

Transcript

Matters of Engagement podcast

Episode: "Engagement in Context: Reflections from Jenn Broad and Paula Tookey of the South Riverdale Community Health Centre"

<https://mattersofengagement.com>

SPEAKERS

Jennifer Johannesen, Emily Nicholas Angl, Jenn Broad, Paula Tookey

Jennifer 00:07

Hello, and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement and partnership. I'm Jennifer Johannesen.

Emily 00:16

And I'm Emily Nicholas Angl.

Jennifer 00:21

Most of our episodes have been about engagement in institutional healthcare spaces - places like hospitals or research institutes. But of course, there are a multitude of other places where patient or service user engagement takes place.

Emily 00:35

At some level, many engagement issues are the same everywhere. Regardless of the location, there's always going to be tensions related to interpersonal dynamics, power relations, questions of representation and diversity, whether there's compensation and how new people are recruited... the list goes on.

Jennifer 00:55

But depending on the context, engagement may also look and feel quite a bit different. And our featured discussion in this episode helps to illustrate this point. Our guests are Jenn Broad and Paula Tookey. They work out of the South Riverdale Community Health Centre in East Toronto. Jenn is the Program Manager of Harm Reduction and Hep C. And Paula is the Manager of Keep Six, a consumption and treatment service, which is a health service described as a place where people inject, snort, or orally consume pre-obtained drugs in a safe, hygienic and welcoming environment under the supervision of trained staff. I've known both Jenn and Paula for several years, and when we decided to do an episode or two on peer worker experiences, I knew they'd have lots to share.

Emily 01:41

And just to be clear, this episode is not about peer work, per se. After we interviewed Lori Ross in our last episode about her work on peer researchers, well, we wanted to hear from people with peer work experience - from their own perspectives. We usually reserved this space for what we call Patient Partner Reflections - and even though they're not "patient partners", we're turning it over to Jenn and Paula for their insights and reflections on their experiences with peer work. They're well positioned to do so as researchers as well. They co-

authored a really interesting paper - actually more like a case study - with three other colleagues, about the transition from client to peer worker. We'll put a link in the show notes.

Jennifer 02:27

As you listen, we encourage you to tune in to their insights specific to engagement within a community that experiences persistent stigma and systemic discrimination. What we learned from talking to Jenn and Paula is that engagement in certain health related community services, like harm reduction programs, has different and possibly higher stakes for the people involved than what we typically think of as "patient engagement", in mainstream or organizational health services.

Emily 02:56

And one more quick note - it's that peer work can sometimes be idealized and can be framed as a recovery or redemption narrative. We're not getting into any of that in this episode., but we wanted to mention it because Jenn's journey from service user to peer worker, to now Program Manager - it's really compelling. But we're not trying to hold it up as a model for what peer work is supposed to be or look like. And we don't get the sense that Jenn is either. It's just, well, it's her actual experience - which gives important context to her insights.

Jennifer 03:32

Okay, here's our discussion. The first voice you'll hear is Jenn, followed closely by Paula.

Jenn B 03:40

I actually met Paula when I first came to the Toronto Community Hep C Program, as a client. Through various opportunities and trainings, I was eventually hired as a community support worker. And in that role, Paula was the.... she wasn't.... she hates it when I say she was my boss! But really, she was.

Paula T 04:05

Yeah, we, you know, we met initially, as a worker-client relationship, and then to the various opportunities through the Hep-C program, whether it was the advisory peer training, public speaking, you know, various projects... Jenn always was interested in participating and took on things more and more. So when I left my position at the Hep-C program and took on the managerial role, Jenn actually got hired to replace me in the program. So then Jenn took on the responsibility of supporting and mentoring the other Hep-C community workers who were again, recruited from clientele from the clients of the program, who also went through the various opportunities and kind of built their skills to be able to do the work.

Jenn B 05:00

I worked as a registered nurse for a number of years, both here in Canada and in the States. But I also have the lived experience of drug use, adversity, trauma, all of those things. I think one thing that South Riverdale does really well is it tries to create opportunities for people who do have the lived experience, because that's very valuable. There's just things that can't be taught in school. They put quite a heavy weight on lived experience. But of course, there are other things that you have to be able to do and navigate and manage, right? Particularly as you start going up the ladder as I have, to have to be able to navigate certain social systems. So actually have for me having that education was really helpful.

Jenn B 05:53

I kind of know what's expected, right? Like, I know I have to call into work when I'm not gonna be there. I have to navigate different programs on computers. And I have to print stuff up. And just, you know, those things. But those were all things that actually can be taught.

Jenn B 06:15

Everybody has some lived experience. I think that's actually true of the public at large, right. You know, the public at large has had trauma and traumatizing things happen to them. The public at large, you know, whether they care to admit it, has probably also dabbled in drug use. We don't consider anything that we take to try and alter our mentation, or to make us feel better, is drug use. And it's no different. It's just, I think, the differences in how we tend to vilify those that don't handle the coping mechanism, if you will, as well as others. And then we also tend to vilify people who live in poverty. There's a lot of intersectionality and complicating factors, but I think they're all there.

Jenn B 07:25

It's interesting, because it's something that I've kind of been struggling with around.... I think, for sure, my lived experience makes me who I am. I fear.... and, I mean, when we start talking about stigma and discrimination.... I have all those things in my lived experience that are very stigmatizing and discriminatory. And there's a certain... when you disclose, as part of your story, you're hoping that the person or the people or the group that you're disclosing to, is not going to be stigmatizing and discriminatory towards you. Particularly as I've moved up, I feel less and less inclined to want to do that, because I'm afraid I'm not going to be taken seriously. And I don't want it to define who I am. It's only a small part of me. It certainly has a huge impact on how I can do the work and also has a huge impact on how I can relate to others who are also involved in this work, who had the same kind of experiences that I have. But I sometimes worry about a manager from an outside agency, maybe not taking me as seriously.

Paula T 08:59

We shouldn't be putting limitations on people just because where they come from, and give opportunities and see who has the interest and the ability with support and mentorship to take on challenges. And, you know, what to do with that. But the credit really goes always to the individual who takes that on because like Jenn said, I mean, it's never a condition of the employment or the opportunity that we gave that you have to do it [disclose your experience] and I have not really experienced, you know, people kind of constantly going back to where actually people came from. Yeah, like I said, I think that would be inappropriate.

Jenn B 09:42

You know, interestingly enough, when I applied for this job, that posting went up three times. The first time I was like... you know... and a couple people said oh, you should go apply. And I'm like, yeah, no, they're not gonna hire me. And then the second time was like, nah, I don't think so. And the third time I was like, maybe somebody is trying to tell me something, you know? So then I did apply. And well, as it turns out, here I am! And I will say at South Riverdale, I really had a Sally Field moment, you know? Where she's like you like me! You really really like me! I can't even tell you - I can't understate that feeling that I had. Because everybody seemed

to be in my corner. I didn't hear scuttlebutt, like, oh, who does she think she is? Everybody was really, really supportive. And not just people who had at one time been my peers, but also upper management and senior management.

Jenn B 11:03

It hasn't happened at South Riverdale... but I do sometimes think there's a bit of tokenism. Particularly like, Oh, we're putting on a conference or we're putting on a presentation, we really need to have a personal lived experience, and we're going to have them tell their story... I think the thing that we have to be mindful of, in that we have to remember, is there has to be a purpose to the story. You know, it's not just telling a story for the sake of telling the story. Right? And I think that does happen sometimes. You know? And then people (not South Riverdale) but then people sort of pat themselves on my back and like, we involved [trails off]. So I think that also can be traumatizing. Like what is the point, sometimes, of what we're asking people to do? And I think we have to be really thoughtful and mindful about that.

Paula T 12:09

I always felt that it was our responsibility as people who engage with other people, especially people who have less access to information and understanding of how these engagements work - I think it's our responsibility when asking someone to come and speak to something, to also support them and educate them that they don't have to. They don't have to do it at all. They don't have to disclose anything that they don't want to disclose. Sometimes I kind of have a feeling that when people come from really disadvantaged places and they haven't been communicated their value and they don't feel that they have value - when they're asked to do something like that, suddenly their experience becomes their currency. And they might feel that they have to share all the really awful things that happened to them despite how really traumatizing it can be.

Paula T 13:13

And so, anytime I was asked as a worker to see whether any service users or clients are interested to participate in a forum where they will be talking about some experiences from their life, it was kind of important for me to talk about also the cost of that or the unintended consequences of sharing yourself in a way that actually, at the end, does not feel okay. I also like to remind people that information can be used as a weapon. And even though if the initial intention seems positive and you know, we kind of feel that we can contribute to some kind of greater good by understanding or you know, how helping the understanding or education of others... it is not worth it at the cost of somebody walking away feeling worse than they came to it, and feeling violated. And so, I think that is a very important piece.

Jenn B 14:19

I remember being at a conference, and I came up.... somewhere on some video that I said it... and there I was larger than life - just 'boom' - and saying something about drug use, I can't remember exactly what it was.... And feeling kind of like, oh, I don't want that up there. I myself have been stigmatized and discriminated against. Despite how far up the ladder I go, I think sometimes I worry that I'm still... despite, like, you know, having gone through that, and not risen above it but found a way to be positive and to be an agent for change... I still worry sometimes, because not everybody is understanding. And also part of that is my own sort of my own self reflection and my own sometimes self doubt around whether I deserve to be in this position. And so I feel like if I

were to talk about it now, it's not that I would.... I would maybe say it a little bit differently. So it's not quite so glaring. It felt very glaring in the moment.

Jenn B 15:43

You know, it wasn't like I was like, Okay, well, this is where I want to end up. So it didn't occur to me in that moment to censor how I talk, or what I say. And that's not the case today. You know, I'm still very open, but I still am a little bit more cognizant of what it is I'm saying and how that might come across. It's finding that balance between what I'm doing now, my lived experience, and being okay with where I've been. And where I am. That's also a part of that.

Paula T 16:29

This has become increasingly sort of more important to keep in mind because more events are recorded. It also is more public than it used to be. You know, when we say something and it gets posted on YouTube, then we totally lose control over who is viewing it. What context they see it? And do they see the context that this has been, you know, set in. I think that also plays a role for me anyway - that it's less anonymous, it is more public. So you know, we participate in forums that are more public and more accessible to people who might be seeing it or hearing it out of context - this also needs to be considered.

Jenn B 17:20

I think there are a lot of places that hire peers, or people with lived experience, or, you know, who identify in that way. Not everybody does it well. In fact, there are remarkable many that don't do it well. Now, I don't think that that's their intent. It is a lot of work. You know, it's not just enough to hire somebody with lived experience, tight? There's a lot... there's a lot that goes in behind it.

Paula T 17:51

Oh, yeah. And there's a lot that goes or should go behind it before you actually hire somebody with lived experience. And I think that's something that doesn't always happen. Well, you know, hopefully, you can create a small community of peers of their own where that's a learning place where people don't feel stigmatized and shamed and discriminated because of the experiences that they have. And as a matter of fact, kind of flipping it upside down: it is the experiences that people have that is the strength. Why we are interested in engaging with them is for them to be able to teach us and bring their experiences as a skill - or how to turn that experience into a skill.

Jenn B 18:45

If I take a look at my journey from when I, say, first met Paula, to where I am now... if I actually correlate that to my drug use, my financial situation... my housing situation absolutely improved. From being marginally housed to, at times, homeless. To like, actually, in my own place. And if I take a look at my drug use that has actually through all these opportunities - that has actually decreased too. In not only how often I but how I use drugs - like, not being as street- involved. That changed as more opportunities came my way. So I may have still used drugs - but the way in which I used was very different. And to the point now where I don't use drugs because, well, frankly, I don't have any space for it. There's no room for it. I'm in a place now where I'm like, I want to stay here. And if I want to stay here, I just can't use drugs. That's a personal decision that I've made for myself.

Paula T 20:10

I think there is actually a big difference between the kind of patient advisory board from the Hep C program, and the kind of advisory board that a hospital would have. All the members... all the members were the clients. And the Chair is the client as well - is a board member who is a client. So this is not a mixed board. This is not a board where you have like a representation of various, you know, capacities, roles, and then a couple of patients.

Paula T 20:52

I used to attend meetings that were like that, and I was kind of the frontline community rep. And I was the token frontline worker. And I did not feel that I was empowered or supportive to actually add to the experience as I had it as a frontline worker, bringing some of the concerns and challenges experienced by myself, as somebody who's trying to provide services and link people to resources - I did not have a voice. I did not have a voice. I did not feel that even if I brought myself to speak, I didn't feel that what I said was reflected or even understood. And so I think there is a big difference between spaces where people come together who have joint experience and a joint goal, and are facilitated by somebody who doesn't necessarily have an agenda of what the conversation is and what the outcome of the conversation is - as opposed to being able to tick off a box that they had a representation of the people who the conversation is about. But really how meaningful that representation is, is never spelled out.

Jenn B 22:17

I was actually on something - not that long ago, within the last couple of years - where I felt very much the same way that the language that was used I wasn't understanding, the processes that were being used I didn't understand. I didn't really feel like I was there for any real reason. Everybody wants to talk about how they have... they get input from various ways, but I often sometimes wonder if there isn't an ulterior motive or an agenda that's already like sort of set and being pushed forward. And that is actually to the detriment to the spirit of what these boards advisory committees should and need to be. And I don't know whether it's bringing together a group of people with the same sort of background? That then can...[trails off] So you know, you put doctors and researchers and finance people on a board with someone with lived experience - or someone who's identifying to the experience, not to their job...? It's very intimidating. It's incredibly intimidating. And I actually don't think, yeah, as I said, I don't think it's actually to the spirit of what that work is supposed to be about.

Jenn B 23:55

And so I think it's incumbent upon agencies that have these kinds of committees, that they really look at what the makeup is of those committees. And I also see that, oftentimes, it's the same people being on these committees, and they're pushing their own agendas, and they're being identified as "community" - but I don't really feel like they are, to be perfectly honest.

Jenn B 24:26

If you're on one of our boards, first of all, I think you have to be a user of that program. So I think that's first and foremost. And we want people to actually be meaningfully involved. So the request isn't just, you know, come to this board meeting and have a light lunch and a meal and we'll give you two tokens and \$20 and see you later. No, we actually want them to do some work. So we actually want people's input on program development and

program implementation and evaluation and we want to hear their ideas. No matter how strange they might be. And we view it as: there's no agenda for us. It's going to be in where they take it, where they lead it. But there is work to be done.

Jenn B 25:23

I just want to say one thing that keeps going through my mind. I do think that people in a hospital may have a different view of what needs to happen to improve services, then say, people who have actually used the service of the hospital. And that may look very different. But both are equally important. I think what happens sometimes is that they don't... they haven't learned how to put those two together. And merge. Like they're equally valuable, but different. One doesn't come at the expense of the other.

Emily 26:12

Thanks to Jenn Broad and Paula Tookey of the South Riverdale Community Health Centre for participating in this episode. If you have any questions or comments, please get in touch at mattersofengagement.com. And don't forget, we now have a listener phone line!

Jennifer 26:32

The number is 647-812-2909.

Emily 26:38

See the contact page for details.

Jennifer 26:42

This episode was written and produced by Jennifer Johannesen and Emily Nicholas Angl, with generous financial contribution from the Ontario SPOR SUPPORT Unit, or OSSU, which is jointly funded by the Government of Ontario and the Canadian Institutes of Health Research, or CIHR. The views and opinions expressed in this episode belong solely to the producers or their guests and are not to be considered endorsed by OSSU, the Government of Ontario or CIHR.