

Disability Done Different: Episode 26

Prof Julian Trollor and Dr Peter Baldwin on...building a Healthy Mind

Podcast transcript

Hosts: Roland & Evie Naufal

Guest: Professor Julian Trollor & Dr Peter Baldwin

Start of Audio

Maia Thomas

DSC is a team of 33 people across Australia all working together to bring specialized training and consulting expertise to providers in the disability sector.

Evie Naufal

All right, here's what's going to happen now.

Roland Naufal

Hello and welcome to our podcast.

Evie Naufal

We are DSC. Your turn, you're the boss.
Disability Done Different: Candid Conversations.

Evie Naufal

Hope you are ready because we're starting.

Roland Naufal

Welcome to Disability Done Different Candid Conversations. Welcome, Evie.

Evie Naufal

Welcome, Roland.

Roland Naufal

And welcome Maia our producer. So our guests today are Professor Julian Trollor and Dr. Peter Baldwin and Maia this was your idea, you put together the concept for this podcast, what were you thinking?

Maia Thomas

Well, Dr. Peter Baldwin and I are actually quite good friends, and the concept came about after some Zoom wines when he was telling me about his work on Healthy Mind, which is an online mental health program being run by the Black Dog Institute. And we got talking about the clinical trial he's running for people with intellectual disabilities called ID2 and we thought it'd be a good opportunity to chat to himself and Prof Julian about the intersectionality between health and disability, and also what's happening in the ID space.

Roland Naufal

Well stay with us on the podcast Maia and if you've got anything to contribute, just jump on in. So let's kick off with Prof. Do you mind if I call your Julian, Julian?

Julian Trollor

Absolutely.

Roland Naufal

Julian, you're the chair of Intellectual Disability Mental Health and head of the Department of Developmental Disability Neuropsychiatry undertaking work in clinical neurosciences data linkage, policy analysis, service evaluation, ageing, and dementia in intellectual disability. Now you guys specialise in plain English. Do you get much grief when you tell people what you do?

Julian Trollor

Look, it's a really good question. When I'm asked what I do, I just say I'm a doctor that helps people with intellectual and developmental disabilities with their healthcare needs, and I do a lot of research in this space as well.

Roland Naufal

It's a really interesting space and I'd be really looking forward to exploring it with you as we go. And Peter, you're a Clinical Researcher and Clinical Psychologist at the Black Dog Institute, but the thing that probably pricks up a lot of people's interest is that you worked at NASA working on mental health services to astronauts. And I just had to kick off with, did that help you prepare for what we're experiencing in COVID working with astronauts?

Peter Baldwin

Clarify that I worked in consultation with NASA. I don't think NASA would ever employ me, but oddly enough, part of that project was looking at how we deliver mental health services to people in extreme isolation, so you're not too far off. Definitely, it's been on my mind about how we do a better job of delivering mental health services to people who can't be with each other.

Evie Naufal

How is it that the two of you come to be working together?

Peter Baldwin

The Black Dog Institute in consultation with Julian and the team over at UNSW put together really what is the world first, fully automated self-guided online mental health tool specifically for people with intellectual disability. And it really grew out of a shared passion between the organisations for making mental health care available to everyone. So it was the first time we all got together to talk about these things and how we might actually build a website that was really usable and inclusive and yeah, our relationship with Julian and his team at UNSW has been instrumental in that.

Julian Trollor

Of course when Peter came along from Black Dog, it was a no brainer, this is a very important project because I'm sharply aware of the mental health needs of people with intellectual disability and thought this was a fabulous idea.

Roland Naufal

So could you give us a bit more detail on electronic mental health, how that actually works, and then double down on that and tell us how it actually works with people with an intellectual disability?

Peter Baldwin

Sure. So obviously at the moment electronic mental health is really on everyone's minds, and at Black Dog we spent a lot of time thinking about the best way to do it. So sometimes it might be a website, sometimes it might be an app. It might be a telehealth service where we give some people face-to-face work and other people website work to do. But really, it's about using technology to connect people and ideas, and then what we noticed the more we did that is that we were doing it for people with a certain kind of brain, we weren't doing it for people who had different kinds of abilities and we were leaving people out because of that. So we started to think that if the promise of digital mental health is mental health for everyone, it has to be for everyone. So that's what really sparked the idea of how do we adapt the tools that, you know, Australians we know that they use them and we know that they benefit from them, how can we make that available to all Australians regardless of their ability level?

Evie Naufal

So when we think about web accessibility, I think the first thing that comes to most people's minds would be things like, you know, colour contrast, and legibility of text, things that are really looking to support someone with a visual impairment. How does that work when you're catering to a cognitive accessibility requirement?

Peter Baldwin

That's a great question, because of course, all of the things that you just mentioned about accessibility are still part of the picture but we have to think about things like memory, can people remember passwords. Language, can they understand the language that we would normally use. Different modalities. Some people work really well with written language, but others prefer to hear it spoken or need it spoken. And incorporating all of that into web-based technology is actually quite tricky, but it's actually been a really fun and rewarding challenge to build a website that includes all of those things.

Evie Naufal

I bet.

Roland Naufal

So could you give us an example Peter of where you'd work with a person with a cognitive disability and how they would access it? Would they access it themselves or with a third party assisting them, what sorts of questions are they going to or issues are they going to be working through?

Evie Naufal

With Healthy Minds specifically?

Roland Naufal

Yeah.

Peter Baldwin

Yeah. So it's designed for people to either use it with a carer or use it by themselves. Some people will benefit more if they use it with a carer, but we put a lot of thought into making sure all of the language is easy to read. There are explainer videos for everything. Anytime text appears on the website, people can click a button to hear it read to them as well. So it should be, it should be easy for people to access, and then we thought about the content itself, what is going to be most useful to people with intellectual disability and the kinds of mental health challenges that they face.

So we worked in really simple exercises to help people calm down, think a little bit more clearly, plan their week, and include things that are really meaningful and important to them and enrich their relationships. And of course, unsurprisingly those are all very familiar mental health challenges that everyone faces, it was just a case of thinking about how best to help people with intellectual disability engage with those kinds of strategies.

Roland Naufal

One of the things we'll be talking about a bit as we talk about intellectual disability and disability in general is the loneliness that comes with being a person with a disability. We've done a number of podcasts when we've talked about 'othering', and I imagine both Julian and Peter you're well on top of the concepts of 'other' and being different to everybody else. How much of the problems that we face, that people with disability and intellectual disability face is social isolation caused or provoked or I don't know what language you'd use, but maybe you can help me out either of you.

Julian Trollor

Yes, look, it's certainly an important factor, but it's one of many, people with intellectual disability often lead very fulfilling, productive, and connected lives. And so I think the flip side of what you're saying is, in fact, there are certainly a lot of people who are leading very fulfilling lives, but there is a very high burden of mental health conditions and concerns for people with intellectual disability. And one of the things that feeds into that is social isolation, but it's one of many quite complicated and interacting factors.

Peter Baldwin

And perhaps just to add to that, yeah, I think that concept of 'other' has really been on our mind from a research point of view as well. We've been really careful to design the research study in an inclusive way, because we know that belonging is a really important part of people's mental health. So we've taken the approach of including people in the design phase, in the research phase. And we're really lucky to have some really amazing people with intellectual disability who, you know, come along and tell us whether they feel included or not, or whether what we're doing will help people feel less 'other' and more a part of everything, and that's really important to us.

Julian Trollor

I'll just add to what Peter was saying, there's an adage in the disability area that says 'nothing about us without us'. I think that really typifies the approach that Peter and the team have taken in developing Healthy Mind.

Roland Naufal

And Peter, you touched on a sense of belonging, and ever since I first saw Maslow's Hierarchy and I saw right down at the bottom that one of our basic human needs is shelter, food and we're gregarious, we need to be with other people, and you've gone straight to sense of belonging. And when I've been working with workers who work with people with disability, and particularly intellectual disability, I talk to them about the opportunities that they have to belong. And they'll talk about everything from, you know, the footie club to the church, to family, to all kinds of things, and then we

ask them to reflect on the opportunities for people with an intellectual disability to belong, and it gets pretty quiet pretty quickly. Is that one of the issues you're confronting?

Peter Baldwin

I think definitely. Yeah. And it's an issue, not just in community organisations, but also in clinical practice, in research. When we do ask that question, you know, what opportunities are you creating for people with intellectual disability, it gets just as quiet. People don't often have a good answer to that and then start to feel uncomfortable about that. And so I think, you know, what we've tried to do with this project is not only build something for people with intellectual disability, but show other researchers and clinicians that it can be done by providing an example. And also obviously as we do as researchers by producing literature, papers that show people how we do it. So when people have those discussions in the future, they've got a really clear example to point to.

I asked one of the people with an intellectual disability, you know, what do you think this website is for? And he wasn't quite sure. And I said that, you know, it was to help him be happy. And he got quite tearful and looked at me and he said, I'd really like to be happy. And that was a moment for me where I thought, wow, this is, you know, we really have built something that might, might touch people and might improve people's lives. And it really sort of, it really spurred me on to make the tool better and better.

Roland Naufal

And Julian, can I just ask you a question too. When the National Disability Insurance Scheme was first brought forward back in 2012, 2013 it wasn't originally conceived to have mental health as part of the system, and mental health has always been seen prior to the NDIS as a very different, often not even a disability, it was mental health. It's now being nationally characterised as a disability.

So you're working in a space now that's become very much a part of the disability genre or yep that seems like reasonable language, yet disability itself is rejecting the medical model. So we've moved past the medical model, we're only just starting to incorporate mental health and disability, and Evie spoke about intersectionality at the start, which is a pretty new term that's emerging. You're working at the intersection of a whole lot of complexity. Is that a question?

Julian Trollor

Look, it's a really good observation and you're quite right that this intersectionality is challenging as we move somewhat away from the traditional medical model of disability to a social model. One of the strengths of the medical model is in terms of rigour of assessment and conceptualisation of the contributions to conditions, which cause disability. And so we mustn't throw out all of the aspects, some of which are positive, but of course the move to the social model has been incredibly helpful as we think about inclusive societies in which we encourage everyone to thrive. And I think as a professional working in health, I see a huge gap between health services and systems and disability supports and systems. These are exemplified in all sorts of areas, including for example, around the regulation and oversight to do with chemical restraint or psychotropic treatment in the context of challenging behaviour. It's where we see a set of regulations and a way of governing the administration of that somewhat lacking in medical input, even though medical practitioners prescribe medicines that are used as chemical restraints. That's just one simple illustration of the gap or current void between services systems. But there are many interconnected systems which need to work together well to properly support people with disability and we tend to see the siloing and gaps between each of those.

Roland Naufal

And when you think about it, you brought up on there too restrictive practices is a really good example where sometimes the policy is way ahead of the practice, which is in a different place to the different bureaucracies and systems, which underpin it. And you just illustrated that the medical system which

plays an important role, isn't being taken incredibly seriously. The Quality and Safeguards Commission with its approach to restrictive practices is not really in touch with what's happening in practice in the field, it can't keep up with what it's done.

So again, I just want to push this concept of intersectionality, because it's so interesting. It puts an exponential number on complexity doesn't it, if you're just dealing with one system that's complex it's hard enough, but when you get complex systems colliding across three or four areas, which is where you work Julian and it's your space as well Peter, it gets pretty fricking difficult doesn't it?

Julian Trollor

Look it can get difficult. I think the way we need to proceed is to have a different way of working that creates a shared space. And some of the joys of the NDIS is that people can access individualised funding and have choice and control. But some of the difficulties entailed is that there's not funding to assist people to access health care or to coordinate between the different elements of their care, including in sectors such as health. And coming back to your point about the importance around restrictive practices, obviously this is of immense importance in the Disability Royal Commission, which next week is commencing its hearings on restrictive practices, one area of which obviously is psychotropic medication prescribing.

Evie Naufal

Quick clarification and I'm already nervous about getting this wrong, just to clarify the difference between the medical model and the social model of disability. The medical model of a disability is a way of looking at disability as a deficit or an illness within the person. And the social model of disability is where we say that, you know, the person is who they are and the disability is the environment. So, that for somebody who might use a wheelchair, the classic example is that the disability is not that their legs don't work in the same way, the disability is that there aren't ramps everywhere. Have I got that all right?

Julian Trollor

That's a really good illustration I like it.

Roland Naufal

Can we just go to really fundamental stuff. So one of the things we did in disability 20 years ago when we started moving towards the social model was to stop differentiating between people with intellectual disability and physical disability and different disabilities. And I think it's partly been to our detriment because we don't really understand the different cohort needs. Having a disability in different cohorts has different needs. Everybody's an individual, but there are some cohort-specific issues. You folks both work on intellectual disability and you work on mental health. What is that overlap? Why are you looking at intellectual disability and mental health other than the disadvantage, which is obvious and people with cognitive disabilities having difficulty accessing mental health, but what are some of the precursor issues. Am I more likely if I have an intellectual disability to have a mental health issue and if so, why?

Julian Trollor

Essentially we can think about vulnerability or risk to mental illness arising from a number of different domains, one of which is of course biological. And for some people with intellectual disability, the cause of the disability is related to a genetic syndrome, which in itself may be one that also confers risk to other conditions such as mental ill-health and certain physical health issues, which can also feed into a mental illness.

A simple example is that for some people with intellectual disability, their syndrome may also put them at a higher risk of epilepsy, which is a non-risk factor for mental ill-health. Another example would be a person with Down Syndrome through having an extra copy of Chromosome 21, also codes for a

protein precursor of Alzheimer's disease. And so with increasing age, that person is at increased risk of development of Alzheimer's disease and dementia.

So there are two simple examples of how biological factors associated with a disability might actually confer a higher risk of mental ill-health.

Julian Trollor

But then around the person, there's obviously an interaction with society and our experiences as we travel through life might expose us to all sorts of positive and negative experiences. And some of the negative experiences might be experienced more commonly by people with intellectual disability.

Some things such as neglect in early childhood, trauma and abuse and being a victim of crime and violence might feed into that risk. And then there's the way our society embraces people with disability. Unfortunately, for many people with disability, they may have experienced marginalisation or rejection in personal relationships and more broadly in our society. And that can feed into a sense of lack of confidence, lack of sense of place and purpose.

People may also have experienced difficulty in transitions, for example, out of education, to employment. And so the same roles that help most of us buffer risk of mental illness, such as participation in society, fulfilling work, fulfilling relationships, might be eroded because the supports are not there for the person. So all of these factors can interact to create some vulnerability.

Roland Naufal

Gosh, that just raises so many issues Julian, a couple that come to mind. I'll start with one, which is, I think sometimes we head down this road with a simplistic view that people who have difficulty communicating their issues manifest that in behaviours of concern. I'm using the language, the coded language, that people act out when they can't communicate properly. And all we have to do is to support people to communicate properly and things will get better, create environments where they communicate more easily, and there's a truth in that. But what you're pointing to is the depth of issues that people may have encountered. It's not as simple as just removing a restrictive practice, which is an incredibly important first step, but there's multiple layers underneath that, that we need to explore, to support a person who's having mental health problems and having difficulty communicating those. What sorts of things can be done to support people who have mental health issues and intellectual disability?

Julian Trollor

Fundamentally, Roland, I think we have to do a better job of creating inclusive societies. Earlier in the podcast we touched on the concept of, it's sometimes easier to make adjustments for people with physical disabilities or sensory disabilities, and that we do it relatively poorly for people with cognitive including intellectual disability. So when we're thinking about the way in which we value people and include people and enable people to participate in society. We really need a better job at all levels, whether that's thinking about planning in local government, whether that's thinking about our services and communities. Whether it's thinking about our local clubs and churches, all of those places and spaces are ones which need to have clear plans about how to support people and encourage the engagement with people with cognitive disabilities. So I think that's a key change that is slower to happen than say creating an accessibility ramp for a person with mobility difficulties.

Roland Naufal

Peter, did you want to add anything there?

Peter Baldwin

Yeah, absolutely. I think, you know, I totally agree with everything that Julian's saying about, fundamentally we need to look at systemic issues and we need to do that not just in intellectual disability of course, but it can be tricky. And I always come back to research about what people need

psychologically to be well, and all humans have three psychological needs. Autonomy, so having choice, mastery, knowing that you're good at something and being able to develop skill and relatedness connectedness. And so I think if listeners are sitting here wondering what can I do if you are building systems, organisations, communities, think about those three things. How could you support someone with an intellectual disability to have more choice, to find something that they're good at and get better at it, whatever that be and however small those steps might be and then relatedness, how can you do that in a connected way?

Roland Naufal

Autonomy mastery and connectedness. I do a lot of work in Sydney with an organisation that brings in, they've brought through about a thousand workers now. And we talked to them over two days and we talk about a lot of these sort of concepts. And we asked them, what the most common word is that they think that people with an intellectual disability hear in their lives, do you want to guess what that is?

Evie Naufal

'No'.

Roland Naufal

That's the word, 'No' you can't do this by yourself. 'No', you can't eat that much food. 'No', you can't watch TV. 'No', you can't do this. And so that concept of autonomy and the word 'No' don't go that brilliantly together, they're opposites, that's an anathema. The concept of mastery over something when you're not given the opportunity a lot of the time to even think about what it is that you want to master.

I often give the example of two young women with Down Syndrome who went to day programs for 30 years to learn a bunch of things, including every Thursday they'd be learning to cook Spaghetti Bolognese. And they never mastered that because it wasn't something that was in what they wanted or were able to do, and we've already talked about that sense of disconnectedness. So Peter, you talked about those three concepts when you're working on the bell curve, people with an intellectual disability are pretty much at the wrong end, aren't they?

Peter Baldwin

Yeah. I mean, I think the end of the curve that they're at poses a lot of challenges, but I don't see it as insurmountable by any means. People can still have at least some autonomy. We can give people choice. Mastery might look different in the life of someone with an intellectual disability than it might in yours or mine. I have never mastered making any kind of meal myself. I have other areas of mastery and, you know, working with people to define what does it mean to you to be really good at something, or what would you really like to be good at? And then relatedness, you know, you mentioned that word 'No' and I can only imagine how many times that people with intellectual disability hear that and you're absolutely right, it's a barrier to fulfilment of those needs. But my most loathed word is the word 'Should' because that comes with unrealistic and rigid expectations. So I think it would be great for people to think about the expectations that they bring when they're working with people with intellectual disability and what their expectations are. And how can we reset those so people can have a little bit more choice, gain a little bit more skill and confidence and have a little bit more connectedness in their lives.

Roland Naufal

So I've got one final question, which is the nuance of disability and it bothers me a lot. I've been in the sector now for 30 years, when new players come in and talk about disability as though there's a homogeneity there. And what both you Julian and Peter have highlighted is the heterogeneity that the nuance, the difference between a person with Down Syndrome around the things that are important to

another person with Down Syndrome around the things that are important, let alone a person with motor neuron, mental health issues, MS or whatever. And so just the level of complexity the level of nuance, and I don't know if either of you want to make a comment where people think that disability is somehow something we can treat with a single focus?

Julian Trollor

Absolutely, I agree with you Roland. I think at a top-level in terms of formulating appropriate policy and services, we must realise that sometimes it's useful to speak in a collective way about people with certain types of disabilities so we're able to communicate effective messages. A simple example is some of our research has investigated the mortality rate and rates of potentially avoidable deaths in people with intellectual disability. And so putting all people together for that analysis is very useful, but when it comes to preventing deaths, obviously a very person-centred and individualised approach is required. Each person is different, has different health and other needs, different choice, different preferences in life and the way they wish to live, and with whom they wish to engage and so on. So we must make sure that at the level of the support of the person that is very much tailored to the preferences of the individual. So I think both approaches are valid, but need to be used in different contexts.

Roland Naufal

So thank you very much, Professor Julian Trollor and Dr. Peter Baldwin it's been a really interesting discussion around the intersectionality between mental health and disability.

Evie Naufal

Thank you.

Julian Trollor

Thank you for your time.

Peter Baldwin

Yeah. Thank you. It's been great.

Roland Naufal

Great. Thank you.

Evie Naufal

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