3.4. Accessing drug and alcohol and mental health services is not simple

Participants shared how they initially discovered drug and alcohol services and mental health services, and the barriers they faced in getting the care they needed.

3.4.1. Drug and alcohol services

Most participants either made a self-referral to drug and alcohol services or were referred by their GP practice.

For those who accessed their GP for support, a few participants shared that their GP practice only provided them with a list of services in the area, meaning the onus was on the individual to request help. In some cases, participants did not feel comfortable contacting drug and alcohol services themselves and/or needed support or motivation to access care and suggested that GP practices could play a more proactive role in making referrals.

"I had been to the GP two years prior to that and I wouldn't say I got fobbed off, but I got told what services are available and then it's up to you to go and find those services."

"Sometimes people want the doctor to refer because they don't know how to speak to them or do the referral."

In addition, a few participants felt their GP practice did not adopt a holistic approach to their care and did not take into consideration all of their needs when suggesting support for them. Lastly, two participants said they were denied treatment by a drug and alcohol service because they were not drinking enough, which left them without care and support.

Although, most participants were able to access drug and alcohol services promptly. However, location was a key barrier preventing access, with some participants having to travel long distances to get the support they needed. Nonetheless, participants were grateful to those drug and alcohol services that assisted with their travel expenses. Another significant barrier was employment and working hours; a few participants shared that they found it difficult to attend group sessions during their typical working hours. One participant said they were reluctant to access support in their local area in case they were identified by people they know, while a couple of other participants said shame and stigma were factors preventing them from getting the help they needed.

However, some participants shared that they were in denial about their substance use and were not ready to accept support.

"I forced myself to a GP office because I needed help with my alcohol and I felt they were quick to say 'Right you're going to CGL' without trying to find out what I need."

"With XXX it was like we can't help you, you'll have to come back when you're drinking heavier and you're trying to stop drinking. When you're drinking everyday then we'll help you."

"It's very taboo. No one understands, not even your family. That's a challenge within society and culture."

3.4.2. Accessing mental health services

Similar to drug and alcohol services, most participants who have used mental health services made a self-referral. Others spoke to their GP practice who then made a referral for them.

"I put mental health on the eConsult and got a phone call back in two hours and phoned me up every few weeks to see how I was getting on."

A key barrier to accessing mental health services was shame and stigma, with participants reluctant to seek support as they felt it was a sign of weakness.

"I do worry about judgement, trying to get help through the doctors for mental health seems like they will just judge me."

"I come from a generation where mental health was a taboo subject. You were laughed at."

Another key issue was waiting lists, with some participants having to wait for several months or even up to a year to be seen by mental health services.

"I've been waiting a year for a referral from the GP to the mental health services and finally got in. I'm still waiting for an appointment."

Claire's story about stigma

Claire* has experienced ill mental health from a young age and has since relied on drinking alcohol to cope.

"I've always suffered with mental health since quite a young age, I think ever since I was a child I've gone through a lot. I did like the one-off drink, like every weekend… but it did get to the point where I was relying on that."

Despite this, Claire is reluctant to access mental health services due to stigma and fears about not being listened to.

"I think there's a lot of stigma isn't there with it."

**Please note a pseudonym has been used to protect their identity.*

3.5. Positive experiences of using drug and alcohol and mental health services

Participants shared their positive experiences of using drug and alcohol and mental health services, and the improvements that could be put in place to improve the care people receive.

3.5.1. Drug and alcohol services

For most participants, they had very positive experiences of using drug and alcohol services and felt they received high-quality treatment. They commented that they experienced a sense of belonging, felt welcomed and found the staff to be kind, supportive and helpful.

In particular, participants shared the value of group work and how sharing their experiences with others boosted their confidence. The empathy and understanding within the groups enabled them to share their challenges and also to be held accountable by their peers.

Participants added that one-to-one support is also an essential form of support they receive, sharing that it allows them to disclose issues that they might not want to share in a group setting.

"It makes you feel somebody's actually listening to what you've got to say. You've got a voice and hopefully this will help other people in the same situation as you."

"You've got a lot of support from the staff – the staff are brilliant."

In addition, participants praised the care and support they have received from their key workers and the benefits of them often having their own lived experience.

Although, others shared that the high turnover of key workers can be problematic, commenting that they had multiple key workers since accessing the service and found it difficult having to retell their story to new people.

"My key worker is a diamond, they're great."

"Some of them has been through it too and can understand and relate."

Some participants also compared the support they received from drug and alcohol services to a "production line" with a few stating they felt abandoned by services, despite still needing support. They were also frustrated that their treatment was limited to a number of weeks which they felt was not sufficient enough.

"It's like a production line, you're in, you're out. And that's it."

"I had detox and then I went to recovery groups for eight weeks after and then they just drop ya."

Lastly, some participants said they received poor communication from drug and alcohol services and found it very difficult to get in touch when they needed to speak to someone.

"It's a nightmare, when I've tried to ring XXX you have to go through a single point of access and you can hold on there. I have in the past tried numerous times in the day and just left the phone going."

"It's so difficult trying to get information from anybody – the number of times I've had to ring XXX and you have to leave a message and they don't get back."

3.5.2. Mental health services

Most participants who accessed mental health services tended to have a positive experience, commenting that they felt in a better place and had greater control of their condition.

"I've been in and out of therapy, I've finally come out the other end so now I'm not a panicker or worrier anymore."

"I got some CBT therapy a couple of years ago, this was because I diagnosed alcohol as one of the main problems, and I found that to be very good actually."

In particular, participants praised the support they have received from care coordinators and psychiatrists in helping them with their mental health.

"The care coordinator has been fantastic."

"My psychiatrist has been really helpful in supporting me."

However, some participants expressed their frustrations about the poor communication they have received from mental health services. One participant also shared that they felt stigmatised by their therapist and suggested their concerns about their mental health were not taken seriously.

"It's so difficult, the number of times I've had to ring the Complex Needs team and they don't get back."

"I felt stigmatised by my mental health counsellor because it was never taken seriously, it's never taken seriously until it's too late."

4. Conclusion

Despite many of the participants expressing that their or their loved one's substance use is a consequence of their ill mental health, the majority of people we heard from faced significant challenges in getting support for their mental health, whilst still using substances. Most participants were refused care for their mental health until they had stopped using substances, including a few who were living with suicidal thoughts and/or had attempted to end their lives.

Participants shared that drug and alcohol services and mental health services are not integrated and do not collaborate or communicate effectively, with participants often going back and forth between the two services.

Participants generally had positive experiences of accessing either drug and alcohol, or mental health services separately, providing examples of receiving high-quality care and treatment. However, as identified, the core challenge is the relationship and partnership working between these services to support people with co-occurring needs.

It is crucial that actions are put in place to improve this and to ensure those living with co-occurring needs receive the care and support they need.