

## **Sara** **Lived Experience Lead**

Hi, so my name's Sara and currently at Capital I'm called Lived Experience Lead. I've worked for Capital for about three years now and I've had several roles. My first role at Capital, I was a supervisor for the peer support wards.

We had three peer support wards across West Sussex, Langley Green, Meadowfield and Oakland and I supervised the peers that we have there. I did that for a while and then I very nicely got a promotion into co-production lead, which is for a lived experience advisory group that Capital hosts and they really help to shape and challenge services in West Sussex. So that was a really exciting job and I did that for a year and then just more recently I've been working for West Sussex County Council's drug and alcohol partnership.

So we're commissioned by them to be their co-production, so we're doing all things co-production for the council around drugs and alcohol at the moment. So that's what I'm doing right now for Capital.

### **What makes CAPITAL unique and what do you enjoy about CAPITAL?**

Capital is definitely very unique. I really love working for Capital. It's really different to any other organisation I've worked for before and I've worked in mental health for a long time. I've worked in mental health for well over 10 years now.

But Capital is so unique because the first thing is we all have to have lived experience, so we all have to understand what it's like to suffer with our mental health. So not all of us are diagnosed, but some of us are diagnosed, some of us have mental health conditions or just identify with mental health issues and so that makes it really unique. It makes it quite challenging as you can imagine at certain times, but we really do come together as a family and we really understand each other.

So you know if we're having a bit of an off day or our mental health isn't that great, we can really speak to each other and it makes it such a warm environment, so many people have said to me that being part of Capital feels like being part of a family and it really does. It's like a big family, you know, so it's great. It's very, very unique to any other job I've had before.

### **How does the uncertainty around Peer Support make you feel?**

The peer support part of Capital is obviously really what Capital is all about. So we are peers, so we all have lived experience, so we really work in peer support and more recently we've lost some of our commissioning around the peer support in our inpatient wards in the hospitals and that's actually really devastating because I know that's a really valuable service to actually get to speak to somebody in hospital that's not in uniform, that looks like you, that really identifies with you know who you are, has been sort of simply walked in your shoes. I think that's so important that we are in those acute wards and unfortunately that part of Capital will be going soon.

As far as I'm aware, we're really trying to save that part but that's all down to commissioning and how things are going in West Sussex, things are really uncertain in mental health. But aside from that, we also do peer support in the community and that's something we're going to move towards more, you know, if we can't be in the inpatient hospitals and I think people have even said they'd even volunteer their time at the moment. We're big on paying for peer support.

What we don't want to do is that everyone, oh we're a peer, we don't need to get paid for that work. We really think that peers deserve to be paid and we really value, you know, I can't think of the word volley for that, it's the word really volley for them to get them paid and we always have done. But people have said, you know, the money's not there but absolutely we're going to the community because we really want to help people, that's what people at Capital are like.

So I think there'll be a lot of that going forward while we're waiting to build on our funds. I think we'll find that people will be helping and to run the groups that we run in the community. We run a lot, we've got them in Crawley, East Grinstead, Bognor Regis, they run all over West Sussex and we'd like to do more of it and we'd actually like to really sort of do some more specialist groups in the community, really, you know, maybe a men's group would be good.

We really identify there's lots of men that need help at the moment, you know, I'm in the Bognor area and I know there's a real need for groups in the community at the moment and we know that there's a mental health crisis, you know, mental health's getting worse yet there's big funding cuts at the moment right now so we have to really do what we can to kind of help people in our community and that's what the peers really want to do and that's the power of peer support is they just want to be helping others and to be fair it really helps them too. Peer support is a two-way thing so, you know, by helping others, you know, it automatically makes you feel better, it shows peer leadership, you know, people are just building together so, yeah, so it's a real shame if we have to see some of the peer support work go in West Sussex.

### **What will the impact be in losing the peer support service?**

I think the impact of losing the peer support service will not only be devastating, like I say, to patients, particularly in our inpatient wards, you know, if we lose that service that would be devastating to them, it would be equally as devastating to the peers and we have a lot of peer support workers across those three hospitals, some of them have worked for us for years and years, I think one of our peer support workers might have to quote me on this, I think she said she's been there in 20 years so, you know, Capital's been going for 30, they're really invested in their work and they will be devastated, they won't be able to find a job the same, you know, like I say, the way that we understand each other's mental health, you know, our CEO Duncan's great as well, he really gets it, he really understands, you can go to Duncan and say, you know, I'm not having a great day and he will really understand and you don't always get that with an organisation so, I think not only is it devastating for the patients, devastating we have to use some of the community drop-ins but also devastating for the peers that are doing that work, it'd be a massive for them to have to lose their jobs, especially it's just before Christmas, let's face it, that's not great either so, at Capital going forward, if we can go forward, we're a very, very small team and we're small anyway, I mean, I

think people think we're a lot bigger than we are because we do a lot of work and we try to shout out and get our name known in West Sussex and get into as many meetings as we can and really get our voices heard but actually we've always been a small team and we had, I think it's, Duncan will quote me on this if I'm wrong but I think it was 81% in cuts or something but basically means our team's going to be tiny and most of staff will be leaving and most of them are peer support workers.

### **What would you like to say to Commissioners?**

What I would say to commissioners is, do they not understand how shutting things down and I understand, I think we're re-evaluating how mental health works, I kind of understand why we're bringing things down to the ground again but actually to bring things down that are working to then start them again because undoubtedly these things will start again, cost so much more money in the long run, you've got to train new staff, you've got to advertise those jobs, you've got, you know, all the admin that comes with all of that and starting again just seems to me to be costing a lot of money and I think if they actually really valued the things that are going on in the community and we've had some really good quotes from people who have used that service, who've been in hospital that say it's been invaluable to them that I think we've had people, I'm sure we've had people say it saved their lives so, you know, why would we not think that's really important and why would we think, you know, sort of getting rid of that, try and start again in a few years, I see it all the time in mental health, it's actually not very cost effective at all.

### **Why is lived experience important?**

I think lived experience in mental health is absolutely essential, I mean it's what I've helped Capital to produce two reports actually and we were also part of the needs assessment, the West Sussex needs assessment, mental health needs assessment and in all of them people have talked about peer support being the number one thing that they really like, I think to be able to talk to someone who has walked in your shoes, who really understands what it feels like to have mental health issues or drug and alcohol issues, as I was saying I work for drug and alcohol partnership for Capital and it's exactly the same asks, it's we need, we want peer support workers, we want people with lived experience that understand what we've gone through and we're not saying there's anything wrong with learned experience, we really understand that that's a need as well, but it's been a request and I've worked.

Like I said, I've worked in mental health for a long time, it's been a request for a long time, people requested peer support workers as having somebody that really understands them with empathy, they feel they can be much more open, they don't feel as judged, you can't judge if you've been through something yourself, so I think, you know, like I say, it's an ask, people are asking for it, they're saying and it's been going on for years, yet it doesn't seem to be ever the service that people have been asking for and I think it would be cost effective, let's face it, you know, although we're big fans on people getting paid, it's a lot cheaper actually than to run some of the larger services, I think it's a really good intervention as well, we keep talking about interventions, I think if people can attend a peer group, you know, talk to other people with lived experience as well,

you know, that all there is a group and that you're not all offloading it actually and people say this, it stopped them going to A&E, it stopped them going into hospital again, you know, it's just given them enough of a lift to get through the next few days and to know they've got a group or something, a peer-led something going on the next week, so I think they should be invested in and not taken away from it.

### **How is Lived Experience utilised in Coproduction + the Drug & Alcohol Partnership?**

Yes, so currently, as I was saying, I'm working for a drug and alcohol partnership who are West Sussex County Council and Capital's been working, we've been working for them, we've just finished our first year with them and it's really interesting work actually, so what we've been doing is we started off with two reports, so one of them, they were all the lived experience reports, one of them is for people who have used drug and alcohol services in West Sussex and the other one's for people who've lived in temporary accommodation and I think with the two reports combined, we saw sort of well over, I think, 60 people, might be more than that actually, and really talking about their experiences.

Like I say, temporary accommodation and drug and alcohol, so that was really the basis of the work and then from that, we started to what people asked for, which was interesting, it was peer leaders and peer support was one of the things that really came through, so capital, sorry, drug and alcohol partnership then commissioned capital, they gave us an additional £40,000 originally to actually start commissioning some small projects in West Sussex and today we've got nine, which is amazing and that all together, I think, has come in under £65,000 to have those nine supported projects in the community, capital support them and they're really different, they vary so many different things.

We've got two women's well-being groups, one in East Grinstead and one in Worthing, we've got Pot Roast, which is running Turning Tides, so it's making healthy meals with food bank food at Turning Tides and they actually have a drop-in there, we've got one called High On Health and he's working out making healthy mixers, healthy coffees and healthy alternatives to smoking, that's High On Health, so that's sort of actually making products on that one and the same guy, Javel, is also running a project called Guidance versus Grooming and he's working very closely with the police and with the prison services and that's going to be a TikTok series, sort of aimed at younger people that might be going into gangs or getting groomed into gangs, so that's really exciting, we've got so many diverse projects going on.

I can't think of them all off the top of my head, so that's been a really nice part of the project and the other thing we've done, something else that came up out of those two reports again and again, was people wanted to get treated with dignity and respect, so how we've gone about that is we've gone about training the staff in West Sussex, so specifically concerns around housing support staff because we went into temporary accommodations, so that's one thing that we're working on at the moment and we're actually co-producing e-learning for all housing support staff across West Sussex.

So that really feels like we're starting to tackle that and the other thing we're

doing for other staff across West Sussex is specific substance use and trauma-informed training and that's going live at the moment and that's being rolled out to Jobcentre Plus, to the police, probation, social services, that's going far and wide and that training has been received really well and we've actually got the people that helped to co-produce that training also co-facilitating that, they're called RC Expert, so the people that attend the training come and ask them just a little bit about their experience of trauma and substance use from a lived experience perspective, so that's been really good and I've had really good results of that, so we've been doing lots of really good work with the council and we'd really hope to continue with that work, but unfortunately we have very similar circumstances, whereas councils are restructuring everything come March next year, so we're really hoping that work continues, but at the moment we just don't know what's going on with that, but it's been really exciting work and it's great from a personal perspective because I came into capital with my mental health issues.

I've been diagnosed with emotionally unstable personality disorder, but I also have substance use issues, up till 17 years ago I was using crack cocaine and heroin and it got really really bad and out of control and like I said I'm 17 years clean now, but it was really weird actually because just a few weeks before this job came up I was saying how much I'd like to work in drugs and alcohol again, I think the two things really overlap, mental health and we've identified that everybody who's taking drugs and alcohol in those two reports identify with trauma of one way or another, so you know the two things are so interlinked, so it's really nice to be able to bring drugs and alcohol into the conversation as well and the council have been great actually, they've been really good, they've really let us co-produce this whole thing from beginning to end, which is quite rare.

I've worked in co-production for a long time and co-production is very often tokenism, it's just you know using a couple of people or throwing one person in a meeting but not really co-producing it, but this has literally been all the way through co-produce, we'd have an oversight group which involves our commissioners and people with lived experience and the staff team, so that's been really good to steer the whole project from a co-produced you know opinion the whole way through and not just one person's opinion, so it's working really well, so loving that part of the work.