**“Koori Survival Show”**

**Host: PAULINE**

**Guest: Kerri-Lee Harding**

**Transcript by Leilani Fuimaono**

BETTY: You are tuned into “Power from the Margins”, right here on 3CR Radical radio. It's Disability Day broadcasting from 7:00 AM till 7:00 PM. BETTY in the chair with you, AKA also known as Kerri-Lee Harding, and I'd like to welcome to the program the host who's going to interview myself today, PAULINE?

PAULINE: Yes.

BETTY: Hello?

PAULINE: Hi. I'm so excited.

BETTY: I'm so excited about today. How's today been so far?

PAULINE: It's been an interesting day. I did live breakfast radio for the first time with Ayan and my friend Leilani who you'll also hear later on in the day with our other friend, Ngino. They've got their own show coming up later in the day.

BETTY: Good. So you've been on air since 7am this morning?

PAULINE: I have.

BETTY: Oh my goodness. Have we got you a coffee or water?

PAULINE: Yeah, yeah. I went down the road and got a coffee after the show.

BETTY: Oh, good.

PAULINE: Got here just at seven o'clock, right on the dot. I left my house at five o'clock.

BETTY: No, what?

PAULINE: That's how long it took in traffic. So I live out West, western suburbs-

BETTY: Oh, my goodness,

PAULINE: ... and it was like a car park today. The road.

BETTY: I came in from the East this morning, I went for a bit of a drive. It was the same thing. It was like a car park. I just think with the government at the moment, with all these roadworks, they've just decided to do them all of a sudden, it's like, they've done nothing for the last 20 years in terms of quite radicalizing the commuter system for vehicles. But look, I haven't noticed a lot of roadworks the last 20 years, and all of a sudden, bang. It just seems we're being just bombarded by roadworks every direction you go.

PAULINE: Same with my- that's like in my area. Because where I live, it was a new housing estate that was put upon ... well, been urban sprawl upon what used to be farm land, which used to be, and always was Aboriginal land.

BETTY: Which was stolen land?

PAULINE: Stolen land. Yeah. So they built all these some suburbs now and they already knew that it was going to be one of the biggest suburbs in Melbourne and yet--

BETTY: Really?

PAULINE: --they're only now just widening the roads. Like all of the people built houses there and moved there first and now they're deciding to widen the road. So I don't understand.

BETTY: That doesn't make sense.

BETTY: But we're not here to talk roads today, are we?

PAULINE: No, we're not.

BETTY: I can hear all sorts of accessibility issues coming at me when we just had that little yarn there as well. If you do have accessibility issues then for roadworks then the public transport can change its agenda for the day. We've had a lot of trams strikes lately as well, which has made me think particularly on those days of people with a disability, people in wheelchairs.

How are you going to get around, if there's no trams? I just don’t understand, I understand why they're fighting for their rights, for the unions for Yarra trams. I do understand all that. But, it's at a cost of other people's personal health I think on days like that.

PAULINE: Absolutely. To be honest, I don't even catch the tram that often because not all of the stops are accessible. So even if the trams are, unless it's an accessible stop as well, I can't really use that.

BETTY: So do you have in your mind, which are clearly accessible stops and which ones aren't or you just find out when you roll up (excuse the pun)?

*[laughter]*

PAULINE: Perfect pun. In the CBD I do, but elsewhere, no. So I don't even-

BETTY: Try and negotiate?

PAULINE: I don't even try because it's just so ... It's more efficient for me to just take other forms of transportation. But it's also really expensive because I end up, having to take cabs, which is not ideal, but I have to anyway if it's uphill. So even if still has accessible transport, but it's a really steep incline. Once I get off the transport, I'm stuffed, right?

BETTY: Stuffed, yeah.

PAULINE: So I have to rely on vehicles and cabs more than I would like to.

BETTY: Yeah. And I don't know if you know about, but I did have a brother of mine, a blackfella brother, and he had a taxi card, so I'm hoping you have access to something like that.

PAULINE: I do. And it helps so much because I end up-

BETTY: Oh, thank goodness.

PAULINE: ... spending most of my money on transport. It's a hassle and it's so frustrating because people have been campaigning for accessible public transport for decades.

BETTY: Yeah. It's ridiculous. We do not have it. It really is.

PAULINE: It's just not a priority for able-bodied people. That's really why ... it's not an election issue. If there was more of a hubbub and allies decided to join that fight, we would get something done around that. But I don't think they just going to listen to us.

BETTY: It's hard for a person who does not have a disability, it's hard for them to imagine what a day in the life of a person with a disability is day in, day out. It's not on their radar. Yeah?

PAULINE: Absolutely.

BETTY: When you're a person living with a disability such as myself and yourself, it's on your radar all the time. You know? Yeah.

PAULINE: Yeah.

BETTY: But for me, it's quite different to your situation. Your disability is visible in terms of you having to access a wheelchair each day to move around. My disability is invisible to people, not to me. Maybe to me, maybe I'm still in denial about my disability, that can happen, I think.

I think I need to talk to someone about that at some stage. But yeah, I've got a hidden disability. So, that kind of means that, if I get on a packed tram and I don't carry a walking stick with me all the time.

So if I get in a packed tram and need the disability seat, unless I say something, which I'm always too shame to say something, I won't sit down. So then I'm forced to stand up and lose my balance and be in more pain. So, that's kind of a tricky one. That's-

PAULINE: That's really bad, and I actually do relate to that too because before I was a wheelchair user, my disability was invisible as well, and so I spent my teens "looking normal", but some-

BETTY: Whatever that is.

PAULINE: Yeah. So people would just see a black girl and just assume, "Oh, she's standing, she's abled." But I was probably more disabled in some ways because now I “BYO” chair. You know what I mean?

BETTY: A lot of that. Yeah.

PAULINE: So if I get on a train, I don't need anyone to give up a seat for me. I've got a seat.

BETTY: Yeah, exactly I love that.

PAULINE: It's the ambulatory people. It's people like you. It's people who need a seat and his disabilities aren't immediately apparent who need those spots. So less judgment would be really helpful.

BETTY: Yeah. Can I tell you about a time that I've just recently been judged? I'll talk to you in a moment about a whirlwind trip that I've had to the UK and back. And it was some ... actually, I was feeling really sick.

So if I'm not sick with my disability, I'm either sick with something, I'm sick a lot, it's just my life. I was feeling really nauseous and really sick and I had to go to the bathroom at ... we just got off the tube from the British museum and I don't know, which tube sta- oh we were at Hammersmith station. Those people from London will know what I'm talking about. Those people who aren't will not, and I apologize for that and basically I had to find a toilet real quick, yeah?

So I went and saw a security guard. I'm like, "I need to use a bathroom please." I'm hobbling along. I'm in pain because I'm always in pain. That's part of my disability. Found the toilets, and then I worked out that you've got to pay 50p for the toilets.

PAULINE: Oh, what?

BETTY: I know. And I'm like, "Oh my God, I've never seen this in my life." But then next to the toilets there was a disabled toilet that you didn't have to pay for. And there was a cleaner there, and yeah, they lock up their toilets in the UK. I think it could be a terrorism thing or maybe a drug user thing, I don't know. But even when you go into a cafe, you need to ask the waitress for a code to put into the toilet to go in.

PAULINE: Wow, okay.

BETTY: Yeah. So, there was a cleaner at the door of the disability toilet and I said, "Oh, I need to go to the toilet. Can you please open the door for me?" And she looked at me up and down. Just real slow way too. So I felt her eyes just look me up and down and look for that disability.

Where is it? Why is she wanting to use a disability toilet? You could see it all over her face. I just looked at her and I said, I'm disabled. Well that's all I said. And then she actually had to radio through to some guy in the control center to unlock the disabled toilet as well.

PAULINE: Wow. That’s a bit much.

BETTY: That was my recent experience with being judged, but not judged too much because I think once I did tell her that I had a disability, she opened that door straight away and she obviously was aware that people do have hidden disabilities. So, yeah, just a recent experience that I had.

PAULINE: Yeah. It's really, that reminds me, a friend of mine who has an invisible disability, psychosocial disabilities, wears a pin now. It's a little bottom that just says “I have an invisible disability. please”. It's basically just a badge just to-

BETTY: How fantastic.

PAULINE: Yeah. Just to sort of flag like,

BETTY: Yeah, hey.

PAULINE: “Could you back off please?” Or even just-

BETTY: “Could you give me a hand?”

PAULINE: “Hey, give me a seat”. Yeah. And I think I actually have to check in with them if it works or not.

BETTY: That's, yeah. Good idea.

PAULINE: But you shouldn't have to go to that length, where a big sign around your neck saying, yes, I'm disabled.

BETTY: Oh, that's it and nobody wants to question me on a tram because they don't want me to ... I'll go to great lengths. So, I'll go wild. I'll go, "You don't want me to take my shoe off, do you want to see it?" Sometimes, I'm sort of thinking, well what if somebody says something to me or what do I say? "Oh, sorry I don't have my disability pass on me today."

PAULINE: Yeah. Oh, well let's talk about that because you just mentioned taking your shoe off. Could you explain why that would be a thing?

BETTY: Yeah, let’s explain. I've had an amputation of all of my toes on my left foot, so that's my permanent ongoing disability that I live with. It's something I've never experienced before in my life.

It happened in about 2010 I had a blood clot in my leg, so either I was going to lose my leg in the operation or lose my toes. I came out of the operation on the trolley and I looked to my mate who was there and I said, have I still got my leg? And he said, "Yeah." So I smiled. I was really happy, but I didn't have my toes.

Spent three months in hospital, had to learn to walk again. Which was, something when you're not used to that, that's can be quite shocking. Shocking to ... So I couldn't even make a cup of tea. My mum had to come down from Queensland to take care of me because I was on crutches.

So even if I made a cup of tea by myself, I literally couldn't carry the cup of tea to the coffee table. And then we had a fight at one point and my mum left and I was literally just stuffed.

PAULINE: Oh, man. No, could you access carers?

BETTY: No, not at that time. I wasn't on disability at that time. It just happened. And it took me a few years to, make that change, but that's something for another day that we'll talk about. So, but this trip, can I tell you about my trip?

PAULINE: Oh, please tell me about the trip. Yes.

BETTY: And it actually gave me more of an insight into what it's like to experience life and trekking around the globe. If you've got a disability.

PAULINE: Because this was your first time overseas, wasn't it?

BETTY: Totally my first time overseas. Yeah. Which, I was really questioned. Really questioned the fact about whether I should be going or not because my health is so bad. Yeah. It was like umming, ahhing. “What if I get sick?”. I ended up getting sick overseas by the way. “What if I get sick? What if I get sick on the plane? What happens?”

Then I just decided to bite the bullet. I went “You know what, if I don't do this now, I'm never going to do it” and don't let your disability stop you. Don't let your mental abilities or disabilities stop you as well, and just go for it.

So, off I went and found myself trekking around London, which with the woman who hobbles along with no toes on one foot, that was pretty hard. But I managed to get around that and I got a double decker bus tour one day, which was just perfect.

So I've got to see everything. But you know what crossed my mind? I thought people in a wheelchair can't access this bus or then might be able to access perhaps the lower floor. I'm not sure. Maybe they do, but they would not be able to experience what I experienced up on the top level.

That's a whole new experience to compare to what it is down on the lower level of the double decker bus. So that was interesting. And the other interesting bit, the hard bit was that we had an apartment and there was about six flights of stairs. Those little London cottages, so they're really skinny and really tall. So I'm having to negotiate them every day with my no toes on one leg, it was really hard.

PAULINE: Wow.

BETTY: Really hard. But, we decided at the end of the trip that my type of holiday for in the future, if that'll ever happen (which I hope it will, Pauline) but my type of holiday, because of my health and my disability, I need to be sitting on a beach with a cocktail.

PAULINE: That's .. yeah.

BETTY: In one hand and just laying there with my feet up. I'm not one to be trekking around cities and day tripping around because it's not physically possible for me. We went to the British museum for half a day and then I got sick, I got really sick and I was in so much pain that we had to go back to the apartment.

I was so disappointed because I didn't get to see the blackfella exhibition at the British museum. And that's what I wanted to see. But I still saw all the other stolen items that the British have taken from other nations around the world. It was quite an emotional experience walking into a room filled with stolen possessions.

PAULINE: Yeah.

BETTY: Totally, they weren't even mine, but gee, the emotion that I felt was just great sadness. That people put such things on a pedestal and such admiration, but that's actually someone's possessions and their religion from their country.

PAULINE: Oh my goodness.

BETTY: Saw all the beautiful sculptures that they've stolen from Egypt and from the Greeks, and the sadness that overcome me. But yeah, back to my disability, I could only do half a day. So, now I've got in my head, “I've just got to go back, I've got to see the rest of the British museum that I didn't get to see!”.

I did go into a fabulous shop that I found, the shopping's amazing. I didn't have a lot of "bangu" (that's money in my language) to spend, but there was this fabulous shop that I saw and we went. I said to my mate, "Can we go in and have a look?" And he said, yeah. And it was an umbrella and a walking stick shop. Yeah. Wow. The most amazing walking sticks I've ever seen in my life were in this shop.

PAULINE: Wow.

BETTY: I can't remember the name of the shop, but I took photos of it and-

PAULINE: I'm going to get that later.

BETTY: Yeah, I'll get that off you because I said when I need a walking stick mate, my next walking stick, I'll be coming back here mate. Mind you, I looked at one of the umbrellas, it was, 300 pounds.

PAULINE: What are they made of?

BETTY: So, that's what I'd like to know. Which works out to be about 600 Australian dollars.

PAULINE: That's wild.

BETTY: So I can't even imagine how much their walking sticks would be, but they were just the most beautiful walking sticks I've ever seen in my life. It was almost going into a Harry Potter shop. It was just so old and-

PAULINE: Okay. Yeah. That style.

BETTY: Yeah. Totally cool. Totally cool. So when I need my next walking stick, which is really soon, I'm going to look them up and hopefully they've got a website and I can order one online. Because I try to manage without one if I can. Because that may trying to hide my disability as well. I admit that. Maybe there's a shame factor associated with a walking stick that I consider. Which I need to get over.

PAULINE: It takes time.

BETTY: So for me, I'm in a lot of pain all the time because if you imagined, say if you get your hand and you clench your fist, and you see your knuckles there, that's what it's like walking on my left foot. You can hear the sound I'm making on the radio desk, but that's what it's like and it's not a nice feeling.

PAULINE: Painful.

BETTY: It's very painful. Yeah.

PAULINE: Do you get phantom pains?

BETTY: I do get phantom pains. Yeah. I get a sensation, like I need to scratch my toes, so I'll go to scratch, but I'll actually scratch my skin and then I'll still feel the phantom scratch up above where my toe should be. It's really weird.

PAULINE: Yeah. The nerves are weird.

BETTY: Yeah. Nerves are weird, aren't they?

PAULINE: That's wow.

BETTY: Yeah. So it's-

PAULINE: Are you on medication for the pain?

BETTY: I'm on a lot of medication. Yeah. And for the pain as well, daily. Which I need to take. If I don't take it, it's not worth getting out of bed. Some days I can't get out of bed because of the pain.

PAULINE: Then there's side effects of-

BETTY: Of that.

PAULINE: ... pain medication and it's, yeah. It's a whole thing.

BETTY: Yeah. I don't want to be on pain medication. They wanted to put me on. One particular doctor wanted to put me on methadone for pain! I'm like, "What? Are you serious?" And they're like, “yeah”.

I'd have to go down at the clinic, which is okay. I know people have to do that. Every day and collect your ‘done in the morning. And the doctor said yes. I said, "I don't want to be on methadone.'

No any particular reason I just don't want to be on methadone, thanks. So they put me on another painkiller drug, which seems to be working well for me, which is good.

PAULINE: The walking stick, because you said you might need one, is that to do with balance or how would it help?

BETTY: Yeah, it would help with balance. Yes. So sometimes I look like I'm a bit drunk because I'll lose my balance even if I'm just standing up straight. So you can imagine if I'm walking and sometimes I lose my balance, I can look like I'm drunk. Yeah. So absolutely would help.

I've got one stashed away at home that I use on certain occasions, but I'm a bit shame too. So I try and be strong and use what abilities I have got within me at the moment. Because I know there's going to be a time I’ll need to rely on that 24/7. Yeah?

PAULINE: Yeah.

BETTY: So for now I want to be strong and tough and that's a black woman in me. Is to be strong and tough and “I don’t need that yet”. I’ll need that when I need that. But for now I'm going to make sure I can try and get around without it. So, and it'll probably help with the pain as well. So maybe I do need to. Having this discussion is some ... Made me think more about getting a walking stick. Thanks Pauline.

PAULINE: How can you make it easier for you maybe?

BETTY: You'll see it.

PAULINE: But it is hard.

BETTY: And it's good for public self defense as well.

PAULINE: Oh, yes. Doubles as self-defense?

BETTY: Yeah.

PAULINE: Yeah, there's a whole thing within disability. I don't know ... What do you call it? Disability culture, discourse. I don't know what the word is, but-

BETTY: The disability world.

PAULINE: The disability world, about reclaiming mobility aids, and that shop that you described as kind of part of that in a weird way because, seeing the beauty in them and seeing how they help us-

BETTY: Feel cool about what we're dealing with.

PAULINE: Yeah. Taking pride in that. But that takes time because there's so much stigma culturally related to mobility aids and they're associated with age too, like old age that goes, ageism there crossing over with ableism-

BETTY: Because sometimes, I'll admit this and I've never told this to anyone. So you're hearing this for the first time. Don't tell anyone Pauline.

PAULINE: Oh, it's just us. No one else's listening.

BETTY: The walkers, that the elderly men and women have with the scene often think that I would love one of them to get around with because I can only walk so far before, the pain is just unbearable and I need to sit. So it’d probably be maybe a block. Then it's just, no, I need to sit down. So, that would really help me. But then I'm thinking, no, they're for older people, and I have stigma surrounding that.

PAULINE: Yeah.

BETTY: Imagine if I have stigma, how do people without a disability, how do they think?

PAULINE: Yeah. Well that's where it comes from. That's where the stigma comes from. It's from people who don't have disabilities putting that on people with disabilities.

BETTY: Yeah. Well, I've actually got some good news, I've got approved for the NDIS, so they're going to help me with mobility aids, which is really good.

PAULINE: How did you find that process? Because that's something that I'm still yet to go through.

BETTY: I found it very long. Which is what most people say, but I think I've noticed that it's been in the media a lot over the last two years about the delay or possible delays that some people are experiencing, the holdups. So I think my claim might've been processed a bit quicker because of that negative media perhaps. Maybe they got their workers, “Quick, you better file those a bit quicker in your little office”. I don't know. But mine seemed to go ... it took about six months altogether, which seemed like a lifetime, but I got a text message yesterday saying it had been approved.

So basically NDIS is just a support system offering you more support to help you live your life like a normal person, whatever that is, in a normal daily situation.

PAULINE: Yeah, and it's arranged around goals, isn't it?

BETTY: It is arranged around goals and achievements and your work goals. For example, goals around your home for example, around cleaning and hygiene, those sorts of things. Personal hygiene, actually I don't really know. Not personal hygiene. I don't know what I'm talking about. That just came out.

PAULINE: You want to say self care, like taking care of yourself.

BETTY: That's what I'm trying to say. Thank you. Yes. What did I say? I said-

PAULINE: Hygiene. But that's part of it.

BETTY: Hygiene, yeah, self care.

PAULINE: That is part of it.

BETTY: Yeah, totally self care. Like I said, some days I can't get out of bed because of the pain that self care stuff or having support around that will hopefully make my day to day living better and up to that standard of, what a normal person would be experiencing, on a day to day basis. We've only got five minutes left and I can't believe it.

PAULINE: Oh, good. And Gavin's on next, I think.

BETTY: Oh, Gavin with Billabong Beats and he's doing a special, he's doing, let me see here. Oh, well he does a deadly program, but he's talking with connecting home with the CEO and Connecting Home for us blackfellas is a place where obviously it's the name speaks for itself. If you’re stolen generation mob, you have access to facilities through connecting home, which is really fantastic and we need these supports in our community.

So Gav is going to speak to the CEO of Connecting Home, which is a service for the stolen gens and as I've just mentioned. And he's going to talk about their NDIS crew and how Aboriginal people with disabilities can actually access the NDIS, which is great.

So, for me, how I accessed it, just to let you know, I didn't really know much about it. I didn't know if I'd be eligible at all because it's such an unknown world of the NDIS to people who aren't on it.

So having to navigate through that can be quite difficult. But I was actually in hospital last year, for a stay and one of the social workers gave me a card with a number with the NDIS number and I literally rang up that number, registered.

Then of course you’ve got to do all the forms and check in with all your health practitioners and get their support, and then it gets assessed and then it finally gets approved.

So for me it hasn't been too much of a bad experience. To hear that it's been approved, I could just cry. I could almost cry. That's going to change my life and it's going to make things better for me. Life's hard enough with this disability. We need all the help we can get. *[crying]*

Come on now change the subject now sis. *[laughing and crying]*

PAULINE: We’ve got two minutes! Shout out to your cat.

BETTY: Yeah. Shout out to my cat who, she was a rescue cat but in more ways than one, she's rescued me. She's my mate and she's my therapy cat. So on those days where I can't get off the couch, I can't get out of bed because of my disability, my mental health issues, my cat's there for me. And she doesn't talk back and I liked that about it.

PAULINE: She does have sass though, doesn't she?

BETTY: She does have sass, her name is Princess, that’s all I need to say. You know what? I was going to plan on playing some songs, but we haven't played one song. That's okay. We don’t need to.

PAULINE: That's okay.

BETTY: We'll play one at the end as we cross over to Gav's program next.

PAULINE: Is Gavin coming in here?

BETTY: Yeah. Gav is here already. He's always here super early.

PAULINE: This studio?

BETTY: Yeah. I think so. He'll just swan on in probably, as we do at 11 o'clock. So all is good. So one minute left on the clock. Wow. Thank you for the chat. It's been an eye opener for me because I've opened up some wounds that need addressing.

PAULINE: It takes time. Be patient with yourself.

BETTY: Yeah. because I'm not too far away from I guess where you're sitting, literally sitting, physically sitting where the doctors have told me if get another blood clot. That's it. My leg will be chopped off so I'll be in a wheelchair. So, I try to make the most of every day. I can because I know that's an extreme possibility.

PAULINE: Yeah. But also know it's not the worst thing in the world.

BETTY: Absolutely not, and I like that that's on my radar now because I have a much better understanding of what people who may not have other people's abilities, what they go through on a daily basis. It took the amputation to do that. It took the amputation to do that, which is sad I guess, but sometimes we need, I think it was a higher power's way of slowing me down in life. I was going a bit hard and a bit fast at one stage and I needed to slow down. I think it was someone's way of saying slow down, and it worked.

PAULINE: Blessings come in weird ways. That's true.

BETTY: Yeah, they do. Things happen for a reason. Smack bang. Right on 11 o'clock as we wait for Gavin to come into the studio. Thank you so much Pauline Vetuna.

PAULINE: Thank you. Thank you.

BETTY: Thanks for organizing such a wonderful Disability Day broadcast. Thank you for having me.

PAULINE: Thank you for sharing your story. Oh my goodness. This is the first time I've had to sit down and properly yarn, so.

BETTY: I know and it just seems it's you and me here just having a cup of tea. Thank you to our listeners for listening in for the last half hour. It's been deadly having your company and thanks for listening to me bang on about my health conditions too.

Which I don't get the chance to sit down and have a yarn with anyone about this, unless it's a health professional. So it's actually really invigorating and refreshing to sit down and talk about these issues. As hard as it might’ve been. There might've been a few tears this morning, but I thank you Pauline.

PAULINE: Thank you.

BETTY: Well done. On the great days broadcast, we're going to go to a song and then Terry Nullius will be in with Billabong Beats. He's going to be speaking with the CEO of Connecting Home, which is a mob, a service for mob who are from the Stolen Generations. So he's going to talk about the NDIS and how you can access it.

So really important. Yeah, really important program coming up next and keep listening to power from the margins this December the third at 3CR. We'll be programming right through the lovely Pauline has worked really hard and tirelessly bringing us a program right up until 7:00 PM tonight.

So, whether you have a disability yourself, even if you don't tune in and have a listen and get informed, educate yourself on this issue because there's a lot to learn and as you can probably tell, I'm still learning. I'm going to go to a song now, which is a happy song, handed over to Terry from Billabong Beats. This is, don't worry, just be happy. Blekbala Mujik. Thanks Pauline.

PAULINE: Thank you.

*[‘Don’t worry, be happy” by Blekbala Mujik plays]*