**Interview with Sara McQueenie and Liz Wright**

Liz

This is a Women with Disabilities Victoria podcast.

We acknowledge that these podcasts were recorded on the traditional lands of the First Nations Peoples of this country. We acknowledge their Elders, past, present, and emerging. We acknowledge that sovereignty has never been ceded, and that this is, and always will be, Aboriginal land.

From the Outskirts is a series of podcasts featuring women with disabilities who live and work in regional Victoria.

I’m Liz Wright, a disability activist and advocate. I’m also the Manager of Community Inclusion and Women’s Empowerment at Women with Disabilities Victoria.

All the interviews were recorded in each person’s home or workplace, so from time to time there is unexpected background noise.

We hope you enjoy.

Artist, writer and presenter, Sara McQueenie has lived a creative life. Co-host of the ground-breaking disability show, No Limits, Sara has been instrumental in raising the profile of people with disability.

Please be aware there is swearing in this episode.

There is also reference to mental health and anxiety, so please take care when listening, and if you need support or assistance, please call Lifeline on 13 11 14.

Sara

Hi there. My name is Sara McQueenie, and I don't do labels anymore because I've had enough labels in my lifetime, and I'm currently on Dja Dja Wurrung land. Never ceded. Indigenous people's land forever. Power to the people.

Liz

Amen. Sara, how long have you been here?

Sara

I've been here majority of my life. I left and have lived other places. Magnetic Island, Mullumbimby, Melbourne, all the M's apparently, like my name McQueenie.

Liz

Yeah.

Sara

And they were all incredibly powerful timeframes.

Liz

In what way?

Sara

I think the experiences were profound. So now, if ever I need to reset, I will always go back to Mullumbimby because it was a place of creativity and fortitude and heart-felt love and kindness from people. It was exciting because I met lots of friends that are still lifelong friends.

Liz

Yeah.

Sara

And that was, you know, 25 years ago, 30 years ago. And Magnetic Island was just bizarre.

Liz

It's a bit of a mad place, isn't it?

Sara

It is. They say it's surrounded by crystals and so it magnetically - that's why a compass - it doesn't work. And because I'm a spiritual being, so I get there and would keep a record of my dreams and my journeys.

I love places that have lots of international people there. So Magnetic Island was that. There was, I think 2,000 residents at the time, again we're talking 25-30 years ago, and you know we had…in the fish and chip shop was a Japanese male ballerina…I used to work in the art gallery and that was some people from other areas in Australia that used to have possums in their bra because they worked the wildlife area…

Liz

So little baby possums baby feeding…looking after…

Sara

Yeah, yeah, yeah. And all of the artwork in the art gallery was made by people on the island. And when I think about it, it was really quite parochial and rural art, but quite naive as well. And yeah, I think everybody there has a touch of genius to them.

I arrived there with Virginia, a mate of mine who's now living in Norfolk in the UK. Gorgeous woman. The first time we met each other it was like: Oh my God, she's married, two kids, blah, blah, blah. But it was like, where have you been? I’ve known you all my life…

Liz

Oh.

Sara

One of those meetings. So, we had gone up to visit her friend Troutie, who was…I think it was Troutie - a woman - who was in Townsville – I was on holidays for a week, and I was like: let’s stay at Magnetic Island for three months. OK. Why not?

(laughter)

Sara

So, we took the ferry across, and it was the first time I'd ever seen dolphins, so I was like: Oh, this is a blessed journey. And once we got on the island, it's much cheaper to actually hire an apartment for a long term stay versus a holiday stay.

Liz

Yes.

Sara

So, we were living on Picnic Bay. I'd walk out and have my breakfast every morning for $150 a week. Like, insane, ridiculous.

Liz

Oh, wow.

Sara

So, the army nurse who lived above us, she came down, she said to me: So how do you go to the toilet? No introduction. No hello, how are you...

Liz

What was what was her indication that she needed to ask you that question?

Sara

Oh, because prior to being in the wheelchair, I walked like a helicopter, I suppose. I moved from side-to-side…

Liz

With sticks?

Sara

No. And no, prior to sticks. I didn't get sticks until I became pregnant with my son, which was 27, so this is two years later.

Liz

Yeah.

Sara

The whole pregnancy changed the whole balance of my body…

Liz

Your body.

Sara

Yeah. So, she had seen me walking out from across Picnic Bay, and she was like, an army nurse…

Liz

Yeah. Very practical.

Sara

Very practical. Why she needed to know particularly about how I toilet myself is beyond me. And I didn't have the confidence then to say none of your business…

Liz

None of your business.

Sara

Yeah, you know, and you get indoctrinated within the medical framework that you answer any question about medical stuff with ease because you don't have any boundaries or barriers attached to it. Not so much now. If anyone now asks me, I'd tell them to stick it.

Liz

Yeah.

Sara

Yeah. But I think we learn that, and we practice that. Anyway, so I told her and she's like: Oh, OK. And because I have a stoma and a bag, which I've had since I was three years of age…

Liz

For those people who don't know what that is, can you explain?

Sara

Yes. It meant that at a young age it was seeing that I…my bladder wasn't able to control itself due to lack of muscles. I'm spina bifida. So L4, L5 is where my spine opens, and the nerves come out causing a lump. That means that L4, L5, which is kidneys, bowels, bladder, you know, anything from the waist down, there's partial paraplegia.

It was interesting, and still to this day find it makes me a little angry, I think, if I was in another state, I wouldn't have got a stoma and bag, but because I was in Victoria at the Royal Children's, they gave me a stoma and a bag.

Liz

And that was the all-round process for anyone with spina bifida?

Sara

At L4, L5 who didn’t have any bladder control…

Liz

Yeah.

Sara

Or a minimum bladder control…

Liz

Yeah.

So, what that means is, stop my bladder growing, so I couldn't actually change to any other form of equipment later on down the track.

So, they cut a small bit of intestine. They put it on your stomach, on the external part of your stomach, and they join your ureters, which normally would join to your bladder - they go from the kidney to your bladder. They go from the kidney to the actual small intestine that sits on the surface of the skin.

Liz

OK. Yeah.

Sara

Yeah. So, I had a major issue in high school where I had an ulcer formed on that.

Liz

Oh.

Sara

And so, I would just get bags, bags of blood. It was just disgusting…

Liz

Oh god.

Sara

So anyway, I had to go and have that revised. That being said, that caused a whole…Year seven, eight, nine, truly I didn't spend a lot of time at school and…

Liz

So, it’s still all going to the Children’s. So, not any work here in Bendigo?

Sara

No. Once you’ve got a specialist at the Royal Children’s, you’re pretty much allowed to go there ‘til you’re 21…

Liz

Yeah.

If you’ve got a birth defect – because they’re also taking statistics on you the whole time you’re there as well.

Liz

So yeah, because it’s a teaching hospital as well, isn’t it?

Sara

It is a teaching hospital, often the specialists are doing papers on you, the orthopaedic ones often did them on spina bifidas, because our hips form differently to your hips, etc. etc.

And so, I missed a lot of schooling, Years seven, eight and nine, which I do believe has affected me as far as my writing and my cognitive comprehension ability is concerned. I’m very intelligent, don’t get me wrong…

Liz

Oh yeah, no doubt. But it’s affected you in that you have to double check your spelling, grammar, that kind of stuff, because they were formative years of learning, that sort of thing…

Sara

Yes. Absolutely.

Liz

Yeah. OK.

Sara

And even though it was the 80’s and I don't think we did a lot about grammar - we did a lot of grammar within the school system. I do know that I write sentences back to front. Now, I don't know whether that’s a form of dyslexia that I haven't had…

Liz

I’m feeling like it could be.

(laughter)

Sara

But I haven't been diagnosed for it…I could be too late now…

(laughter)

Liz

Let’s just leave that for now…

(laughter)

Sara

But, yeah, the ability to tell a story, I'm very black and white, so I don't know how to flourish things. Which means, I mean, if you hear me talking, you get there and go, sure. But my ability to talk and my ability to write are two separate entities.

Liz

Yep. If you're a diary keeper and a dream journaler…

Sara

Yes.

Liz

And you have trouble writing, how do you work it out? Does the story make sense to you as you write it, or do you correct it and like just go back through, through, through and put it in an order that is more mainstream?

Sara

In answer to your question, what I do is I would do it all in point form first. So, all the actions that have taken place, then when I'm writing it - because I've got a computer just for writing which I don't put on the internet - and that…then I will develop it and I will set scenes and…but that's come from reading books and watching movies and understanding that people need to know what surrounds them. A narrative isn't just…and doing some workshops like with Hay House…

Liz

Yep.

Sara

And listening to …Julia Cameron, the Artists Way, started with her, and now this one is called The Vein of Gold, A Journey to Your Creative Heart. Fantastic. Found it better than Artists Way to be honest.

Liz

So, the only thing I remember about the Artists Way, at the time, and it was a recommended book by a friend, was that, just write every day.

Sara

Yes. Morning pages.

Liz

Yeah. And it's practice and routine and yeah, I think that's a good practice.

Sara

But I think it's a great mental health practice.

Liz

Yeah.

Sara

I found, after my work cover injury, which I was so inundated with thought processes and injustices and having to do practicalities, but just doing the morning pages allowed me to clear my mind slightly by doing the supermarket list of things that I need to action, you know, which was great.

The other book, which I would have to say is fantastic, is the Writer's Journey, Mythic Structure for writers is by Christopher Vogler, V, O, G, L, E, R…

Liz

So, by mythical stories, does that mean, like archetypes?

Sara

Yeah, yeah, it's archetypes, it's the soul's journey…

Liz

Yeah.

It’s the journey, you know, and it goes full circle. You've got to, you know, be tested on that journey and you've got to come to some sort of conclusion and learn something at the end, blah, blah, blah. So, it's the kind of stuff that's used in every movie in Hollywood at this point in time…

Liz

So, you’re still writing, you’re still journaling, all that sort of stuff. What's your art practice?

Sara

This actually leads into my art practice. I don't paint and not write. They actually… they're both aspects…so, in the future, when I actually have exhibitions, there'll be writings to go with every painting.

Liz

And audio description obviously.

Sara

Of course, I was just going to say that before you rudely interrupted me.

(laughter).

Sara

She's quick off the mark folks.

Liz

Hang on, we're just really trying to outdo each other.

(laughter).

Sara

She’s so cheeky.

(laughter)

Sara

Yes, so all of that, and I would love to make sure that it is completely accessible for as many people as possible.

Liz

Yeah. And that's, that's the goal; for as many as possible because I think if you set yourself the challenge of saying for everybody, which is a beautiful goal and that is, you know, the ultimate goal, but it can often be the paralysing goal if you can't get to that to that point of, making sure you know…

Sara

Yup. You have to be a little bit responsible for yourself and your own…

Liz

Exactly.

Sara

Your own needs because no-one, no-one in this world is going to be able to assess your needs or think about your needs more than yourself.

Liz

That's right.

Sara

Yeah. So even though I went on a holiday just recently, a good friend of mine has a portable ramp and she bought the portable ramp, because you never know. We never used it…

Liz

Yup.

Sara

But you never know when you're going to need it, you know? So, that’s another story.

Let's talk about businesses that actually say that they are accessible and they're not. Let's talk about businesses that apply for funding and say that they are, and use their funding for access, which is just to pat themselves on the back. Let’s not. I might get angry.

Liz

Well. No. Let’s talk about where things can be done well, and things can be done with little expense. These things don't have to be like the big thing. It doesn't have to be the most accessible bathroom room or whatever. And I do want accessible bathrooms, but these small gestures of: I've got a ramp, it will work. I can get you in here. You can be with your friends… around it will work.

Sara

And it's interesting because I remember being on a Board and that being discussed as an option and it was saying that there was policies from… first of all, the businesses were saying that they wanted to actually have funding available to them to get them, fair enough. And even though I would see it as a tax deduction. It was also seen as an issue because of the pavement policies in front of shops and them needing to be…

Liz

Clear for cane use…

Sara

Obstacle free…

Liz

And all that sort of stuff.

Sara

But it's like it's something that you're putting down and picking up in a matter of five minutes, you know, So…

Liz

You can argue those sorts of points all the time, but if someone's just plonking down a ramp, you go inside, it gets picked up…

Sara

Yup.

Liz

Whatever.

Sara

And those little things make such a huge difference because what you, you feel like you’re seen. You feel like… like for example, I went to a shop up in Mullumbimby and literally the step was maybe 20 centimetres high…

Liz

Yeah.

Sara

So, I can flip my front wheel up one step, but there was no way I was getting the back wheel up, so I had to get a friend to lift, and she’s a little short arse like yourself…

Liz

Yeah.

Sara

She had to lift the wheelchair up and push forward. And try to get - that's a very unusual movement forward for people…

Liz

Lifting up and forward, yeah.

Sara

And you get to the stage – there was not a dressing room that I could try. So, I just was stripping off in the shop because you get to the stage when you've had your body shown and viewed and poked and prodded and you are an experiment that you actually have no boundaries about just taking your clothes off in the middle of a shop. Do you know what I mean?

Liz

Well…

Sara

Because I was trying something on. It wasn't just random.

Liz

Yeah. You weren't just showing off.

(laughter)

Sara

Ooh, look at this, look at my tan lines.

Liz

I just think it's not that, it's not that difficult. It…like, a lot of stuff is not that difficult. Like aisle widths, making an accessible change room, all of those things have been built up over years and years and years of resistance to seem like a big financial…you know… inconvenience instead of an investment in someone who's going to spend money if they can buy clothes in your shop.

Sara

Absolutely. And if I…I will not spend money in a shop depending…

There was this beautiful crystal shop, there were two steps to get me in. The actual lady who was on the phone talking to somebody, while I stood there on the wheels, about maybe two or three minutes. A man went past and said: Do you need a hand getting in? I said: No, no, no, I'm just waiting for somebody. But what I was doing is testing to see if that actual woman was going to engage with me or not because I had money to burn, and she lost the sales. So… which is completely fine because I won't…if somebody is not engaging with me, then I won't spend money there…

Liz

No.

Sara

And the people who are with me won't spend money there…either.

Liz

No, no, no. You spread the word.

Sara

Absolutely.

(Music playing)

Liz

Now, can I just bring you back from holidays back to here, living in regional Victoria?

Sara

Yeah.

Liz

As a regional woman, what you were saying earlier was that most of your care was at the Royal Children's Hospital, so that incurred a lot of travel.

Sara

Yup.

Liz

So, a lot of family involvement.

Sara

Yup.

Liz

Incurred a lot of travel but probably incurred a lot of organisation, probably traditionally from guessing your age, mainly your mother around childcare and stuff.

Sara

Yeah.

Liz

While you were on the road, that kind of thing. What were your siblings like with you?

Sara

They are incorrigible is what they're - they're cheeky little monkeys.

Liz

Yeah.

Sara

They would actually do…they’re gorgeous and they're supportive, as much as I will allow them to be, they would say that I'm far too independent and don't actually say when I need help, which drives them a little bit to distraction at times because if I'm in trauma or pain, I shut down, I go into the cave.

So, in answer question, yes, I have a father and a mother. Every year I would have to go to the Royal Children's Hospital for a check-up, which would be an all-day event, and I would vomit in the car the whole way down and everyone...

Liz

Because of nerves?

Sara

Nerves. We called it car sickness. But it I didn't realise that my body actually shut down. So, I have very many faces that I put on as presenting, which I think a lot of people with disabilities do. But it never ceases to amaze me when I pull out a facade and someone goes: Oh, you're dealing with that very well. And I’m like: Actually, I’m dying inside…

Liz

Can I ask you, when you had Joseph, did you have a caesarean?

Sara

Yes, elective caesarean. But I knew that would happen because my pelvis is naturally different because of the spina bifida.

Liz

Yeah.

Sara

So, there was no, there was no choice, no option.

Liz

Prior to the caesarean. Did you do the shutdown?

Sara

No. Well…

Liz

As in, the quiet inward facing rather than the outward facing?

Sara

Yes and no. I was in a domestic violence situation with my, his biological father, which didn't sort of manifest… it was emotionally volatile then. So, I was internal anyway because of that. And…but… and I was living out in a property, we'd been isolated, the typical, you know…

Liz

Yeah.

Sara

Stuff that occurs…through violent situations. And so, I was very aware of Joseph in, in my stomach and what he was doing. I always knew he was a boy, even though I didn't have…

Liz

Any tests.

Sara

Yep. And I didn't have any tests to see whether he had spina bifida or not either. I didn't do any of those things.

Liz

Now tell me why?

Sara

Ahh…

Liz

Because there's all different schools of thought.

Sara

Well, I got my period during the whole first trimester, so I didn't actually know I was pregnant until I was four months pregnant, until I went to put those jeans on and went, Oh my God, Hello? There's two inches in the middle of that zip.

(laughter)

Sara

So, he wasn't planned. That being said, I always knew, even though at the Children's Hospital they'd said: If ever you're going to get pregnant, you need to take copious amounts of…and they would have given me the stats at the time, but I can't remember them…of folic acid or folate, etc. three months prior to conception.

What I had been doing is I'd been going to the gym and taking large quantities of vitamin B, multivitamins, etc. so that could be the reason why he doesn't have a congenital disability. I don't know. But my sisters also needed to make sure that they were taking during and prior to their pregnancies, large amounts of folate as well. But they have no idea why spina bifida is caused, so…

Liz

And is it anywhere else in your family?

Sara

No, not historically.

Liz

Ok.

Sara

It wasn't in the generations of grandparents nor in great grandparents, so…

Liz

Before that, who knew?

Sara

Yeah, exactly.

Liz

Yeah.

Sara

There's no record. It's not like it's on their Census. Is there a disability…?

Liz

No. I mean, even on the Census, basically the disability question is: Does someone help you out at home?

There’s two questions. And one is: do you receive assistance or support at home? Is one of the disability questions and I can't remember what the other one is, but it's pathetic.

Sara

Yeah.

Liz

So, there's no - what disabilities are people getting? Or, you know, are we sorted out into our sensory, physical, psychosocial or…

Sara

And I wonder if that's because they get the stats from other areas like the Royal Children's Hospital, etc. As far as that's record keeping, as far as…

Liz

But there's all the acquired disabilities, you know, ABI’s and whatever. So, I mean, there has to be some way to collect that. But I don't know who’s…someone will listen to this one day and be shouting at the, you know, the machine going…

Sara

This is how you do it…

Liz

God, you two are old - you’re idiots!

Sara (singing)

This is how you do it, baby.

(laughter)

Sara

And maybe it's like, they go to TAC, WorkSafe, GP's. You know. They’ll have their own little internal medical stuff…

Liz

I don’t know… you're more of a believer than me.

Sara (singing)

I am. I am. I'm a believer. I'm a believer…

(laughter)

Sara

Of spirit over religion, thanks.

Liz

So, Joseph's 27?

Sara

He's 28.

Liz

28.

Sara

Just got back from his first tour of Europe and loved it so much that he's like, I have to go back. I have to go back.

Liz

And is he living in central Victoria too?

Sara

Yeah, he lives like three blocks away...

Liz

Oh, that's nice.

Sara

Yeah, it is nice. Mind you we’re never in each other's pocket. Do you know what I mean? We've never had that relationship even though as a sole parent…yeah... it's always been mainly because it's about him. He needs to have his own life, his own friends…

Liz

So, tell me, how it was being a sole parent with a disability in regional Victoria?

Sara

Exhausting. Absolutely exhausting. Especially also because I was doing….OK so I had Joe, separated from my partner because he was physically violent, so that court case system, change of name, the whole shebang. Then I went up to Mullumbimby with Joe. I'd lived up there before and I needed to find my joie de vivre. I needed to find my joy again…

Liz

Yeah.

Sara

And so, I went up there. I met a friend of a friend was moving from Hepburn and or Daylesford and we said would share a house. He had a daughter. I had my son. We thought that we'd be amicable…and so we did. So, we shared house for a few months, and when I say a few months, it would have been like six months to a year.

Liz

Yup.

Sara

Then…so the ease for me was that Joseph was breastfed for the first year and a half. I think. So, there was no needing to…I think if I had to boil bottles and do this and do that, it would have just been horrific. I had him in a pram majority of the time so I could move. He would even sleep next to me in the bed in a pram as a baby.

It's just what you're used to, and I think it's…I have come from a very…I have a tribal mindset in that it's important to have, you know…I didn't immunise my child at the immunisation dates. It's when he was more mature when I knew his immune system was more kicked in. I believe in it takes a village to raise a child. But at the same time, you know, for example, when we're in Mullumbimby and I needed to go the supermarket and Joseph was two… I would never, I would never have a harness on him. I just don't believe in constraining a child like that.

Liz

Yup.

Sara

I would not like it for myself, so why would I do it to somebody else? But he ran down the street and I had to say…there was a woman down the end…grab that child!

Liz

Yeah.

Sara

And one person didn't. But another mother behind that who's obviously grandmother, she knew to step in…and just because…when they make a runner at two years of age, they're just testing the boundaries. So that was…

Liz

No, it's not naughty. It's just running.

Sara

Yeah, it’s just fun. So, I realised that he needed to run. That's what I realised. I really tried to where I was physically unable to do the running, the ball kicking, whatever, it was about putting him in sports, it was about peer development. So…

Liz

But a lot of that is lonely work when you're on your own, I think.

Sara

Well, I made sure that I was very much part of the classroom and very involved with his friends. So, it was things like…cause, I've always had a courageous spirit in that I don't mind being the first one to speak.

Liz

Yeah

Sara

I don't mind being the first one to, to move forward. I've always tried things for others, so I could then give them information so if they wanted to do it, they can do it with a little bit more ease in their heart.

Liz

Yeah

Sara

It's just I think it comes from a Scottish grandmother to be honest. She was a communist and walked with the men and you know, so I think that hutzpah comes from her. She was loud, short, and proud, and I think that's me to a tee.

(laughter)

Liz

Now, speaking of loud, short, and proud, you've got a performance and creative arts background.

Sara

Yeah.

Liz

So, you were on TV for I don't know how many years?

Sara

Eight years?

Liz

So, eight years, No Limits was pretty much a ground-breaking show. I really, really loved it. I thought, this is excellent. Like here are people talking about their bodies, fun things, difficult things, ridiculous things. What was that experience like?

Sara

Well…

Liz

How did you get there?

Sara

Yeah, let me just take you to the lead up. So, I was working with the Futures for Young Adults program, which was a pathway.

Liz

Yeah, 18 to 21.

Sara

Yup. 18 to 21, bridge building. Where do you want to go? What do you want to do? And there was a level of funding attached that. I noticed… and I work between Bendigo, Castlemaine, Castlemaine, and Maryborough.

(laughter)

Liz

Castlemaine.

Sara

Castlemaine and Maryborough. So, I had, I had 80 people on my books, and I noticed within all of those people that none of them had social skills, adult social skills, and it was just like: They don’t know how to go to a pub, they don’t know how to go out to an event, they don't know how to buy a ticket. What's going on here? And I am I am doing a wide brush…you know…a brush stroke when I'm saying that.

Liz

Yeah, yeah.

Sara

Yeah. So, I decided to set up CreateAbility with… in conjunction with Club Wild from Melbourne and…cause they had skills within the dance party scene.

Liz

Yeah.

Sara

And, also another, John Willis at a business here in Bendigo, and to set up social events in actual real pub situations and they were adults, they could buy beer if they wanted to. There can be support staff there and just develop those skills.

And out of that there have sprung marriages and they've sprung, you know, people developing in a whole lot of different areas. Then as a part of my scope there, was that I would try things that others may want to try in the future so I could then come back and go, then this needs to occur, this needs to occur, this needs to occur, because I was a Supports Need Assessor, so I wanted to evaluate what support needs may be needed in those environments.

Liz

Yeah.

Sara

TV and film was an area that hadn't even been touched. So, I saw an ad for it.

Liz

Where did you see the ad?

Sara

I don't even know...

Liz

Because I don't even reckon you would have got Channel 31 here.

Sara

Oh no we didn't get Channel 31. I didn't even know where they advertised. I think I was on… because there was some form of group chat kind of thing, and let me tell you, I wasn’t into disability or acknowledge my own true disability until I started CreateAbility…

Liz

Yeah.

Sara

And then I was like: Oh, maybe I'll go to Melbourne and…so there must have been like a disability chat site on the internet somewhere that I linked in with that has to be it And I applied, I got an interview and I interviewed, I think with Stella and George, it was a group interview.

Liz

Yeah.

Sara

And we all looked great on… behind the camera together…

Liz

And you all sounded great.

Sara

And we had an instant rapport. An instant rapport and just there was a, a joyful sort of banter between us all, which was great. And I was probably like ten or 15 years older. So, I already had a child. I've been to university, I've been…I was working in the sector, not-for-profit sector in disability. I think Stella at the time was in teaching. George had finished his degree. He was a doctor…

Liz

He was a doctor, yeah.

Sara

And…I mean it was, it was, it was a beautiful concept that allowed us all to flourish, which was great, but not without difficulties.

(Music playing)

Liz

To find out more about Women with Disabilities Victoria, go to: wdv.org.au

Liz

Well, I think doing community arts is really, really interesting space, but doing community disability arts is a more interesting space because there's an expectation that people with disability will do stuff without renumeration or recognition and I have a huge problem with that. But it seems to be the nature of the beast. It's getting way, way better. And you know…

Sara

Like it should…

Liz

As it should. But there was, there was a period of time where you could get a Coles or Myer voucher for participating in something…

Sara

I mean how fucking offensive is that? I'm just giving you my skills, my abilities, my knowledge, my information, and I receive nothing.

Liz

Yeah.

Sara

You know, it's… and first of all, you create it in your mind as going: OK, I'm learning skills here, I'm networking, there's lots of soft opportunities that you're getting…what I call soft opportunities you're getting from it.

Liz

Yup.

Sara

But that only goes so far. And then…especially if I was the only one…oh there was a few others that were rural, maybe around the Frankston area, that kind of thing. But for me it was a four-hour trip and initially in the first couple of years I wasn't getting petrol money, it wasn’t getting food money, I wasn’t getting clothing money. It was all out-of-pocket expenses.

Liz

Yeah.

Sara

And, and then that changed depending on the funding applications and what monies came through. But, you know, it should have been supported. It really should have been…it was being aired on Channel 31 nationally. It was winning awards.

Liz

Yes.

Sara

You know, and it really set, set the groundwork for quite a few people to jump off and, and further their careers, which was fantastic.

That being said, it was an exhausting day. It would take two weeks to recover from. You would be doing…two-hour drive down. It would be hair and makeup, do four shows, no script. You got an idea of who was being interviewed, etc. two weeks prior, you had to do your own research on those individuals…Yeah, and that's what it was. It was fly by the seat of your pants.

Liz

How did it end?

Sara

It continued on after I left, I left I think because…oh after my work cover injury…and the last show I did was actually me in hospital having surgery.

(laughter).

Sara

I did it with Akash and I've never watched it. I've never watched it. I probably never will watch it…

Liz

Yup.

Sara

No Limits itself was a disability specific talk show, interview show, discussing disability in all different frameworks…in our lives, as well as people who came in, who were interviewed. We had engineers from Western Australia where there was one motorbike that Stella was on the motorbike behind me.

Liz

Yes! I've seen that photo. That should be framed. That’s awesome.

Sara

It’s beautiful…

Liz

Yeah.

Sara

And yeah, the wheels…you would come to a stoplight and the wheels would come down like training wheels on the motorbike but give stability.

Liz

Oh, you actually rode it.

Sara

No, we didn’t. We were sitting on it…

Liz

Oh Jesus, I was going to…

(laughter)

Sara

My legs can touch the ground. I have ridden a motorbike before, but it was a PeeWee 50.

Liz

Yeah.

(laughter)

Sara

Difference. A big difference. And that was through a bush block. But yes, that is what it was.

And so, there was, there would normally be three people on the panel. Somebody would be chosen as the main host for that show. And then we'd have, you know, there might have been some filmography that had been done on-site out, out somewhere, you know, maybe looking at some Paralympic kind of things in an oval or…I don’t know…whatever. So, and then there was, you know, us flying off and rockets at the beginning in the start of the show…

Liz

So, with the whole No Limits thing, I'm really interested that you applied for it. I mean, I know you're a natural performer and you're a singer and you're from a family of creatives, and you went and applied for a show that was around people with disability. How did that work for you?

Sara

What I found interesting Liz, is I went under the pretence that I was going to learn what was needed for other people to possibly be in my position, you know, is that what were the access needs for…if any of my individuals from Bendigo wanted to join in?

And what I found was not only a peer group of disabled people, but that I realised that I was disabled and that I'd been living…not necessarily a lie, but my coping mechanism was to…not disassociate from my disability but sort of pigeonhole it over there and only when I ever hurt myself or…which happens often when you've got partial paraplegia and things turned from a small cut into an ulcer very, very quickly.

Liz

Yes. Yup.

Sara

Everything goes to surgery. There's always a domino effect from everything…that I found myself within that.

So that's probably another reason when I said about a soft outcome for me was that I learned about myself. Mind you, I did actually get some ableism from the other people with disabilities in that, I was seen as not disabled enough.

Liz

Yeah.

Sara

I'm not quite sure where that fucking mindset comes from because it's like, who is anybody to judge anybody?

Liz

I know where it comes from. It comes from the fact that if you appear to be coping or if you appear to be happy, or if you appear to manage in public, then there is this perception that life is easier for you than for them.

Sara

Which is a crock of shit, because what you're doing is better at masking, which is a mental health issue.

Liz

Yeah.

Sara

You know, it's, it's that you've had incredible amounts of trauma and that to survive you've put on the social mask, which I know this is exactly what I do in a hospital environment, sit up with the nurses, make sure that you have great relationships with the nurses so your ability to survive is better. It is a survival coping mechanism.

So, it never ceases to amaze me how people come up with those perceptions. So, it wasn't till I actually spoke about my stoma and my hospitalisation, my bag and blah blah, blah, blah that people went: Oh, you actually are disabled enough. And I was like: Fuck you.

Liz

Yeah, yeah, exactly.

Sara

Yeah, atrocious. So anyway, that being said, I found myself and I recognised myself. But that was never discussed within the show. And I don't think our lives…I hate surface conversations. It's like, don't give me the surface. I'll always want to see, what's the meat, what's underneath? And because for so long I moved around Bendigo, thinking am I the only disabled person who's actually going out here? And of course, there's invisible disabilities and I understand that…

Liz

But there isn’t much high-level visible disability here. Even now. I do see more wheelchairs and I do see more people with other aids, and I've seen people with canes and things…

Sara

Yeah. In the last ten years.

Liz

Yes, but there isn't a high level of volume and I think that's why it's undervalued here that, oh, unless there's a lot of you, we well, we really don't have to do much. And I think what happens is people stay home.

Sara

I agree. And it's like having to train people to think outside of themselves where we don't think outside of ourselves. But I think as a disabled person…because we've got a certain aspect of advocacy…

Liz

And activism…yeah…

Sara

We have to think outside of just ourselves. Like just recently I went to, on holidays and I had the general manager of the resort asking me, you know, how are you finding access and what are you finding accessible and ra, ra, ra, and I was like…I don't want to think… in my mind…I’m not saying this to him. I'm going, I don't want to think about this. I'm actually going on holidays to remove myself from my disability, which is all encompassing, hyper vigilant. I'm hyper vigilant anyway. And now I need to put on like the Edward de Bono hat of thinking about access needs for other people as well as myself, which I do as a default. I never just think about myself in that context.

Liz

But you would potentially write a review when you came home.

Sara

Give a feedback sheet, absolutely.

Liz

Yeah, but you don't necessarily want to discuss your whole life and your personal stuff, unless there's a problem, while you’re on holiday.

Yeah. Yeah. While you're on holiday...

Sara

Which I’d already done twice, while I was there.

Liz

Yeah.

Sara

Yeah. You know, I've got a loud voice. I can be assertive…again, it's a facade. It's not the natural me. I'm actually a natural introvert, not an extrovert, so it takes me a lot of energy to present and be there. It's much easier for me to be on stage in front of 1,000 people versus, you know, the one-to-one interactions…

Liz

Yeah. Yeah.

Sara

So, you know, and the parting of the ways that wave that occurs when you're going through a line of people.

You know, I actually said to one… this girl, as she saw that I was there and sort of moved off to the, to the side away from me and said: I'm not contagious. And another woman said: Oh, I want one of those. And I was just like: No, you don't. So, it's there's still this element of my legs or your sight or how others perceive the world through their disabilities is still a little bit fun, still a little bit left of centre, still a little, you know…it’s…not taken seriously…

Liz

Well particularly if you seem to be a person that manages…

Sara

Happy…

Liz

Or a person that is happy…

Sara

Yep. Which takes a lot of fucking work as we know.

Liz

Yeah.

Sara

A lot of planning, a lot of research…like if I if someone says to me: Are we going out for dinner? And I've got some friends who think about this, they'll get there and go, we're at this restaurant, there's a…there's an accessible park out the front. You just need to roll in. And I'm just like, that is so fresh and amazing…

Liz

Which it shouldn't be.

Sara

Which it shouldn't be.

Liz

No.

Sara

No, it shouldn't be. If you want my company, as I want your company, then we just all think about these things, you know? Yeah.

So, it truly is… every disability has their different... like my car is my legs…so, if people take it, or I don't have them, I feel vulnerable. I feel less able to move, I feel unseen. I feel like everything's ripped away from me at that point in time.

So, it's a huge thing for me to, A) for me lend my car to somebody else or b) for it to be away getting, you know, fixed, or serviced or whatever.

Because I the idea of using taxis…I can use a taxi. But again…because I've got anxiety, an anxiety disorder, which is connected to my Work Cover issue and accident… that…I just I get, I get so anxious prior to having to use any of those scenarios because A) If I don't specify that that I need a sedan…because a wheelchair taxi…because they don't have shockers. So, because I’ve got a pin in my hip… and my spine is my issue, that I end up with in extraordinary pain after a small taxi ride in an in an accessible taxi.

And I'll never forget we were in a meeting once and a taxi company here in Bendigo actually verbally assaulted me because they said to me: You don't use our accessible taxis anyway. Well, they'd looked me up, obviously, but there was a reason because there…and I said at the time, that's because your accessible taxis caused me incredible pain. But he was talking about the, the experience of Uber and other share drive businesses.

Liz

Yeah.

Sara

Overtaking and were they going to be accessible, and they were saying no, only taxis were going to be accessible. Well, we now know Uber's accessible, and you know, there's now another taxi company here in Bendigo and so that's broadened that spectrum. But yeah, it's hyper vigilance is, is disability.

Disability is all encompassing unless you're in your space that you've designed yourself that is set up for you. Otherwise, for me, I'm looking at bumps in the road, I'm looking in guttering…cause if my wheelchair gets buggered from going over a gutter… again, I'm stuck in the house, can’t move for a couple of weeks till it gets fixed.

Liz

Yeah, it's. It's great. Like your home is highly accessible. You know what your limits are as far as leaving the house and things like that. Where do you paint and where do you do your creative process here in like in your home or have you got a studio?

Sara

I haven't got a studio because I haven't found any accessible as yet. I'm going to actually talk to the university and see La Trobe and see whether there's an option of me as an outsider to…even though I would be considered alumni… to see whether I could actually use one of their studios ongoing and paying for it.

Sara

Latrobe Art Institute in View Street…

Liz

Yeah.

They offered me a residency in return to talk about and write a review on access to their building, which I did, which they have actioned. So, kudos to them.

What I found was phenomenal at the time, was access to doctors and people who have great credit within the university or the academic world and could give me feedback on my work…critique.

Liz

Yeah.

Sara

Which I wasn't able to get in the university or outside of it in any other way. And so that was phenomenal, and I really was incredibly thankful of that opportunity.

My sister got cancer at the time, so I wasn't able to make as great an opportunity or use it as best as I could because I wanted to be there for her. But what I've done since is actually ring around to find out whether there's any other accessible residencies, of which there aren't. There's, there's different ones for like writing and, and…but none for the visual arts. There's a different thing you need. You need windows. You need a certain light when you're actually painting…

Liz

But do you think that's a regional thing that that we're very short of that kind of space and input and that there's a lot of metro money going into arts spaces in the city?

Sara

Absolutely. I do. Absolutely I do. I've heard since that Monash Uni has made an accessible residency next to Monash Uni and maybe they're doing it just for their students, but there needs…I mean, Arts Australia need to actually look at that. I actually contacted Arts Australia and asked them do they know of any accessible residencies - they didn't get back to me.

So, you know, it's, it's frustrating because I know…part of my actual voice within the arts is about spirituality in place. So, every time I go to a different space, a different environment, I'm actually capturing that through my art. There's also other things I do, which is my worthies, which is people who have influenced my life historically. So, I've done portraits around them…

Liz

Like, who?

Sara

Well, we’ve got Frida here…

Liz

Yeah, she's beautiful.

Sara

There is Ly de Angeles, who's actually Lore. She's a white witch and philosopher. There is…Stella, of course, Stella, because of course I worked with her on No Limits. So, I've just started that process, so there's more to come as far as the portraits are concerned. I also am looking at the circle in an abstract…Wassily Kandinsky is one of my favourites as well as Hilma af Klint.

Sara

I'm all about colour. I'm exploring the circle as a Zen circle at the moment, as in a self-portrait in abstract fashion. And wabi sabi, which is like imperfection, imperfection.

Liz

To finish up, would you say you are a proud disabled woman or would you...What would you say?

Sara

I would say I'm a proud disabled woman. I would say that my disability does define me, but it's not all of me. And it impacts on my physical world, but it doesn't impact my spiritual world and my internal world.

So, which I find that a paradox at times, because how I present to the world is very physical, and yet there's a whole other aspect of self, going on inside.

Liz

Sara McQueenie, thank you very much. It's been lovely being with you today, spending all this time with you and having a chat about your life. So, thank you.

Sara

Thank you, my love. It's been good to see you again, Lizzy. Bye everybody. Thank you.

Liz

(music playing)

You can check out Sara’s artwork on Instagram @saramcq\_art or @crochet\_by\_queenie.