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Unfiltered Podcast Series Transcript - Episode 4

Clare: Hello and welcome back to the next episode of ‘Unfiltered’. My name is Clare. I'm your host and I am joined by two fantastic advocates for the disability sector, a very good mischievous friend of mine, Mr. Andrew Fairbairn and the wonderful Mel Hawkes as well. So, we're going to start off guys I might start with you, Mel, because beauty before age.

Let's start with, tell us a little bit about yourself.

Mel: About myself? Oh, you put me on the spot. I'm 43 and had my disability since I was two. I use a wheelchair and I live with my retired assistance dog, and I am the WA Associate Director of Physical Disability Australia amongst many other things that I do too.

Clare: You're very busy. And Andrew, how about you? It's a long list for you.

Andrew: How about me? Yeah. Hi everybody. It's lovely to be here. Thank you for inviting us, Clare. It's lovely to work again with Mel and especially around the whole...being...me being the president of the Board of Physical Disability Australia.

I work in the disability world in, I have many different hats. I, my day job particularly is working for an organization called Limbs for Life, which is the peak body for amputees in Australia. In my volunteer work, as I said, president of Physical Disability Australia. I also sit on the board of the Australian Federation of Disability Organizations, AFDO, which is based in Melbourne.

And I am a board director for the West Australian Youth Jazz Orchestra. Because that is my passion outside of the disability world is playing jazz, playing music. I live a very busy life and it's really nice to be here and have a chat with you guys.

Mel: Yeah.

Clare: And on Sundays between the hours of two and four, that's when he sleeps. [Laughs].

Andrew: [Chuckles] If I’m lucky.

Mel: So, in the morning, that is. In the morning..the morning.

Clare: Exactly, so guys, I've saved the kind of really tricky questions for you both because I think you're gonna get a little bit fired up and I'm really keen to hear what you have to say. And we are gonna be talking a lot today about ableism. I'm gonna kick off with the first question, “So I keep hearing about the word ableism. What is it?”

Andrew: It's a really good thing, this is just voice because you can't see my head. So that's a really good thing. Look this is, I struggle with this word a lot. I did some research when Clare - when you asked me to do this - and I just want to share with you from the Oxford dictionary, the dictionary's definition of the word ableism is, “Discrimination in favour of able bodied people.” Now, that rears its head in our world in so many forms, in so many forms. Everything from housing to employment to health to disability itself. It's such a broad concept. Ableism is everywhere.

You can say - it - it's a form of discrimination in that space that I'm going to take this person for the job because that person identifies as being disabled or having some - living with a disability. I am going to take that person into my rental home because if I take that person, then I'm going to have to make some adjustments to the house and I don't want to do that.

So, it's a nasty thing, for me as having a physical disability lower limb amputee. I don't experience it as much, but I see a lot of it, and I will always call it out when I see it.

Clare: Yeah, you have to otherwise, we just keep letting it slide.

Andrew: Absolutely.

Clare: Yeah. Mel, how about you?

Mel: I work with, I work for DFEDS, the Department of Fire and Emergency Services, and they say the behaviour you walk past is the behaviour you accept.

And so, when you do see something that doesn't sit right, you have to do something about it. And it's always good to use your voice and speak up when you see something you don't like, or you're caught out, or someone's, yeah, behaving differently because of your disability, or treating you differently because, or unfavourably, yeah.

Andrew: I agree a hundred percent but you know what, Mel, that's a really interesting point because for someone, for us in the physical disability space - I know you're a full time wheelchair user - me being an amputee, I use a prosthetic leg, I also use a wheelchair - Ableism is worse for those people who don't have - who have invisible disabilities.

And I – look, Clare, I remember back to the conversation we had when you shared with me your diagnosis and your words to me were thank you for not making a deal out of it.

Clare: Yeah.

Andrew: But see that to me, that's the hardest part is how do you work with somebody who does have a diagnosis, ADHD, autism, whatever, and you can't see it, but then, 'Oh, you don't look disabled.'

Clare: Yeah.

Andrew: Uh, what does disabled look like?

Clare: Yeah.

Andrew: It's pretty bloody obvious for me and Mel, right? It's really obvious.

Mel: I can't hide mine, especially on a resume or anything, I can't hide mine at all and normally my employment history or my volunteer history is all to do with disability organizations.You can't hide it. Employers are going to know that I have a disability from my photo to my resume, and I think it's worse for people with a speech impairment too, because they can't even do an interview without disguising their voice or anything as well.

Andrew: Absolutely.

Mel: Like cerebral palsy, has a speech difference.

Clare: Yeah.

Andrew: We've both had a lot of experience with that with one of our particular board members and – and - it was hard. It's a struggle. But I think it's, we know what it is. We know we need to call it out, and I love that quote Mel, “The behaviour you walk past, is the behaviour you accept.” That's leadership 101, and I think there's more people in the world need to actually understand that and need to take that on board, for sure.

Clare: Yeah, I completely agree. I've experienced ableism a few times. You've been with me actually, Andrew, when we've travelled and I've shared with you, like every now and then Mel, when I've had really hectic days or really full-on meetings or big days of big things, I go and I ask for something as simple as early boarding. And on more than one occasion, I've been told no or I've been told, no, you're just trying to jump the queue. And I'm like, what queue? I have an assigned seat, but in those situations, it can actually make the difference between a really comfortable, successful flight for me or getting on board really stressed out.

Mel: Yeah, it does -Say that I get my money's worth for the flight, I'm first on and last off.

Andrew: [Laughs] I'm usually first on and last off because I have a - I’ve got a - my, my seat's right at the back end of the plane because I can't stand sitting in the front end of an airplane.

Mel: It's just so funny when the seatbelt light gets off and you're parked and everyone's ready to jump up and they've jumped up and they're grabbing their bags and it's, “See you later. I'm stuck here until my chair comes. You guys all rush off but I'm stuck here. Enjoy the airport, I'm still going to get my bag at the same time as you guys.”

Clare: Yeah, exactly. Or my favourite is when you're sitting there waiting for them to get you off and they're cleaning around you [chuckles].

Mel: Oh yeah, I've had that too.

Andrew: [Chuckles] Oh yeah, absolutely. Yeah, that's funny.

Clare: Oh God. I think we need to do a whole episode on travel actually.

Mel: That's why I haven't in ages now. I'm too scared to get on a flight now. It's just all the stories that you hear.

Andrew: [Chuckles]

Clare: Okay, so moving on to the next question is, “Why don't disabled people like it when I call them inspiring?”

Mel: Because we're generally not inspiring. It's happened to me a few times on the bus when people are like, “You're going to work? And you're all on your own? You've got a job? Oh my God, you're amazing. I'm just getting on the bus. Just like you, going about my day. I'm not amazing.”

Clare: Yeah. It's that whole Stella Young thing. I'm not inspiring because I got out of bed and remembered my name. Like I'm just doing the same thing you guys are doing.

Mel: Yes. Yeah. I do like it when they want to know more, like getting out of bed is a huge thing for me. I rely on people to help me get out of bed and shower and toilet and dress and have breakfast and do all that sort of stuff. And then I've got to, pack my bag for lunch and make sure my dog's right for the day.

And before I leave the house, it's a long process to get out of the door. Yeah. So, it is nice that people acknowledge that it's not as simple as them just getting up and doing it themselves. But. Yeah, I'm just going about my day as normal as I can be, like they are too.

Andrew: I think it's a - for me - I want to - I want people to see me as a person, not as a disability attached to that particular person.

I'm a very big fan of Stella as well, and I've seen that, that TED Talk many times. I must admit, as I'm getting older, that the getting out of bed part is, yeah, that's pretty inspiring, trust me. Because if I forget that I don't have a leg, I just stand on, I'm literally going to hit the floor. [Laughs]

Mel: And you're a big man too, that'll be a crash and a half.

Andrew: And hitting the floor, yeah exactly, it's gonna hurt. It does hurt because I've done it. I've, I've literally woken up, gone to get out of bed, and fell on the floor because I tried to stand up. But anyway, that's just my issues. I'm getting old, so that's fine.

Mel: You better get your brain checked.

Andrew: Yeah, my brain wasn't awake. That was the problem. But they see that. I think it's for me I just want to be accepted and seen as normal as just a normal human being, going about as Mel said, going about my day to day life. I don't need accolades to go to the shops and buy my food and my groceries or go to the petrol station and get fuel in my car. It's funny how a bias and perception come into this. I honestly think, and I - and this is where the thing with Stella is really pertinent, that TED Talk.

I honestly think that it's - we are - we offend people by being and doing and taking up space in an able bodied world, if you want to put it that way. So, do I deserve to be in that world? Does Mel deserve to get on a bus and go to work and have a job when there's so many people who are able bodied who don't have jobs? Stuff like that. And you go, “You know what? That's just crap. That is just a - such a crap attitude.”

Mel: It puts them to shame that they complained.

Andrew: Exactly. Exactly. My point, Mel. Exactly.

Mel: I'm only complaining about the trivialist thing, and then I come along and be like, “Oh geez, you've got it way worse than me. What am I complaining about? My sorry life.” It puts them in perspective and makes them shameful that they can even think that they had the worst day ever.

Clare: Yup.

Andrew: It's funny how 'cause I acquired my disability later in life, right? And it's funny how people view you differently. I've had people when I've been in my wheelchair, rolling around the shopping centre and people I've known for years and years, turn around and walk away. Because and I know it's not me, I know it's them. It's their attitudes and their bias and their perspective that they can't deal with this.

Mel: You reminded me of a really funny story. This girl I worked with, and I ended up in hospital with a chest infection, and the hospital was like literally across the road from where we worked. So, a couple of them came over in their lunch break to visit me, and I was in the bed sitting up having lunch and one walked in and was “Oh my God, Mel, you've got a bum.” Like she never contemplated that I actually had a whole body, cause it's hidden behind my train in my wheelchair. And there I was on a bed, it's “Oh my God, no, you've actually got a bum.”

[Laughter]

She saw me as a whole person for the first time. Laying in this hospital bed. And it was like, changed her perspective of me as a human being. And it was just so funny. Yes, I've got a bum. I sit on it all day long.

Clare: I bring my own seat to the party.

Mel: Yeah, but I think because she'd been so used to seeing me in a wheelchair and all of a sudden I was in a bed, she saw me as just the same as her, I was still a person.

Andrew: Yeah, yeah that's true. That's really true. I remember waking up from my amputation and then like in my drug induced fog, shall we say, looking down at my legs and seeing my foot on my right leg and then just like nothing on my left leg. And it was like, “Dude that's really bizarre to look at that because yesterday, like two hours ago, I had two legs and now I only have one and a half.” [Chuckles]

Clare: Yeah. And you know you’re not an axolotl it won't grow back.

Andrew: It's not growing back. That's right, mate. Absolutely right.

Clare: Yeah it is interesting how people's perceptions change. So, when I started becoming a bit more public about my diagnosis, because I felt more comfortable, like I said to somebody, again, a very good friend. And I said, “Oh, you know this.” And she goes, “Oh, so what are you going to do about that?” And I'm like, “What, what do you mean? What am I going to do about that? I'm like exactly the same person I was 20 seconds ago. What's going on?” It's funny.

Andrew: It's weird how society views you in general, like Australia is a very multicultural society, we've got deep roots in our indigenous communities. We've got people who've only been in the country for 20 minutes, and all that melting pot of bias and perception coming together creates that whole thing around - I see someone, to me - a sunset is inspiring and then a sunrise the next morning is going to be because I know I'm going to have another day.

If I get out of bed alive, I'm good. That's it.

Clare: And don't fall over. [Chuckles]

Andrew: Yeah, note to self. Don't fall over. Exactly.

Clare: Oh, that's a good question. So, you've got a couple of really strange ones as well. So, one of the people that we met asked. “Is it okay to ask you how you got your disability? If I don't know you, how do you feel about that?”

Mel: I don't mind answering questions like that. Especially kids. I have deformities in my hands, and it always makes kids stare. But I prefer them to ask straight out, what happened. And I usually make a joke or this one's great for high fives, I have one opposite each other. “Can you do the same shape with your hands?”

And they try and be like, “No, it's so hard.” And it's “Yeah, but I can still function like this.” I prefer them to talk about it and ask questions and get it open like that, rather than go, “Oh, mom, why is her hand like that?” I prefer to be asked straight out and I'm quite happy answering.

Andrew: Hey Mel, do you find that kids are a lot more inquisitive than adults?

Mel: Yeah, probably.

Andrew: Yeah.

Clare: They don't have a filter.

Mel: No.

Andrew: What? Sorry?

Clare: They don't have that society filter of what you, how you’re supposed to be.

Andrew: Yeah. Yeah, that's true. Like for me, it's a tough one because I acquired my disability later in life and it's not the same as living with it all your life at all. I do, cause I'm coming to the point now where I don't even remember what it was like prior to my amputation, we're coming up on nine years. And all I remember from prior to was the pain and like self-medicating, booze, drugs, all that sort of crap, right. So, for me having, electing to have a leg taken off is not a normal thing to do anyway but I've found post-that it's been really interesting to see how people have reacted to it and responded to it.

I much prefer people to come up and ask about it. Kids are naturally inquisitive, and they will ask. I don't like it when their parents drag them away for asking the big fat bald guy about what happened to his leg. I mean you both know me, so you know that all my sockets have always been colourful and bright and there's a story behind every single one of them.

So, I'd much prefer to share that with people. I know that like Stella talks about those teaching moments and we're not your education. But I think to some, in some degree, if we don't talk, there's a line, right? There's a line of education and there's a line of being a pain in the ass and you cross the line from being education to being a pain in the ass, then I'm not going to talk to you, and we own that.

Mel: Yeah, if you're on the train - a crowded train - and you're asking -

Clare: Headphones in - [Chuckles]

Mel: Yeah. Then it's just no, not a time and a place for doing this. But if you're on your own or -

Andrew: Absolutely. Yeah. Absolutely.

Mel: And I've started online dating and I'd much prefer a guy to ask me what happened and what I can and can't do upfront, especially if we're gonna be dating and, getting in a relationship, I'd much prefer them to know. What I can and can't do up front.

Andrew: I'm not allowed to do online dating. My wife won't let me.

Mel: Yes, so she shouldn't either.

Andrew: [Laughs] Sorry. I had to throw that joke in, Mel.

Clare: This is a PG podcast. Oh, my heavens. A couple more questions and then we will sign off for the week. “How do I shake someone's hand if I've only got one?”

Andrew: Ask ‘em.

Clare: You just use the other hand.

Andrew: Ask ‘em.

Mel: And um, through COVID I found it really helpful that you were doing like the elbow bumps and my hands aren't really the right shape for shaking and I prefer a left hand shake anyway because I don't have much movement in my right arm but yeah it became normal just to do an elbow bump or a fist pump or something and that works way better for me.

Clare: Yeah, yeah.

Andrew: I've got a - obviously in my - in my community - obviously I've got a bunch of friends who were below elbow amputees/above elbow amputees some of them bilaterals - so both - and then you really want to - you really want to - you really need to ask how that works when they're bilateral, right?

Clare: Yeah. Yeah.

Andrew: But I – look - I don't think most people are not going to - they're not - like it's that old question is, “How can I address you?” “My name is Andrew.” There's a good start.

Clare: Yeah.

Andrew: Just ask a question.

Clare: They act all precious about it, don't they? They're like, “Ooh..”

Andrew: Yeah. and then it gets to that stage where they get so worked up that they end up just walking away and you've that there's a such a missed opportunity of being able to share something with somebody about you and about your disability that is now gone because they couldn't work out how to ask a question.

Mel: Yeah, yeah it’s really funny, isn't it?

Clare: Or so shocked that I could actually answer it myself and not let my support worker answer it for me.

Mel: Yeah, that drives me crackers when people talk to the support workers and you're like, “I'm right here.”

Andrew: That's one of the main reasons why I got into the disability world was exactly that because I was working prior to my amputation, working as a direct support worker, I was working with a bunch of older guys with acquired brain injuries and I'd take them to the bank and I'd take them to Centrelink and stuff like that because I obviously don't drive and nine times out of 10, the tellers and the Centrelink staff, they'd talk to me before they talk to the person. I was like, no, I'm not here to talk to you. I'm here to support him. He's talking to you. We don't understand him. That's your problem. Not mine. So, you deal with you work it out. You work out how you're going to communicate with him because he's your customer, not me.

Clare: Yeah. And it's people don't realise that - I've tried to change that thinking around, this is my support worker. Actually, no, this is my employee.

Andrew: Yep. Exactly.

Clare: Yep. I'm the boss. I'm in charge.

Andrew: Yeah. Oh, absolutely. If I had to have, if I don't use support workers, I don't need them. Maybe one day down the track I will, but no, in that whole case, they work for me.

And if I don't like what they do, if they don't like what I do or the way I do things, then that's fine. There's a door don't let it hit you on the butt on the way out. It's that simple. This whole thing is about, it's about us. It's not about other people. And it's not about how - support workers who don't want to wear a uniform and all this stuff - if that's a requirement of the job, that's a requirement of a job. Yeah.

Mel: I like hiring people that have no experience whatsoever. And then I teach them everything that I like and my way. And I have no idea that it's wrong or right or anything. It's the best way ever.

Andrew: But it is right. It's a hundred percent right for you.

Clare: Exactly. But don't you think that's really a cool way because you get people who've been in the industry for a really long time and they come with all of their inherent biases and things like that. So sometimes it's actually much easier to teach someone or support someone to understand the right attitudes from the get-go rather than have to get all the old rubbish.

Mel: Nurses! Nurses are the worst.

Clare: Really?

Mel: People who've been nursing for 20 years or something, “They're like, yes. I know how to do that, so you don't have to tell me.” “Yes, but you've never done it to me, there's a right way of moving me, and there's a wrong way of moving me, if you don't listen to me, I'm going to get hurt, and you will too.”

Andrew: Absolutely, 100 percent agree with you Mel absolutely agree with you.

Clare: There's a whole conversation around our own expertise in our own lives, isn't there?

Andrew: Yep. Definitely.

Mel: And if you’re cutting up my dinner and I'm going to be feeding myself, you need to cut it the way that I can feed myself easily, it makes sense.I have it cut a certain way just to make it easy for me to eat that way. If you’re eating it, you can cut it anyway you like – but I’m eating it.

Andrew: If I'm going out - if I'm going out for dinner, don't you dare touch my food.

[Laughter]

I don't need you to do anything to my food. I'm a lower limb amputee. I might struggle walking upstairs, but I'm not gonna struggle eating my dinner I’ll tell you that right now. You know what I mean?

Mel: When I go to a restaurant and I'm ordering say like the fish and chips, I'll often ask for the fish to be cut up for me. Sometimes they do a fabulous job, like they'll cut it before they batter it. And so I've got little fish nuggets, which is the best thing ever.

Like the first time it happened, it blew me away that I actually could think of something to make it not look like a dog's breakfast once it was cut up. But other times they just make a mess of it. And it's just yeah, you never know what you're going to get. But it's better than my food getting cold and my support workers food getting cold next to me, while they cut it up.

Andrew: Absolutely agree. Yeah. It's all about us, mate. All about us.

Clare: We’re a paying customer, why can't we have what we want? If the pesky Americans can have what they want, we can have what we want, right?

Andrew: I'm into that. Absolutely right. A hundred percent.

Clare: So, we've only got a couple of minutes left so, “Can I use the accessible parking or toilets if I don't have a disability?” And, “Go!”

Mel: No! No!

Andrew: No, and...maybe.

Mel: It depends on how busting you are and how long the queue is. I'll let you in if you're only going to be two seconds. I might take 20 minutes.

Andrew: And that's fine. Yeah, no - are we going to - are we answering that question? Are we going to do the other question?

Clare: We're doing it now.

Andrew: For me, stay out of my parking bay - a hundred percent - unless you've got an ACROD, if you've got a - unless you've got a current ACROD parking permit - stay the hell out of the bay. Big time. Also, I would also say that for people with disabilities who use ACROD parking permits, make sure you understand the rules and regulations around them. Because if you're not actually, if I'm driving my truck, I'm not leaving my vehicle, I'm not actually allowed to park in those bays.

Clare: Exactly.

Andrew: So, there is rules around that.

Mel: Yeah, I often get my driver to run into a shop and, "No, you can't park there. I'm not getting out." They're like, "Why not? You're in the car." "No, *you're* not disabled. You can park across the road. You can walk further."

Andrew: Yeah, exactly right. And as far as toilets go – look - parking accessible parking is law and it's legislated in law. So, there is, there's law around that. And it's obviously a finable offense. As far as accessible toilets go, they are not legislated.

They do not have to put them into shopping centers and stuff like that. That being said, if they do have one, I would encourage the able-bodied folk who are listening to this to stay the hell out of them. So that disabled folk who've got, who are part of our community can actually access them when they need them.

Clare: And not just stay out of them, maybe don't use them for your storage either.

Andrew: Oh, that too. I'm looking at the time and we don't have time to go there, but that's a whole - another - another one I'd be very happy to discuss with you another time, Clare.

Clare: Sounds like a plan, sounds like a plan.

Andrew: What was the other question? What was the other question you asked?

Clare: If there was one thing you could change to make the world more accessible for us, what would it be?

Andrew: We need to be at tables. We need to be involved in decision making and planning and co design, proper codesign, and we need to have our voice heard right at the beginning and all the way through any process that's got to do with anybody.

Clare: Yup, sounds good.

Mel: And pay us to be at that table too. We don't want any more disadvantages.

Clare: Yeah. That would be amazing. Oh, wow. Hey guys, this has been a really fantastic conversation. Thank you so much. We are out of time and I feel like I could have you back for a whole series, just the two of you.

But thanks heaps for your time and we will see you, hear you, talk to you next time for the next episode of 'Unfiltered'. Thanks guys.

Andrew: Thanks, Clare. See you, Mel. Thank you.

Mel: Bye.