

Peer Support in early intervention services: A Fireside Chat with Jason Grant

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Megan Silvestri (MS): *Wonderful. Thank you everyone so much for joining us today. We're super excited to kick off this first fireside chat with stability leader, Jason Grant. These chats are really an opportunity for stability leaders to share their mental health insights based on their experiences and expertise. And during this first chat, we're really excited to hear from Jason on his insights, being a peer support worker in early intervention services. So Jason will share for about five minutes, and then we will have time for questions and discussion. So without further ado, I'd love to introduce Jason Grant, stability leader from the UK. Take it away, Jason.*

Jason Grant (JG): Okay, thanks, Megan. Firstly, thank everyone. Good morning, good afternoon, good evening, depending on where you are. And thanks, everyone for being here today. It's a really good, it's really good to be with you. And hopefully I'll be able to share some insights and really welcome your questions afterwards, as well. So um, so as Megan said, my name is Jason I kind of brand myself as a lived experience consultant. I'm from West Sussex in the United Kingdom, and usually it's quite sunny. But today, the clouds are over us today. I'm going to be speaking about early intervention in psychosis. So, for those that don't know, about five years ago, I had my first psychotic episode.

I was in hospital for about 10 days, and then I got introduced to the early intervention service. And that was really pivotal in me being able to kind of gain a sense of my own experience, and also getting the help and support I needed to kind of move forward. And luckily, to say five years on, I'm still not been back into hospital, and I'm still able to kind of process and function. And what I try to do mostly is use my experience to help others.

So, what the early intervention service does is a community-based service. And it's for people who are experiencing their first episode of psychosis. So what we aim to do, we aim to kind of provide like a positive first interaction with mental health services. The idea is to reduce symptoms and support people in their recovery. The support is that for three years, as I mentioned, and the idea is to work not only with the person, but also with the person's family as well. And to really enable that person to be in that community is really important. And lastly, it's kind of like based on evidence-based treatments. So ideally, everything that they're giving you would have been kind of evidence based and there's a large body of research behind it. So the team is made up of doctors, nurses, social workers, occupational therapists, psychologists, pharmacists, and now they've introduced in wonderful peer support workers.

The NHS is in a current position where they're trying to utilize more people with lived experience to try and improve outcomes. So I'm kind of part of that vanguard, and I think ultimately, it's about providing an element of hope. And also making sure that I can use my recovery, my resilience and my self-determination to really try and make a difference for people in my local area. So I think that's all for now. As I said, I'm open to questions. I look forward to hearing from you.

MS: *Thank you so much, Jason, for sharing. And before we go into a time of questions, our team has a question for you. Can you tell us a story about someone that you've helped?*

JG: So basically, I've only been in the early interventions for about six weeks now. And so most of our content, we're not doing any face to face contact at the moment. So most of our contact is over the phone, or via video chats like this. And so one of the ways I've been able to help is that actually, because I think the biggest issue that people are facing, whether they've got a mental health condition or not, is that loneliness, and loss of social connection. So actually, I shadowed one of the nurses and they had this person and they weren't really sure what to do with them. So they kind of knew that they were missing their social support, so I said we need to get them into the working together groups.

Luckily, I'm at a very forward-thinking trust. So we have these meetings, a bit like The Stability Network, where, people can come online, they can see other people with lived experience of mental health conditions, and just have this open conversation about where people are at, and everybody offers suggestions about what they could do to kind of alleviate some of their loneliness. So we run these working together groups, and there's about three of these a week, but the funny thing is that the nurses had never heard of these groups. And because I think sometimes when practitioners are working, they're really focused on other things, they're not really focused on the kind of holistic support that people need. Whereas because I've been through the service, I'm able to know what's out there and able to kind of make that suggestion for the person. So yeah, it's every little bit of knowledge and information that we can share is really appreciated.

MS: *Thanks, Jason. So, we do have another question that I think you answered this a little bit in your last answer, but I'll ask this one anyway - how does it benefit someone in mental health crisis to have a peer support advocate?*

JG: Yeah, I think for me, it's about having somebody who can identify and really fully understand and appreciate what you're going through. I didn't want to kind of go into too much detail about psychosis, but it's a very scary experience, it's probably one of the worst experiences I've ever experienced in my entire life. When you're in it, you don't feel that there's a way out of it at all. And when you're interacting with people, like with professionals, it can almost feel like they're telling you what to do, but they're not really understanding what's really going on for you, and how difficult it is for you to just get out of bed in the morning.

So I think having a peer, someone who has actually been through it themselves and has walked that journey, and just to be able to kind of sit with somebody and really listen to what they're going through. And just say there is light at the end of the tunnel that there is hope. I think that's the most vital thing. And one of the things that really encourages me - so I'm involved in a lot of mental health advocacy, and I love joining groups, like The Stability Network, where I can meet other people that are going through similar experiences because, like fundamentally, yeah, mental health is a very lonely journey. So if you meet another person that's gone through a similar situation, it makes you believe that, you know what, it's possible for me to function as well. And it's possible for me to have some sense of life as well. So I think it's vital, the peer support model. We're not judging people or making sure they're

adhering to medication or talking to their counselors. I'm just there to make sure there is someone they can speak to on that personal level, and we can just talk about life in general. I think it's vital to meet people who've gone through similar situations, really, because it's helped me in my life as well.

MS: *So important. Thanks, Jason. Great, we have a couple of questions that have come in. And this next one is also anonymous. Do the main national mental health charities do enough for minority groups in the UK, in your opinion?*

JG: It's a difficult question. So what I should say, is I'm also a researcher and we've been doing this project in Manchester, looking at ethnic inequality and severe mental illness. And we've been running this study for about a year. So this is before COVID and before Black Lives Matter. And actually, we were at that time, we knew that there was a problem in the UK, not just with charities, but with other services as well, like the NHS, where some ethnic minority groups were not getting the same positive outcome as other groups like white British people. And so we identified this as a problem, but I think with COVID, and Black Lives Matter these issues are coming to the floor for everybody to see in its entirety. But I think in the UK, we have a big class problem. And I don't mind talking about class problems. I'm not sure if you have the same class issues in America, but in the UK, how you speak, how you present yourself, you get judged by professionals for not looking or fitting into the right spectrum. And unfortunately, a lot of the people that we're studying in the Manchester study, are people like that have been refugees and asylum seekers. They've left war torn countries, they come to the UK to get refuge, and then they experience racism and discrimination and they're not getting the support they need. And so there is a big problem.

What I would say is that I think some charities do a lot of good work. So I'm involved in something called Time to Change which is a campaign and it is run by Minds and Rethink. I would say that Minds has local and regional charities that really do a lot of good work on the ground. So not just in West Sussex, even in London, so I'm originally from southeast London, as well, where my family are. And my mum has been using mental health services for about 30 years. And actually Minds operates her group as well. So I think some charities do good work, but it's obviously piecemeal. It's like a postcode lottery. So it depends where you are in the country and how active people are. So there is a problem. I think now people are starting to recognize there's a problem. And hopefully people will start addressing what some of these issues are. But yeah, I don't have an answer. As to - yeah, I think some charities are better than others, obviously. But there's always more that can be done.

MS: *Great. Thank you. And this next question somewhat relates to the last one. Have you seen mental health services improve over your lifetime?*

JG: Yes, I mean, where do I start? I will tell you a little story. So as I said, my mother has been living with mental health challenges. She was diagnosed with bipolar when she was 17. She had me when she was 21. So, for my entire life, I've seen my mom go through the system. But even before that, my grandmother had a mental health condition that was undiagnosed. And services didn't pick her up at all. But with my mum, she used to be sectioned and the police would come into our house and take her away to the hospital. So I had a really traumatic upbringing. And in my mind, these mental health services never made my mom better. Whenever she came out of hospital, it was almost like she was

worse than when she went in. So obviously, I had this fear of mental health services. And obviously, unfortunately, for myself, I had my own experience when I was 35. But I was lucky, it was quite late. I already had my own identity before I fell into services. My experience has been absolutely positive. And again, it's a bit more complicated. So, I had my first episode in Brazil, which was horrendous. And a second episode in the Czech Republic, where I was in the psychiatric unit. It was kind of like groundhog day; you wake up, they put you to sleep, you wake up. It's a real mess. So by the time I got into the UK system, actually because I could speak English maybe and because of the way I talk and present myself, I actually got the help and assistance that I needed. I was out of the hospital within ten days and got three years of support from early intervention and that really helped me to grow as an individual and be confident in my own identity and not shy away from speaking about mental health as well.

So, I think services have improved a lot. As I said before, in the NHS, they're employing loads of peer support workers. So I think in our trust, we've got about 37, across the county, and they're always recruiting. So now most of the jobs, they require you to have lived experience in mental health. So that's been really vital. I think services will continue to change. Hopefully, we get to the point where we don't have to be feel ashamed, I guess, or embarrassed or feel that we have something to hide in terms of our mental health experiences.

MS: *This next question, I think you talked a little bit about this in your initial talk. But for those who are not familiar with psychosis, can you talk a little bit more about recognizing what that looks like when someone's having an episode?*

JG: Yeah, my wife would probably be the best judge of this actually. She's like my sense checker; I always think I'm fine. But she's the one that tells me Jason you're off-kilter. I recognize my symptoms mostly with sleep.

That's when I know I'm going to be off kilter, if I'm not sleeping. Another thing is that if I'm not taking care of my hygiene, so if I'm not shaving or washing, and I start feeling like I'm just fed up about life: feeling dejected, not feeling connected to people. I stop talking to people, I stop phoning people, and stop connecting with others. And then it gets a bit more real. So maybe I start hearing things. I'll be walking down the street and think this person is talking to me, and it comes out of nowhere. But luckily, as I said, my first three episodes were really traumatic. I've had a couple of blips, so I've had kind of ups and downs. But usually I notice how to catch it before it gets too severe. So, it's not an easy road to live with these experiences. But as I said, I think once you understand what the signs and symptoms are, you can then mitigate them and do something about it.

MS: *Okay, thank you. Can you walk us through your day and tell us what that looks like?*

JG: I can tell you what I did today. I cycled to work, and I love cycling. That's me time. I get to work in our community, but it's basically an office, it's like a big, big house with different services. But because of COVID, most of the team works remotely. So I go in because I need to get out of my flat. I like going to an office. I turn on my emails, usually I get a few emails from different people.

At 10 am, we have our zoning meeting. So that's where we discuss all of the cases. We discuss any new referrals. For today, we had a referral, quite a sad one, I won't go into too much detail, but they used to work for the NHS, and they had a psychotic episode. So I mean, this is real even for people that work in these services, so we were discussing that case, and then we discuss anybody that's in the hospital, and they have to do assessments. So they have to, and again, this is the most probably the saddest part of the job is they have to assess whether somebody actually had a psychotic episode or not. So sometimes people present with loads of other conditions, like severe depression or a bit of mania, but if it's not psychosis, then we can't take them on board. After that, then they have this traffic light system, where they have people in red and blue and green and then discuss what's going on for these people. And at the end of the talk, we discuss any other business, so that's a really intense hour with the whole team and we do that by skype.

After that, I then have a one to one with one of the nurses and they were just talking me through, their caseload and telling me about different people that are on their caseload and some of the stuff that's going with on them. I was trying to explain to them what I could do to offer help and give some suggestions. In the afternoon, there's a massive network. I'm sure in the US, there must be something similar. In the UK, we have loads of network and all of the early intervention services in the south of England are part of a network. So today we had a lecturer and it was actually a researcher from Australia. She collaborated with researchers from Canada. And they were talking about the impacts of COVID on early intervention in psychosis, because, unfortunately, services are now starting to see a massive uptake in people experiencing first episodes. So that was quite an interesting discussion.

Most of my day is basically spent online. I've been listening to zoom, we're having conversations and chatting away really, but I'm always the person in the office. The receptionist is in there as well. And I have to pick up certain things like today, we had medication dropped into the office as well. And I have to kind of make sure it goes to the right person. So it is quite, it helps me to kind of feel like I'm actually doing something.

Moving forward, it's a bit unfortunate because we thought we were coming out of COVID. And it feels that we're getting back into a second wave. Who knows, because we really need to get back to having groups and activities for people. Because I think fundamentally, even myself, all of my activities or my social wellbeing and things that I used to do they don't exist anymore. And I thought that people on our caseload, they're probably really missing out from that social interaction. So it's about trying to understand how we're going to work digitally, but also have that human element as well. So that's, that's the kind of in a nutshell, and then the cycle home. I live by the sea. So it's a really nice place to live.

MS: *That's great. Thank you. We actually received a couple questions about COVID. So I think I think that answered both of those. But if you have anything to add, someone had asked how has your work changed since COVID? Which I think you answered, but if you want to add any thoughts there?*

JG: Yeah, I suppose the biggest change is that everything is online. And it's funny, because before COVID hit, our trust they were trying to do digital interventions. And everybody was hesitant, everyone was like, no, that's never gonna work. It's never gonna work. And what they found is for those that can

get online, actually, they've had far more interaction. I mentioned the working together groups earlier, they're having more attendance on those working together groups, because everyone could do it from the comfort of their own home. Whereas before, you'd have to physically go to a location. And that used to be a big challenge for people. I suppose I'm conscious of those that can't use online technology, because I know when I was in my episode, I thought my computer was talking to me and all sorts of chaos. So I know for some people is going to be a bit much to actually go online. But for those that can actually use it, there has been an uptake in engagement, which has been surprising.

***MS:** Great, I don't see anything coming in. I think we can all agree this has been really inspiring, really insightful. I just thank you so much, Jason for embarking on this journey with us to share this first fireside chat. And I know there was a lot of unknowns and you just beautifully navigated this whole session. So with that, Jason, do you have any closing thoughts?*

JG: No, just thanks for your attention. It's always weird talking into a laptop. It's nice to know there's people across the ponds that are taking these matters very seriously. And, yeah, it's great to be part of the Network.