Inform Podcast
Episode 15: Disability Pride Transcript

Kirby Fenwick

Hello and welcome to Inform, a podcast where you'll be hearing from people with disabilities, as well as industry experts, on a range of topics. I'm your host, Kirby Fenwick.

In this episode of Inform, we'll be discussing disability pride.

Our guests today are artist and disability culture activist, Larissa MacFarlane who is both 51and 21-years-old—more on the later—and 17-year-old Issy, who works for a youth disability organisation.

Neither Larissa nor Issy are experts, what they're sharing today are their personal stories of disability pride.

Larissa MacFarlane

My name is Larissa MacFarlane. I just want to acknowledge that I'm speaking to you from the land of the Boon Wurrung one of the five language groups of the great Kulin nation. And I also just want to acknowledge and respect all the self-advocates and disability activists that have come before me here in Australia, because they've really paved the way for me to be here today speaking to you about disability pride.

I am a white woman wearing a collection of flowers and stripes in different colours, and that don't match. I'm 51-years-old, and I also am 21-years-old—I have a brain injury.

Yeah, so I acquired a brain injury coming up to 22 years ago. I think living with a brain injury, like probably living with any other type of disability is, is makes you really different in the world. And for a long time, I found it really difficult to sort of identify with my brain injury in a positive way, because all the messages around me was sort of saying that I was a tragedy, and that it was so sad that I had lost, you know, things and, and I was also seen as difficult and, and so it took me a long time to sort of start to see my brain injury in, see the great things that have come out of it. And also to see, see the value in disability and disabled culture. And part of that was owning how old I am. Because literally, when you have a brain injury, your world changes, your personality changes, and you have to learn everything again. And in some ways, I'm really young. But I'm also really old.

So another big part of who I am as a person with a brain injury is that—so I became an artist after my brain injury, I had no interest in art beforehand at all. I was a musician, and I lost that ability to understand music after my brain injury. But I had this great passion for what I could see. And so through that I became an artist. It was a very long journey took years. But I was quite passionate, and I practiced a lot and became an artist.

Kirby Fenwick

For Larissa, self-advocacy provided a way to connect with disability pride

Larissa MacFarlane

For me, you know, I do, I feel like I'm a child of self-advocacy, because I'm a child of that being grassroots being disability led, speaking for ourselves. And when I say self-advocacy, I'm specifically talking about group self-advocacy, not individual self-advocacy. I mean, there's that individual self-advocacy, we have we—we need to do for ourselves, which can be really hard, which, which is why I like to align myself in peer spaces so that I gain strength from other people.

And I suppose, my, my passion, I suppose, for making artwork around disability pride also started in those spaces, because I would look around at my peers. And not only did I feel comfortable there, and did I feel able to identify with confidence as being disabled and having a brain injury. But I also—whereas I wasn't able to do that so much in other space—but I also looked around and I saw amazing people.

I think that people with brain injury are actually some of the most interesting people on the planet. But it's such a well-kept secret (laughs). And so I suppose, ah, but I also saw that these amazing people didn't have a level of confidence or pride in themselves. Like I didn't. We didn't respect the journeys we've taken and the stands that we make and the work that we do. We weren't, we find it difficult to value it. And it took me a long time to work out why. And so I pondered this question for years, because I found myself, as an individual, I would experience shame about identifying with disability or identifying with a brain injury, outside of those safe spaces, those spaces in my community. As an artist, I got messages that I really shouldn't talk about my disability because my art wouldn't be taken seriously. And I and so I did, I tried to keep this a bit of a secret or hide it, because I really just couldn't understand why I kept feeling this shame and this, this need to silence part of myself.

And I think it hit a—there was a turning point where about eight years ago, nine years ago now, I suddenly realised that I had this awesome skill apart from my art, but after as a, as a result of my brain injury, and that's that I do handstands, and I started doing handstands six years after my brain injury. And I'm not even sure why I started, I was completely obsessed. I was 35. I'd never done a handstand as a child. But I was convinced that I needed to do a handstand. And it took me months and months and months and months. But when I finally got there, I just kept going. And so I still today do a handstand every day. And it's a really important part of managing, managing my pain, my chronic pain, but also managing my stress, managing myself, it just manages lots of things about my body and my brain and my mind.

But I found, I suddenly realised I'd been doing these handstands every day for seven years. And it was a secret, and no one knew. Very few people knew. And it was partly a secret because it's, it's not a performance. It's something I do just for me to make myself feel better, but I was hiding them, I'd go around the corner, or I'd go off to the toilets and do a handstand in the toilet. Like I was, I felt that I needed to keep this hidden. And I realized it was because it was connected to my brain injury.

Because why was I hiding this, this awesome thing, this thing that I become so good at because if you do something every day for so many years, you get really good at it.

And so I realised, I don't know, that's maybe I went, I need to do something about this. I need to come out as a hand stander, I need to come out as about my brain injury. But, but I was still quite a young artist. So it took me a few more years before I started then taking to the streets and doing street art about my handstands as a way of sort of claiming space. And claiming this as my space I was putting images of myself in a handstand with my walking stick and usually with some words written in there about the experience of disability or brain injury or why I was doing handstands. So it was sort of quite subtle as a, you know, it wasn't loudly saying disability. But I came to understand that this was about my way of trying to celebrate who I was and try to be public about it. So I look back and I realised that was really one of the beginnings of exploring how to do this thing called disability pride.

Kirby Fenwick

In 2017, Larissa created her first disability pride mural.

Larissa MacFarlane

The reason I initiated the first Disability Pride murals because I wanted to know more about disability pride and I wanted to find a space to do it. And I wanted to do it with my, with my friends, because when I do things with my disabled friends, it's easier.

The final point where I started going I have to do something, I want to do this mural was when I learned about the Disability Pride movement in America, and found out that they have annual Disability Pride marches. And that blew my mind. And I was like, that's amazing. And how come we don't have anything like that? How come Australia doesn't have a culture of pride marches?

And so it then became about how can we do something in public space on a wall. Because that's what I'd started doing was putting artwork on walls. And, yeah, so I mean, you know artworks take, they don't just happen. They take years of gestation. And I look back now and I also see that I was talking about doing a disability pride mural, I didn't call it a mural, it was just going to be a disability pride work of some sort. And I was talking about it for a year or two, not really knowing what I was talking about. And I think that's how we make artwork is we need to talk through ideas, and eventually we commit, and yeah, so it was amazing.

The first one was end of November, it was a few days, about a week before International Day. And it was part of, my local council had like an evening Arts Festival, and I'd applied for a spot and then I put the call out to all my friends saying and by this stage you know I'm quite, I'm fairly well connected across, you know, within brain injury and people with intellectual disability, people with mental illness diagnoses and lots of other people with physical disability.

So I had like, a lot of people to call, call on. Not everybody was interested. I think that being part of a disability pride project was a bit much for lots of people. And, or just, you know, a difficult concept. A lot of people did hop on board, and they were like, nervous, really nervous. Because it was a big step to identify in public space. But yeah, anyway, I asked people to send me their artwork, send me their images of themselves, send me anything, anything really that represented themselves.

I invited people to be political, if they wanted. To be, you know, to be strong, to be or not just to, to be who you are. Because I think that I was interested in exploring the, what is disability culture, and that is really anything that all of us are. And we're all so diverse, and we all have such different experiences. And I wanted to unite it all under a disability pride banner, which is what we did.

So my practice is doing paste ups. So people sent me their artworks and some other people I worked with them to create something or an idea. And then I had all these images and these words, and I printed them all out on paper on a really big machine.

And we all turned up on the night. We had a little scaffolding, mini scaffolding, and we pasted it up onto this big big wall. This is a big wall. It's like 16 metres wide. And I think it's 10 metres high. Not that we were able to get that high. We only got up about two meters. But still a big wall. And we pasted up. We had a wonderful time getting our hands mucky with flour and water glue. And we made this beautiful mural.

Kirby Fenwick

Unfortunately, the mural was taken down not long after it was put up.

Larissa MacFarlane

It’s something that I wish had never happened. Because it sort of put a real dent in me and some other people, and lots of other people too. But yeah, unfortunately, a week later on the early morning, after International Day of People With a Disability that Monday morning, it was removed, the whole thing was removed. And it was done by the graffiti team, anti-graffiti team that the council contracts to and I never got to the bottom of it. I imagine it was a mistake. A mistake of ableism but it was really sad. And it was quite shocking. And for many of us, it felt, yeah, it was really painful. And it was really difficult to come back from

My vision for it was in so many ways, so naive. So I envisaged in 2017, that we would put up this mural, and it would just have such a big impact, and everyone would, all the disabled people, all my friends would be going ‘Oh, this is awesome. Can we be part of the next one?’ Because it was, we're going to do it annually. That was my vision. And, and also that people would see it and suddenly understand that, and stop being so ablest.

But, um, but you know, it didn't happen like that at all. We did, just to finish the loop, we did actually go on to replace the mural. And it is bigger than and better than it was before. That was in the next year. And we did it as part of the Fringe Festival. And it is actually still there today.

And I do think even though it feels like movement has been slow, I do think that mural has changed has, has shifted the conversation or maybe, maybe it's just so many people now are talking about it. So it gets mentioned and, and I'm so proud to see when people start identifying with disability pride or talking about it, it's so amazing.

Kirby Fenwick

Like Larissa, Issy's path to disability pride was encouraged by their involvement in the wider disability community

Issy

So hi, I'm Issy. I use they them pronouns. I'm currently residing on the land of the Wurundjeri, Woi Wurrung and Boon Wurrung people of the Kulin nation. So I pay my respects to their elders past, present and emerging. I'm disabled, I'm queer. I'm currently in year 12 at an alternative school. But I think more excitingly, I am lucky enough to work for a cool disability youth organisation where I get to work with and for other disabled young people.

Kirby Fenwick

Earlier this year, Issy wrote an article for Inform about their path to disability pride and how working with other young disabled people helped them get there.

Issy

I wanted to kind of think about, like, recognise how grateful I am to be in a position that I am disabled, but I'm also working in the disability space, and recognise the, yeah the privilege and power that I've gotten from all the learnings I've had in my role. And I think that's definitely the key one for me, like, you know, I've learned a lot about you know, I suppose, scientific understanding and facts and like social model of disability and all that good stuff as well.

But how it all kind of hit me as being someone who works in that space and thinks about that all the time, was kind of like massive, and I thought, bridging that connection and realising that for myself, and realising that it actually was the opportunity to work in the space and work for other people that allowed me to feel disability pride for myself and I thought that that was an important thing to communicate. Because I think sometimes how people view disabled people is that we’re either really, really like struggle and hate the fact that were disabled or that we're inspiration porn, and that we're so proud of it, and that there isn't an in between and I think communicating the journey and yeah, what the reality is, was really important to me

It definitely was kind of, yeah, seeing it before I could believe it and then yeah being like weirdly disconnected from it. And I think for a long time, I kind of struggled with this, these polar thoughts where I was like, ‘Okay, I'm not disabled enough to be disabled, let alone, you know, have disability pride,’ or like, on the opposite to that, just being like, so kind of upset at the world and like my disabilities for how much I felt I was debilitated by them, but that wasn't something I even wanted to be proud of, it wasn't something I wanted pride in.

So that kind of, you know, admittedly toxic, like dichotomy of thoughts was probably the reason why it took me so long to kind of engage. But I was lucky enough to work for just like a super cool organisation, that is like by and for disabled young people, where I, you know, worked with other disabled young people to achieve their goals, and work on actions and make change, but also, like, directly and indirectly helped them to feel disability pride. And I was doing the job for a while before, like, the hypocrisy kind of set in and I was like, ‘Oh, that's kind of ridiculous that this hasn't felt like a reality until now’.

But when I kind of realised and had that kind of, you know, stereotypical breaking point, like, oh, like, light bulb moment, I realised, oh, like my awesome like disabled colleagues, and like, the people I work with, have disability pride, and I want them to and I think that's incredible, then maybe I can, you know, mentally slowly let myself you know, fill their shoes. And, you know, it became like a kind of a day by day even like a task by task thing that I kind of gave myself a little bit of permission to, you know, feel it until, you know, slowly but surely it became a habit. And now like, I feel like it's a bit naff, but like, yeah, I feel like my like, ready power stance is like proud if that makes sense.

Kirby Fenwick

Issy says that alongside this work with young disabled people, engaging with the disability community has also helped them.

Issy

I think it kind of gives me permission, not that I should need permission, but gives me permission to be thinking about these kinds of things. If that makes sense. Because a lot of society doesn't really want you to talk about your marginalisation and your intersection. So if I'm kind of doing that, in the context of listening to what other people have to say, and reading what other people have written, and seeing videos and pictures and stuff that other people have posted and communicated, then it is something that society perhaps would make me feel less guilty about.

So that perhaps was the initial kind of, like reasoning for that. But then, you know, as it went on, longer and longer, I just, like, you know, slowly, you know, liking and commenting on more posts, watching more videos, that kind of stuff, I realised how, how much I related to it, even though I knew obviously I did because I was disabled, but it just like, it felt that, they did feel like a community in a way that other communities don't necessarily feel like that, like, you know, the school community. I'm a part of that because I go to that school. But you know, being in the disability community and seeing people online and social media, and sharing and engaging in that way, that felt like, that really felt like my people if that made sense. And that really allowed me to do that kind of, you know, self-discovery. I know that's a bit of a buzzword, but enabled me to do that and then realise the impact of it on my life and what role I needed to play in my life regarding my disability.

So to me, I think Disability Pride is the reclaiming of, you know, the shame, the devaluing, the invalidation, the discrimination, all of these loaded things that the abled world and its institutions of power put on us and taking that back, and owning it and owning you know what they don't really want us to.

And so having disability pride or really working towards it, and practicing it, is an act of defiance. It's an act of protest. But I think it's more importantly, like, an act of power, like, it's a choice to take up that space that we're traditionally told we're not allowed to. And I think kind of another layer on that is, it's important because it allows us to, like, realise what we really are and what we're really capable of, because it's not as if you have disability pride, and then suddenly you have unrealistic expectations of yourself and think you're superior. It's, unfortunately disability pride is just seeing you as the awesome adequate person that you are.

Yeah, just one thing on Disability Pride generally. Like noting that things that we do, are not despite being disabled, but we are disabled, and we're doing them and that's cool. It's not we're doing them and it's this massive feat, because we're disabled. And that's such a burden.

It's like, cool, we're a person, cool we're disabled, look, we've also done these things. These are all like, equal feeling things and, you know, making sure that that is the case. And hopefully, if people understand that a bit more, the whole inspiration porn kind of hyperbole of what an assumption of disability pride could be will go away.

Kirby Fenwick

Like Issy, Larissa believes that disability pride is not static, but an ongoing process

Larissa MacFarlane

The other thing I'll say that disability pride too is that I see that it's a practice. And it's something you just don't suddenly get you don’t suddenly go, hey, I've come out. I'm disabled and I'm proud.

It's about owning my life and owning my stories, and being able to identify with them in a way that doesn't include shame. In a way, where I can be proud of who I am. And, and the steps I've taken, the interests I have, the things I do.

It's also about challenging attitudes. So by proclaiming yourself, I like to introduce myself, as you know, I'm a proud disabled woman, I still find that hard to do in public spaces. But when I do do it, I can, I know that the audience sits up. And this is predominantly a non-disabled audience will sit up and go, ‘Oh, oh, that doesn't how, How can you be proud of a disability?’. So it's about changing attitudes, and, and shifting it away from sort of negative stereotypes. Disability Pride also is about shifting away from inspiration porn, as well. It's also about building a sense of disability community and disability culture.

A big part of disability pride, for me was learning how to challenge, having a framework of understanding to challenge the shame, which I came to learn was internalised ableism. And that's where the people, my culture around me is ablest and so I can't help living in this culture to take on that ableism and then I find that I'm turning it onto myself. And so I'm then finding fault with myself because I'm only taking on the attitudes of society. And I think I saw that disability pride was like an antidote to that. It was a way of practicing and saying, there's nothing wrong with the word disability. There's nothing wrong with the word disabled. And what is at fault is our society which puts in barriers. And those barriers might be physical or there might be attitudinal. They’re barriers where people can't get employment. They're not treated in the same way, have difficulty accessing health care or housing. So many barriers.

Yeah, as I said, I struggled a lot with noticing how I was experiencing the shame and noticing the stigma that my friends had, and I had, and wondering why we had it and trying to understand how to get rid of it. And it wasn't til I discovered the social model of disability that really explained to me the way that in opposition to the medical model of disability which sees that my body and my brain is a problem and my body and brain needs to be fixed or cured or managed.

Instead, the social model of disability sees that it's actually the problems lie within structures of society, and that disabled bodies are not wrong. And they really more represents, you know, the, the wide diversity of human experience.

So discovering the social model was a really big turning point and discovering alongside that ableism. And the internalised ableism that I was experiencing as shame. And learning, learning having other people state it for me. So, some great people like here in Melbourne, Jax Jacki Brown, and Carly Findlay, they've both spoken about disability pride and what that means. And when I heard them do that, that really helped me to start it start to articulate it for myself.

Yeah, and I do know that since I discovered disability pride, and since I discovered the social model, and it has made a really big difference in my life, it's given me more confidence, it's made, it's probably made my life more difficult in some ways, because I can now see structures of discrimination more clearly. And, you know, that's pretty hard to know when you see it all the time. But it has given me a way to sort of try and address it as well, and try and speak back to it.

But I think it's times like these where I try to remember there's an awesome poem, that a legendary US activist poet, called Laura Hershey wrote some time ago, I think, around 10 15 years ago, and it's called Practice to be Proud [You Get Proud by Practicing]. And it's all about trying to practice disability pride. And so I would like to, I'd like to recommend that, you know, you go and look up that poem and read it because it gives me solace when I need it. Yeah.

Kirby Fenwick

Thank you for listening to Inform, a production of Independence Australia. Inform is hosted and produced by me, Kirby Fenwick. Our managing editor is Alison Crowe.

You’ll find links to the resources mentioned in this episode, plus more, in the show notes at informonline.org.au

Our thanks to Larissa and Issy for sharing their stories of disability pride. If you have your own story of disability pride, we'd love to hear it. Get in touch by emailing Inform@iagroup.org.au
That's I n f o r m at iagroup.org.au

This episode of Inform was recorded and produced on the lands of the Wurundjeri people of the Kulan nation. We pay our respects to elders past and present.

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