

Peer Chat With - Rai Waddingham

Peer support groups

Podcast audio transcript

Intro:

Hi, you're listening to the Making Recovery Real podcast with the Scottish Recovery Network and friends. Stay tuned for insights, ideas and stories to help you make mental health recovery real where you are.

Lesley:

Hello and welcome to something I'm really excited about today. This is our first ever peer chat as part of our new work at Scottish Recovery Network within our peer recovery hub. And I'm really, really pleased today that through the power of technology and time travel I'm welcoming Rai Waddingham. How are you?

Rai:

I'm alright thank you, glad to be here.

Lesley:

Rai is someone who I have been aware of for so many years now and a massive influence on how I think about my own experiences of psychosis and being involved and having a voice. Rai- you've done so much. Rather than me introducing you, do you want to say a little bit

about yourself?

Rai:

I live in Leicestershire in England. I have voices, visions, unusual beliefs and a whole host of stuff that gets diagnosed... well, I've been diagnosed with various things, but most recently schizophrenia-woohoo. I'm part of the international Hearing Voices movement, so I'm Chair of the English Hearing Voices Network and part of Intervoice, this international body. I am an open dialogue practitioner, a trainer and a supervisor. A mum. And also do a PHD, so yeah, kind of busy most of the time.

Lesley:

You sound incredibly busy.

Rai:

My life is this world of mental health that I came into without really meaning to. You know I fell into it when I was about 20 and I kind of never left. What I found is a vocation. If I hadn't entered hospital when I was a teenager, I probably would be in a different world, a different life. I wouldn't go back and change all the crappy stuff that happened, I think just because I'm quite content with where I am now in my life and it feels like I've got a purpose.

Lesley:

Yeah, I think that's something I can relate to as well. When you end up having these experiences at quite a young age, a pivotal age as you enter adulthood. And my pathway was going one way and then I

became unwell and through choices and opportunities, I'm doing what I am today and I can't envisage doing anything else because it feels so good. It has its challenges at times but it's a way to connect with people. Let's talk about peer support groups. What are they? (laughs)

Rai:

That's like the simplest question but also the really hard one too. Like, on the surface of it, it's just a group of people that come together around a particular shared issue. For me, a lot of the peer support groups that I've been involved in and then facilitated are hearing voices ones. So, they're groups for people who have voices, visions, other sensory experiences.

And it's just about coming together, sharing some of what you're going through, supporting each other. And just creating a space where it feels ok to be yourself. There's something really powerful about that for me. There's something around it reducing the isolation and the shame and this sense that there's something deeply wrong with me. I'm not worthy to be around other people.

It's something around building up knowledge, it's a bit subversive really. We're in this field where professional and academic knowledge is the big, they take up a lot of space. And they've got their value, but many of us have had our experiences overwritten, obscured, reframed, interpreted in ways that don't feel so comfortable. And peer support groups allow us to kind of find our own stories, re-find our own stories and connect with that and build up our own knowledge, separate in many ways to the professionalised knowledge.

And a place of empowerment, I guess. It's where I learned that I had something to offer.

Lesley:

That's important, isn't it, because when you get into that situation where you feel that you don't have much of a say, or things feel outside of your control, both internally and externally people are making choices for you. To begin to get that back again is quite liberating.

Rai:

Usually, and I think when I entered the peer support groups and hearing voices groups many years ago. I'm not saying how many, but more than a few, I didn't even feel human. I didn't feel that I belonged in the world. And it was through connecting with others that heard voices and recognising their awesomeness and their diversity, it allowed me to allow people to connect with me. And that's how I started to feel part of the world again.

Individual peer support can do that I think, but when you've got somebody opposite you, even if they have shared experiences, it's easy to see them as better than you, like more advanced, more sorted. Peer support groups, I think it's easier for it to feel a bit more horizontal, like the people in the group are in a similar place. And it overturns that kind of hierarchy that's there all the time I think if we have a paid role.

Lesley:

Yeah, that's a really interesting way to think about it as well because I remember, probably the first peer support group that I went to was a

hearing voices group and though I'd met people in hospital who had similar experiences, I think just because of the place we were in at the time, it felt - yeah, we were there for each other, we could support each other. There was a real connection there and a real solidarity around - I'm here for you. There was something about being in the group, because we were outside of hospital we were slightly more together within ourselves to be able to just be open and discuss things and feel safe to do so and feel that was safe to do so and that you weren't going to be rushed back to hospital. I'd hear other people talk and think, gosh, I hadn't thought about it that way. That's really insightful. I wonder if I could try that, I wonder if I could think about it that way.

Rai:

That's a huge thing, because I probably spent about 8 months in hospital before I was discharged, and then went eventually to a hearing voices group. But in hospital, I did not want to hear about coping strategies. I did not want to do the mindfulness, you know, I just wanted to get rid of my voices. But it was in the peer support group that I started to learn strategies because I heard other people talking about them and it wasn't like they were being forced on me. It was like there was a buffet. I could maybe pick something out of the buffet if I fancied it. But I didn't have to.

Lesley:

You said there was a bit of time before you went to your first group. What persuaded you to go, or what got you across the door?

Raj:

The first time I saw the leaflet, I was like, no. Why would I want to go and talk about my voices? I've been spending years in hospital trying to get rid of them. And I had no conception that talking to other people who went through it would be useful. I was set up to expect the doctors and the nurses would be the ones with the expertise. I think it was desperation.

One thing that helped was reading a book about someone else's experiences: *Phone At 9 Just To Say You're Alive*. Which was someone local to me, Linda Hart. And it was mad, that I'd spent ages in hospital but not really heard about other's experiences and not really talked about my own that much. And then I was reading this book about someone from my local area and just drank her experiences and some of them were really different to mine but there was this sense of connection still, like I could recognise bits of it. And then I think it was my third or fourth hospitalisation, aliens were talking to me, I was completely overwhelmed and figured that I wouldn't survive if I kept going through this cycle of admissions. So I thought, I've got to give it a go.

I didn't have high hopes for it. But the funny thing was, when I left that group, I felt massively elated. It wasn't the best group in the world. It was good, but I was only in my early twenties and everyone else was like 35 plus, 40 plus, which now doesn't feel so old. But back then it was a huge difference, they weren't my peers in terms of age or where I was in my life. But I recognised so much of what they said and I felt like for

the first time I'm not on my own. That maybe there's a place I can talk. I didn't talk much back then. But it was like a possibility.

Lesley:

That sense of just, maybe.

Rai:

That bit of fire I think got ignited, the first time I heard someone talk about their experience on a stage, I was like, wow- all these doctors and nurses are listening to lived experience. Maybe I could do that. And then I was like, no, it's not going to work. But then just little sparks.

Lesley:

Slowly beginning to step outside of yourself and step into what else is out there and take your path, cautiously. You've been really quite instrumental in Mind in Camden.

Rai:

So after a little time of going to it, I began to co-facilitate the group. Mainly because we were offered 20 quid a session for anyone that would co-facilitate. So we all put our hands up. No idea what I was doing, but I had some experience there. I went off and became a musician for a few years and then saw this amazing job advertised at Mind in Camden managing the London Hearing Voices Project, that Jacqui Dillon had set up, who was chair of the national network at the time. And its main role was to recruit new facilitators, support groups to set up, support the existing facilitators. So I got to do training for the

facilitators, I got to develop a peer support network. We started off with adults but then developed a programme with children and young people, and then going into prisons and forensic units.

I learned the most about facilitating through that project, because when you're trying to explain it to other and help others get into it, it really questioned a lot of what I thought I was doing as a facilitator and started to really clarify it for me

Lesley:

A lot of people that I've spoken to and we as an organisation have spoken to, but also for myself, it was just that initial thing of- do I want to do this? - and there was part of me saying, yes and at the same time, I'm too scared, I don't want to muck it up, I don't feel confident, blah blah. So it was almost like I was putting myself off. And it was only once I started to do things I found that I was able to do it. But I would have really benefited from some ways to help me to think about what I was doing and why I was doing it. But I was interested when you said part of it was learning by doing as well.

Rai:

Now I cringe a little bit when I look back on my early facilitation. Just thinking that I had this idea that I needed to understand other people's voices, that I needed to do something, whereas the more I've been in facilitation, the more I've realised that it's trying to hold a space. I think I started off more as a leader and I've had to really step back over the years.

I use my lived experience whenever I work, in facilitation or not, it's part of who I am and where I've come from. How do I want to use that in a group? Why am I even in the group? Could the group just be there without me? Possibly. I have a use in that I'm a steady point in the group, someone who, with my co-facilitator will be there most weeks. It's partly about just setting a tone that it's ok to be a bit vulnerable and it's ok not to know stuff.

My style as a facilitator is to speak about what's going on in my head. So if I'm worried that I'm being a bit too forward, saying too much, I might say- you know what, I'm hearing my voice here and I feel like I'm taking up a lot of space. I'm just going to step back. You know, it's showing that it's ok to not get things right as well. When a group is working really well as a peer support group, other people are providing support to each other and you are less central. That's always what I want to aim towards.

If I'm working for an organisation I've got some quite specific extra roles like, I'm ultimately responsible for what people end up calling safeguarding. Making sure the room is booked, the practical things that I might have a particular role in. That doesn't mean I have to do everything. I can delegate or we can kind of come at it together, I just have the ultimate responsibility.

Lesley:

I remember doing that with one group as well. Together we worked out who was going to do what and alternated things between weeks, so it felt like a lot of the responsibility for the practical side of the group was

shared. So somebody would take on responsibility for bringing the tea and coffee, somebody for the milk and somebody for the biscuits. There's something about tea and a biscuit that just makes things happen. You know, these things help oil the wheels, I would say, of a good group.

Rai:

They're informal spaces so often halfway through, or at the beginning or the end we'll have a break so people can just chill. For someone like me who gets really socially anxious, those bits are really challenging, because I think, do I talk to people, do I not? But for other people, to talk about your favourite biscuit is a lot easier than talking about hearing voices, to start with.

Lesley:

Some people when I've been training in peer support groups, people go- what if people go off topic and don't talk about the voices and don't talk about the subject of the peer support group. And my vibe generally is, I don't think anything is off topic. If nobody has talked about voices for the entire group, or visions or anything in that ballpark, I might flag it. I'll say- we haven't talked about this yet, we might not want to and that's fine, but just naming it. Then people can choose to carry on or not.

Rai:

Often when people came on the facilitation training they were craving a map, a guide. How on earth do I do this facilitation thing, step by step. If x happens, what do I do? The challenge for people on the training

that I was running was that we started from the values, what is this thing called peer support? Some of the values of the hearing voices movement, that there's no one way of understanding voices and that everyone has a right to their own beliefs and all these core values, that we spent quite a lot of time on, with the belief that if we hold these values in mind, it then becomes easier to think about how would I deal with x or y situation.

That was so frustrating for people but I still think it's the most helpful way of teaching facilitation, because if we respect a plurality of explanations, if someone comes to a group and believes very strongly, for example that they have schizophrenia and that medication is the way forward and that other people should take medication and someone else comes believing that their voices are spirit and feels very strongly and thinks everyone else's voices are spirits, we can respect each other's beliefs, which is a very important part of the group, but we can't talk for everyone else in the group.

So it gives us an understanding that we don't have to agree with one over the other, even if we might agree with spiritual or schizophrenia beliefs. Our job is to respect each person's views but also set a limit for talking about others. And this idea that there might be some other views in the group and that's really important too. And so the values then lead, how do we facilitate in this really respectful way.

The other thing that I found really useful is the importance of being an imperfect facilitator.

Lesley:

Ooh, tell me more.

Rai:

If you are the best facilitator in the world. I've met some of them who are just fantastic. It's brilliant, but no one else in the group will necessarily feel able to take over your role and have more power and agency in the group, because you've got it - sorted, you're amazing. And so, in my view at least, being slightly imperfect, messing up occasionally, apologising, being very human, leaves space for group members to take on more responsibilities too to help you out. It's less of a gap, it kind of brings you together a bit. You don't have to have it all sorted. You're there for the group but you can be humble.

Lesley:

It helps you connect much more with people when you are yourself. Being able to own it and say, that wasn't so great, ok, that's fine. It allows people to feel that they can also try things and they're not going to be held up to such high standards.

Rai:

There's that sense that the group can help you. The longer I've been doing this, the more I've been really encouraging people to take it to the group. So go - ok, I think this was a really tricky week last week, how was it for you guys? What could we all do differently? What might make this work?

Group members have so much resources and ideas and wisdom that they can bring to a situation. And if we, as facilitators are thinking it's all on us, we're kind of doing them a dis-service. And putting ourselves under incredible pressure.

Lesley:

It then helps me to connect to people outside, in my wider life and build better connections with people than I may have had previously because I would have run away at the first hint of conflict. Whereas now it's just like, ok, maybe think about how we could do this.

Lesley:

Is there anything else that you would like to share, just as a closer?

Rai:

If people are listening to this and they're moderately terrified of groups. I am terrified of groups. They are the site of a lot of my trauma, my bullying, various things I've been through in my life and yet I keep coming back to creating peer support groups, they're such a big part of my life.

Groups have challenges and there can be really big things happen in them. But actually most groups are full of people that really really want the space to be ok and there's something appealing about being part of these groups and seeing that people are generally awesome. And I hope that maybe some of the people that are listening are tempted to give it a go.

Lesley:

Brilliant, thank you so much for this today Rai. I hope people in Scotland and elsewhere who are listening to this have found it really helpful and if you're thinking about getting more involved in a peer support group- give it a go.

So Rai, if anybody wanted to find out more about you, where could they find you?

Rai:

They could find the Hearing Voices Network in England at www.hearing-voices.org or my own website which is www.behindthelabel.co.uk

Lesley:

Fabulous. Thank you so much for today and hopefully we'll speak again soon

Rai:

I hope so.

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