**Interview with Elise Stewart and Liz Wright**

Liz (music playing)

Hello and welcome to one in a series of podcasts about women from rural and regional Victoria and Melbourne outer east living with disabilities.

I'm Liz Wright and today I'm talking with Elise Stewart, CEO of Deaf Hub, Bendigo. Whilst Elise discusses some challenging topics, she's funny and honest and this is a really fascinating conversation.

Some of the content contains swearing and some of the content may be considered triggering.

Please enjoy and if you have any issues, you can call Lifeline on 13 11 14.

Elise

Rock 'n' roll. Let's go. I'm Elise Stewart. I'm known as Ellie in the Deaf community and I'm from the Dja Dja Wurrung country.

Liz

How long have you lived here?

Elise

On planet Earth, I've been here for 35 years since Sunday.

Liz

Happy birthday.

(Laughter).

Elise

Thank you. I’ve been in and out of Bendigo. I moved here when I was 12. I left my family, my mum and stepfather and siblings and moved over here with my old man. He left his wife and we moved here because it was the only place we could go to a school that had a mainstream Deaf facility, Deaf unit for high school for the regional area.

Liz

So what school was that?

Elise

Golden Square Secondary.

Liz

Really? Which is no longer.

Elise

It was the biggest mistake they made. It was one of the better schools that they had. It had a facility in there and it was the only place that a lot of us regional kids could attend to. Otherwise, you had to do boarding in Melbourne or boarding here in Bendigo if you were from a regional town further away.

Liz

And I imagine if you're not around other kids who are Deaf or other people - like if you’re the only disabled person in the room - it can be very lonely.

Elise

Absolutely isolating. And I mean, not even just being the only person, it’s still isolating regardless, being Deaf. Isolation in my own family, even in my own immediate family at home, every aspect of life can feel isolating.

Liz

So not your family of choice, which is with your wife and children, but your family of origin you're talking about?

Elise

No family of choice as well, because everyone's hearing and I'm Deaf.

Liz

Okay. Right. So that's really, really hard. How is it manageable for you? Because we all know that, you know, when you're the only person with a disability and other people don't understand or don't see it, it's exhausting.

Elise

Oh, absolutely sister. Absolutely. Yeah. It's just, you know, and I go in waves where I let it get to me a lot. So, I’m just coming out of it to be honest, a real, I guess a depressive wave.

I would go in waves every six months or so because it's just like I said, it gets really exhausting. And then you kind of put it aside and go, right, I'm trying to communicate with my family. I'm tired, I'm exhausted. I need you to meet me halfway, sign with me please or, you know, instead of me lip reading all the time.

And it’s hard with little kids, you know, they forget, and it's easier for them just to talk because they know that I can respond verbally, but to convey it, like for them to convey the meaning and me to receive it, they need to sign sometimes, and kids’ facial structures changes very quickly so lip reading is always changing.

My communication method is all about expressions as well. So lip reading, a lot of people are under the idea that lip reading is 100% accurate, so whatever information is coming from a mouth, that's what we're getting. But lip reading is combined with facial expressions and body language as well, so lip reading is only 30% accurate for those who actually grew up aural Deaf.

So aural Deaf is a person like myself, who was I guess, forced, is the worst word to use because it seems to offend a lot of people when I say forced aurally Deaf, but to assimilate in the hearing world, we were forced to lip read and not sign, and family didn't take it on too well as much as they like to say that they tried to sign all the time. But it was just easier for them to talk and make sure that I was looking at them.

And it’s the same thing with the children. It doesn't matter what they're saying or whatever it is. They might be saying something, trying to say something, but their body language is saying a different thing. And that is quite confusing, and the frustration for children. And my kids, especially is that they’re trying to say something, but their body language is telling me the opposite. And I would say: You're confusing me. You’re, you're telling me this, but your body is saying that.

Liz

You said things come in waves as far as how you feel about being isolated or included, and I imagine there's, you know, resentment and sometimes grief. But how, how are you managing that?

Elise

At the moment it’s a very raw time, because just recently, well this week, we had two community members commit suicide. So it’s moments like that that kinda give you a bit of a tap on the head and shoulder and say: Hey mate, it’s fucking shit, it's hard. But you know, look what's in front of you, you’ve got a beautiful wife and children.

Yeah, it’s hard sometimes, but I mean, I've got to find ways to be grateful for what's in front of me and what I've worked so hard at getting for myself in my life. So currently my wife and I bought 17 acres a couple of years ago, and we've got, you know, alpacas, goats and sheep and chooks and, and all that, so when I’m having my worst times, I usually just cut myself off from the hearing world and I throw myself into the animals - animals are my…

Liz

Spirit people?

Elise

Absolutely. Yep, yep. Really if it wasn't for animals, I don't know how much longer I would be around for. They really lift me up in my worst times, as well as my wife, she knows when I'm having a hard time in those dark moments, she’s always there, no matter what.

(Music playing)

Elise

You know quite often when you're born Deaf, you're the only person in the family that’s Deaf. We call the generational Deaf; born of a Deaf to the Deaf, we call them the lucky ones.

And a lot of people turn around and go: Why would you call them the lucky ones? And it's like well they've got access to communication right from get-go, and identity right from get-go.

But when you're the 90, 95%, it's actually going up to 97% as now, which is what I fall into, that we don't have identity at the start, we don't have a connection right from the beginning. We do with our Mum and whatever, but it’s different, you know, you’re different from everyone.

You know, when you're the 97 percenter, you have a different relationship to what everybody forms in the family. You know, you're kind of the black sheep of the family. You know, there’s always inside jokes, there’s always, you know, even if there’s an argument happening around you, we’re the last ones to know what the fuck is going on.

And that happens every day in life. Like, for example, if you’re sitting down watching telly, and you put the subtitles on, the government news breaking, you know, when they say authorised by the government, where they have some sort of thing, you know like updated information about COVID, or the floods or whatever, that's not even captioned.

They don't even allow captioning for that. So vital information is missed, and you know, I say this every day with my wife, we sit there and watch telly I would be like: There we go, just another form of discrimination right there, you know, the caption can't even come up on that.

Every channel on the TV isn't captioned. People think that you just need to put the subtitle button on and the captions work automatically. They don't understand the program has to fund that. And it should be mandated that the Australian Government should, make every goddamn channel subtitled or even have an interpreter on the screen, you know, especially for those, you know, authorised by the government updates or information.

Like with the floods happening now, you know, I had to call around to the councils in all regional towns and the SES controller to make sure they organised an interpreter for those community meetings.

I could only get through to one person out of five regional towns that are affected by the floods right now as we speak, to actually get an interpreter there. And all these towns that I called had Deaf communities in them.

Liz

That’s appalling.

Elise

You know I'm trying to advocate - I’m in Bendigo. We're not affected by the floods like you know Eucuca, Moama and Shepparton are, and you know, there should be already a criteria that if there’s an emergency, bang, make sure this has happened and make sure these people are notified. But because we’re such a minority, it feels like we’re such a minority, but we're *not*. We're not really a minority. You will know and meet a Deaf person in your lifetime more than you would meet someone who speaks French.

(Music playing)

Liz

So tell us about the Deaf Hub.

Elise

I was very successful with a grant application with the help of my wife and another very close friend of mine, Michelle Taylor. You know, I saw this grant 12 hours before it closed.

Liz

Oh, my God.

(Laughter)

Liz

Oh, my God.

Elise

Yep. And I quickly put together an application and then I got my wife and Michelle to proofread it and English it, because English isn’t my strong language, written anyway. And everyone teamed up together and I've got Michelle next to me and I'm ordering food, feeding her while she keeps going.

And we were like: What do we budget for? And we just went a million dollars.

Liz

Oh, wow.

Elise

You know, I felt like Doctor Evil, you know, one million dollars. And just on a whim, just did it and then found out we were successful and so that was really good. And, you know, we went through a lot of trial and error with the auspice arrangement we had before and changed the auspice contract to somebody else, as it just wasn't the right fit, and, and three years later we're still rolling on and we’re successful to top up the funding again.

Liz

For another two years?

Elise

Yep til June 24. As much as there’s resources out there and information about Deaf awareness, blah blah blah blah blah blah, I was finding myself having people you know randomly rock up to me and be like: I've got a 50-year-old mate or a 70-year-old friend or whatever, and they've never learned to sign and they can't speak, or their, the main person had died. So mum was always their main communicator, or their or their daily life navigator, and when they passed away, they got no one else around to help them get through the rest of their chapter in this life.

So, I was seeing a lot of that happen more and more and I wanted to be, I don’t know, a miracle worker and put an end to that and create a safe space for Deaf people to come by and come together and have their own events or just a place to chat.

I thought: You know what? There’s not enough evidence out there or data, unfortunately or research evidence of lived experience of Deaf people living in the regions.

Relationship breakdowns in families as we get older in life and a lot of people were getting confused about why that was happening, so I decided to go and do a documentary and I interviewed 27 people around regional Victoria from, you know, four-years-old right up to about 80. And it was never going to be a live stream documentary, but it was a Disability Royal Commission submission.

Liz

Oh, wow.

Elise

And I did that.

Liz

And did you present it at the Commission?

Elise

Yep.

Liz

How did that go?

Elise

I got applauded and a lot of people in tears, and they actually came to me from Brisbane and said, you know, we need help translating some of these things, because I actually interviewed a refugee, and that just absolutely blew my mind more so not just having the language barrier but cultural barriers. It was tenfold for them.

So what happened when I submitted all this work there was hearing for different categories and they were basically, you know, asking me to guide them through a translation of what the Deaf people were saying even though we had interpreters on their documentary with us, some people still couldn't even understand what these people were saying because, A. they’ve had no access to the language, some of them, or sign language, and so they had their own miming, gestures and made-up sign language.

And I managed to - because I got to know them over a period of time - I used to travel up to where they were to get to know them before I did the documentary, to kind of get their communication style and actually introduced sign language to them as well, that we were able to…their world opened up because they were finally able to communicate with somebody.

I guess because when you, when you talk about languages, a lot of languages are auditory. So, this is visual. So, people who are used to auditory living, because it’s an auditory world we live in, their brains are developed to hear language and communication and process things a certain way, but we Deaf people, special people (laughter), we process things a whole lot different.

Our neural pathways are being created to communicate and process things differently from the auditory way.

So, I guess that would be hard for a lot of people to understand that AUSLAN isn’t a written language, it’s a visual language. It's just different. So, it is hard for people to, to grasp that. And I get that.

It's different everywhere. Even state-to-state is different. For example, the sign for fruit here - I've got my hand on my chin and all my fingers…and my palms are flat on my chin, and so when you bring your hand down and close your fingers into your fist and kind of hit your chin, that's the sign for fruit. But over in NSW that’s pregnancy.

Liz

Oh (laughter).

Liz

I’m up the fruit (laughter).

Elise

You’re a fruit (laughter).

Liz

Yeah. So, it's dialectical as well.

Elise

Yes, and it's exactly the same within indigenous language in Victoria. We know there’s over 500 spoken languages, dialects, right. But state-to-state it's a little bit different, but we can pick it up you know. When you’re a visual person and a visual communicator, you can get there.

Liz

Rub it in (laughter).

Elise

But we can do tactile signs too. So, a tactile sign is where my hands will go inside your hands or yours and vice versa and we sign that way.

Liz

OK. We can be friends for a long time (laughter).

Elise

Yeah. So I won't rub it in (laughter).

Liz

Thank you.

Liz (music playing)

This is a Women with Disabilities Victoria production for International Women's Day. There will be more in the podcast series, which will be released at the end of June.

Liz

So with the Hub, how many members have you got and how does it operate?

Elise

Look, when we first started out, I went very broad just to see and try and identify what the needs were and what the community is wanting. And it's different for everybody. So, for example, a lot of people, particularly Deaf people, will come to me for access to information, for anything, so it might be contraception; it might be: How do I pay a bill? Yeah, it might be: I've met someone and I don't know, they're hurting me. Is it normal? You know, it's not all bad news, it’s really just giving them access and linking them to the right services. Sort of like a support coordinator, but we don't get paid to do that.

Or it might be that they just want to meet another Deaf person or it might be just that they want to sit down and talk to another Deaf person for the first time and feel that commonality, not like they're an alien on this planet. Usually, the first time someone meets me, the first two hours is them crying.

Liz

But I understand, probably when people meet you they go: oh my god, what a relief.

Elise

Yeah, yeah. Absolutely.

Liz

Here’s someone that gets me.

Elise

Yeah. Someone understands without having to say anything. Or even to explain to their partner why things are not working in their relationship because of communication or why that person thinks the way they do, because of the limitations of access to information right from birth.

Or it might be that I might have to go to a school or a kindergarten or a job and provide Deaf awareness training or, you know, whatever it may be.

Yeah, I'm their person for anything. I will never say no to anything, to anybody. I would never leave anyone behind. If I have to drive, you know, eight hours away because I heard there’s a Deaf person in the community and they’re just struggling, and they've heard about the Deaf Hub - someone around them generally - I would drive over there and just make an appearance.

Like a weird stalker. No. (laughter).

Liz

No, I was thinking I think you’re adding to your own exhaustion. (Laughter). Eight hours in a car drinking coke from McDonald’s.

Elise

Yep. Absolutely. Yup. Like I said, the idea of someone feeling alone out there in this world is a horrible place to be.

Liz

It's heartbreaking.

Elise

Yeah, yeah.

Liz

It is heartbreaking.

Elise

And I don’t want anyone to experience that, particularly, you know, from something that is not of their own fault.

We’re put on this earth for a reason. You know the way we are. I'm always, I used to be like: Why am I having to open the door every day and struggle with daily barriers, you know?

And then there’s that little voice somewhere, they just says: You know, you've been here, you’re put on this planet for a reason, the way you are for a reason, whatever that reason may be.

There’s a thing that I've always…felt I’ve always been a person for tokenism, and I fucking hate it.

Liz

Yeah.

I went through a really hard time with accepting awards. I was nominated for a lot of, you know, Deaf Australian of the Year this year. And I still haven’t processed that as a thing of pride, a place of pride.

You know, it kind of feels like I’ve been put on a pedestal for the Deaf community, that you know, she can do it, you can do it, we all can do it. And that's a good thing to - you know - to role model I guess, but it comes from a background of you know, for example, back in, when I tried to get into TAFE, well, I got into TAFE for nursing, and they weren't going to let me in because I was Deaf. I literally had to face the panel to get in.

Liz

Yeah.

Elise

I passed all the, you know, the pre-requisite stuff and I did everything just like every other person had to and they weren't going to let me in. And I literally fought my way, clawed my way in and found out that people were getting into the course and it was starting like the next week, you know, like what’s going on here?

And they were waiting on a result of an answer back from the Disability Liaison Coordinator, and I’m like: Why is the DLO making a decision about my ability to become a nurse? Anyway, long story short, I got in and head down, arse up, really showed ‘em.

The first year was really hard I had to interview for placements. Everybody else didn't have to have interviews for placements.

Liz

Yeah.

Elise

It was an automatic placement that you have as part of your course.

Liz

Yes.

Elise

But I had to have interviews and it was just one thing after the next. And you know, I fought against it and, you know, I made a bit of noise. But then, you know what - why, why am I fighting this all the time? I'm just going to put my head down and arse up and show them who I am and what I can do.

Turned out to be Dux and Victorian Student of the Year and whatnot. But again, at the end of it all, they awarded me those things and my depression just hit. I spiraled down into a really dark place, because again, it was like: You know, you made me prove myself to you so much and then you wanted to award me with…

Liz

Yeah.

Elise

…the work I’ve done and give me the recognition for that. The constant, I'm having to prove myself to people to fit on this bloody planet.

Like right now, my left ear is throbbing with pain. I've got a cut from my mould that I have to wear just to assimilate in the hearing world.

Liz

Yup.

(Music playing).

Elise.

It’s constantly us having to assimilate to make them comfortable or feel like it's okay to have us around or you know…

It's constant, constant, constant where we have to do the work.

And that was why I created the Deaf Hub so that I could have a workspace where everyone was Deaf and everyone around me was signing and things like that.

Liz

Yeah.

Elise

But as soon as you leave the Deaf Hub and go down the street or go get your coffee up the road or get in the car to go fuel up or whatever reality is in your face. It’s an auditory world we live in.

Liz

Yeah.

Elise

So that was why I created the Deaf Hub for that, for that reason. And you know, everyone that’s come to work there, are too scared to go back and work in the hearing world. So there was that pressure on me to get a lot of goddamn money…

Liz

Keep it sustained.

Elise

…and keep it going. Yeah. So, it's one of my proudest achievements actually.

Liz

How many people have you got working there?

Elise

So, in the past, we've had five of us working at once. But during COVID I had to let go of people.

Liz

Yeah.

Elise

And then, you know, when people got the skills they wanted and they were empowered to go up to the next level and work elsewhere in another Deaf organisation or maybe step back into the hearing world again with that little bit of confidence behind them of the knowledge that there is EAF, and workplace modification and there is a place that they can tell their work colleagues to come to when there are issues in the workplace.

You know, so we’ve created that safe space that people can come and go from.

Liz

So when you said you started off broadly, did you eventually rein it in a bit?

Elise

Yes. Yep. We’ve done that. And that's where I've got it down now, down to what we've, we've got happening now, which is great.

But the problem is that everybody wants to learn AUSLAN, everyone wants an AUSLAN teacher in their school or kindergarten or…and that is brilliant, but I just don't have the people to staff it.

Liz

Yeah.

Or, or the people that have the skills and the qualifications to do some of the things that need to be done.

There's a lot of barriers being put up for Deaf people. They were excluded right from the start. So, you know, not having access to education and language from get-go, means that the demand to have AUSLAN qualified teachers out there now is not highly possible because the greater community, we don't have access, never had access to that education 20 years ago, 15 ago, and it’s a bit late to teach them at the university level.

Liz

Yeah.

Because when I say that, you've got like 30-year-olds, 40-year-olds, 20-year-olds, they've got the education level of a fourth grader. So that’s the problem we have. We've got the high demand that we need…

Liz

What do you mean as a fourth grader? Like primary school fourth grade?

Elise

Yeah. Yep.

Liz

Right. Okay.

Elise

Yep, yep. And that, that’s a very generalised…well, that’s pretty much what it's like for children who have been through…well, our group, our community, our culture, whatever you want to put it, access to education has only just got better in the last maybe five or so years, depends on where you were, really. But yeah.

Liz

So in a rural and regional context, if you wanted to do immersion and like, you're totally Deaf and you want to be on an academic pathway, you'd have to leave the country, wouldn't you?

Elise

Yeah pretty much…go to the city.

Liz

And have to go to the city, yeah.

Elise

Or…people ask me….if your child was born Deaf, what would you do? Where would you go? And I’ve said Shepparton Guthrie Street Primary School, every time.

They've had a Deaf unit, a Deaf facility in a mainstream school around the region, around this area…they actually opened it when I was in grade one, so we’re going back many moons ago now and it’s got one of the best, successful programs, of how they do their program. But that's not available everywhere.

Then you’ve also got Melbourne, they've got their own Deaf schools and that. So you either go to Shepparton or you go to Melbourne and that's still happening this day and age. I mean we've still got children… up in Bendigo, we've got Kennington Primary School that has a Deaf facility and then you've got Bendigo Senior Secondary and Bendigo South East. So there is a stepping stone pathway, and it’s again, choice and preference for families where they want to send their children…but yeah.

Liz

So, a lot of those kids would be boarding or living with other people if they're from further out rurally?

Elise

Well, generally their families would have to move or they just to try and get VT’s, visiting teachers in the area. But visiting teacher would come to the school maybe once a week for about an hour with that Deaf kid in the classroom. And most of the time they should check and see if their RF’s or if their technology is working, not actually working with the school to make sure that these kids are getting access to education.

But the worst thing is that the VT’s that we have, they don't even know sign language themselves.

Liz

See that’s ridiculous.

Elise

So when I talk…when you ask me about the qualifications for the Department of Education…

Liz

Yeah.

Elise

…is it still being done right? No.

Liz (music playing)

To find out more about Women with Disabilities Victoria go to: [wdv.org.au](http://wdv.org.au)

Liz

I know you're really passionate about the Deaf Hub, and I know that it's been around, you’ve got refunding and there's going to be so much more great stuff coming. How did you get into it?

Elise

Yeah, good question. There’s a really fantastic person in Bendigo named Kim Muller.

She used to work for Expression Australia, well actually it was tendered with Bendigo Health for a program called DAV, D.A.V which was the Deaf Access Victoria program, and it was coming to an end of the contract and she felt that you need a Deaf face to be able to push the agendas that she was trying to push. Cause usually we all know that - you know - that whatever disability you have, it’s no use coming from an able-bodied…

Liz

Yeah.

Elise

…it still needs to be pushed, but she was filling in the role, worked for a person before her who had passed away and there with no-one else around in the Deaf community to step up and take the job, so she took it on. And she did a goddamn amazing job.

Liz

Yeah.

Elise

And for years she was trying to get me to come into this kind of area, and I was like: Na, na, na, na, I'm not doing it, I'm not doing it. And she kept twisting my arm and eventually, I broke…(laughter)…and she obviously could see.

Liz

She’s persuasive.

Elise

Yes, very persuasive, very persuasive. But, you know, and she comes from a great, you know, a good place.

She obviously could see the connection I have and the work that, you know, I've done now. She could see that that is what I was able to do. Because I was also nursing before I became a Founder so I was very passionate about health.

Liz

Yeah.

Elise

And you know health is a fundamental need, that we all need, that every human needs. You need to have access to health information to have a good, healthy life.

And she could see that there was a big gap in that, so we teamed up together to make health information accessible for Deaf people. So we did a few, we actually did a video production together, a Deaf person’s journey in mental health. What happens when they come into the mental health area of the hospital.

Liz

Yeah.

Elise

Unfortunately, it still happens to this day. And so we created a really good video and yeah, she managed to get me into this area.

Liz

What are you going to do if you want to have a change in direction? And how are you going to feel about leaving something you've established if you choose to do that?

Elise

Well, funny you say that. You know, for a long time I was like: I'm never leaving this, this is my baby you know, we have finally got a place for our people. But like I said in the beginning, because when I set this up in the start, it was done at a very broad range and we've got it now in a direction we want to go, but I burnt myself out very quickly.

You know, I had people calling me from Mildura, Echuca, even Queensland.

I had mothers calling me from there to advocate for them, for their children, themselves and all that. I'm kind of like the one person for what feels like a million people…and I don’t really… I don't have a team to bounce that around with or a mentor or anyone, so it’s really burnt me out quick.

And I am changing my career at the moment only because I had a spinal surgery done this year and, and got my body back.

Liz

Yeah.

Elise

And I'm not an 80-year-old body anymore. I'm back at a 35-year-old woman and I'm actually gonna, I’m doing, I’m becoming an apprentice in solar, electronics, an electrician in solar panels.

Liz

Wow.

Elise

So yeah, I'm doing that actually part-time right now, as well as managing the Hub. And I’m so excited, but also nervous to see whoever takes over. Well, I still will be the Chair of this.

Liz

Yes.

Elise

I still will be volunteering my time around it and supporting the people that do take over. I will still be here, you know, and like I will still be a role model.

Liz

Yeah.

Elise

You know, I don't know any Deaf female electricians.

Liz

Na.

Elise

I'm still going to be part of the role model program that the Deaf Hub has for our children out there that we go to.

Liz

You're going to be my electrician.

Elise

Exactly.

Liz

Yeah.

Elise

Your electrician, and everyone else’s electrician, right.

Liz

Yeah.

Elise

You know, and I hope more girls get on board about wearing a tradie belt and get out there. And Deaf girls especially, you know, and Deaf boys as well.

And that’s a big, big issue that we have is that anybody that’s Deaf in the trade world, well, any job, it’s hard.

Liz

Yeah.

Elise

Because everyone’s talking and you're on the roof. They're inside the roof, sitting together having a lunch break or whatever.

You miss out on everything. You miss out on all the jokes, you miss out on the laughter. You can't keep up with everything. So, quite often a lot of Deaf people will work for a while and then they go on the Disability Pension because it’s too hard. It's just so hard to fit in.

So, you know, part of me having a lot of different careers is to show people that any, any Deaf person, you can be whatever.

I used to be a mechanic. I used to be a barmaid. I used to work on a dairy farm. I’ve started a lot of business at up.

Liz

Yeah.

Elise

And I used to be a nurse. Now I'm an electrician, becoming an electrician.

Liz

Yeah. Yeah.

Elise

So you know, that’s part of, I guess, something that I really want to showcase to everybody - that be whatever the fuck you want to be.

Liz

And I think that's a lovely way to end. Thank you. I just loved it.

Elise

No worries. Thanks for having me.

Liz (music playing)

To find out more about Deaf Hub Bendigo, you can see them on Facebook at DeafCommunities.org.au.