

Transcript

Matters of Engagement podcast

Episode: "Walking a Tightrope: Inside the Engagement Professional Role, with Kelli Dilworth"

<https://mattersofengagement.com>

Jennifer 00:00

Hello Jennifer here... just wanted to pop in and let you know about another collaboration between ourselves, Matters of Engagement, and SPORcast and PEP Talks. Together, we'll be hosting an interactive, one-and-a-half hour live panel discussion on Tuesday, February 2. You can join us, Jennifer and Emily, along with Bev Pomeroy, Paul Fairie and Sandra Zelinsky, for this interactive session, where we'll all be sharing our experiences with podcasting and inviting audience questions, comments and ideas. So please check Twitter, our website (mattersofengagement.com) or just look in the show notes for a link where you can sign up for this free event. Hope to see you then!

Jennifer 00:45

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

Emily 00:53

And I'm Emily Nicholas Angl.

Jennifer 00:58

Well, we did it! Here we are at our last episode of Season Two. We've been poking and prodding at patient engagement and partnership for a few months now. And while, of course, not everyone will agree with our takes on things, we do know we've struck a chord with listeners who have been looking for platforms and spaces to have these kinds of conversations. And since it's not likely we'll be gathering at conferences again anytime soon, we're hoping this podcast provides an opportunity for listeners to think along with us, through some of the thornier issues. I'm pleased with how things are going and I think we're finding our groove. But something I'd like to consider for next season, or whatever the next phase of this podcast is, is to figure out a way to more easily connect with listeners to get feedback on our work, but also to understand how they're processing some of the topics.

Emily 01:50

Yeah, podcasting is a great medium for bringing voices, literally, to a potentially unlimited audience. But you're right. Even though we get feedback and comments through email and Twitter, I'd also like to explore how we can foster a bit more interaction with listeners. Could be through occasional Zoom chats maybe, or maybe a voicemail line. Anyway, something to keep exploring.

Jennifer 02:14

Yep, so, on that point of striking a chord with listeners... our guest is someone who has listened intently to each episode, and she reached out to us - not to appear on an episode - I think she was a bit surprised when we asked! - but rather to let us know that the things we talked about really resonate with her. Kelli works in the child and youth mental health sector. And she talks about the tightrope she walks between the organization and the people she's engaging. Her role is complex and multifaceted. And, as she told us, our podcast give voice to some of what she experiences and thinks about.

Emily 02:53

Kelli Dilworth works at the Ontario Center of Excellence for Child and Youth Mental Health, an organization that supports the child and youth mental health sector through a number of initiatives and services. Their approach to developing and delivering that support is done in active collaboration with young people and their families. In healthcare spaces, we often see engagement practice as something separate, maybe adjacent, to everyday operations. But here, youth and family involvement is deeply embedded. Kelli's title is Knowledge Broker. She's responsible for supporting agencies and their engagement efforts, and implementing quality standards for youth and family engagement.

Jennifer 03:35

So just one more thing to say for a bit of context. We actually spoke with Kelli a few times and thought we were headed in a totally different direction. We knew that youth engagement was potentially something to look more into. And that there was also a lot we could learn from engagement practice in the mental health space. But as we got into the discussions, it became apparent that maybe there was a different but equally important story to tell. So we've put aside the ins and outs of Kelli's job per se, and instead wanted to share her reflections and insights about her role - the rewards and frustrations that come with both her official responsibilities and the personal obligations and commitments she feels to the young people that she works with. It really is a tightrope and Kelli's honesty and openness help us get a better understanding. Here's Kelli:

Kelli Dilworth 04:29

The people who don't do engagement work maybe don't have a great appreciation of the amount of relationship building that is key to the success in the process. I know, you know, when you're talking to organizations who really support engagement work, but also have needs to get things done, you know, in a certain way in a certain time frame - that relationship piece is hard to explain as a staff person. So I think people in this role struggle with this too. So how much time do you spend doing "get to know you" pieces and icebreakers or things like that, to make people feel comfortable - because those are important and their skills - but how much of that do you balance with not wanting to also make it too fluffy or too outside of what people are actually there for? This is kind of that tightrope piece that I think you've also heard me talk about. It's balancing between these two worlds one where you're trying to get people to be themselves and to speak openly, but you're also trying to steer a conversation to make sure you meet the needs of why you brought people together. And it's sometimes a tough place to be.

Jennifer 05:48

This tightrope analogy is really apt, and it runs so deep and multiple layers. Now, Kelli just spoke about the more visible tension of building trust, as part of trying to get things done on behalf of your employer. But she also

talks about walking her own internal tightrope. She has a particular expertise and training, which is important and useful. But she also has to really listen and think on the fly and meet people where they're at. And it means she sometimes comes up against systemic restrictions and inflexibility. When that happens, she feels the weight of having to navigate what are sometimes conflicting interests.

Kelli Dilworth 06:32

I've been in this particular role for only about four or five years, but previous to that I've done a lot of different work in engagement spaces. And I think that's part of the tricky piece of this role is you need to have an understanding of process, of things like implementation science, evaluation, performance measurement, all of the pieces that support an organizational structure or a system structure. But then you also have to be fluid enough - fluid's not the right word - but you'll have to be able to pivot enough to know that, you know, within these processes are people with lived and living experience, who are there because they want their voices heard, and they want to make a difference. And so building relationships with people individually, and as a group, that's also a skill set, that really takes a lot of learning on the fly and learning as you go.

Kelli Dilworth 07:35

And I think that's why if you meet anyone who works in engagement spaces, they're kind of a person who works in a space that's really difficult to define, and sometimes to explain, and that's why when you get them together in a place, they have a unique way of talking about things because they understand the importance of honouring the voice of the person whose voice they're amplifying. But they're also a little bit constrained by some of the pieces within an agency or an organization or a system that they know to be true, that they're also pushing up against.

Kelli Dilworth 08:15

So for me, I see the role as a place where some activism kind of takes place. You know, I'm not a decision maker, I can't make sweeping changes, I know that systems are complex. And I know, at the same time, that the best way to make change is going to be to make sure that it's the voices of people impacted and affected by the system and often marginalized by the system that are going to make the difference. And those are the voices that I have the power, in my little role, to bring forward and to really help amplify. So I'm always in between these two worlds and feeling the weight of wanting to honour what family members - and youth, sorry, I work with both, that's why I'm interchanging - what they are saying and feeling. But also honouring the sometimes real restrictions and dilemmas of being within, you know, a certain structure like a hospital or like a funded organization.

Emily 09:18

I think for jobs like this, where there's a built-in degree of managing this sort of tension, this push and pull, there's a risk that you could become cynical or maybe lose connection with why you're there in the first place. Maybe it's unavoidable, or something that comes and goes at different times. Kelli navigates this all with awareness and reflexivity, and remains optimistic in the potential for the work to help repair people's relationship to the healthcare system. She also keeps her focus on creating a safe space for honesty and dialogue, not pushing for or expecting particular outcomes.

Kelli Dilworth 09:58

I really try to be a source of kind of information - kind of an information exchange between two groups - as opposed to bringing in my own personal experience into the space. And I know that's a controversial thing to say, I really know that. But it's a choice that I've made, because I don't think my experience in this context is helpful, except in the way that I work. And so in that way, I make sure that I hear what people are having to say, that I create space where they can hopefully be vulnerable. And for me, the most important piece is creating space where people can be critical, and assuring them that actually, I know that the folks that I work for want people to be critical, and want people... and I don't know if this is the case in all spaces, but... to let them know that despite a system that sometimes fails people, there are people within that system, trying really hard to make changes, and sometimes they're constrained by things. And voice of people with lived and living experience really makes a difference.

Kelli Dilworth 11:19

I'm also though keenly aware that that's a privilege that I have is, you know, working with an organization that is there... that, you know, that space and youth and family members who are participating - their voice, the nature of engagement, will come and go, will ebb and flow, people's participation will, you know, sometimes be a lot and sometimes be a little. And making sure that we create space where that's okay as well. Where missing meetings, you know, sometimes not being well - that's normal, that's part of the package if we're asking people to participate. We're having to ask them to come as a whole person, not just for the piece that we want them to be

Jennifer 12:06

Yeah. Listening to Kelli, you can really hear how passionate she is about her work. And not in an unabashed, enthusiastic way. But in a thoughtful and reflective way. This kind of work, combined with a high degree of personal responsibility she feels to carry out the work with integrity... well, it can come at a cost. Kelli spoke candidly about being the one in the middle.

Kelli Dilworth 12:33

So sometimes I feel like I am the container for people's needs, like so the voice of families, but also the voice of the organization. So feeling, on the one hand, I'm that container. But on the other hand, I feel like I'm sometimes "holding the bag" so to speak, - I'm that container, that I'm responsible for making sure that I absolutely am correct in the way I'm bringing people's voices forward. But I'm absolutely correct in being clear about what people's voices can do and what impact they're going to have. I'm responsible for having people feel like they're engaged and that they're making a difference. But yet, I don't have a lot of control over a lot of the decisions of things that take place. I want to bring forward people's voices, but I don't want to speak for them... I feel like I'm kind of the messenger for both sides. So I'm not quite the voice. But I'm not quite the staff or the decision maker. I'm always in the middle. And I'm always holding that tension, and almost protecting both sides. So making sure families know that there are people within the systems who care, but also letting people within those systems who care, know that families and youth have felt let down by the system. Or marginalized or made vulnerable or all those things. So it sometimes takes a toll on people doing the work. And yet, this is the work I want to be doing because I think this for me is where change happens. And thinking of your last episode, I visualized someone talking about the "swirling around" almost - is that enough? Is just doing that in itself worth

doing? And I think it's one of the many pieces that can be done. It doesn't always work. But sometimes it does. And that's what makes it worthwhile. And it works for both sides. It's this interdependent kind of dance that can be really effective, especially when done in an authentic way.

Emily 14:44

As we've discussed before, patient engagement activities are sometimes implemented without much reflection on the purpose of the engagement and without due attention to how patients may be experiencing things. I do think it's common that engagement professionals come from Communications backgrounds or other areas of corporate life. They just may not be aware of what's at stake for patients. But Kelli is especially attuned to the potential needs of the engaged youth and family she's working with. She might not always know going in what's exactly required. But she's aware of the need to meet people where they're at, and taking her cues from there.

Kelli Dilworth 15:24

In this space, one of the most important things, especially in child and youth mental health, is to not create harm, to make sure that people are being supported - not just in their ideas and their thoughts, but within their mental health. Because often, folks around this table either have experienced or are experiencing some... you know... part of their journey involves some really difficult, some difficult things and difficult healing, that kind of thing. And so making sure that the person in this kind of space also knows how to ensure safe conversations. The planning that goes into something that can seem so engaged - I think that's also where you will hear engagement folks talking about the amount of planning and learning from our mistakes that we have to bring into this space. Including making sure clinical support is available. Ensuring that we have backup plans for when people get triggered and having to pivot around acknowledging that these conversations for people just aren't about ideas or concepts.

Kelli Dilworth 16:38

They're about people's experiences, and sometimes about their traumas. And sometimes, you know, we have this idea that people can put those aside in order to answer a survey question that seems pretty straightforward about how the intake process should look. Or how opening the front door of a space where youth are supposed to feel supported. Even these conversations - they can bring up things for people that we want to be really careful and mindful of. Like, I really strongly believe there is an ethical imperative to ensure that the people in this role as well understand that piece of it as well. And understand that things that might seem small, you know, sending out a small survey, or the way that we ask questions - those are all really important to spend a lot of time looking at. And how do you write that into a job description?

Jennifer 17:45

During our conversation with Kelli, we reflected on some of the other conversations we've had with patient partners who have talked about how sometimes engagement is a bit ad hoc. There may or may not be a process. There may or may not be a feedback loop. There may or may not be a way for patient partners to know what they've contributed, and how it's been valued. Kelli was circumspect describing some of her organization's approach, but also acknowledging that things can be imperfect.

Kelli Dilworth 18:18

We've recently created a measurement survey to look at engagement across agencies. And so we did have the folks with, you know, the PhDs in Evaluation, the people with strong implementation skills, but we also at the table had youth and families to make sure that they were part of that decision-making process. So that anything that we are putting out, you know, follows a validated process. But that's often in the research space. And I think what I'm hearing you say is, is in some of those other spaces, where it's not as formal, and the way that sometimes information is collected, just kind of goes nowhere or it takes on the position or the opinion of, you know, of an individual. And I think some of the things that I do or that we do within our process is making sure that feedback loops are always part of that process.

Kelli Dilworth 19:15

So making sure that people have a chance to see what information was gathered, and then have a chance to fix it or change it and to see how ultimately their information was used. I think that's really key. But I'm not missing your point of "who decides?" - like who actually gets to make the decision about what's being asked and how the information is being used.

Kelli Dilworth 19:44

Sometimes it's a swing and a miss. And I feel that. Like when that happens, I really feel it. And I think talking to someone else who has experienced that as well, is kind of the only way that I'm able to reconcile. I'm sometimes very angry at our system. I'm sometimes very angry at the way things are. And I'm sometimes very angry at, you know, youth or family members who can't see that we're just all trying so hard. Like, I carry that. And I don't know if that is a strength or a weakness, but I think a lot of people in this role feel that. And that's why I think it's such a unique space. Because it requires an understanding of both sides. But also, sticking with it in between supporting both sides and feeling like that there is some value to doing that. Or else why would I put myself through this? Why would anyone put themselves through it, if you didn't feel like it's making a difference?

Kelli Dilworth 20:47

I think both sides want the same thing. And that's for things to get better and be better and work for youth and families in the mental health system. That to me is important. That tension is not in opposition. It's working toward the same thing. And we all have a role. And sometimes it's hard. Sometimes we move forward. We flick that elastic rope, you know, quite far, and sometimes it flicks us back in the face. But, you know, we get up and we just keep walking in the same direction. I don't know, I feel really strongly about honouring both sides of that rope, or both sides of that tension.

Jennifer 21:30

Hey, Emily.

Emily 21:32

Hi, Jen.

Jennifer 21:34

After getting to know Kelli, it's become so much clearer to me that it's not just patient partners who face challenges with how engagement is implemented. Engagement professionals like Kelli, also experienced

frustrations and limitations and disappointments. I have to admit, because I'm not usually on "the inside", I don't often see the inner workings of engagement from an organization's perspective. You've definitely had much more exposure than I have. So what's your impression?

Emily 22:04

Well, Kelli has the rare privilege of working for an organization that's committed to the work she does. And I got the impression that she feels well supported in her role. She also works with a team of peers who understand the everyday tensions and challenges. But yeah, that's not always the case. Sometimes being the engagement person doesn't even come with a proper job description or clearly defined responsibilities. It's often not full time, or it's a secondary responsibility that has to be performed off the side of the desk, with little support or even attention from co-workers. That comes with its own frustrations for sure. As Kelli mentioned, people who don't work in this space can make assumptions about how simple or easy the job might be. It can be anything but. It's messy and complex and can be unpredictable. It's definitely time intensive. For Kelli, that's part of what makes it so rewarding when she does feel she's brought people together in a productive way.

Jennifer 23:08

This was an important episode for us to include in our series. My own mission personally, and one that I brought into this podcast project, is to look at engagement and partnership from a fairly dispassionate distance. And to ask things like, what are we doing? Who is it serving? And what are we perpetuating through engagement practices? But this encounter with Kelli is, I think, a good illustration of how maybe it's possible to work within the engagement field... I mean, she's right in the belly of the beast!... and use whatever power you have to advocate on behalf of those who may suffer at the hands of the system. And we've had other guests as well, like Lucy Costa, Amy Katz, Melody Morton-Ninomiya, who are under no delusions about who they're working for. But each in their own way, they're pushing back against unjust or harmful practices.

Emily 24:03

Yeah, at this point, I've developed a rather complicated relationship to engagement and partnership, even as I continue to engage and participate. I have our work on this podcast to thank in part for that. But, you know, joking aside, I'm actually hoping that we've done the same for others: complicated their relationship to engagement and partnership. Put aside some of the enthusiasm and infused more complexity into the work. I agree with you about Kelli. I think she's showing that when can be in the work and maintain that critical reflexivity.

Jennifer 24:41

There just aren't enough platforms or spaces for these kinds of discussions. And hopefully, our little podcast project fills some of that gap. And we have to give due credit to OSSU, the Ontario SPOR SUPPORT Unit for investing in us and this project. It definitely wasn't without risk. But I think even the most staunch supporters of patient engagement and partnership would see the value in preserving space for critique.

Emily 25:07

Yeah, I'm really looking forward to carrying on and seeing what's next. There's still so much ground to cover.

Emily 25:16

Big thanks to Kelli Dilworth for participating in this episode and sharing her thoughts and feelings with such honesty. And thanks for listening! If you have any questions or comments, please get in touch through our website at mattersofengagement.com.

Jennifer 25:32

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