

Season 3 Episode 8: [Simone]: Eyles

[music playing]

[Narelle]:

Introduction

Hello.

Welcome to another episode

of the Digital Access Show. In the last six or so weeks, we've actually

been talking about... digital accessibility,

what are the issues? What are the barriers? And you know, we haven't looked

at physical accessibility, because obviously

that's not part of our work, but it's another problem that

people with disability have. It's a common issue. Then we have lack of employment, lack of community opportunities, where people with

disability can be just part of... society just like everyone else. The perfect person to talk about what the underlying cause of this is [Simone]: Eyles

from Disinfluencer. [Simone]: thank you so

much for coming on.

[[Simone]:]: Thanks for having me.

[Narelle]:

[Simone]: tell us a bit about your work, so that people can understand... why you actually do have the knowledge, and you can talk to what

we want to talk about today.

[Simone]: Okay. Disinfluencer helps businesses

and brands be inclusive, and we do that with our

inclusive stock library. That's our hero product offer, and we also have education for

marketers on how to be inclusive. I have a young adult who has a

disability and a chronic illness. So, as a marketer and as a mum, I was kind of tired

of never seeing our... family represented in

media and marketing. As consumers, you know, we have brands and

products we love and use, but I never saw... those products marketed to us. So, I went to a few brands

and I asked them why, and they pretty

much told me that, they didn't have

access to talent. So, I kind of sat

with that for a while, and here we are with with

Disinfluencer to fill that gap.

[Narelle]:

So, what you're saying is that the excuse was, they didn't have

access to the talent. Is it a mindset underlying that

that they didn't go looking... for the talent? Or, what's the

cause of all this? What's the cause of the lack of digital accessibility, the lack of physical accessibility? What's causing the issue that it's such a big problem? Because we're a huge number of people.

[Simone]:

Yeah, a massive untapped market.

Understanding Accessibility Gaps

So, there's a few things there, I'd really like to unpack that with you. So, the obvious one is the stigma. Now, I feel disability is the final frontier, and when I say that, I'm talking about, you know, if we look at... the culture of disability, when people think of disability, they think of advocacy or care, and they don't see people with disabilities as regular people, which we are. So, there's that cultural shift. Not understanding the market opportunity. So, one in five people have a disability. It's an 18 trillion dollar global market that no one is kind of tapping into, or I guess, especially in

this tough economic climate, It kind of does

my brain a bit wild, like, why no one's doing that. And I guess, I think there's a barrier of access from their end as well. I don't want to make excuses, but I think, you know, if you are a brand

or an agency or a business, and you want to have

like a beautiful commercial, beautiful creative... that features people

with disabilities. Where do you go to get that? There isn't really anywhere that,

you can come to Disinfluencer, but do you know what I mean? There's not many

places you can do that. And I guess, you know, I think, finally to that, we have people in positions of power that... don't know what to do,

so they don't do anything. And that's, again,

not an excuse, but we need to have people with disabilities... brought into those rooms, brought into those conversations

early to co-create, and have those conversations, so that people with disabilities are included in the mix.

[Narelle]:

People would say the NDIS... is there for people

with disabilities, and why should there

be anything more? What's your answer for that?

[Simone]:

NDIS vs Everyday Inclusion

Well, the NDIS is, this isn't, I'm not

talking about the NDIS. The NDIS is a Service National Disability Insurance Scheme. So, if you have a person with a disability that needs support, you know, that's not, that's a support... service. What I'm talking about is mainstream everyday life. Like you said, access to technology, access to employment, access to opportunities. That is not the role of the NDIS. People with disabilities, it is varied and needs support. And as a taxpayer that I've paid my taxes my whole life, and just like the roads we drive on in Australia, we should have access to that support. What I'm talking about is kind of above and beyond, and separate to the NDIS. I'm talking about... businesses and brands thinking of people with disabilities not in a care role per se, but as a customer, just like their other target segment customers. And how are they marketing to them? How are they including them? How are they employing them? That's the question I want them to be asking themselves, because if you have... people with disabilities in your workplace. People have people with disabilities in your workplace. I don't have a disability but I have a child who does. I can bring so much more to that workplace... than, you know, I've kind of got skills that you can't learn. You've had to learn the hard way.

You know what I'm talking about. Problem solving, resilience, grit. And, you know, no one's having those conversations. And back to what I said, why is that? The stigma. There's no culture. There's no celebration. There's no disability pride. We have a disability pride month, which isn't really that big in Australia. But when people think disability, people think the NDIS,

care support advocacy. People don't think opportunities, pride. What can this person do for me? How exciting is this? Could that be my customer? No one, do you see what I mean? Like, that's the problem.

[Narelle]:

And I agree with you because I do think it is. I know for me, obviously, people realise I actually can't see much, I actually see double now, which is even worse. So what I do see, I see two of. People will give me something, and I'll say, oh, look, do you have it in a digital format? And they'll say, oh, I'll read it to you. But I'd like to read and think about, you know, if it's a menu or it's, you know, the ingredients. I mean, who can read the ingredients on a can anyway, let's be honest. But, you know, all of those things, giving me the access so I can do what I want, so I don't have to pay someone else to do it, because that's also the other side of the equation. But it's including me as a normal person.

[Simone]: Yeah, and you are a normal person, and that's my point, right? People see people with disability... as someone who needs care and support. They may need care and support at doing this or that or whatever, but in their day-to-day life, you know, I think.., and this is kind of, you know, really the biggest issue here is this assumption. People don't talk about it because of the stigma. And I say to people, we were just talking before we started about the health system.

[Narelle]: Yeah.

[Simone]:

The best way you can include anyone... is ask them what they need. You don't have to, no one has to read anything to you.

[Narelle]: We were talking about the health system, and the issues and that people just have to ask.

[Simone]:

Yeah, like what support do you need? How can you access this service? Because me, for example, now I'm representing my son, Josh, who's autistic and intellectually disabled, and also has kidney disease. So, for example he's very... funny with what he eats, and he doesn't take tablets. So, not once was I asked what are his sensory issues, or how can we support him while he's in hospital? And then, you know it was not until I saw some tablets on the floor that I asked, what's going on here? They're like, we just gave him his tablets. And I'm like, he's not going to take tablets. Now I told them repeatedly that, but again, there was no system in place for them to capture that knowledge, and share it amongst, you know, the shift nurses and all the team, that this person doesn't... take tablets, you know? And it was, they're the kind of things like that's a pretty, that's a very specific issue, but it's, this is what I mean. This is just the conversation we need to have with people. There's nothing anyone needs

to buy or do or get extra to do. It's just a conversation,

like he doesn't take tablets. What's the plan? What can we do? Can we dissolve it?

Can we get in a liquid? That's it. That's it.

[Narelle]:

That's it, because you think about it, in a hospital, they are like, are you vegan, do you eat fish? What are your dislikes, and you know, your dietary requirements. How hard is it to ask, what are your sensory requirements?

[Simone]:

Yeah. And that's kind of interesting you say that, because that's the example I give, you know? There's no stigma about being a vegetarian. So, you know, and it's just a simple, you know, again, you have to eat every day, and dietary requirements is a pretty standard question. So why can't we have, you know, and that's kind of why I start and talk about... accessibility statements a lot, or you know, if you have an event, you can simply, instead of thinking, well, of course, your event should be accessible. If you have on the ticket, what are your accessibility needs? And ask the people what they need. Now, if I go to an event, with Josh, I know what his accessibility needs are. I can suss it out and be like, yeah, that's accessible. I'm comfortable with that. I

could go. Or I could be like, you know, I could request this thing, for example. And it's as simple as that. It's as simple as asking and not assuming. I think back to the awesomeness of people with disabilities, is they will have the answer you need. They'll tell you.

[Narelle]: Yes.

[Simone]: You don't have to magic up anything. It's not hard. They'll know all the things cause of their lived experience, and their resilience and grit. And they will have the solution you need. So ask them, and they will give it to you, and everybody wins.

[Narelle]: Yeah, exactly. I actually think that whole thing comes from a... position where people think... that people with disability are not whole, and that they can't look after themselves. It's a very ableist mindset. It's actually a very disabling mindset, because that takes away from the person with the disability... what they can do.

[Simone]: That's a real big part of what I do at Disinfluencer, and why I talk to the brands, and we want that marketing and advertising, because... we need to break that stigma. Now, when I don't see my kid or my family represented in media and marketing, that irks me. But when people, everyone else... doesn't, like, this is the problem, right? It's not just for me to be seen or represented, it's for everyone else to see people with disabilities... in everyday settings, in everyday things. So it's not, we've got this kind of separation, this, what's the word?

[Narelle]:

Segregation. It's a form of segregation.

[Simone]: Yeah. So, when we see people

with disabilities in ... marketing and advertising as consumers, not in a form of getting support or care, we can see people, you know, that's kind of the first step. And that's why I made Disinfluencer. And that's why I'm going to

the top, because we want people, the big brands to be... showing their customers, all of their customers, so people can be represented, but the general population can see, like you said, people with disabilities are

people just like everyone else. They're not broken, they don't need to be fixed.

They are your consumer, and why aren't you marketing to them, or representing them in your business?

[Narelle]:

You said earlier that the response that you got was, I don't have

access to the talent. Now that you've provided the access to the talent, what are they saying?

[Simone]: They are grateful. And... a big part of what we do at

Disinfluencer is education. So, there's barriers on both sides. And again, I kind of took on this role without it being a role of, I'm like, I'm here for all your questions. Ask me all the things, because what happens is we speak to people, I've worked with incredible, inclusive businesses and brands, but then they don't market it, because they don't feel confident marketing it. So, I empower those teams to market their inclusion, because there's no point doing

a body of work to be inclusive, or to have a sensory room, you know, to

change the lighting, to have quiet hours, if you're not then telling

those people about it. And I think, again, it comes back to the stigma of... we've got people in teams that... are trying to be inclusive, that really do want to be inclusive, but they're kind of held back. And again it's about... finding businesses like mine, and there's plenty of businesses out there that can help you market your inclusion, but also educate you and empower you to be inclusive. People with disabilities are busting to be included, and you know, I'm always raving on about my mate Kelly's quote, "Inclusion is like cheese. You can never have too much but some is better than none." We need something. You need to start. Yes, there's lots of things to do but having an accessibility statement, doing image descriptions, putting captions on, marketing your inclusions. I, as a consumer, have my values, and when there's an inclusive business, I will spend my money with them.

[Narelle]:

And you've got it spot on.

Barriers in Employment & Business

One of the things that... disappointed me

I think when I stopped coding, I was getting to the stage where I was really struggling to code, that was so disappointing. And there was a grief process, actually, because I really did love the work I did. I really loved it. And I moved into other areas in that organisation where I worked, and it was still inaccessible. It made no difference. And so, then I had to think about it. I think, well, what am I going to do? I'm not a sitter. I just can't just sit. I've got to keep doing things. And then... and there's a lot of us in the boat, where we have to build our own businesses, and we've got no other option. And that's sad, cause building your own business when you've got a disability... is an extra layer of difficulty that people can... never really understand, because you're not

only dealing with the business, and everything that entails, you deal with a disability that may give you health issues, that may... Some days you just can't work, no matter how much you want to work, but the business still has to keep going. But you can't just sit in a corner. That's not going to help.

[Simone]:

Yeah, this is something I think about a lot as well, because I, you know, I have my own business, and why do I have a business? Because I can't go to work because I'm a carer.

[Narelle]: Yeah.

[Simone]:

And I try and think of the positives. Like, I'm lucky to have a business. You know, and I just think of I'm probably the exception, we're the exception, because a lot of people that have a disability or in carers roles, probably don't have... You know, it's so hard to start a business when you're a carer, or have a disability, like, oh my goodness And you have to have like some kind of domain expertise. Like, I'm a graphic designer by trade. I've done marketing, you know, that's kind of what I'm doing, and I'm just doing it in a disability kind of niche now, but I've got those kind of skill sets to lean on. But yeah. I get a lot of purpose from my work, but I kind of joke with my husband all the time because he plays like lotto with the people at work, and they have morning tea, and I'm like, I'm sitting in my kitchen with my kids. And that's kind of how my work goes. And I get, I'm starting to get invited to a lot of really cool things, and I just can't go because I have a child that, you know, needs to be cared for, and I just can't go to

Melbourne to an event. I can't even go and get an office outside of home, because I need to be home for school and all that stuff. So, it is a challenge. And I think, again, there's incredible businesses and business owners that... facing so many challenges, and do business with them, support them.

[Narelle]: Yeah.

[Simone]: See?

[Narelle]: Yep. And that's perfect, because that's what it is. You know, for me, like, I'm a carer for my mum. I look after mum, but mum doesn't need most things. So, you would've heard the microwave in the background. Because I work from home. I can, I'm a bit different in that my mum's, you know, mum can go out and do things. I don't have children that are still growing up. Mine are adults. But it's other issues for me. Well, you don't go out. You can't. Or, you know, it could be, it's a really, really hot day. You don't take a dog out on a really, really hot day. There's things that we can't do, or that change, and I don't like the word limit, that change the way we have to do things. And I think... the bottom line in everything, though, is that mindset that... people with disability can't do it. They need to be supported. They need to be helped. They need to be cared for, because I don't think that's the right mindset.

[Simone]: No, it's not. And I think everything you said, like we have these challenges, but this is kind of what makes us unique, because, you know, there's like a military term, adapt and overcome. Now you can't, you might not be able to do some things, but you're still doing things, right? Yes. And it might not be in a nice, neat nine to five, Monday to Friday. That's how I think of it. I have some days where I'll be up at six, the kids aren't up and I'll smash out some work. And then, you know, during the day, it's hectic and I can't

do a thing, you know? So, it's kind of like, again understanding that... people with disabilities and their carers, especially the business owners, are working under extraordinary circumstances. And that makes them like even better to do business with, cause if I can get up at six and I can work around all the crazy, and I'll still get the things done. And give us a chance and support us, because, you know, again, I think too, like just recently we've, you know, Josh has just spent like eight weeks in hospital. Paying for parking twice a day, paying for hospital food, going back and forth to hospital. Like, it costs a lot to have a disability. Like it's expensive, and you know, I want to have purpose and I want to earn some money, and contribute to my family, so this is how I do it, and this is the only way I can do it, you know? So, I'm trying my best and I'm doing my thing, and I'm hoping for impact and change. I do that from a place of lived experience, and a place where, I said before, like, I can't sit here and be angry at everyone because of how... inaccessible they are or how they're not inclusive, so I have to... be the person that educates and supports people. Yeah.

[Narelle]: You're finding now that people are coming to you, and asking, what do we do?

[Simone]: Yeah. And you know, just like before we started when we're talking, I've done a lot of work putting Disinfluencer out there, and making it, you know, like our branding is really fun and creative.

[Narelle]: Yeah.

[Simone]: I really, do a lot of social media marketing. I really try and put myself out there that I'm approachable, and that you can ask us questions, and yeah, those... those meetings are coming, those people are coming to me now and it's exciting, you know, because

I honestly believe... like I said to you before, it's no excuse, but businesses and brands really do want to be inclusive, but with no experience or exposure, where do they go? Where do they start? So I'm trying to say to people, like, start with something, do something, like talk to me. Let's have a conversation at least. And then from there, you know, you might not need inclusive stock images. Like, I'm a marketing, you know, kind of business. So, that kind of fits with my niche and I know marketing But I also know people like you. I know people like Kelly. So I can refer them to my network. That's another thing, too.

Community Networks & Collaboration

There's this incredible network ... of businesses that are... led by people with disabilities, or carers that are so siloed. And like you said before, this is something I'm working on this year, is bringing that network together because... we all face those same challenges. And I guess, you know? Again, it's lonely, and it's hard running a business, and it's even lonelier and harder running a business from home when you have a disability and like you said, you can't get out because of your carer responsibilities, or because of a health issue or because of some access issue. So, how can we connect better as business owners to have a collective voice to make the changes we want to see?

[Narelle]:

I think that's the best... question we could finish this episode on because, yeah, how can we do it? How can we as a society be more inclusive, and realise that we're all normal, we're just different varieties of normal. Different limitations. I always laugh and say, my sons now are going bald, something in my family, and that's okay. They save on shampoo and conditioner, so it's all good. You know, it's not the end of the world. We just do things differently.

Simone, how can people contact you... to keep the conversation going? And to ask in the marketing area in the branding area, what can be done to bring about inclusion?

[Simone]:

Best place to find me is at our website, disinfluencer.co. Or reach out to me on social media, and I'm happy to chat to anyone. I really love talking about disability. I'm on a mission to take disability mainstream, so each conversation I have with that takes us one step closer. So, I'm here for all the conversations. I'm here to help businesses and brands be inclusive. So if I can't help you, I'll know someone who can. But yeah, like, call me.

[Narelle]:

Thanks, Simone.

Thank you so much. Yeah, what can I say? That's some powerful information there from Simone, and it's really appreciated. And it seriously is. It's just a change of mindset. Knowing to ask the question. So, we'll see you on the next episode. If you like what we do, please like, subscribe, review, share. We love feedback, good, bad, or ugly. Let people know that people with disability are just normal people and join us on the next episode of The Digital Access Show. See you then

[Narelle]:

If you like what we do, please share, review, like, subscribe. You can find all our old podcast episodes on YouTube, and also on our website, dasat.com.au. We really do love to receive any feedback that you can give us. So, we'll see you next time on The Digital Access Show. Bye-bye. [music playing]