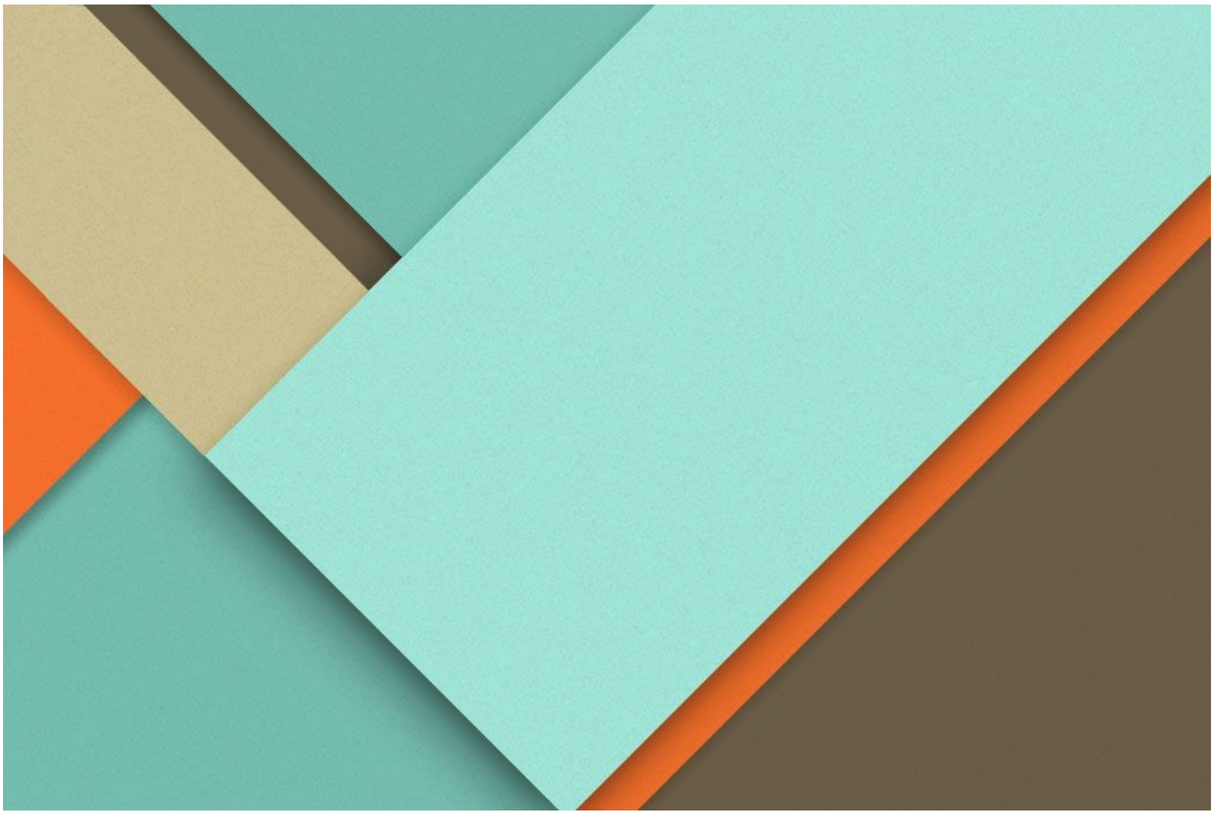

Bec Waters

Transcript

Podcraft Productions

Varnya (intro):

In this episode, we chat with disability scholar and advocate Dr. Bec Waters. Bec is an occupational therapist who teaches at Curtin University. She has some really provocative and eye-opening ideas about the way we support people with disability. This was one of my favourite interviews of the series - I hope you enjoy it as much as I did.

Varnya:

There are a lot of people out there, who like to help people they regard as vulnerable, or in need of assistance. While these individuals likely, or perhaps probably, have their hearts in the right places, I'm interested in your opinion on how they, sort of help perpetuate certain stereotypes about that vulnerability, about that need.

Another really simple way of putting it is what's wrong with helping people? As most people understand it.With the advent of the NDIS, people with disability in Australia have, in theory at least, more choice around how they are supported. Often, this support comes in the form of support workers or carers. These individuals are employed to provide all sorts of assistance - whether it's help with cooking, getting around the house, or getting out to meet people.

Bec:

It's an interesting thing, isn't it, because as a society, we see helping as a positive thing. When we see people in distress or discomfort, our first response is to think, "What can I do? How can I help?" That's grounded in a whole heap of assumptions about people's so-called vulnerability, I suppose, and whether or not they actually are in need, particularly for people with disability, for example.

It comes back to what we think is a good enough life, or the type of life that people should be aspiring to. Those starting points about our values and our beliefs about people's lives, then drive an inherent response to want to get there and make their life more like mine, [laughs] for want of a better way of putting it.

But who said anywhere along the way that any of our individual lives was the right life to live? I'm very much an introvert, for example. I'm very happy in my own company. Other people might say that I might need to live a more extroverted life. A life full of seeing more people, and more experiences, and more levels of risk, for example.

I'm quite happy being an introvert. I'm quite happy with the number of relationships I have in my life. If someone's starting point is quite different to that, then they're driven to behave in ways that might take power away from the way that people want to live.

Varnya:

If I'm understanding you correctly, we look at what our personal ideal of a life should look like, and then we project that onto whatever person we meet. We decide for them, "Oh, well, this is what you should be doing, so I will help you achieve this."

Bec:

Yeah. I think that's almost our default starting position in humankind. We're social beings. We want to be in connection with other people, but the flip side of that is we need to be way more in tune with that being our point of view, not the other person's point of view. That we need to start in all of our relationships with where the person's at.

We know that when we're making new friendships, for example. You're trying to get out in the world and meet some new people, and we do that by joining in activities or events or participating in things that we find mutually beneficial or mutually interesting, but we experience them in different ways.

Varnya:

How can assistance be offered in a way that is empowering, or is the notion of assistance wrongheaded, to begin with, do you think?

Bec:

I think there's a couple of things at play here. When we talk about people, particularly support workers, for example. Who are employed to provide personal assistance, care support, help to so-called access to the community, or whatever the other funky “service land” terms we give it, they're employed relationships.

That in itself brings a whole heap of assumptions and baggage and starting points. For people with disabilities, the reality is people need help. People need physical help, but the way in which that help is delivered comes down to the relationship, comes down to trying to work out who has the power in that relationship.

Typically, and traditionally the power has always sat with the more able person because we live in an ableist society, so that's where the power sits.

Unless you are a very reflective, very critical thinker who isn't into power and control and telling people the way that they should live their lives, the risk is that you will overrun and override, the type of support that people need to live their life, and do what it is that you think they should want to do.

Helping, or assistance, or providing assistance, or support, or whatever it is, is a very fine line for people who are employed in those positions.

Typically, in my experience anyway, people who are employed in those roles aren't always reflective and don't always think about why they behave in certain ways when they're actually providing that support.

I think it requires a much higher-level of thinking and reflection than we often give it credit for. If you really want to put the power in the hands of the vulnerable or the marginalized person, that's going to cause people to become uncomfortable. It disrupts the traditional power narrative.

We're seeing it play out with the Black Lives Matter movement at the moment - a marginalized group of people who are now starting to have their voices heard in ways in which white culture is struggling with because it disrupts the norm.

It's the same with disability, you take out skin color you put in able versus disabled, it's the same thing. You take out able versus disabled and you put in gender.

We're getting to a point in our society where all of our traditional power bases are being disrupted and I think that's a good thing. What we're seeing in disability is just another version of that.

Varnya:

I'm thinking too in the event even that you had say, a support worker, who was very reflective and who was interested in handing that power back to the person they are supporting. But, because of the way the services are delivered, and because of the corporate structures around those services, and because of the risk management that's involved with those corporate structures, even if you were a support worker who wanted to hand the power back to that person, I imagine that you would run into a whole lot of difficulties doing that.

I don't even know whether you would be allowed sometimes to do that because of risk management issues.

Bec:

Sure. That's because we have a capitalist neoliberal way of managing payment for support, meeting a social model way of supporting people. There's always going to be a clash. There's always going to be a clash. There's always going to be issues of risk management, there's always going to be issues of duty of care.

The problem is that we actually take away (we, and when I say we, I mean services.) People who are employed by services, sometimes inadvertently take away people's power under the guise of duty of care because we say, "Oh, no, you can't do that because the procedures won't let me or the rules won't let me or the whatever."

We don't allow people the right, the dignity of taking risks. We dress it up in this kind of "but I'm employed by, and the rules are, and the procedures say and I can't do that because" or, whatever. But we forget, particularly in the Australian context now, the person who holds the purse strings is the person with the disability in terms of National Disability Insurance Scheme funding.

We're always going to have that jarring because it's a capitalist economic system rubbing up against a social model, socially grounded way of supporting people and I don't know what the answer is by the way. [laughs]

Varnya:

Yes, it's a thorny one. The thought that occurs to me when we talk about the power dynamics inherent in those relationships and their lack of willingness for corporate players, or for support workers, or for the system to permit people with disability to take their own risks and to be allowed to take the same risks that the rest of us take. The thing that occurs to me is that it's treating those people as if they were children, not as if they were adults.

Bec:

Yeah, that's exactly right. For me as an academic, I go back to thinking about some of the stuff around Wolfensberger and his writings around social role valorization, etc. He talks about the typical negative life experiences of people who are vulnerable.

That's part of it, you take away people's power, you take away the opportunity. They become scapegoated, they lose the relationships that they build, or the ones that are paid to be there in their lives. As soon as the money goes away, then the relationship goes away.

That's one of the fundamental problems we have in our system is the people are only, well not only, but it's more difficult to build relationships in non-paid kind of circumstances for people who are marginalized or vulnerable, than it is to pay someone to be there.

That's the way our society's been established. Who has the power? Who's the most desirable? Who do we pay our attention to, etc.

Varnya:

A couple of weeks ago, I spoke with a guy, a sociologist actually from University of Wollongong, Roger Patulny. He was talking about the difference between emotional loneliness and social loneliness. The idea that you have this industry fulfilling the social loneliness and ignoring completely the emotional loneliness.

The carers or support workers in the lives of some people with disability, they're not only providing logistical practical assistance, but they're also providing social connection. Do you see that as an issue with this model?

Bec:

Yeah, absolutely. I think it's complicated by a number of things. It's complicated by the fact that people are paid to be in people's lives. Like the rest of us when we move jobs, would say to our workmates, "Oh yeah, let's keep in touch, and we'll catch up for coffee or drinks or dinner or whatever." You might do that once or twice. Then you move on to your new job, and your new place, and your new workmates. Unless those are very, very strong relationships, most of them go by the wayside.

So, if you think about that, someone who's employed by a service provider to provide support to someone with a disability. That's not to say that they don't build some relationship of care. That's not to say that they might not even progress that to some kind of friendship relationship, or being friendly.

But, the reality is, even in the best of human relationships, we've got to work really hard to maintain those. Once that employment relationship is gone, and the person is not paid to be there anymore, those relationships are even more difficult to sustain.

We're not just talking about that social connection, we're talking about the emotional connection that people have. If there isn't the emotional connection, then it's less likely the social connection will even continue.

Varnya:

It's so tricky, isn't it, as you said it's obviously a flawed system, but then what's the answer? What's the better solution to the issue? Because assistance is required and sometimes the system works really well. When you have that kind of weird duality of the role. Where it's logistical and practical support, but also the sort of social support - and then when the person moves on, it's really upsetting.

Bec:

It's upsetting because there's a paucity of any other relationships in someone's life. They don't have continuing family connections. They don't have the continuing friendships that they had from high school. From where they used to work or, where they used to play basketball.

It’s a dual-edged sword because part of it is that social support that people need to connect and do things, the leisure activities in our lives that bring us together and form them, the emotional relationships, the sticking-with-it.

I always think I should go and learn yoga. Yoga would be really good for me. But the amount of physical effort, first of all, that takes me to get in the car and drive to a new class and find out where the class is. Then to make sure I've got dinner on the table for my family before I go. Then you’ve got to put all this effort into meeting new people. If you're lucky, you might build a friendship with someone. But the period of time between actually trying something new and building a friendship with somebody often takes -- let's continue with the example -- multiple visits to the yoga studio before you see a familiar face. Then you might say, hey, and then not overnight, but over the next few weeks, you might end up having a chat or whatever. It's the mutuality of participating in something, whether it's our work or some kind of leisure activity or a hobby that provides us then with the opportunity, not just to build the social connection, but to build that emotional connection with other people.

It's the emotional connection that we all pine for at one level, and it's the most difficult connection to assist people with who are physically or intellectually or cognitively prevented from being able to engage in those kinds of activities.

Varnya:

For me, with my sister, for instance, the pandemic highlighted one particular support worker and the importance of that role when that person could no longer perform that role due to the unusual circumstances of pandemic.

Have you anecdotally heard any stories around this weird situation we find ourselves in this year or have you had cause to sort of think about those issues in this context?

Bec:

I have heard anecdotally of people having their support immediately ceased. Their physical support immediately ceased. So for people who had multiple days of personal care support, to go to the toilet and have a shower and do all those sorts of things. I have heard stories of those hours being cut considerably. I've heard stories of what we would call social community connection sort of stuff, just cut off. Going out in the world, to a painting class or going and doing your shopping or whatever, support being immediately ceased. It's been pretty awful for people fullstop, it's been pretty awful for everybody. But the impact of it has been even more significant for people who traditionally rely on those types of services and support, to just live their life.

Varnya:

It's massive, isn't it? For me, it exposes the vulnerability of the whole system.

Bec:

It also exposes the vulnerability of people who...Think about women in FDV, family domestic violence, situations suddenly in lockdown with their children and their abusive partner, for example.

We're not just talking about people with disability, or people who require other types of support. We're talking about other vulnerable groups of people. One thing that I noticed about COVID, and COVID lockdown and moving to online versions of life is that it highlighted the really good relationships that we have in our lives generally.

Our really good mates would connect and send text messages and connect on Zoom calls and whatever, but I think it also really highlighted the negative aspects as well.

People who are really struggling perhaps with depression or mental health issues or who might've just been faking it through in the real world and then were suddenly thrown into COVID lockdown. I think that's highlighted the difficulties that people face on a day to day basis, certainly that’s been my experience.

I think COVID is going to offer us a whole lot of opportunities, but the downside of COVID is we're also seeing the worst of people. We're seeing a very individualized response to some of the requirements around wearing masks and going into lockdown and not leaving your house or not leaving your community to try and stop the spread.

My perception is people are very tied to, "Well, what's it going to mean for me?" Not necessarily, "What's it going to mean for my neighbor or my family or my extended family." We're not paying attention until it's someone that we know who has it.

Varnya:

It's interesting, isn't it? I felt like for the first few weeks, maybe even for the first month, there was a coming together because of the unusual universality of the experience. There was just a bit of a banding together approach, but I found that very quickly changed into an individualist, dog-eat-dog is a bit harsh, but protecting of oneself, or maybe one's immediate family at best.

Bec:

I don't know. I think it's a little bit of a fight-or-flight reaction in a lot of ways. There's plenty written about the deterioration of the traditional community over the last several decades. The response is what we're saying - pockets of people doing really beautiful things, like looking out for neighbors and looking after the elderly, and that sort of thing.

But I'm seeing more and more not very pleasant side of people, [laughs] I guess, very individualistic responses. "But what about me? Whose situation is the worst? Well, you think that's bad? Look at my situation." The reality is it's pretty bloody ordinary for most people, but the impact of it is very, very different for some of those folks who've lost their day-to-day supports, for example.

Varnya:

For sure. Now, I do have a reputation for being a bit of a Pollyanna, so you can slap me around if you like.

[laughter]

But I do wonder if there is a vaccine found, if we all can go back to semi-normal life, and if this becomes a distant memory, I wonder in that event if the shutdown might engender some empathy around just the concept of isolation and the concept of social isolation that is more commonly experienced by people who are vulnerable, people with disability, or people who are just socially isolated ordinarily within society because there's been far more of us who've experienced those feelings of loneliness and social isolation than we would have previously.

Do you think there's a rare window here for some real empathy and connection, or do you think I'm being a Pollyanna?

Bec:

I think there's always a window of opportunity. I don't think though that we're going to see that groundswells that tips us into that being a new way of thinking about things because...well, why do I think that's the case? If we go back to what I just said a minute ago, which was around the individualistic fight-or-flight, what's-in-it-for-me responses. We're too interested in our own personal circumstances, let alone what it means for other people as a society. I would love to say that I was wrong.

Again, if I took a drone's eye view of what's happening in the world around, particularly, even in the last 10 years or the last 20 years since maybe 9/11 or whatever, we've seen massive changes around gender politics, we've seen massive changes around race politics. We're starting to see massive agitation and political responses around disability. We're in a massive period of change. I don't think we're going to see things as a result of COVID quickly. I don't think they're going to be significantly obvious, but I think if we were having this conversation in 10 years' time the landscape is going to look very different, particularly, around the typically marginalized groups that we've just been talking about.

It feels like there's a groundswell for all of the groups of people who would be traditionally marginalized, traditionally vulnerable. Things are going to look different, but I'm not sure that we're going to see a lot in terms of empathy and connection for a long, long time.

Varnya:

You still used to sound quite hopeful there though. It sounds to me like if we were having this discussion in 10 years -- am I wrong? -- you do think that there is cause for hope?

Bec:

Yeah, I think there is cause for hope. I get the sense as a world and as a planet we're going through a very painful rebirth, for want of a better way of putting it. The ways in which we've done things traditionally are no longer going to hold up. They're just not. They're just not going to hold out. This world where we position some people as other is unsustainable.

Varnya (extro):

Dr. Bec Waters, chatting with me about issues of disability, power and the concept of help.

I’m Varnya Bromilow and you’ve been listening to the Connected Us podcast. You can find the rest of the series at the Befriend website...that’s befriend-dot-org-au or wherever you find your favourite podcasts.

Thanks so much for listening. Stay safe and see you next time.

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