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Fulfilling Lives
South East Partnership



The Perspectives Project - Part II

Learning from people with lived
experiences through substance
misuse treatment and mental
health support

MAY 2021

About Fulfilling Lives

Fulfilling Lives South East Partnership works across Brighton & Hove and East Sussex and is one of 12 projects across England where National Lottery Community Fund investment is supporting people with complex needs.

The purpose of this initiative is to bring about lasting change in how services work with people with multiple and complex needs and we collaborate with partners to work towards this objective. We are committed to putting co-production into practice and value the voices of experience. We also recognise the value of trauma informed approaches in our work and the work of others.

Website: www.bht.org.uk/fulfilling-lives

Blog: www.fulfilling-lives-se.org/

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PERSPECTIVES

1. Introduction

This report summarises the findings from research into what good psychological support can look like for people who have co-existing mental ill-health and substance use, prior to them accessing formal substance misuse treatment. The learning from this report is generated by people who have lived experience of this and explores how trauma impacts on peoples' engagement with support and how services respond to those who have multiple needs. The aim of this work has been to listen and learn from those who have direct experience in this area and is an important complement to our earlier Perspectives Project study that discussed the topic from a professionals' viewpoint.

Across 2020 and 2021 we interviewed 6 people who had experienced substance misuse support services and touch points with mental health services during their journeys into recovery. Their experiences and perspectives on the support system are captured in this report.

CONTEXT

Our interest in this area comes from our commitment to supporting people with multiple and complex needs who have 'coexisting conditions' – mental ill health and substance misuse.

A recent snapshot of our client group highlighted how substance misuse and mental ill health are the most common problems for people on the Fulfilling Lives South East caseload (94% and 96% of the project's caseload respectively). There is a high degree of overlap between the two conditions, with 90% of beneficiaries experiencing both and there is a corresponding prevalence of complex trauma amongst beneficiaries.

A significant proportion of people with multiple and complex needs are effectively excluded from formal mental health assessment and treatment pathways due to presenting with behaviours resulting from complex trauma coupled with substance use.

Current clinical pathways often require an individual to address their substance use before mental health treatment can be provided. Unfortunately, the current substance misuse treatment system is often difficult to navigate for people with the most complex needs, especially when their mental health needs are considerable.

Given these barriers to accessing and engaging with formal treatment, how might we adapt to better support people who have multiple needs? Our case work over the past six years has pointed towards the need for therapeutic support for complex trauma, to help build psychological resilience and stability, in order to make access to substance misuse treatment possible. However, we wanted to explore this further with those who were in recovery and hear what had worked well for them – what was it that has really helped them reach their current position? We feel this couples usefully with our companion report – Perspectives Project: Professionals' Views – to help spark debate on this subject and to see if ideas and reflections from contributors could point us in the direction of new ways of working to help provide better support for people with multiple complex needs.

We hope readers will find connection and challenge in the conversations in this report and that this can contribute to the shape of future services and the ways in which we all work.

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2. Methodology

To gather our data, we conducted semi-structured interviews with 6 participants from Brighton and Hove and East Sussex. These took place October 2020 – March 2021.

The transcribed interviews were then analysed using inductive thematic analysis, where interviews were reviewed and grouped into themes. This process was co-produced by members of our Systems Change and Service User Involvement teams and facilitated by the Research and Evaluation Officer for Fulfilling Lives South East.

The semi-structured interviews with contributors centred around a set of 5 questions that can be found in the Appendix.



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3. Learning from Lived Experience Conversations

The exploratory conversations we had on the topic of psychological support and treatment pathways highlighted a range of important themes, as well as indicating areas of consensus between different individuals. Our central findings have been summarised by theme to provide an overview of the discussions and viewpoints.

1 MOTIVATORS FOR CHANGE - ACCEPTANCE, TRYING AGAIN, MEETING GOOD PEOPLE

There were several common factors that contributors highlighted that were motivators for change and key to their accessing support, broadly these fell within 3 categories: acceptance, the importance of trying again, and meeting supportive people.

Contributors spoke of a need to have faith in your key workers and support staff and that committing to the process was important. Most commented that this worked best when treatment steps were not forced from the staff side, and how this helped provide space for people to pivot from resistance to acceptance before engaging with any formal treatment or therapies.

'Because you're there voluntarily, you want to go there, you want help. It's not the staff's fault. They're there to help you. And it took me a while to realise that, but when that light bulb moment did go off in my head, that the staff were actually helping me, it got a lot easier. I accepted that I'm here. They're here to help me. And I worked with them instead of against them.'

Some contributors emphasised the importance of self-willingness and self-determination in getting to and engaging with treatment and support services.

'There was a hell of a lot of negotiating with myself throughout it'.

Structured groups pre-treatment was highlighted as useful to begin understanding yourself and as such, cultivated motivation for change.

'There are also a couple of other groups, Smart and Act, which are more structured and good for teaching you tools in order to deal with things such as cravings and things like that, and giving you a bit more of an awareness and knowledge.'

2 SUBSTANCE MISUSE STAFF – BEING THERE AND VALUED ATTRIBUTES

There was focus from contributors around the type of contact and interaction they had with substance misuse key workers and other support staff pre-treatment, with many praising the support from their SMS worker. Most reflected that support workers and services being available and ready when the client is ready to commit was deemed important. One contributor accredited the support and sense of permanence that came from the keyworker as lifesaving.

'He was the only person really [substance misuse key worker], I would say in the health services that stuck by me. I continued with what I was doing but, if it wasn't for keyworker, just hanging on in there for half an hour a week and asking how you are doing etc... I don't know if I'd still be here.'

'It was at that point I realised the substance misuse care co-ordinator knew what I was really up to all the time, but they were not going to force you into doing something you didn't want to do. So, they wait until you are ready.'

'Yes, there's a prep group that you have to attend that was on every Thursday. And you just go in with other people that are waiting to get in [rehab]. You know, you have to show up quite a few times to show that you want to get into treatment. I was quite drunk at a few of them because I was just in an awful place. But they let you sit there and have your time. So, the first time I went in there [rehab], they let me come to the house and have a look around and meet the people that were living there before I moved in. So, I thought that was quite nice.'

Contributors spoke widely of the attributes of SMS workers that had helped enable trusting and productive relationships. Across the conversations, the following attributes were repeatedly referenced and felt to be particularly valuable: being consistent in their availability and approach, holding space with clients, acting as advocates to unlock access to wider support services, challenging clients in a way that suited their personalities and being compassionate.

'I kept my meetings with my key worker, even if it meant I used just before I would still go and meet him and he was there and I felt like in some kind of way, him just being there he held me and continued to hold me and I could see sometimes the fear in him. He had that kindness and he was my connection with reality - actually maybe there was some hope there.'

'I was really quite pushy about it, as was my key worker, and we managed to get some counselling sorted out, and some psychotherapy sorted for me.'

'I could text her at any time, but the phone would only be working in business hours. But if I texted her the night before she would get back to me the following day, she texted me back or called me back to make sure I was all right. So, she's very caring.'

Contributors also reflected on positive experiences of being in formal treatment services and being supported by their rehab key worker to address mental health issues and past trauma.

'My son's been adopted, and she knew how to sort of ask me questions around that really delicately to get me to open up about it.'

'All in all, thinking about where my mental health is now, and thinking about my confidence and anxiety, the rehab I was at done an amazing job. They switched my whole way of thinking.'

3 THE UNKNOWN - THE NEGATIVE IMPACT OF 'NOT KNOWING' ON WELLBEING, PRE-TREATMENT

When thinking about rehab and the preparation involved to get there, contributors spoke of the need to de-mystify and make clear the process. Some contributors commented on there being a lack of information and practical support available. This compounded feelings of trepidation of entering formal substance misuse treatment.

'So I went, I was terrified, but I got there.'

'I wasn't given information beforehand, I was told someone was going to find my key worker but, to be fair, my key worker didn't really know anything about the place. They were still in transition between one organisation taking it over from another organisation, which I understand. So I didn't know what I could or couldn't take.'

'I didn't know what to expect I literally thought all I had to do is take a pill and I'll get better and I really didn't think I needed to attend groups or put work in.'



4 PERCEPTIONS OF MENTAL HEALTH SUPPORT

Some contributors reflected on how falling between the gaps that can often exist between substance misuse and mental health services has a particular impact on clients with a coexisting condition.

'Then I saw this guy from the mental health team, at the NHS hospital on the hill. He was a lovely guy, really friendly. But in essence, he said there was nothing they could do to support my mental health because it wasn't a mental health problem it was a drug problem. And that was it.'

'I think, for a drug addict, there's so many different forms of denial, but I think one form of denial is looking only at that secondary thing, that mental health problem of depression or PTSD or whatever it might be, rather than maybe you could be an addict, maybe that could be the crux of your problem along with the other things. But that denial, not having access to explore mental health services as part of that is really difficult.'

'What CGL have now provided, which I think is really good, which maybe would have been useful to me a couple of years ago, was a trauma group. They have started a trauma group and I do that every Tuesday.'

Contributors commented on the mental health support that was available after entering rehab, where the link between substance misuse and mental health issues was explored in depth through group work and 1:1 key work support. This was widely valued by contributors.

'The behavioural therapies like CBT worked for me amazingly.'

'And I feel when I moved to the second house, that's when the mental work started, you know, like digging into the deepest things that were really painful. And the first house is sort of a quick house, like a 'get-well house', and it's a bit crazy, I suppose, because people are all at different levels. Some people are at the beginning of like heroin detox and Valium, some at the end. So, it's all different personalities. But when you get to the second house, it definitely settles down and you spend longer living there. And I just felt the support for me at the second house was better.'

'We could if we wanted to, see a psychologist. I didn't myself, I didn't feel like I needed that. But there was psychologists on offer. There was mindfulness and yoga, meditation and acupuncture. I know a lot of people did see therapists when they were in the St Thomas Fund. Me personally, I never felt I needed it. So, I didn't do it. But the option was there.'

Some contributors reflected on the current mental health support offer not being enough; that it can be impossible to be sober without support. There was suggestion that interventions could take place in steadier moments in a person's life, for example, when someone is taking lower levels of substances as a form of maintenance.

'My mental health luckily hasn't been bad. I've just got anxiety and depression, but they just will not offer you anything, it's just, "take these pills," or "go to these groups". You're not allowed to see anyone until you're sober. You're at the doctor's because you're desperate. Being told you need to be sober, it's impossible. I do understand why they say it because obviously your head isn't straight when you are using drugs or alcohol, but it doesn't mean you're always out of it. Sometimes you're just maintaining, you can still have a normal conversation.'

5 THE IMPORTANCE OF POSITIVE RELATIONSHIPS ON MENTAL HEALTH AND RECOVERY JOURNEYS

Throughout conversations with contributors, being able to build strong, trusting relationships with support workers was thought of as a key element of progressing one's recovery journey and having a successful outcome from accessing treatment. Substance misuse workers were praised for approaches to developing these relationships. There was a sense from contributors that connection was very important, as was being encouraged to develop positive decision making about how to engage with the support on offer.

'I was called in the room [staff room] after a community group and I thought I was in trouble, even though I knew I hadn't done anything wrong, I thought I was in trouble. And they said "Where's it all gone?" I said "Where's all what gone?" And they said "Your anger - your body language, that meeting we just had in there, was incredible. You gave amazing feedback. Your body language was approachable." And that's when I had the light bulb moment: "Oh, I see what they're doing here now. They're trying to help me!"'

'So, seeing my key workers taught me that to reconnect is good. I was aware of this concept of reconnecting with people and the universe at large early on in my recovery. I realised that I would have to start mending the connections that my addiction had broken.'

Reflections from contributors suggested there was something about the timing of when these relationships with professionals were formed that spoke to the skill of key workers that converged with when the client was ready to fully commit. This echoes the need for workers and services to be available when the client is in a place to fully engage with the support on offer.

'I think I'm very lucky as well that my counselling with Rise fell in at the same time as I got sober and after my detox. Because I had that, I was an emotional mess three months ago. One minute I was crying and next minute I was OK and I was crying again. Everything was coming back, and it is a vulnerable time, but I have my counsellor to speak to and literally just say exactly how I felt and get it all out.'

6 REFLECTIONS ON STRESSORS IN THE WIDER SYSTEM

A number of contributors shared reflections on stresses on the wider system they had noticed and its knock-on effect to the client experience of the service. These pointed to concerns about staff availability and resources available in support services to meet client needs.

'Looking back, I can say that they were having staffing problems and so on. So I think that's why my treatment was stretched a bit thin.'

'The way they're dealing with it now is saying that the recovery workers, I think that's what they call care coordinators now, are too busy. So, what's going to happen now is the recovery workers [care co-ordinators] are going to call you once every three months, and that's 4 times a year.'

7 JOINED UP WORKING AND/OR LACK OF

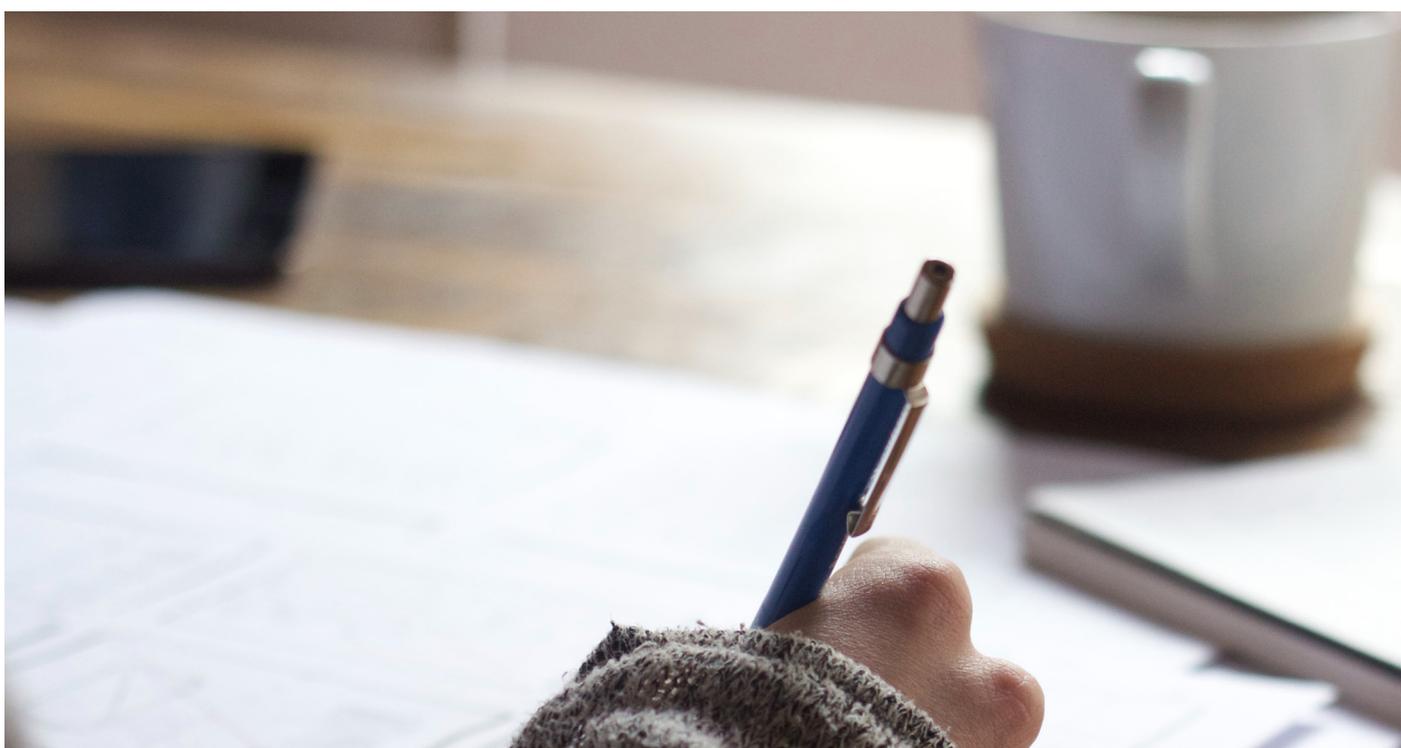
Contributors broadly speaking wanted to see more joint working between services and that not doing so was detrimental to those attempting to access support. Some described gaps between mental health and substance misuse services, others pointed to challenges between wider health and housing services and their substance misuse service. A lack of resources was recognised as an issue, but partnerships between organisations was viewed as vital by contributors and that this was an area that could be improved across the wider system.

'The other one will say it's a mental health problem. And then the other services will say it's a sexual health problem, rather than saying let's get together and do something together and work together and do something, because it's just avoidance at the moment, whatever it's wrapped right up in, it's avoidance and avoidance just doesn't work because these people are drowning.'

'...I think the obvious answer is it all needs more money and needs proper funding and the structure you're investing in - mental health and housing and drug abuse, all these things that are treated separately should certainly be treated more holistically.'

'Yeah, that is what I think because of my experience, the way the system is set up - completely compartmentalised. And it's not down to the workers and the people in it, because they do what they're told - you're allowed to do this, you're not allowed to do that and I know it because of my work. I've seen the other side of it, too, and I still believe there is a big problem there that's not the people working in it, it's the way it is.'

'My key worker has really fought hard for the mental health team to kick in, and they did do an assessment earlier in the year - a phone assessment, the crisis team did and then once again passed it back to substance misuse.'



8 IDEAS FOR IMPROVEMENT

Being seen as an individual by staff when you are in the toughest of times was something that several contributors touched upon: when this was felt to be taking place, the impact was extremely positive and when it was felt to be lacking, this often led to people feeling disengaged, frustrated, misunderstood.

'But I think the more they could see me actually as rather than this absolutely hopeless person that was going to die, which I was, if they can actually see the person that's inside, if they can get a little bit deeper and show some compassion that's what really helped me and that's what [my SMS worker] was able to do.'

It was really valued by contributors for there to be a range of activities to support wellbeing and peer support in services to help someone stay well whilst in treatment. One suggestion for improving the experience for people going through pre-treatment was a prep group to talk about what rehab is like. At the heart of this idea was awareness raising so people know what to expect from entering and being in treatment; one contributor spoke about it in terms of psychosocial pre-treatment interventions. There was acknowledgement that peer mentors in pre-treatment can play a vital role in whether someone will successfully complete treatment. Additionally, there was a message to services to listen to lived experience and for lived experience to guide practice to help get it right.

'It would be nice if they had, like a group to sort of tell people what it's about. Like in the prep group that they have ...it's sort of more like a check-in. There isn't really anything else. You know, just to be able to be explained what will happen when you go in, you know what the rules are. Just an idea of what you're getting yourself into, because sometimes people would come in and, you know, if we have to check in or we have to like we have to give feedback sometimes, which is quite scary if you've not done it before. People can leave. It scares them and they just walk out.'

'I think if I had been told that we can get you in touch with this peer mentor, who can call you, who can take you along to groups, I think I would have felt more comfortable because I am aware that is what the peer mentors do and maybe just getting a bit more knowledge because I really didn't know, and I think if I'd known at the time what I know now, I probably would have put in more effort.'

'I would like to see for people who are new coming into treatment and detoxes some sort of awareness group, because it was another world to me. I didn't know what to expect I literally thought all I had to do is take a pill and I'll get better and I really didn't think I needed to attend groups or put work in.'

'tap into the people with the experience because, if you don't, chances are you're going to get it wrong.'

9 THE VALUE OF PEER SUPPORT AND RECOVERY COMMUNITY ON WELLBEING AND PEOPLES' RECOVERIES

From across the conversations with contributors it is apparent that the value of a peer support network and the recovery community cannot be underestimated. Having open lines of communication with peers and access to a supportive recovery community were seen by some as the first steps in preparing to accessing treatment. Contributors felt that making new clients aware of their local recovery community network and any peer support offer that is available is vitally important and should be among some of the first information people are told by services about treatment. Recovery community led activity was seen as vital to building connections with others who have experienced the same issues. Some contributors suggested more peer support should be available to support people to attend groups to alleviate anxiety. Attending groups can offer a sense of not being alone, knowing others have had similar experiences.

'I also got a lot of use out of therapy groups like, for instance, trauma groups that I've done with Rise and I now do with CGL you get to learn a lot of coping mechanisms and you get peer support, and it's nice to know that you're not alone.'

'It's nice to have those recovery groups that aren't always just talking about problems with drinks and drugs, so I think Cascade's [Brighton & Hove recovery community café] are brilliant.'

'But something they never told me of. I found this out from a Big Issue seller about Cascade's café and stuff like that. I was just a bit gutted that I found out about the café so late in life because the café is my big thing now. It all started there. I went to meetings in there and then I went to another one. And then a St. Thomas fund meeting upstairs in the Cascade café.'

'...I think I've just about managed now to have enough friends, especially friends in recovery, that I could talk to any number of people. And we can all share something with each other if we are feeling lost. There's enough people around now, I think I could call and say this isn't good, I'm not feeling great, and they would know what to do and put me in the right direction and give me a hug.'

'So, I think all I was getting was suggestions to go to groups and I was feeling a bit scared and nervous and anxious about going to groups with people I didn't know discussing drugs and alcohol. It all seemed overwhelming for me.'

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4. Next Steps and Questions for the Future

To build on the work of 2020 and early 2021, we would like to continue collaborating with partners and people with lived experience nationally and locally in 2021. This will include:

- Bringing together contributors, local commissioners and local services to discuss the perspectives shared in this report and the companion report with a view of staff working in these support systems and consider together improved ways of working that we could implement locally.
- Continuing collaborations to trial new ideas for supporting people with complex trauma who have coexisting conditions to support them to help prepare for accessing formal treatments.

For Fulfilling Lives South East this project has sparked a number of questions to consider for 2021, including:

- To what extent do we all agree on where responsibility and resources sit in the system for supporting people with coexisting conditions and complex trauma presentations to stabilise and access support?
- How do we want services to respond to the behaviours of those who are affected by complex trauma?
- How might we better support staff within clinical and non-clinical services to nurture trusting and authentic relationships with people who are affected by complex trauma?
- What steps can we take to develop a support system that can better meet the needs of this group of people?
- How can peer support be woven more consistently through support offers?

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5. Acknowledgements

We are thankful to all those who not only shared their story with us but also shared their views and perspectives on the wider elements at play in support systems. Their openness and reflections add to our confidence that there are already positive practices that we can enhance and build on whilst also highlighting elements that do not work so well and could be changed. Sharing personal stories is not often easy, however, contributors have been bold and generous with sharing their experiences and we are very thankful. Special thanks also goes to the team who facilitated these conversations in a supportive and professional way – thank you to Aditi Bhonagiri and Ian Harrison.



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6. Appendix: Questions Discussed During One-to-One Conversations

1. Can you describe the type of support you remember having from your support workers before you started your substance misuse treatment?

(Examples of types of support worker we mean – CGL, Pavilions, Mental health teams, Oasis. We're looking for descriptive responses from people that we can then later analyse for elements of psycho-social / educational support.)

Possible follow up question:
 - a. How did the worker help you prepare for starting treatment? i.e. conversations, specific tasks, what was discussed, etc).

2. Did you receive any mental health support before you started substance misuse treatment?

Possible follow up questions:
 - a. What did this look like?
 - b. Did you continue to have mental health support whilst you were in substance misuse treatment?
 - c. Did you have any contact with a psychologist before you started treatment?

3. Did anything work well for you? If so, what?

4. Was there any support that you didn't have that you wish you had?

5. Is there anything else about supporting people to access substance misuse treatment that you would like to share?



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