

Making disability and art work

Tyson:

Hi, my name is Tyson. Welcome to the Making It Happen Podcast presented by Access2Arts. In this podcast series as a team, we are seeking to examine the roles of the producer in the South Australian deaf and disability arts sector.

Access2Arts is a disability-led arts development agency, and the peak body for arts and disability in South Australia. Access2Arts acknowledges that we and our home are in Kaurna country. We respect Kaurna elders past, present, and emerging, and through them to all Aboriginal and Torres Strait Islander peoples. Please enjoy the podcast.

Welcome to Making It Happen Podcast. I'm your host, Tyson, and today we're honoured to have a special guest with us, the incredibly talented Libby. Welcome, Libby.

Libby:

Hi. Thanks for having me.

Tyson:

No worries. In one sentence, please describe your remarkable career and your impactful work.

Libby:

Oh my goodness, one sentence. I'm a writer, comedian, cabaret performer, and the work that I do is mainly based around chronic illness and disability.

Tyson:

Amazing. Amazing, that was really tight. What inspired you to become a producer in the disability art sector, and how did you get started?

Libby:

I mainly just because I needed to produce my own work, because I was just starting out doing things that I needed to put on the stage. And so I needed to do it myself. And then through doing that, my shows got bigger and bigger, and so I ended up producing that. And then I produced a venue and I produced shows at the venue as well and different organised workshops and other kind of things.

So I produced a number of different things on a number of different levels. But I think it all was based around wanting to do particular work and it, not being there, so just doing it myself.

Tyson:

Yeah. Regarding collaboration and impact, could you share an example of a project you worked on in the disability arts sector and how you ensured accessibility for everyone who was involved?

Libby:

My show Endo Days is about endometriosis and chronic illness, and that show is for people with chronic illness. So it's really hard to get people to come because they're chronically ill. So I had to try and make it as comfortable as possible.

And I did that by running the first show in my own venue and making it super comfortable, to the point where if somebody was having a pain flare, I'd just pop off the stage and go and heat up a wheat bag for them.

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Interactive.

Libby:

Yeah. Just making sure everybody was comfortable, having it at a time that suits people. So earlier, the better, because we get tired by the evening.

Tyson:

Yeah.

Libby:

And that was how I did it. And then just listening to what people needed. And then when I opened my own venue, Prompt Creative on Pirie Street, I made sure that it was wheelchair accessible, that I was able to have a variety of different acts, and I guess productions, here. But also that it was small enough that I was able to manage it myself, because I don't want to bite off more than I can chew when I'm also chronically ill and neurodivergent.

Tyson:

Yeah. I see.

Libby:

In terms of collaboration though, collaborating with other artists. I've just written a book called Endo Days as well, and I interviewed a lot of different artists that are from different backgrounds and abilities, spicy brains, and not, like me.

And it was interesting to hear what they needed and what they wanted and how we could collaborate, and the fun things that we could make together. Because I think the more spice the better.

Tyson:

Yeah. And how's that book going?

Libby: It's ready to be released. It'll be released next week.
Tyson: Oh, cool. Next week, wow.
Libby: Yeah.
Tyson: Wow. That's exciting. Congratulations.
Libby: It is exciting. Thank you.
Tyson: Yeah.
Libby: Thank you. It's been a big undertaking and it's been really exciting and terrifying at the same time.
Tyson: Yeah. Doing a book is a big milestone for a lot of people or artists.
Libby: Well, when I was approached to do it, I thought, well, how hard could this be? I'm a writer, I can do that I like to talk. And it turns out it's really hard.
Tyson: Yeah.
Libby: And I was only diagnosed with ADHD last year, and I'm 46 this year, so I've lived my entire life as an undiagnosed person with ADHD. So writing that book was particularly hard because of my executive dysfunction.
Tyson: Yeah. Wow. But you got through it, did it.
Libby: I did it, yeah.
Tyson:

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Yeah.
Libby: I did. Thank goodness for all those moments of hyperfixation.
Tyson: Yeah.
Libby: They're very helpful. They got a book written.
Tyson: Yeah, for sure.
Libby: And being able to talk to lots of people and learn so much about the experiences of the people with chronic illness and differently abled people and different backgrounds and genders all across Australia And how they live with chronic pain, and how they have their relationships and what they need as we was the best thing. And I've got no regrets. It was a really hard thing to do, but I loved it and I'm glad that I learned so much.
Tyson: Yeah. Does the book augment the show?
Libby: So it's funny because the book informs the show and the show informs the book. So I talk a lot about the show in the book, but I also learned so much about things from the show. So a lot of stories that people tell me in the show, just part of conversation when I just ask questions and people are very generous with their information and their time when I'm doing the show.
So with their permission, I've put some of that into the book. And it also informed which directions I wa going to go because of having everyone's so very, very different and having the most incredible responses from people and wild stories of misdiagnosis and just medical gaslighting, and inaccessibility and all that kind of thing.
It meant that there were so many more stories that I needed to tell and people that I needed to help give a voice to. And that was all done. Because of theatre-
Tyson:
Yeah. Wow.
Libby:

That was done.

Tyson:

That's-
Libby:
Gives us a voice.
Tyson:
Yeah, yeah, for sure. And did you find a common voice through all the variations of
Libby:
The stories are very similar in that a lot of people waited a long time to get diagnose

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The stories are very similar, in that a lot of people waited a long time to get diagnosed, so had to make accommodations for themselves over the time. And that can lead to a bit of trauma and not trusting the medical profession and doubting themselves and being gaslit, but also gaslighting themselves sometimes. And intergenerational stuff as well. It does actually have a genetic leak as well, that we know of. So yeah, the ADHD has just made me completely forget your question, but here we are. I'm

Tyson:

We got there. We got there.

sure we got there.

Libby:

Yeah.

Tyson:

What steps do you take to ensure that events and projects in the disability arts sector are accessible and welcoming to people with disabilities?

Libby:

Do you know? I'm still learning a lot. And I'm still getting past my own, I guess, internalised ableism that I fought so hard for my whole life to not be disabled, because being disabled was bad.

And now I realise that I have been, I am physically disabled and I'm neurodivergent and I have got a learning disability, and that's something that I now need to come to terms with. And it also means that I need to make allowances for other people, and it means that I need to open my ears and eyes a lot more to things. And so I'm constantly learning.

So it's not just enough that my venues and my projects are wheelchair accessible. It's not just enough that I've got space for people with mobility aids. It's not enough. But that's what we tend to think, is accessibility. Whereas I need to be a lot more in tune with how my events are received on a sensory level as well.

And sometimes I'm not, because I'm hyper, I'm a sensory seeking kind of a person. But I know that there are people who are not going to be able to deal with that. So there's so much more I need to learn. So what I do at the moment, of course, I ask and I listen and I learn.

But what I try to do is create a safe environment that I would feel safe in, and then ask my band and the people who are involved in my show what they need. And then if somebody tells me, well, actually that doesn't work for me. Or if part of my audience will be, I can't deal with what you're doing now, or something like that, then I listen and I change it.

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Tyson:
Yeah.
Libby:
So I'm not always going to get it right, but I'm going to try.
Tyson:
Yeah, we're all work in progress when you're diagnosed, and also with access and improving accessibility for yourself and the audience and making it inclusive. In these podcast interviews there's been a common thread of a access rider for producers and performers in a way, which is a great concept to request or to curate, when you collaborate with artists, when you produce for people, and also communicate with venues.
Libby:
Yeah, that's a good idea. And people always ask you what your accessibility needs are. And I guess for me, because I've spent so long trying to just push through and being a bit of a martyr until Because for endometriosis, there's a seven-year delay in diagnosis time. For me, it was 22 years between presenting with symptoms and actually being diagnosed.
So by that time, the idea of just pushing through, getting on with it, suck it up, shut up, keep going, it's pretty deeply embedded. So when somebody does ask me what my access needs are, I don't want to say anything. I don't want to rock the boat. And luckily are really good like that, they say, what do you need? And I'll go, oh, no, no, nothing. And then they say, what do you need? And then I'll tell them, and then it will happen. And I'll be, ooh, well, that makes it easier to perform.
Tyson:
Yeah.
Libby:
I could've asked for that before. Why didn't I do that before? And I think that makes you a better producer, when you're treated like that as a performer, because you think, well, I want my performers and my audience and anyone involved to feel comfortable and to feel safe and to have what they need in order to do the best show that they possibly can, because that's the end goal, isn't it? Is to do a good show and to have an audience walk out, going, that was the best thing I've ever seen. And they can only do that if they feel safe and accepted.
Tyson:
Yeah. Yeah, totally. It's a funny feeling not knowing you are entitled to access and inclusion. Because no one's told you or-
Libby:
That's right.

Tyson:

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Or that self-denial. And that you've almost put yourself in a glass cage or a glass cell, in your mind that I can just get on with it. And pushing through that and being able to voice that requires a bit of courage and practice. And then you see everyone is accommodating. It's not as bad as you think it is in your head, especially the first time you try it.

head, especially the first time you try it.
Libby:
That's right. And it's a nice surprise.
Tyson:
Yeah.
Libby:
I remember I tried to apply for a parking permit, because it's getting harder for me now. I've got my endometriosis and adenomyosis as well as fibromyalgia and now arthritis as well. And so it's getting harder for me to walk around. And I use a walking stick. And I went to my GP and I was amped up to d

harder for me to walk around. And I use a walking stick. And I went to my GP and I was amped up to do this, and I was ready to ask, can you sign off on a parking permit? And I was ready for her to say, no, what's wrong with me? You're ridiculous. Of course not. You can jog.

And she was year no problem. And I was so ready for a fight. I was so hypervigilant and just ready to

And she was, yeah, no problem. And I was so ready for a fight. I was so hypervigilant and just ready to take her on. But, oh, okay, cool, thanks. And now I've got one, and it's great. And it's so much easier, because now I can do more because I'm not so exhausted that I...

Tyson:

Yeah.

Libby:

I'm coming to terms with there being options for you and utilising them is pretty cool.

Tyson:

Yeah, it is. Isn't that? Yeah. And it allows you to be more productive and just have that, a few extra battery cells in you for creativity and self-care and all that kind of stuff.

Libby:

Yeah. And I think when you're the boss, when you're the producer, when you're the performer, when people are looking to you because you're in charge and they want to be in safe hands and they want to know that it's going to be okay, there's a particular level of trust when you're in the arts because people are looking to you to take them through this journey, because arts can make you vulnerable, and it can make you feel things, and it puts you in situations where you might have to express yourself in ways that does make you a little bit more fragile. And you need those accommodations, and you need that accessibility, because otherwise you can't be what everybody needs you to be.

So having those has changed my life, and I've had to, over the past year, I can't believe that I've lived this long without making accommodations for myself, but anyhow, I'm getting better at it. For the past two years, I've identified as a disabled person, because I have mobility issues. And since doing that, I've felt more empowered than ever. But I avoided it because I thought maybe it might disempower me, but it

hasn't at all. It's so much easier. And I use a walking stick and people say to me, oh, no, that's terrible. It's not, it's great.
Tyson:
Yeah.
Libby:
Great, because it helps me. I can lean I'm leaning into this.
Tyson:
Yeah, literally. Yeah, absolutely. Yeah. Oh, that's fantastic. It could be our generation as well. We're a similar age, and I remember as a child and a teenager that there wasn't much access and inclusion or even awareness.
I remember having trouble doing sports and stuff like that, and the PE teachers didn't really accommodate, but just had to push through. But yeah, things are quite different now. And that it's great being able to be in a position to help people.
Libby:
Yeah. It's nice to be one of the ones who's pushed for that change as well. There's some people who are, well, I had to go through it, and so they should too. And then there's other people who go, no, I feel maybe I suffered so that no one else has to. And pushing for change based entirely on what you've had to deal with, I think is one of the most important things you can do.
Tyson:
Mm-hmm. Do you think you've grown as an artist and a producer through your experiences with disability?
Libby:
Exponentially.
Tyson:
Yeah.
Libby:
Yeah. I think there's no way that I would be the artist that I am now without my diagnosis of chronic incurable illness. In fact, that's the thing that got me up and moving. It was through my endometriosis and adenomyosis. I've had had 11 pregnancy losses, and it was through that grief and that trauma that I needed an outlet.
And so I started making comedy. I started making theatre because I needed to laugh through that pain. I

needed to have something, some sort of outlet. I was so sick during that. But I don't know whether I would've done all of that without that gritty stuff to push through. And without going, well, I've just had this diagnosis of endometriosis, well, now what? I need to tell people, I need to tell people that it's okay. And I need to tell people that we've got a voice. And I need to do that by making them laugh and making

them sing and making them happy, because there's still some hope and we can get through this together.

So without that, I don't know. Because I think I found my voice. I think I found my voice through this. Because I finally accepted who I was, rather than being so angry at myself for not being able to do things and not knowing why. For 22 years I would go to doctors and say, I'm in so much pain. And they'd go, well, you're anxious and you're depressed. And I'd say, well, but nothing's wrong. Nothing's wrong in my life. I don't have anything to be anxious or stressed or upset about.

So I think when I finally got this diagnosis, that there was actually physical, there was definitely something wrong in my body, it was liberating, so liberating.

Tyson:
Yeah. Wow. In some, would you consider a blessing?
Libby:
Yeah.
Tyson:
Yeah.
Libby:
Yeah, definitely. And I don't know a life without pain. So I can't think about that. I can't think about what it would've been like to have been diagnosed with ADHD as a student who was struggling in school. I think I would just get really sad about it if I thought about that. All I have is now, and now that I've got a voice and a platform and can make theatre and can make comedy and make people happy and talk about these things and represent, I think that's the best. And I couldn't be happier in my life at the moment with all these diagnoses.
Tyson: Yeah, for sure.
Libby:
A whole alphabet. I thought I looked okay.
Tyson:
Yeah. That's amazing. Are you aware of the stoic philosophy of, the obstacle is the way?
Libby:
No, but I love it.
Tyson:
So-
Libby:

Tell me everything.

Tyson:

It's a thing I've leaned into all my life as a child and as an adult, the disability or the obstacle has been the way and it gives me freedom instead of limitation. It's just a lens and a paradigm you lean into, flipping it into a positive and as a growth opportunity.

Having that resilience and grit is a beautiful thing to be able to work on. And I think as an artist, you get the opportunity to create richer work as well, having these kinds of obstacles, which are gifts in some ways, almost a muse.

Libby:

Agreed. Absolutely agreed, yeah. I felt when I got my first diagnosis, I felt this door that had been locked for so long had been opened for me, and I could finally walk through and see what was on the other side. And whatever was on the other side I don't know whether I'm going to like it. I don't know whether I'm going to be able to live with it, but at least it was open and I could go through.

And could've just not accepted the diagnosis, or I could've just gone, yeah, okay, cool, that's what I'm living with now, but did. But I'm a teacher, my trade, and it's in my DNA to impart knowledge, and that's what I wanted to do. Because I thought this pain that I've lived with, it's been since I was a teenager. And I know the conversations about period pain and just body stuff and all the icky stuff, that starts in high school. We talk about it. People generally just... I guess I'm stereotyping a bit, but people who were assigned female at birth, we do tend to natter about that kind of stuff.

And so I got together with the Pelvic Pain Foundation of Australia, and we wrote PPEP-Talk, which is The Periods, Pain and Endometriosis Programme. And we got funding from the state and national and federal, sorry, governments to put together this programme, which is now in schools across the country. And it's a fun educational programme that's really non-threatening and accessible to people with all genders and abilities and walks of life, I guess. And that's what I wanted to do.

And then after that, I thought, all right, well, what's next? What do I do next? I need to produce something else. And so I thought, okay, well, comedy is what I do. So I let that, the endometriosis

education programme fly off, and I started writing this cabaret. And I wrote the first one, and I produced it at my own venue, and I thought, maybe 14 people will come to this, so I'll get 14 chairs ready. And it sold out, and a 100 people came. It was standing room only. And I thought, holy moly, people want to hear these stories. So I did it again the following year, and we sold out 10 shows.
Tyson:
Wow.
Libby:
And I thought, okay, these are the stories. This is what I need to do, I found my voice, this is where we need to be. And I felt liberated, and I felt empowered to do that. And it did actually feel like the next step of where I needed to be to endotain people. I probably need to trademark that, don't I?
Tyson:

That's a very punny... Very punny. I'm going to go back to one of the questions about challenges, advocacy and promoting diversity. What are the significant challenges faced in promoting inclusion for people with disabilities in the arts? And how can these challenges be overcome?

Libby:

Look, I think visibility is key. That you can't be what you can't see. And seeing, I guess, cisgendered, heterosexual able-bodied, white people on your TVs and your movie screens and your stages for 100s of years has been really difficult. But it's hard to break that with a lot of people who are able-bodied playing disabled roles for a long time. And the attitude that disabled people are unreliable or they can't or they're not able to play the roles themselves.

And so breaking through that, I think is going to be... And it's happening. And you see it happening, and it's beautiful. It's great. There's so much more of people on our screens and our stages and in our ears and in front of us who are being visible. And I think that, that's probably one of the biggest steps.

But I guess other challenges of, I guess, infrastructure hasn't caught up with what we need. And you can have theatres and venues that say they're accessible, but then the green room is down a flight of stairs.

Tyso	n:
Oh,	yeah.

Libby:

So that's tricky, because then it separates people a little bit more. So there's still a really long way to go, but I feel we're getting there. From my perspective it's hard for me to comment. As a teacher I have to be inclusive, that's my job. And I've found that to be easy sometimes and challenging at other times.

But I think getting to the point where I'm accepting my own neurodivergence and the physical limitations, I'm realising how inaccessible the world is and how much more I could have done and how much more I need to do, and how much more the world needs to do. Look, again, I've gone off track, but...

Tyson:

No, that's all on track.

Libby:

Okay. Well, I guess the disability and accessibility, all that kind of thing is on track, but we haven't got enough. It's still a long way to go.

Tyson:

Work in progress, yeah.

Libby:

What do you reckon? You reckon there's more to go?

Tyson:

I'm here to ask the questions. It's a work in progress, I think. We're doing well in 2023, and there's always more to learn and more questions to ask from the community and a lot more collaboration.

Libby:

Listen-

Tyson: Listen.

I'd like to see more aesthetic access baked into future venues and stages and stuff like that. But we'll get there. We'll get, it'll just take time. As we're getting close to wrap up time, let's go down to the conclusion. What advice would you give someone, especially with a disability who wants to work as a producer in the disability art sector?

Make work, just make it. Do it. Call on the people that you know and even the people that you don't. I don't think that I've spoken to anyone who didn't want to collaborate. I think there's so much of it out there. When you look at someone's work and you think, oh, you did good things. And then you feel a little bit of imposter syndrome, so you don't ask them. Just ask them, because they'll want to do stuff with you. And it's the best.
Tyson:
Yeah.
Libby:
Get on board. And put more disabled people on your lineup and put more gender diverse and culturally diverse. Just make your lineups more interesting and spicier. Always make sure that it's not just one particular face or body type that you're working with. Look around you and notice what you need more of.
Tyson:
Mm-hmm.
Libby:
Because if you're just looking at you the whole time, then you're not actually getting the whole rounded amazing experience.
Tyson:
Yeah.
Libby:
So my advice is to get out and meet people, ask the questions. And if you want to make things more accessible for people, then listen.
Tyson:
Yeah.
Libby:

Libby:
I need to do more of it, and I am doing more of it. Listen, ask the questions and put things into practice. It's not enough just to say, hey, what do you need? And then be, ooh, but I can't do any of those things and I'm not prepared to. So don't offer it if you don't have it. And if you can do it, do it. Because you're not just opening it up for your artists, you're opening it up to a whole other audience, and that's what we want.
Tyson:
That's fantastic. Amazing. Thanks, Libby. Any other final thoughts before we wrap up?
Libby:
No. That was really fun.
Tyson:
Cool. Thanks for-
Libby:
Good stuff.
Tyson:
Being a part of it. Yeah. No worries. Thanks for fitting me in today.
Libby:
Pleasure Thanks for having me

This podcast was produced by Access2Arts with support from Arts South Australia.

Tyson: