

Peer Chat With Rai Waddingham

Peer support groups

Film transcript

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 I'm welcoming Rai Waddingham to us in Scotland, so Rai, welcome. How are you?

Rai:

I'm alright thank you, glad to be here having a chat with you.

Lesley:

I'm so pleased that you could join us. For everybody who's listening today, 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:

Yeah, that's probably easier, isn't it? 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. But I guess 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.

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. So today we're going to have a focus on peer support groups, are you up for having a chat about peer support groups?

Rai:

Definitely.

Lesley:

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 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 takes 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 comfortable. And peer support groups allow us to kind of find our own stories and connect with that and build up our own knowledge, separate in many ways to the professional knowledge.

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

Lesley:

That's important, because when you get into that situation where you feel that you don't have much to 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 other 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 more horizontal, like the people in the group are in a similar place. And it overturns that 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, 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 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, 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:

If you're feeling that you have to do something because it's advocated or prescribed, whereas if it's something that's offered and you have a choice and other people are talking about how it works for them or not.

It's really quite interesting how the dynamics play out in that. I think I was someone who always rebelled a little bit.

Rai:

Which I very much admire. I think I was a bit rebellious and compliant at the same time. On the surface of it I was very nice, but I didn't buy into it, I guess. I just didn't feel like it would work for me.

Lesley:

What persuaded you to go? What do you across the door?

Rai:

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 others' 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. 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 Network. And its main role was to help the facilitators do the groups. So, 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 was there for about seven years and it started off as this quite bounded project and then we just kind of, expanded and ran with it.

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, much more than when I was actually facilitating the group originally. And I think, often when I was facilitating initially I didn't have time to think about why I was doing this so I

followed models that I had. We had a clinical psychologist in the group who was a great facilitator, so I kind of modelled myself on him. Which is great, but 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.

Lesley:

You mentioned knowing what your "why" was

Rai:

Yes. Thinking about my role as a facilitator, 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. So the why is that I'm there to help the group and be useful to the group, but not to grab the group by the scruff of the neck and pull it in a certain direction.

Lesley:

Creating that space for people and welcoming them into that space and saying, this is a safe space to be. And it's ok to share and be a bit vulnerable.

Rai:

And process. A lot of 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. And thinking about how people connect with each other, because it's easy as a facilitator for everyone to connect with you and you become this central hub. 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. 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:

Yes, I can go along with that one. That's my experience, I'll talk about anything else but that. In time, that changed and it felt such a relief to be able to talk about things that were going on for me, the voices I heard. And not feel that I was raising a warning bell or anything, it was just I wanted to explore what this is and what it means to me.

Rai:

That's the key, that it can change over time, because 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 like that, 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.

Lesley:

That's a good point

Rai:

So it doesn't become taboo to talk about the tricky issues but also that it's really important to get to know each other and these are big parts of our lives.

Lesley:

Thanks for that.

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 you'd 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, 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.

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

Lesley:

Ooh, tell me more

Rai:

This helps me and sometimes helps others. So 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. Just knowing that it's ok to be yourself as a facilitator, you don't have to have it all sorted. You're there for the group but you can be humble.

Lesley:

I'm nodding my head because I can relate to that. I tried to be this perfect facilitator, whether it was with a group or training, I was aiming to be perfect. And then I realised I was never going to get there. It was always, there was something else to reach for, and then something else. And really, what was wrong with being myself. And as you say, 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, so with my co-facilitator, in the early days we would spend a lot of time thinking about- what do we need to do help this group work better. You know, something's gone one in the group, we spend a lot of time thinking about it. 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 do differently? What might make this work?

And actually that's just so profound, because group members have so many 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.

Lesley:

That's a really good point, you're putting yourself under that pressure, but the power and the knowledge of that group, bring it back. Problem solve it together. Is there anything else that you would like to share, just as a closer?

Rai:

I think that 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. And I think some days, groups have challenges and there can be really big things happen in them. But actually most groups, are full of people that 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. If I can let my own worried down long enough to just be there, people are kind of awesome. And I hope that maybe some of the people that are listening are tempted to give it a go. Have a think about setting something up.

Lesley:

Brilliant, thank you so much. I think you were the person who got me to, well you didn't get me to, but I heard you talk about people being awesome and it really made me think about how I relate to people and I thought, let's see people's awesome-ness. So, thank you so much for 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.

Transcript ends.

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