

Peer research into lived experience of being supported with a dual diagnosis in the London Borough of Camden

“DEAL WITH THAT FIRST, AND THEN WE’LL SORT THE OTHER ONE OUT”



The experiences of Camden service users who want support with both their mental health, and their drug or alcohol use

In Autumn 2014 a group of mental health and substance use service users spoke with nearly 50 people about Camden’s services. This report is a summary of the research, and has recommendations for how services can be improved.

Dual Diagnosis is a term used to describe many co-existing conditions, **for the purposes of this report DUAL DIAGNOSIS describes having both mental health and substance use problems**

EXECUTIVE SUMMARY

Introduction

In the past, it was often found to be difficult for people with a dual diagnosis to get support that works for them; services have focused on either substance use or mental health, communication between services has been fragmented, and staff expertise has been either in mental health or substance use (Social Care Institute for Excellence [SCIE], 2009¹). Recently in Camden, it has also been recommended that effective pathways for those with a dual diagnosis should be developed (Camden Council, 2014²).

Methodology

A group of service users with experience of dual diagnosis conducted research to find out how well services in Camden are currently meeting the needs of those with a dual diagnosis. From July to December 2014, researchers spoke to nearly 50 service users (online, in focus groups, 1:1 interviews, and questionnaires) about what they thought about their support, and how it could be improved. This report outlines current service user experiences, and provides recommendations for what can and should be done to improve services in Camden for people with a dual diagnosis.

Findings

The findings of this research can be grouped into 3 main conclusions:

- substance use services seem better able to support people with a dual diagnosis than mental health services do
- people are reluctant to disclose their mental health experience or substance use to professionals, for fear of consequences for the treatment and support they receive
- if people used different services, the communication between those services was generally poor.

Recommendations

It is the recommendation of this report that service providers action the below to improve the experiences of those with a dual diagnosis in Camden:

- support frontline staff (including GPs, mental health professionals, and substance use staff) to communicate in a way which ensures more service users feel they can be honest about their experiences
- make greater efforts to engage people at different stages of their recovery; excluding those who smell of alcohol from services should be reviewed and relaxed where possible
- explore the provision of a ‘no wrong door’ service that can support people with a dual diagnosis, instead of people having to primarily identify with either mental health or substance use
- research further the prevalence and experiences of those with a dual diagnosis in Camden; this snapshot study can be used as learning for this.

If you would like to find out more about the research, or would like to work with the researchers, contact Rachel on 07770 014 109 or email Rachel.killick@voiceability.org.

¹ SCIE, 2009. The relationship between dual diagnosis: substance misuse and dealing with mental health issues, available online at <http://www.scie.org.uk/publications/briefings/files/briefing30.pdf>

² Camden Council, 2014. Alcohol and substance misuse needs assessment, *Camden profile public health intelligence*, July 2014, available online at <http://tinyurl.com/pt7zr2q>

INTRODUCTION

In 2014, a group of service users with experience of dual diagnosis, and service user involvement staff from VoiceAbility, met to discuss how their experiences could help improve the support and treatment experience of the wider service user community.

Nationally, there are large numbers of people who have a dual diagnosis (Weaver *et al.*, 2003³). This, coupled with the extensive experience of group members, and demonstrable benefit of involving service users in research (National Institute for Health Research, 2014⁴), meant it was agreed that finding out the experiences of those requiring support with dual diagnosis in Camden would be of value.

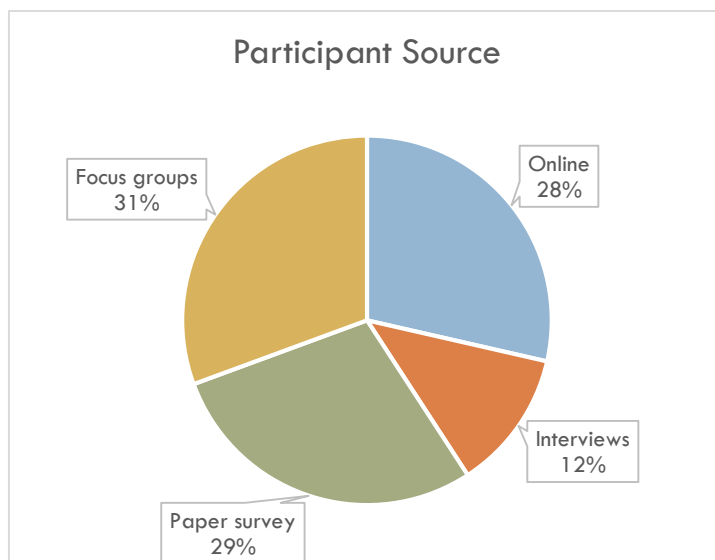
This report details the research undertaken to find out the experiences of those in Camden with a dual diagnosis.

It is hoped these experiences will now be used to help inform future direction for providers, commissioners, and dual diagnosis service user involvement in Camden. For more information about the research, or about service user involvement in Camden, please contact Rachel.killick@voiceability.org or phone Rachel on 07770 014 109.

METHODOLOGY

Following recruitment and training, a team of service user researchers conducted interviews and focus groups with peers to elicit their experience of services. In addition, questionnaires were handed out, and an online survey disseminated. Service providers were also approached to ask for their support in gaining access to service users.

Participants



In total the views of 48 people were gained.

Gender

Approximately a third of participants who disclosed their gender were female (this may in part have been because the majority of researchers were female).

Age

53% of participants were aged 35-55 (which can be said to be representative in part of the wider service user community in Camden; Camden Council, 2014²).

Ethnicity

45% of participants identified as white British.

It is acknowledged that this is not the experiences of all those with a dual diagnosis in Camden; further, more systematic, work could be done to hear from more people with a dual diagnosis, using different services.

Further research with under represented groups could also be of value; this report provides a snapshot of current experience in Camden.

³ Weaver, T., Madden, P., Charles, V., *et al.*, 2003. Comorbidity of substance misuse and mental illness in community mental health and substance misuse services. *British Journal of Psychiatry*, 183, 304-313.

⁴ National Institute for Health Research, 2014. Good practice guidance for the recruitment and involvement of service user and carer researchers, available online at <http://tinyurl.com/q989dkh>

Service user experiences

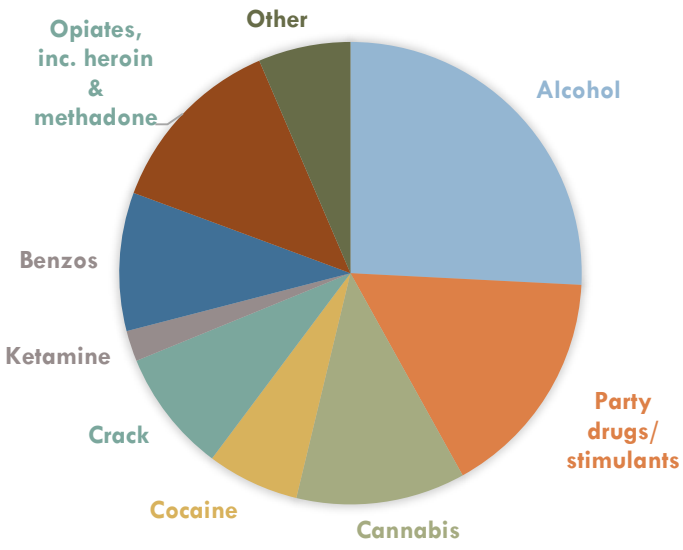
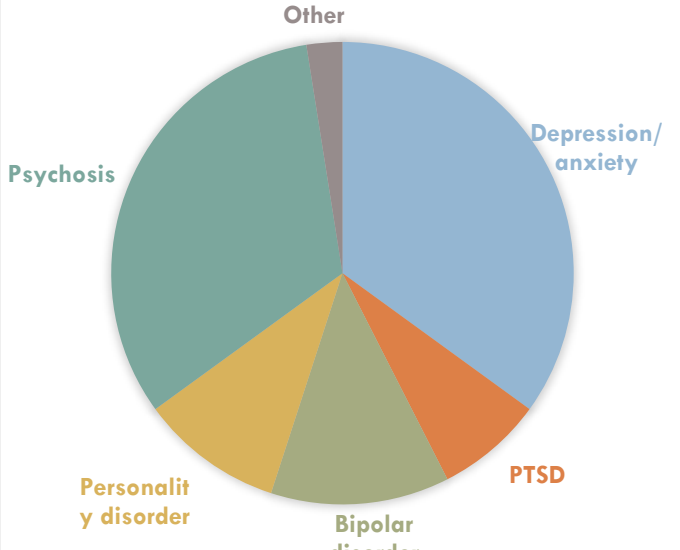
Participants were asked to tell researchers about their substance use and mental health.

“I was using alcohol as a crutch to forget about the past. Then I started to get more depressed.”

“I’ve always been anti drugs. Then 25 years ago I had a nervous breakdown. I lost my job, I had a lot of trauma. So I slipped into that world, drugs helped me to forget the trauma that was in my head.”

16 people chose not to tell researchers about their mental health; 9 people chose not to disclose their substance use. Some service users told peer researchers they were happy to talk to the researchers about their experiences, but not to their service providers – they were concerned that disclosing to providers may have negative consequences for their treatment and support, but felt comfortable talking to peers.

Generally speaking, poly substance use was common, as was experience of more than one mental health issue. The charts below are an indication of the substance use and mental health experiences that people told researchers about; it is acknowledged that this may not mirror diagnostic criteria.

<p style="text-align: center;">SUBSTANCE USE</p> 	<p style="text-align: center;">MENTAL HEALTH</p> 
<p><i>“I have gone from harm reduction, to recovery... [I’ve gone from them telling me] ‘have loads of methadone, swimming in it’ to now; ‘we want you off fast’. I have lost count of the key workers I have been through. I obviously have my substance issues, yet if my treatment had ever been consistent I would not be still at the same [drug dependency unit] now being talked into detox/ rehab to tick boxes. I just want good treatment – consistent, professional... mine is just about the management ticking the correct box – “she went to rehab, we were successful”... I feel I’m on a roundabout, with management’s interest put first, and my treatment that would really work, of no interest”</i></p>	<p><i>“CMHT... - Psychiatrists & benefits advisor excellent. Care co-ordinator was crap. [The mental health hospitals] don’t want to do anything other than put you on drugs... control rather than support. Just started with the personality disorder team, ok so far but there seems to not be much focus anywhere on emotional recovery from severe abuse in your life.”</i></p>

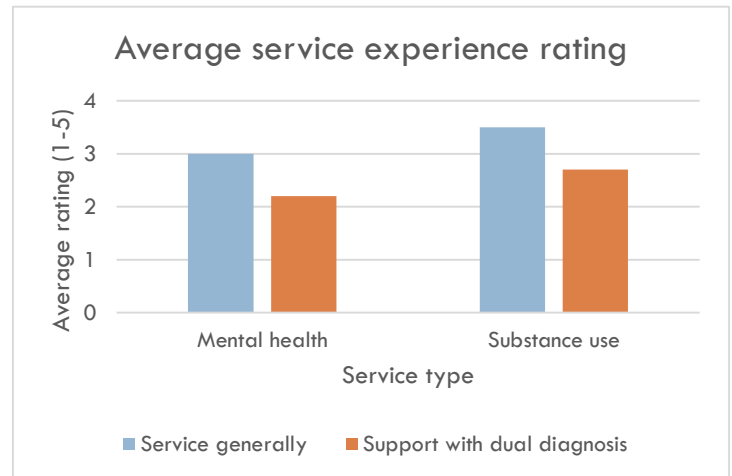
RESULTS

Experience of services

In order to get a general picture of service quality, participants were asked how good the mental health and substance use services they have used were. Participants were also asked how well services supported them with their dual diagnosis. People rated their experiences on a scale from 1 to 5, with 5 being very good, and 1 being very poor.

Although the differences in ratings between services were small, it seems that:

- people generally have better experiences of substance use services than of mental health services
- people have worse experiences in terms of support for their dual diagnosis
- substance use services seem better able to support people with their dual diagnosis than mental health services do.



Communication within and between services

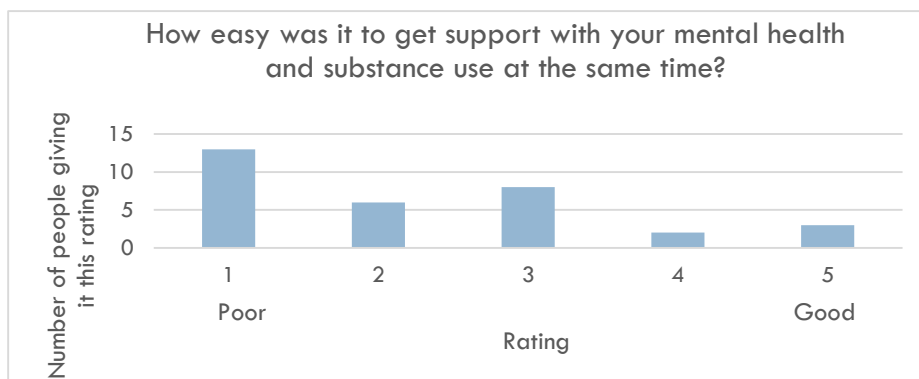
Over half of participants talked about how well services communicated with each other. On average, participants rated services’ communication with each other as 2 out of 5. People talked about being sent to other services for an issue that either mental health or substance use professionals felt they were not equipped to deal with.

“I want my doctor and keyworker to liaise. I very rarely see the same doctor but my relationship with my keyworker is very consistent and I always see the same lady, whom I get on with extremely well.”

“They just look at my mental health, not any drugs I may use. I’ve had counselling at the [mental health] day centre and mentioned these things to them, it’s just gone over their heads”

“The alcohol service were great, but they didn’t acknowledge my mental health difficulties. I discovered they were massive when I stopped drinking. I was doing a detox, but no-one said ‘you could probably see someone about the voices.’ That’s why I relapsed, I thought, ‘I need to have a drink’. If they had worked together, my recovery would have been much better”

Getting support with mental health and substance use at the same time



Participants were asked to rate how easy it was for them to get support with their mental health and substance use at the same time. Overwhelmingly, peoples’ experiences were poor. Just 5 people said their experiences were better than ‘okay’.

A few people researchers spoke to elaborated on their experiences of getting support with their mental health and substance use at the same time:

“My old day centre was great... alcohol units [are] not so good. [you get] 12 weeks, and [then] you’re gone. You miss a few sessions, and that’s it... [and] you can’t get counselling elsewhere for non alcohol related issues, because you drink too much!”

“I had to pretty much hide my substance use, so it didn’t affect my referrals”

“[A crisis service] won’t accept you if you’re drinking. If I’m having a crisis, of course I’m drinking!”

“If I come in the [mental health] day centre smelling of alcohol I’m sent home, it’s their ground rules”

“[substance use provider] didn’t open until 10:30, I was drunk by then. They said we can’t engage with you, you’re too drunk. If I could stay sober, I wouldn’t need you”

“People in mental health don’t want you to drink. You’re trying to see someone and be honest, but it means you can’t get support”

CONCLUSIONS

Based on the experiences of those that researchers spoke to, this report concludes that:

Substance use services seem better able to support people with a dual diagnosis than mental health services do

On average, people rated their support from substance use services with their dual diagnosis higher than the support they had from mental health services. Numerous participants spoke of their exclusion from mental health services if they smelled of alcohol. Some people talked about a perceived lack of substance use knowledge and expertise from mental health professionals, and vice versa.

People can be reluctant to disclose their mental health experience or substance use to professionals, for fear of consequences for the treatment and support they receive

Many participants talked about stigma, a lack of empathy from professionals, and service exclusion criteria having an impact on the likelihood of them being honest about experiences.

“I was 23, my GP was quite a bit older. She just asked, ‘have you been taking drugs?’ She was very accusatory... I was terrified about getting told off... I talked to my GP about my mental health, and lied about my drug use – ‘it’s just a bit of weed’”

“The police don’t seem to see mental health, they think of you as a druggie or a drunkie. They just see their job as sorting out an immediate problem, the drinking and taking drugs”

“I wish they could recognize it more and make people feel free to discuss drug addiction because it’s illegal. I’d like to have felt that I could have gone to professionals to discuss my drug use, I could have recovered quicker; so you can feel you can talk about it without being judged, you’re afraid. You’re fighting it, but you are also living in it”

“People in mental health don’t want you to drink. You’re trying to see someone and be honest but it means you can’t get support. Mental health don’t accept that you have a drink to help you handle stuff. I take a lot of antidepressants and antipsychotic stuff. [Substance use provider] are trying to help me with the drink, then they say ‘you’re taking tablets’. I keep getting told different things.”

“Deal with that first, and then we’ll sort the other one out”

If people used different services, the communication between those services was generally poor

This report concludes that in Camden, different service providers need to be better at communicating with each other. People told us their provider would talk to them about either substance use or mental health, but in some cases would not support them with other issues.

Aftercare/ long term recovery

When talking about what would help them, many participants said they felt that services did not take a long term approach to their recovery:

“Need more focus on emotional recovery from severe abuse in your life, not just psychological band aids/ walls to put you back in a job. Proper recovery!”

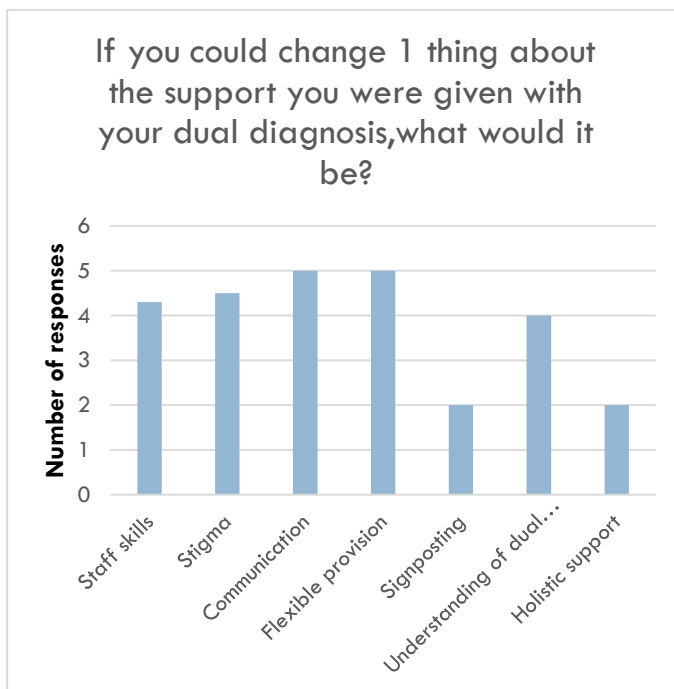
“In the last few months, I had a breakdown. I went to [a crisis house] for 4 months, with their crisis team. We sorted out my flat. Since then, they said they’d get me a [community psychiatric nurse], but I haven’t heard anything. I was promised everything... it never occurred. I sit indoors and think, ‘where are these people?’ It’s like I’ve been left, it’s like they think ‘now you’ve recovered’. It’s as if I’ve been put out of the system ‘it’s ok now’...I’m scared I’ll reverse back into it.”

“I dread coming across a crisis, I get no support now. If you think about what I cost in those 12 years – criminal justice, psychiatry... if I’d had some support, I’d have prevented all that’.

“You need help to keep yourself occupied after you put down the drink – it’s a 24 hour thing”

RECOMMENDATIONS

Just 35% of those asked said they would recommend the services they received to others who had a dual diagnosis. Researchers also asked the open question below; some people gave similar responses:



Based on this research, the following is recommended:

- support frontline staff (including GPs, mental health professionals, and substance use staff) to ensure more service users feel they can be honest about their experiences
- make greater efforts to engage people at different stages of their recovery; the exclusion from services and support of those who smell of alcohol should be reviewed and relaxed where possible
- explore the provision of a ‘no wrong door’ service that can support people with a dual diagnosis, instead of people having to primarily identify with either mental health or substance use
- research further the prevalence and experiences of those with a dual diagnosis in Camden; this snapshot study can be used as learning for this.

Researchers also heard some examples of what works for people:

“At first I was just ‘a drug addict’. Doctors did not want to understand and I was pushed into places like Alcoholics Anonymous, Cocaine Anonymous, Narcotics Anonymous. There was no help in getting me to understand why I was taking drugs in the first place. Once I had my mental breakdown, only then was I taken seriously about my drug use, and why I was taking drugs in the first place. This was when I was told I was self medicating to cope with the sexual abuse I had gone through, and that I had PTSD [Post Traumatic Stress Disorder]”

“Mind in Camden’s social network is very supportive and relevant. You can talk anonymously about benzo issues.”

“I’ve been seeing a psychologist, and also talking to someone who’s been through it. Having the two together has helped me. In 14 years, I never tried to stop drinking. This is the first time I’ve left a bottle of wine on the kitchen side and gone to bed. I’m starting to look after my mental health now as well; that’s really helping”

“I’ve had great help in dual diagnosis. I’ve been using drugs and alcohol all my life. I did everything; heroin, crack, cocaine, alcohol. I suffer from psychosis; hearing voices... when I moved into Camden, they referred me to Response – a street project, they’d support you with drugs if you have mental health problems. They’ve been following me since 1999 – I have a key worker, a psychiatric doctor I can see whenever I need, and a helpful GP. I have a care coordinator for my prescription. He helps me with my benefits, any appeals or tribunals... maybe I’ve been lucky to be referred to this agency... I can call during the week. I know where the help is, I can get support.”

Researcher reflections

“It opened my eyes. I didn’t realise how many times people got sectioned and got let go. You think you’re alone, but there are other people suffering.”

“It’s such a lottery. One person can have wonderful care, and in the same place, someone else can have crap care.”

“For me, I’m taking away the lack of communication from service providers.”

“They came up to us one by one, quietly – they wanted to talk to us, with privacy and no stigma.”

“People were willing to open up to us, because we’d been there, and done it.”

ACKNOWLEDGEMENTS

Thank you to all those who contributed to this research.

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- Camden Frontline’s Recovery and Peer Support (RAPS) project
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- Highgate Day Centre
- Margarete Centre
- Mind in Camden
- Spectrum Thamesreach

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