

[Music] Hello Ladies and Gents. People of the world. Take your pick. All our assistance service dog. They're just as important. Welcome to another episode of The Digital Access Show. This show is where we look at communication. We look at disability and we look at how we as a society and we as a community can improve our communication with everyone. Today's guest, I've only talked to twice. And I met her through the lovely Lisa Young from ieye Low Vision Services. And Jaceen lives in regional Queensland. Gladstone to be exact. So Jaceen Ross, thank you for coming on the show and giving us your time. [Jaceen] Thank you very much for having me, Narelle. I'm very, a little bit humbled, a little bit excited and a little bit nervous. [Narelle] Aah. Well, we're just going to have a chat really. But Jaceen, can you tell us a bit about yourself? Where you came from? Do you have a disability? What is it? [Jaceen] Sure. So Narelle, introduced me correctly. I'm Jaceen. I live in a regional and have grown up in regional and rural settings for most of my life. At eight years old, I was diagnosed with Type 1 diabetes, which is a chronic disease. And progressively from that diagnosis at around 26, I was diagnosed with diabetic retinopathy. And lost my vision to it. Uum. I have some, retained some vision. And while limited, I'm classed as legally blind person. So, I guess the challenges for me have been, you know, a lot of different access points. Medical access, digital access, service access, family, education, employment loss. All of that type of thing that come with living in a rural and regional setting, where, you know, services aren't as available, widely available Um, and time between. So, um, gosh, what else? I also have a couple of other hidden disabilities as well. Um, and yeah, that's, I guess that's me in a nutshell. I live with my partner. I have a 14 year old daughter, as of yesterday. She is um 14. So she had a birthday. And um, yeah, that's, yeah, that's us. And now, um, most of our services are in our capital city around 600 kilometres away. So, medically speaking, we're quite, uh, detached and all of that and spread over 600 k's. Anatomically speaking. Yeah. [Narelle] Yeah, I understand about growing up rurally because I'm like you. I grew up out in the bush. Um, and yeah, I remember as the kid when I actually, we know now when I actually started losing my sight, that even just to get a pair of glasses. It was a minimum hour drive. Sometimes two hours, depending on where the optometrist was, Then you'd wait for six weeks, a month. And then the glasses, they'd arrived in the mail and then your mother had to learn how to fit glasses. Because there was no one to do it. Yeah. Um, in our day, I remember having my first issues at around 12 or 14 with the diabetes. Um, and I was, uh, told I had an astigmatism and needed to wear glasses. Similarly to my daughter. But um, I remember having that appointment and I remember at least like a six month wait just because we were on a pension, um, to go through the hospital subsidy scheme at the time. The waitlist for that was intense. Um, and you know, as a kid, you know, kids are kids are really fond of having a dig and having a go. So yeah, maybe it's, uh, it was quite an interesting experience and comparison to what we have available to us now for sure. But yeah, just [Narelle] Go on Jaceen. Because, because from your perspective, living in a regional area, what, if we break, take each of the challenges down, even transport? What are the transport challenges that you have? Are busses? Or if there is public transport, I'm not sure. Are they set up to help people with disability? [Jaceen] Not really. No. Um, we do have, uh, local buses. Um, I won't even get into the, the ability for public transport. But I will say we do have local buses. Most of the runs are school time. Um, and maybe a couple of runs in between there. Um, that is not accessible to, uh, to people with a disability as much as it could be. Um, the QR codes are unavailable. So when you scan your QR code over for the bus timetable, it's not there. Um, a lot of us

are ringing in. We have to ring our train, our people to book the ticket because the timetable is just insane to look at on a or use voice over. There is just too much. AAh, it's not simplified. Um, there's no tactile markers on our, uh, platform in Gladstone, which is, I've found very interesting. Um, it's. [Narelle] That would be quite dangerous actually. [Jaceen] It is. Um, it's actually public knowledge. You can go on to the website, check out Gladstone's platform and it'll tell you it's got cross bar to the tactile markers. So I thought that was interesting. Um, but yeah, we, uh, and to go from here, say to Brisbane, there's probably one or two buses a day. The 12, 13 hours apart. Uh, same with the train. Um, so yeah, where I wouldn't necessarily, in 2024, I don't think we should be that isolated for public transport. But we are. Um. [Narelle] And you are on the coast of Queensland too, which is quite interesting. [Jaceen] And it's the, yeah, very much so. We're on the major thoroughfare right through to, um, Cairns or Brisbane. Um, so yeah, it's, uh, very interesting. And then, you know, thinking of people out west, um, their limitations for public transport, uh, as, as limited as, as ours in a, in a bigger town. [Narelle] So for you, you'd be very reliant on taxis then. [Jaceen] Uh, yeah, taxis or the, um, the you know, beautiful friends and family, um, who are not working because it is a very heavy working town. Um, which is why we have limited access to, uh, services, you know, through either Vision Australia or Guide Dogs. [Narelle] Yeah. So what about even like doing your shopping? [Jaceen] Uh, uh, my wonderful partner has been the person who goes and does the shopping. Um, whilst he's not working. Um, and so, you know, as he gets back into work, I will have to um, make a change of circumstances, potentially through NDIS. Or if I'm already out and about, I have to ask a friend if I, you know, if they don't mind giving me, you know, an extra five or 10 minutes to grab a few groceries. But I haven't done. Honestly, Narelle, I haven't done a full grocery shop on my own for a very long time. Yeah, very long time. [Narelle] But even are there support workers available to help you. [Jaceen] There are. Uh, you don't have the hours in the plan and accessibility for a, uh. That's a whole different topic. [Both ladies laugh] [Narelle] Yeah, that's a whole different topic there. Yeah. [Jaceen] What's deemed reasonable and necessary in a regional town is not necessarily reasonable, necessary in a, in a, you know, metropolitan area where you have these accesses. [Narelle] Yeah. But it'll be even down to the education system. You've got a teenage daughter. She'd be in high school and there'll be all the, you know, you husband going back to work. So that means then there's more issues there as well. Because the notes coming home from school. The homework, the, you name it. [Jaceen] Yes. Um, already there is a lot of paperwork as she's going into that 14 year old employability, earn and learn phase. But she's not sure whether she'll, uh, stay, uh, learning. She'll, she'll remain in TAFE type education. But she wants to get a job as well. Um, and that's the whole new, uh, ball game to navigate, you know, and if my partners at work and I only get two hours a week support, it does make it very, very tricky. [Narelle] And I know, [Jaceen] Taxing. [Narelle] And I know that, you know, TAFE Queensland, it's not accessible either. Which makes it another issue for you. You know, they, they try to be, but they are definitely not. What about even things, the simple things like we've, we've talked about reading the bus numbers. You can't because it's not accessible. And it's, it's even, um, paying your bills, things like that. Because do you do it on paper? Is the local council really aware of digital accessibility and are your bills, your rates, your water, your, all of those little things that we all use, are they accessible for you? [Jaceen] Um, I think we've been a little bit lucky in the paper format. They will still send them out via paper. Um, however, you know, trying to

get that enlarged. No. Um, I couldn't really. I know they just had a, um, Dylan Alcott's crew come up to do an access and inclusivity planning, uh, workshops, I think they were called something like it, But they got everyone in the same room and did a kind of a community consultant about us, phasing all the challenges with all the different disabilities and hidden disabilities. Um, but as we speak, you know, access, The schools are painful. The school can be painful. They will try to save paper. They will try and put everything on an A, maybe five. I think it's A5. Smaller size. Half an A4. Excuse the dogs in the background, everybody. We, it does make it challenging to sign, because even when you use your little sign card with the cutout in it, you still capturing smaller information that can be really. And we can't read that, because it might be that the printers running out of ink, and they'll still send it out. But it's still legible for them. Or anyone who's sighted. But it's not for us. And so having to get them to send it even on my phone, I have no digital access, because I can't use my pen. It might like my bullet, digital pen. But I have to take the iPad, but the iPad doesn't have cellular data. So now we have to hotspot it. So yeah, I don't think service providers, where it comes to digital accessibility, really know how tricky that is for a person with a disability. [Narelle] Do you think there's much awareness of disability in your region? [Jaceen] I think there is a specific disabilities. So you know your visible ones. So you know mobility, so elderly and mobility, someone with a broken leg. Someone with a cane, walking canes. Somebody with a assistant dog. That's more of a thing for other, as in a, what do they call them? [Narelle] Like calming dogs? Epileptic dogs. [Jaceen] Yeah, yep. But for a person with a white cane, there's a very limited number in our time. I know I'm out and about, and maybe one other I've seen with a white cane. I know there's a lot more out there who see service providers every couple of months. But they're not getting out and about. They are, they're not got the aid with them, like the white cane or anything that is visible. I think for visible disabilities, it is, but for those kind of hidden ones. And you would think, you know, with the amount of population that struggle with the spectrum of vision loss, there'd be more. Jaceen laughs. That's more than two thirds of the, those around two thirds of the population struggle with the sight issues. And yes, still very limited awareness and understanding. [Narelle] What do you think could be done in the region, feasibly, you know, reasonably cost-effectively? What do you think could be done? [Jaceen] That's interesting. So I have a, pardon the pun, I have a vision for building a resource center closer to home. So whether that has resources for sensory issues for ASD and neurodivergence or autism in neurodivergence spectrum, a resource center for vision loss. So, having, like, Toowoomba used to where they have a center to come and, you know, work with us longer through the week, and to have that ability for service providers to come together in the room and have that place where it's, you know, available for training services, aids, all of that. You know, I did have this idea. I'd love to see a social enterprise scheme. Whether I can facilitate it or not. I don't know. But having conversations with people or stakeholders to bring a, maybe like a social scheme for chains and things for those people that can't afford or haven't got access to these aids. There are so many people that cannot afford to go traveling to Brisbane to get training for a cane. I know. [Narelle] Yeah. It, it, it's not just the travel. It's the accommodation. It's the food. It is. And it's, it's having, you've got to have support workers available to get you around. Moving around as a person's disability is not a cheap thing. [Jaceen] No, it's, um, if you've never gone from a rural town and you've gone legally blind and you've maybe traveled to Brisbane once or twice, that is a huge burden.

And I mean it in the most polite way when I say the stress of even contemplating going on your own. So you don't rip your family out of whatever they got going on or, you know, there's been so many times that they said, you know, ooh just, your partner can drive you down and, you know, you've got the school saying every day counts. So for what looks like, you know, a day trip, that's a 12 hour return for us. You know, that it's, it's just not. [Jaceen laughs] [Narelle] It's just not easily done. [[Jaceen] No, it, it shouldn't be a suggestion. [Jaceen laughs. [Narelle] And it's also to, I don't think many people realise, and I, and it would be, I think. I can't talk for every disability, obviously I know for vision impairment, definitely. The loss of knowing where you are, because a person with sight gets oh, you know, "Where the heck am I?" And they get out the map and they work it all out. Person disability has to do it differently and it takes a lot longer. Yeah, we've got the tools. But you've got to know the tools exist. [Jaceen] Perfect example, Narelle. Yes, yes. Perfect example. So recently, this year, I travelled to Bunderberg, I already was for, an eye appointment. [Narelle] And Bunderberg is about three hours. [Jaceen] Just on two. An hour and a bit by car. But about two by train. First time I caught the train. Was so nervous, I had to ring them three times. And this is when I found the platform had no tactile markers. Get to the train station, all the footpaths and things are not set up well. Very rickety, you can't. It, it's whilst it's simple, it's still very unsteady underfoot. Up I toddle. Couldn't work out my ticket because the ticketing hadn't been sent to emails because they spelt name wrong. So human error. I then had to give her the email and go, I've already paid for it, that's fine. Try this one, so they ended up finding the tickets. And then she points, "Just wait out there". And I'm like, standing there with the cane. That was okay. No where comfortable to sit and wait for someone with a disability. My partner stuck around because he was a little bit unsure. Umm, you know, train stations exact, don't exactly have the right societal stereotypes hanging around. So safety, he was concerned about safety and risk management. Jump. Go to jump on the train and the lady says, "Oh just head up towards the end of the train is where your carriage is." And I'm like, how far down is that? She's like, "Oh, just go wait over there." Lucky my partner went to one of the train things. Because I reckon that the train would have just left had I just been standing there? So anyway, I was fine, jumped on. Two hours later, jumped off the other end. Says to the lady, "Is there anywhere to wait when I come back?" She said, "No, the office closes at five. You won't be catching your train till six thirty." So that was already going to be an eleven hour wait. I ended up, the train was delayed, was thirteen hours. I had to wait on the platform from five, four pm till seven thirty pm. Three and a half hours. Just to wait for the train because there was no where safe to wait. Where I didn't have to walk from a, umm pub. Or a sports club. Three or four blocks. Bunderberg has a very high rate of upi lmpw. drug use. And it is unsafe in town. Ummm. She then, my, when I got off the phone, I couldn't access my maps because my network hadn't kicked back in. I had my phone off, asked the lady where the council chambers were. Because the only thing I could think of was to go there and get a map of the town centre. Which she gave me some best direction. She said, you know, just wander up there ten minutes. I think she thought I was a bit slower than normal, but it was only a three minute walk. But yeah, lucky the council there said, "Oh, we have this. But I don't know how accessible it is for you." And I'm like, yeah, I don't, you know, transport wise. Digital, that is a perfect example of digital accessibility failing a person. [Garbled words] [Narelle] What can we, as a society, what can we, as a community do? [Jaceen sighs] [Narelle] From

the disability point of view and from the normal person point of view.

[Jaceen] I think we need to be able to have, you know, at least grace given in our plans for travel and digital access. Whether we're on plans or not. There needs to be a little bit more understanding, maybe more training in orientation. Maybe more experiences out and about where we can build that confidence and, and safety. And, you know, maybe starting in schools before we lose those, you know, visuals about how to navigate an area. Potentially with the vision loss as well. And, you know, society doesn't talk anymore. You can sit on a train and everyone's on their phone. You can sit in a, you know, nobody, nobody speaks to each other anymore. [Jaceen laughs] [Narelle] Yeah. [Jaceen] Yeah. So the confidence level for asking for help. I mean, I don't mind, but that's not easy for everybody. Particularly if you've got other hidden, you know, conditions behind that that, you know, impact your, you know, your confidence about asking perfect strangers for assistance. So, [Narelle] Jaceen, it's been interesting in our discussion. What are some takeaways that we can leave with today that could be thought provoking? Could be something very simple. [Jaceen] I, one of the biggest things is to keep having conversations with people about, you know, digital access and the barriers based by disability. Whether it is businesses, council, medical, schools, having those conversations, having a voice is so, so important. You know, raising, raising a collective voice, I think as well to take that to a more systemic advocacy and awareness phase. Yeah, I think they're the two biggest ones for the moment. And, I guess, don't let anyone tell you that your barrier doesn't matter or isn't, you know, something that, you know, can be easily, you know, navigated because it, it isn't. You know, it really is. [Narelle] That is a good point. That is a really, really good point. Jaceen, look, thanks for coming on and thanks for talking about your experiences. How can people contact you if they would like to keep the chat going? [Jaceen] Yeah, so I have a page called Building Blind Faith on Facebook. Or there's also my name, which is Jaceen Ross J A C double E N. And Ross R O double S. There's only one of me. [Jaceen laughs] Yeah, and yeah, and obviously, by yourself as well Narelle through Digital Access. So if anyone, you know, wants to contact me through you, happy to receive a referral. So, yeah. [Narelle] Oh, thanks. So, Jaceen You're looking at starting up a some form of resource unit up in her area. I urge everyone, regardless of disability, go and have a chat Jaceen. Because Jaceen's got some knowledge that can help our community. So that's our show for today. Thank you very much. If you like what we're doing, please review, like, subscribe, and share it. Just share it to everyone. Because, as Jaceen said, the more we advocate and the more we talk about the challenges, it's not just helping us. It actually helps the community. Because then we become more independent. And with the aim of that, more people will get into work and you'd get some awesome workers. This is, again, we didn't even touch on employability. That's another show by itself. But it does make a difference. So we'll talk to you all next time. See you around. [Jaceen] Thank you very much, Narelle. [Music]