DII Podcast S3E1

Mon, Apr 24, 2023 3:11PM • 30:59

**SUMMARY KEYWORDS**

research, people, belonging, ben, intellectual disabilities, trauma, production, phase, experience, project, intellectual disability, podcast, share, good, institute, researchers, talk, iva, research project, relationships

**SPEAKERS**

Justen Thomas, Iva Strnadová, Isabella Burton-Clark, Benjamin Garcia-Lee

**Justen Thomas**

Welcome to the UNSW Disability Innovation Institute podcast, where we discuss the work of the Institute and other issues related to disability inclusive research.

**Iva Strnadová**

So hello, everybody, my name is Iva Strnadová. And I'm a Professor of Special Education and Disability Studies at the School of Education at the University of New South Wales, and also Academic Lead Research of the UNSW Disability Innovation Institute. And in this role, I would like to welcome you to this month's Institute podcast. And this month, I have the great pleasure of speaking with my colleagues, Benjamin Garcia-Lee and Justen Thomas, about how they work together and how they use the Institute's guidelines, Doing Research Inclusively: Co-Production in Action. Before we start our conversation, I would like to ask Justen to do the Acknowledgement of the Country.

**Justen Thomas**

Yeah, well, today I recognise that we are meeting on Gadigal people of the Eora Nation. So I'm based in Bedegal country, which is Boondi, Bondi they say, known as water smashing over rocks. I would like to pay my respects today to this land, to its people, and Torres Strait Islanders, especially to the Elders present and emerging, acknowledging that non-Aboriginal people are here with us today as well, and I expect everyone here to do the same. I would like to extend this respect to Aboriginal people who are present today. And this land was, is, always will be the Gadigal and Aboriginal land.

**Iva Strnadová**

Thank you so much Justen, much, much appreciated. I would like to start by asking you, Justen and Ben, if you could introduce yourselves, and if you could say a few words about how you started to work together.

**Benjamin Garcia-Lee**

Would you like to go first, Justen?

**Justen Thomas**

I'll let you Ben.

**Benjamin Garcia-Lee**

Thanks. I'm Benjamin Garcia-Lee. I'm the Inclusive Research Development Officer at the Disability Innovation Institute at University of New South Wales. And I'm also a Scientia PhD scholar in the School of Education. My background is in advocacy, social work and community education. I met Justen when I was working as an educator at the Intellectual Disability Rights Service, probably around 2013 or 2014, when I was working with people with intellectual disabilities who had had criminal justice contact, and we had an opportunity to set up peer support groups, and Justen and I worked on that together. And Justen was a very active member of the Redfern group and our working relationship developed from there. Since then, we've collaborated on a number of research and advocacy projects, and I've also been working to support Justen to do his own advocacy and education work. Over to you, Justen.

**Justen Thomas**

Yeah. I was always in and out of the justice system at a young age. I was a young fella with a bit of trauma behind me that lost his way a young age, and obviously, by the time I met Ben for the first time in peer support groups and that, I was still facing courts and all that. And when I got involved in Changing Your Path and all that, and doing new things, I've been able to change my life. I was able to move on from there and discontinue with a lot of the people I used to hang around.

**Iva Strnadová**

Thank you so much, Justen. So, you have a really long history together, you two.

**Justen Thomas**

Yep. And saying that, is that I got the chance to get a My Choice Matter grant, $500, and run a few workshops with Ben and others, then with Caroline there doing other great things, and conferences and that over the years.

**Iva Strnadová**

That's amazing Justen. I would like to now ask you about your research project, I understand that you're working together on a research project that is about belonging. And so I would like to hear a bit more about the project.

**Justen Thomas**

My idea of belonging and purpose: so I've always, my time in and out of prison was that I kind of got into a habit where I didn't feel like I belonged anywhere anymore and to a community and all that, so it was that stage in my life, but part of it was I got used to adapting to the prison life rather than being out in the community where I didn't feel belonging anywhere or had a purpose. These days, I try and make more of a purpose in life and make sure it's valued.

**Benjamin Garcia-Lee**

And in our, in our work together and through Justen's lived experience insights, I think one of the things that unfortunately become glaringly clear is that despite the best of intentions, social inclusion, policy and practice has not resulted in positive quality of life outcomes for many people with intellectual disabilities. And in our work together, Justen and I are focused on working with people with intellectual disabilities who are experiencing lots of different forms of marginalisation, some of the things just there Justen's touched on. And we've been using the term 'complex support needs' in our work to talk about the challenges these people are facing. And we wanted to, and still want to, see if the concept of belonging is a key to better social inclusion outcomes for people with intellectual disabilities. So after a lot of preparatory work together, which I hope we'll have an opportunity to talk about a bit later, I've been talking to people with intellectual disabilities experiencing complex support needs, about their experiences of belonging and not belonging in their lives.

**Iva Strnadová**

Thank you so much, Ben and Justen, and because you are working on this research project together, may I ask, what are you finding out about belonging and people who have complex support needs? What are people telling you about their feeling of belonging?

**Benjamin Garcia-Lee**

Would you like me to go first, Justen, and then you can?

**Justen Thomas**

Yeah.

**Benjamin Garcia-Lee**

What we've found is that belonging is really interesting for a number of reasons. But in our study, in particular, we've been interested in the subjective experience of belonging for our participants, because while it's possible to tell people with intellectual disabilities, that they're socially included, which so often does happen using quantifiable metrics, like workforce participation, or community access, we've been finding that belonging is a much more embodied phenomenon or experience, which is why we talk about a 'sense' of belonging, because it's a feeling and some of the key things that we've found so far is firstly, that belonging is about relationships: to oneself; interpersonally; in the community; and beyond, and really importantly, that belonging is about giving and contributing, and having that contribution valued. Do you wanna say something about that one, Justen?

**Justen Thomas**

Yes. Quite often after having all those few years I've been reflecting on the past; and how we're going to move forward with all this is that, as I feel other people's pain too when you're in prison, that is that, they all are reassuring that there will be belonging and a purpose out in the community where we can move on with our lives, and are able to move on from our so-called trauma that we've been carrying. And it's interesting that over the years that, having gone to conferences, speaking and that, belonging is a big word these days, and because we got a sense of purpose in life and all that.

**Iva Strnadová**

That's a really good observation.

**Benjamin Garcia-Lee**

And if I can add, I think, so, in addition to belonging being relational and being all about relationships, and belonging being about making a contribution, and that contribution being valued, we've had two really interesting findings, which I think we wouldn't have had, if it wasn't for the approach to research that Justen and I are using and for the nature of our working relationship and the way that's allowed us to connect with a lived experience perspective, because these findings haven't been as prominent in the research literature. And the first is that safety is a critical precondition to feeling a sense of belonging of any kind, and that lots of the people we talked to don't feel safe, be that individually, environmentally, or psychologically. And the other big thing that's come out is that belonging is about believing and being believed. Would you like to add to that point, Justen?

**Justen Thomas**

And that's another powerful thing too, is that being believed about our experiences to people, and... because when we were pretty, young and pretty, well, no one believed our story, they always used to throw it off by, 'You're imagining these things,' and other stuff, where, no, they don't actually imagine these stories that they're telling, because they've actually lived it to talk about it. And people turn around in denial. But these days, the attitude has kind of changed though, which is good. It's working towards resurrection of people that have had that trauma and, and then belonging in the community, which was once...

**Benjamin Garcia-Lee**

And as Justen just alluded to, the biggest inhibitor to feeling a sense of belonging that we've found is the enduring impact of trauma in the lives of so many people with intellectual disabilities.

**Iva Strnadová**

And that was, really, exactly the question I was going to ask both of you, whether--because that is something I come across a lot in my co-produced research as well, and that common experience of trauma, different kinds of trauma as well. And so I was just wondering, was it really prominent? Was it that the majority of your participants have had that experience?

**Benjamin Garcia-Lee**

Unfortunately, experiences of trauma are very common. And would it be fair to say, Justen, everybody we've been talking to has experiences of trauma?

**Justen Thomas**

Yeah. And we should know that, we know someone and he's still probably going through that.

**Benjamin Garcia-Lee**

Can you say a few words about the impact of trauma on being able to feel like you belong?

**Justen Thomas**

Carrying that trauma lowers your self esteem. It can be really damaging to a human life, to a way of thinking and making us feel bad about our behaviour, you know, our behaviors and that. A lot of people dealt with it when I was growing up by doing drugs and being on the methadone and that. Some people just couldn't cope with it, they've committed suicide.

**Benjamin Garcia-Lee**

And so it's obvious in what Justen's saying, the connection between trauma and the lack of safety that people feel. So that's something that we're still working on. But something very big and significant that's come out of our work together already.

**Iva Strnadová**

And to me, already, this other point you made about being believed, because that's, that's a very common experience of many people with intellectual disability, that they are not believed in situations where they have been taken advantage of or abused or bullied, or other things.

**Benjamin Garcia-Lee**

And I hope I'm not misquoting you Justen, I've heard you say this in a couple of ways. But I think it's really powerful when Justin talks about, why would I tell my story if it's not going to be believed?

**Justen Thomas**

Exactly. And I remember that one, too. Yeah, why should I care what they're talking about, and people just don't have faith in my words, and another thing too, people should know, is that the old cops today, they're getting better, but there's still similar tactics, especially when it comes to 'system racial,' they call it, racism within the system.

**Iva Strnadová**

Thank you so much for mentioning it Justen. And yeah, I think, as a society, and I would dare to say not just in justice system, but in across different systems, we have still a very long way to go, be it healthcare, be it education, and so on.

**Justen Thomas**

There has to be a way that we can express ourselves, and listening to the way people have different stories about their lives they want to express themselves.

**Iva Strnadová**

And I think it's so powerful, Justen, that you are working as a community researcher together with Ben, and that shows that your story is believed. And you can, with this work that you are doing together, influence many people and hopefully help to make things better for others. Which leads me to another question. What does it feel for you, Justen, working together as a university researcher or in university research, and what does it mean for you to work together with Ben?

**Justen Thomas**

Ben, do you want to start that one off?

**Benjamin Garcia-Lee**

Well, I don't want to put put words, words in your mouth. So I'll mention a couple of other things that we've discussed previously, and then please feel free to add to that. We discussed the way that being involved in university research gives a platform for your voice, as you just mentioned, Iva, that it's validating, and that your story is believed. And it also gives an opportunity to share sort of the experiences of your life, doesn't it Justen, in a way that can connect with other people's stories?

**Justen Thomas**

Yeah, that's generally why we go to those conferences every year, so we can hear other people's stories too, which get very interesting. Especially from a women's point of view as well, from survivors, or that's what they're called, survivors anyway. Yeah. And that's why I've got the platform out there and still working my platform, the webpage, you know, because getting that message out there, you know what I mean? Back to my experience and how things--we talk about changing and what should be changing. We had that discussions ourselves, didn't we Ben, you know what I mean?

**Benjamin Garcia-Lee**

Yeah, how does our working together in its own little way, help to push the...

**Justen Thomas**

Our work goes far because it's getting heard, it's getting a voice out there, those videos that we've been doing and all that seem to be getting across.

**Benjamin Garcia-Lee**

Justen and I don't always use the same language that I might use in some of the things I say to you Iva, but probably captures the essence of it: Justen and I both really strongly believe that co-producing knowledge is so important. I don't have an intellectual disability. And I've not had a lot of the challenging experiences in my life that Justen or a lot of our participants have had. So therefore collaborating means that Justen and I can both bring our unique experiences, skills and perspectives to the work which, I know we share a belief that this gives the work a depth and authenticity that it wouldn't otherwise have. I've read lots about inclusive research and co-production and working together and been involved in projects. But to be quite frank, Justen and I did a lot of learning by doing until I had the privilege through my role at the Disability Innovation Institute to be involved in the development of the co-production guidelines for academics and researchers. And hand on heart, I have to say this has had a significant impact on the way that I think about approach and engage in inclusive research and particularly in the collaborative work that Justen and I do together. The phases of co-production gave a shape to the work that Justen and I were doing and critically posed questions and points for reflection, which I think worked to improve our research in real time. And interestingly because we didn't have the model at the beginning of the project, because we started this work in 2019, it was actually an invaluable resource to help us reflect on what we'd already done and to think about how we could do things differently next time. So the model of co-production developed at the Institute is a really easy to use resource. And particularly, in that it really thoughtfully complements the stages or phases of conventional research approaches. And I'll just really briefly just mention what the six phases are and what the primary characteristics of them are. And then maybe in a bit more detail, Justen and I can talk a bit about some of the activities we did in the first couple of phases. So the first phase is called Initiating. This relates to how the research focus of the project is generated. And for us, this meant a lot of time where Justen and another colleague, who we were working with, Judith took time and space to reflect on what belonging meant to us individually, so that we could come to a shared understanding of what the central topic or focus of the research was about. And this was really important, because we realised that we didn't initially necessarily have a shared conception of that. And the second phase was Planning. And this phase is focused on the design of the project, and how co-production or working together will occur across the project. For Justen and I, and Justen, I'd love if you can say a few words about this, too. A big part of the planning was thinking about what we do when we talk to people about their experiences of belonging, and what kind of interview techniques and methods we would use. And Justen, do you remember we had a lot of back and forth about whether we use body mapping? Or whether we...

**Justen Thomas**

Exactly, that's how we started, wasn't it?

**Benjamin Garcia-Lee**

What can you remember about those discussions? Because it might be different to what I remember.

**Justen Thomas**

Body mapping's about, it was the same thing when you first started peer support and we did those masks and all that, remember that?

**Benjamin Garcia-Lee**

Yeah.

**Justen Thomas**

It kind of gets a sense of people and their goals. Remember, we used to always talk about how to reach your goals: 'You got game?' [laughs]

**Benjamin Garcia-Lee**

One of the really valuable things that Justen and Judith added in those conversations in the planning phase was that they really made me question and change the interview protocols and tools that I'd developed from the research literature. And I think that was a really invaluable part of co-production that actually being able to pilot the interview protocols that we were using, for me to realise that despite my best efforts, I was relying on people responding verbally and not using other means of communicating which Justen and Judith were really good at alerting me to.

**Justen Thomas**

Ben, you used to work with Annika, she did a lot of stuff to assist in getting inclusion, like including me in the conferences. She's the one that kind of encouraged me to go to VALID in the first year, or IDRS. And I found that was pretty awesome to go to a VALID conference in Geelong.

**Benjamin Garcia-Lee**

The third phase, Doing, in this phase, we discuss the activities which relate to ethics and recruitment and data collection, obviously, the critical nuts and bolts of any good research project. And the Fourth phase Sense-making: sense making is about focusing on collaborative data analysis, and coming up with creative ways in which, in my case, that Justen and I can work together to make sense of the data that we've collected. The fifth phase is Sharing, which is about developing collaborative means of disseminating the research findings. One of the innovative ways that we've come up with for our project is that we're going to have a podcast about belonging so that we can have an accessible research conversation about our findings. And the sixth phase is Reflecting. And in this phase, the research team collaboratively considers the research process undertaken and the implications for future projects. So in simple language, that's about saying, what have we done? How did it go? What can we learn from it, and where to from here? These six phases are iterative, and they're not necessarily going to, like in any research project, things don't happen, as you expect. But the beauty of this is you can move between the phases in a way that we've found really complements the daily grind or practice of doing a research project. What are some of your thoughts about having been working on this same project for four years now?

**Justen Thomas**

It must have been something real positive if it's still going for four years, isn't it?

**Iva Strnadová**

That's an amazing answer, Justen.

**Justen Thomas**

If it's four years and it's still going must be really, really...

**Benjamin Garcia-Lee**

And we're still talking to each other, well, more than ever!

**Iva Strnadová**

OK, Justen, what's the best about working with Ben?

**Justen Thomas**

If it wasn't for Ben, I'd probably still be in square one, my self-esteem wouldn't be so good, I wouldn't, I'd have that trust issue with people around me. I'd still be locked up in the cupboard, more or less locked away from people. I guess a lot of it over time opened my eyes and I was able to reflect, I'm always reflecting on how important it is, and how you can reflect on the past and how we can move forward, get rid of the ning-nongs I used to hang around with.

**Iva Strnadová**

That is a really strong bond you two have.

**Justen Thomas**

It didn't happen overnight, it happened over years, and Ben seems to be a decent guy to get involved with.

**Iva Strnadová**

Ben, what's the best about working with Justen?

**Benjamin Garcia-Lee**

I think we share some really strong core values. And I think we care about a lot of the same things. And we believe in working towards changing things for the better. One of the things that I love about that is that we know that that's a hard and a long project and probably life work. So we remember to have some fun along the way so that it doesn't seem too heavy. Working in academic research, the relationship to Justin is so so special to me because it gives me an opportunity to think outside the box. And to not get too blinkered in the way that I think about think about research. And I think we keep each other grounded. I think that's a real positive of it. Something that Justen said I think is critical, if I was to ever think or dare to give advice to others is, as Justin said, relationships take time and trusting relationships take time and research relationships that are asking people to share their often complex and difficult lived experience require a level of trust and reciprocal respect that you don't just form overnight. Would that be fair to say, Justen?

**Justen Thomas**

Exactly, yeah.

**Iva Strnadová**

So you also talked about how you approach the different participants in your study. And you talked about how you talk to them, are you using also other methods to engage them and to really help them to express themselves?

**Benjamin Garcia-Lee**

Absolutely. We've used some creative interview tools involving mapping people's support networks and lives and people having control of that process. So that's often a generative and a visual art space thing. And the other thing is asking people to document what belonging looks like and feels like in their life through the use of photography. And they were things that really were generated initially by me, and were instruments that were really refined through the work with Justen, in addition to that, we've been working, and I accept all credit for the slowness of how we're getting to the goal. But Justin introduced the idea of having a more accessible way to have a research conversation about belonging, and came up with the idea of us doing a podcast.

**Iva Strnadová**

I love it.

**Justen Thomas**

Yeah, and another thing is that's it, and another thing I want to get at is that I've found in the term, instead of wasting my energy going to court, facing court and all that time, I'd rather put my energy to good use, and I thought going along to peer support, meeting new people would help me to turn the corner and I was able to do that. That was the help of Ben again, giving me that hand when I needed it.

**Benjamin Garcia-Lee**

And if we hadn't taken a co-production approach to this project, the idea of a podcast would never have come up. And we also wouldn't be acting on that and actually making it happen so that we will have the more conventional kind of academic outputs for our research. But alongside that, we're going to have a podcast led by Justen, which is leading an accessible research-informed conversation about what belonging means to people in their lives. And I think that's a great outcome of the work we've done together, isn't it, Justen?

**Justen Thomas**

Yeah, I reckon.

**Iva Strnadová**

Oh, definitely. That's amazing.

**Justen Thomas**

It's a great platform for it.

**Iva Strnadová**

And I assume, listening to you two, that there is no way you are thinking about finishing your work? Do you have more research ideas or plans?

**Justen Thomas**

I have hopes to do some international platforms.

**Benjamin Garcia-Lee**

What did you say to me earlier? If I can get this thing finished and have the 'Doctor' bit, then we can get on with our work?

**Justen Thomas**

That's right. And get the work out into the world, international.

**Iva Strnadová**

As your supervisor, Ben, I really like to hear that.

**Justen Thomas**

I'm hoping that some international governments come to the roundtable and we can have a chat about that.

**Iva Strnadová**

Love it. There are many research teams that are starting to contemplate to do co-production, so, to create teams where academic researchers and researchers who have disability work together. What would you recommend to newbies in this area, somebody who is just starting, what are some tips how to make it happen?

**Justen Thomas**

Go on, Ben.

**Benjamin Garcia-Lee**

Well, I was gonna handle that one to you, mate, and maybe just frame it slightly differently about, how do you think people who are doing research in universities should and could work best with researchers from the community with lived experience?

**Justen Thomas**

I mean, making people with lived experience a priority and making inclusion in the research and lots of storytelling.

**Benjamin Garcia-Lee**

It's a great response. And what does that mean? You can even reflect on some of the work you do at the Council for Intellectual Disability in this as well. How can people make research more accessible?

**Justen Thomas**

Easy Read.

**Benjamin Garcia-Lee**

And can you explain what that is?

**Justen Thomas**

Sure. Put big enough words, and pictures along with the sentences.

**Benjamin Garcia-Lee**

Co-production is always worth it. It increases the authenticity, the rigour, and the integrity of a piece of research, that value adds things that academic researchers alone wouldn't be able to achieve in a research study, even from the idea of initiating a piece of research, the types of questions to ask, the types of people to talk to, to find out what questions we need to ask, and then how we go back to people to find out what they think and what the answers are to those questions. And as I alluded to, in terms of how you go about talking to people. Without the input of Justen, a lot of the ways I would have gone about doing my research, even though I've worked in the field for over 10 years, would not have elicited the quality of data and the depth of data that we had. And one of the things that we're really looking forward to now is about making sense of all of that data together. My message would be that co-production is not only an essential way to undertake research in so many ways, but that it's an enjoyable and a pleasurable one. And I think I've learned as much as Justen has over the course of this project. And as our rapport demonstrates, it's the beginning of a research relationship rather than a finite project. And I think that is a really valuable outcome of co-production as well.

**Justen Thomas**

And Ben, one more thing, now, you've witnessed this with me now, when the government-funded organisations, and the government actually say sorry, for the treatment of persons with disability, of trauma, what does 'sorry' mean to you, in your eyes?

**Benjamin Garcia-Lee**

That sounds like a very big question. And like a good research project for us to talk to Iva about doing once we get this doctor thing out of the way.

**Iva Strnadová**

I was just thinking, you are just already planning your huge research agenda.

**Justen Thomas**

There was a Truth Day, it's the truth, Ben witnessed that I had an apology and all that rose up in me.

**Iva Strnadová**

And that's really important, it can really heal some of the wounds from the past, doesn't it?

**Justen Thomas**

Yeah, more move forward. But we need an action plan on it, they're called 'action plans', and it's time to act on changes.

**Benjamin Garcia-Lee**

And it's one of the things I respect most about Justen and I think has really helped me develop as a researcher is, like the way Justin just shared an intense personal experience and moment, but then he instantly has this amazing capacity to reflect on how that could lead to work that needs to happen at a bigger level beyond his personal experience. And I think those insights are just so valuable to the formulation of good research.

**Iva Strnadová**

Absolutely. Have you experienced any barriers to doing research together, and to work together in research? Any obstacles?

**Benjamin Garcia-Lee**

Time can be a challenge, because we're both so concerned with doing things well, and doing things thoroughly. But I think that's just something that needs to be built into a good project plan. Justen and I found that, although it didn't always eventuate, having consistency, structure and regularity, and a good plan for the research is really important. I think one of the challenges can be getting the appropriate recognition for the contribution of researchers with intellectual disabilities. And that often means finding the resources for them to be paid properly for their work. That's an ongoing challenge.

**Iva Strnadová**

And finding, I would add to it, finding accessible ways to being paid.

**Benjamin Garcia-Lee**

Hmm. Can you think of anything else that's been a challenge, or has it all just been plain sailing, Justen?

**Justen Thomas**

Yeah, it's been what you just said, the sailing.

**Iva Strnadová**

That's awesome. That's a beautiful experience to share with our listeners. Ben and Justen, thank you so much for coming and for sharing your wisdom and your experiences of co-producing research. I'm really excited that you have found the Co-Production In Action guidelines useful for your work, and that you were able to share with others, how you have used them, how they have helped you to guide your work. So thank you so much for coming. And have a wonderful afternoon, everybody who is listening to us and stay tuned for our next podcast.

**Justen Thomas**

All right.

**Benjamin Garcia-Lee**

Thank you.

**Isabella Burton-Clark**

Thank you for listening to the UNSW Disability Innovation Institute podcast. The podcast is hosted by the Institute's director, Professor Jackie Leach Scully, and produced by me, Isabella Burton-Clark. We would like to thank our guests for their time and insight. You can find out more about the Institute and subscribe to our newsletter at disabilityinnovation.unsw.edu.au. You can also find further information about the topics discussed in the podcast on our website and in the show notes.