12. Raising our Voices

**Lisa:** I'd like to begin by paying my respects to the Wurundjeri people, to the traditional custodians of this land where we are meeting upon today, for its elders and past and present, and even for the self advocacy people as well, who have passed away too, and who are still here today on the aboriginal land.

**Skye:** We recognize the self advocates who have worked tirelessly over the years for the rights to equality and human rights for all.

**Chris:** Hello, welcome to International Day People with Disabilities episode for Raising our Voices show.

**Skye:** Hi, I'm Skye. I am a person with a disability. I've got an acquired brain injury and I'm totally blind. And the right arm and leg is also paralyzed from a stroke that I had when I was five years old.

**Chris:** Hi, my name's Chris. I'm from Bendigo. I'm part of a self advocacy group Have A Say Bendigo, and I work with the Salvation Army. And I also want to set up a LBTQI advocate group in Bendigo. Raising Our Voices, on every second Wednesday of every month, 5:00 PM on 3CR, 855AM.

**Skye:** We are run by people with disabilities and give people with disabilities a voice on the airways. Nothing about us without us.

**Chris:** Today is a special broadcast for International Day with People with Disabilities.

**Skye:** The theme for this year is health, so we're going to replay an episode we did previously where we talked about health issues and as part of that, we wanted to just say a few things about health. So Chris, you wanted to talk about mental health and the pandemic.

**Chris:** Yeah. I'd like to say that during the first lockdown, I felt really depressed and isolated away from my friends and I really missed them. I just like to have human contact at all times.

**Skye:** That was really hard, wasn't it? In the pandemic, when there was lockdowns?

**Chris:** Yeah, very hard.

**Skye:** Everybody found it tricky. Yeah, I found it tricky as well. And because I've been having, recently, this procedure called serial casting, so they've put Botox in my leg, and then they've plastered my leg in a certain position, to see if we can get the calf muscle in particular to be in a better position for my walking. And we've done that three times over the last three weeks, so it's been really difficult being at home.

**Skye:** So I've had to go home to my parents for that time, so I'd be around people, be around my family. I've had to go back twice to get it re-plastered. It's coming off tomorrow and then I'm going to have an intense burst of physio over a series of weeks. So that's happening. And the theme of this year is bringing it back to health and people with disabilities.

**Skye:** We do access the health system. And disabilities are something that we live with every day. And it's important to remember that. Sit back and enjoy this episode of Raising Our Voices on 3CR, 855AM, where we talk about disability and health.

**Lisa:** Hi I'm Lisa, I'm a self advocate and I'm an ex member of Brain Injury Matters, BIM, and I'm a current member of AMIDA and SARU.

**Lisa:** I also work at the Office of the Public Advocate. Today's show is a conversation about our experiences as people with a disability in the healthcare system. We will cover a lot, but some of the main things we will discuss are the way we have been treated by doctors and other health workers. Access to support and information about the different sections of the health system which can be difficult to navigate, and the cost of healthcare and lack of financial support.

**Lisa:** We want people to know that people with a disability have the right to accessible and affordable healthcare. It's important that doctors recognise our independence. We are in control of our bodies and have the freedom to make choices. Today I'm joined by Heather, Skye and Steve.

**Heather:** Hi, I'm Heather. I am a self advocate. I am also a peer worker for Reinforce and a committee member for Positive Power for Parents.

**Skye:** Hi, I'm Skye. I am a self advocate. I have been a member of New Wave Gippsland and I also work for Sexual Lives and Respectful Relationships.

**Steve:** Hi, I'm Steve. I'm a self advocate with New Wave in Gippsland.

**Lisa:** Before we begin, it's important to say that today we are sharing our own stories. While there are common themes, everyone's experience is different. I want to give a heads up to listeners that some of these experiences are positive, while others are negative and may be difficult to hear. If this show brings up difficult feelings, you can call Beyond Blue on 1300 22 46 36 or Lifeline on 13 11 14.

**Steve:** Hi I'm Steve. I have an ABI and I got my injury four years ago. I spent four weeks in hospital. When I was discharged, I was just referred to the GP. I wasn't referred to any services and I received no information on self advocacy or no information on disability services. My GP was really nice and he knew lots about my medical stuff, but he didn't know where to send me to get help.

**Steve:** So the big issue for me was actually getting information and knowing what support was available. I was lucky because I had a background in social work. So I could do my own research, but that wasn't really easy because I was partly paralyzed and was getting used to using just my left hand.

**Steve:** So the experiences for me having a new disability was a bit different to some others, other people that have had a long term disability or disability since birth. One thing that I've heard a lot through self advocacy groups is that people with intellectual disabilities, I'm sure people with brain injuries have experienced too, but they're often questioned about if they have a guardian or someone that can give consent on their behalf. That's a big issue for some people allowed to make decisions on their own behalf.

**Heather:** I have had many experiences where doctors and healthcare professionals have not listened to me or my choices. I got pregnant and I had a baby 18 years ago. After this, I wanted to get my tubes tied. Because it was an unplanned pregnancy, and I was forgetting to take the medication that I was meant to take to stop me from getting pregnant. And everyone supported me with my decision, except for the doctor. My mum supported me. My case manager supported me. Other professionals supported me, but my doctor didn't. He actually said I would want to have more kids later on, in five years time. And he was really questioning me about the decision.

**Heather:** So when I had a court hearing about getting my tubes tied the doctor actually went to cancel that court hearing so I couldn't go ahead with getting my tubes tied. I knew that it was right for me and doctors should respect everybody's decision whether you have a disability or not. I have also had another experience where I was seeing a new doctor who didn't know anything about me. It was the first time I had seen him, and he was asking me a lot of questions about my medical history and my medication. When I was going through this with him, he told me that I don't have that medical condition, and I don't take that medication. Doctors need to do more training in disability awareness, especially when they are starting out being doctors.

**Lisa:** That's amazing. That's an amazing story, Heather.

**Heather:** Yeah, thank you.

**Lisa:** I can't believe you weren't believed, pretty much.

**Heather:** Yeah. I put up with it but there's a lot of healthcare professionals who do need to have training on disability arrangements and how to respect people with a disability.

**Lisa:** That's right. I think they do.

**Skye:** Just for you to have to go to court just to get your tubes tied, that just blows my mind.

**Steve:** I've heard similar stories from people in doing self advocacy and meeting with other groups of people that question their ability to make decisions about their own bodies.

**Lisa:** I don't even know anybody like that. That has gone through something like that.

**Skye:** Yeah. I think that's more common than you think.

**Lisa:** No, it is. Because there's law that kind of puts all that kind of thing into perspective, but I just find it unbelievable that, that exists.

**Steve:** Yeah.

**Lisa:** I'm thinking doctors with all their education should really respect other people, whether they have a disability or not, they should just be respected.

 But coming from my background, because I've studied human rights, you're dealing with human beings. Who have the right to make decisions, the right to be respected as well for these decisions. And so I don't understand that.

**Skye:** I think also too, that when you're a GP, I'm not sure about other people in the medical field, but I think people, doctors get very caught up in the medical side of things.

**Skye:** And so they forget about what the human cost of what they're asking for. What I mean is, for me, I've got quite complex, not complex disabilities, but there's a little bit going on with my medical condition. And so when I go and see a GP, it takes them by surprise because I do have a bit going on with my medical condition.

**Skye:** So I might be a bit of a rarity or novelty for them. And they want to ask when they want to show other people, that I exist. Depending on my mood, sometimes I'll let them, sometimes I won't, but it gets very tedious.

**Lisa:** Do they ask you for your permission?

**Skye:** Yeah, they always do. They usually do. But it does depend on my mood.

**Lisa:** Yeah, no, fair enough.

**Skye:** Yeah. I'm very sorry to hear about your experiences, Heather.

**Heather:** Thank you, Skye. I just hope everything will get better.

**Lisa:** We're certainly doing whatever we can for that to happen. My experience was actually quite different to all of that, because I had my injury in Greece, and it's like it's on a different planet.

**Lisa:** I was flying back from Greece in a first class plane and I don't remember a single bit of it. And when I got here, I don't remember too much till about a couple of months when I was at rehab. My first memories of the cook at the rehab center making a double chocolate mud cake. And then started to learn how to walk again, how to talk again, how to do many things again. But that's basically my experience and from that I've pretty much come to the conclusion that doctors and medical staff generally should have training for people with disabilities and respect our choices.

**Skye:** And how did you find the rehab, Lisa?

**Lisa:** I went to a rehab centre which was probably the best in the entire state, if not the entire country. I went to the Royal Talbot Rehabilitation Centre, so they were excellent. And we had a really good view. I remember looking over the Yarra River from Yarra Bend, that's where the rehab centre was. So we had an excellent view as well.

**Steve:** And how was your transition from rehab center to home, Lisa?

**Lisa:** Oh no, that was so good. I was basically taken to Saru and to Ross House and to the neighbourhood house that I still go to now. I was taken to these places. That's why I was so surprised by you not having information that's basic when you leave the rehab center or the hospital.

**Steve:** Maybe we should tell all the rehab centers to get in contact with your rehab center and see how it's done. Because it felt okay at the time, but now in hindsight they weren't very helpful with the, with my transition from hospital to home.

**Lisa:** I had a really good transition from hospital.

**Steve:** That's fabulous.

**Lisa:** I didn't have to ask anything because everything was at my doorstep.

**Steve:** It's a model for other rehab centers.

**Lisa:** Oh, most definitely.

**Skye:** It's nice to hear a positive story.

**Steve:** How about you, Skye?

**Skye:** I had my stroke when I was five. A thing that I got taught very much as a kid with a disability, is that you need to be polite to grown ups and I found that hard to be able to say what I actually wanted to the medical staff and to the rehab staff. I found that really hard. My disability was so uncommon that I felt like a guinea pig sometimes. Being shown off and having to be very accommodating is still a problem.

**Skye:** It makes it hard to advocate for yourself I think I really found that quite difficult. And over the years I've had good relationships with my doctors. Just because I've had to do lots of physio and look at different things. Especially getting on the NDIS, that was quite difficult.

**Lisa:** You certainly bring another perspective to it though, to having a disability. I never would have thought about it, having a disability. When I was so young, how I'd go through the rest of life.

**Skye:** Because you're certainly treated, as a medical thing when you're a kid and you're going in with your parents and they look at you not as a kid, but as a medical what's the word? Medical...

**Steve:** Oddity.

**Skye:** Yeah, that's a good word, oddity.

**Steve:** Bit harsh, but-

**Skye:** That is what it is. Having to show that you do have control of your body is quite a thing as a kid. Yeah.

**Steve:** Yeah. So we're going to take a quick break now. We'll be back after the break.

**Jane:** My name is Jane Rosengrave and you're listening to a Yorta Yorta strong powerful woman. On Disability Day on 3CR.

**Nakayn, Liv & Morag:** Hi, I'm Nakayn. I'm Liv. I'm Morag and you are listening to International Day of disability on 3CR. Stay tuned!

**Steve:** Listening to Raising our Voices on 3CR 855AM We are run by people with disability. And we give people with disability voice on the airway. Nothing about us without us. Today, we are discussing our experiences in the healthcare system as people with disabilities. Over to you, Skye.

**Skye:** When I first got my disabilities back in the 80s, healthcare was completely siloed from disability services, and it still is to some extent.

**Lisa:** It's been less siloed since 2006, but this is still an issue.

**Steve:** I've found that health and disabilities are still separated. This can make it easy to fall through the gaps.

**Steve:** This can also make it hard to get funding. This was my experience when I needed a neuropsych report. At the time, health and disability services were separated in the Victorian government and the health section of DHHS said it was a disability issue to fund a neuropsych report. And disability said it was a health issue and I couldn't get the funding.

**Steve:** So I gave up on the NDIS application processes. It was too expensive to get that assessment done out of pocket. I was rejected four times for the NDIS and I'm still not on the NDIS.

**Skye:** Everyone says getting on the NDIS is the thing to do, but if you can't get on it, not everyone is eligible for the NDIS.

**Steve:** Yes. And if you can't get on it, there is other services available. Eventually I found the HACC service, which is the Health and Community Care, HACC, Health and Community Care. If you haven't got NDIS, you might be eligible for Health and Community Care support or assistance. How about you, Heather?

**Heather:** Even if you're on the NDIS, that still doesn't cover everything. I am on the NDIS, but I also have chronic health conditions. I have to see different specialists for these conditions and pay out of pocket and I also now have to pay out of pocket to see my GP, even when I need a script for my medications that I need to take for my chronic health conditions.

**Steve:** That's really hard work. I've noticed that I'm quite privileged compared to a lot of people on DSP that are really struggling. But I've even found it hard at times. Most GPs, just even for a doctor's visit. Even on the DSP, there's a gap. But it's not so much the gap, it's coming up with the full amount of upfront payment before you get the money back from Medicare.

**Heather:** Yeah. I also had to have some medical tests and I told them I was on a pension, on a disability support pension, and the price to get that test done was 400. I was very lucky that I had it done when it was payday for me. And they told me that after I had the test.

**Steve:** Wow.

**Heather:** Yeah, so they weren't being transparent with me.

**Steve:** And I limit my visits to the doctor. Sometimes I avoid going to the doctor when I should because I don't always have access to the full fee up front and I know of other people that don't have the money up front to go to the doctor so they avoid going to the doctor and sometimes end up in accident and emergency because they've got no money.

**Heather:** Yeah. And my medical conditions have worsened up, because I haven't been seeing a doctor because of my experiences that I've had.

**Steve:** Yeah. What about you Skye?

**Skye:** So I have found it really hard to connect with a GP. I've recently moved house to a new area, and the GP I had is really great, but he's back where I used to live and I still haven't found someone where I'm living now. So what I'm doing is doing telehealth with him until I find someone closer to where I'm living.

**Skye:** Yeah, I need to find someone closer to where I'm living, because I'm going through some changes. I'll need to work on that. And also the cost is pretty prohibitive, as you're saying Steve. It's pretty hard to come up with that charge up front. It might be better if Medicare could fund the gap as you're paying.

**Steve:** Yeah, when I moved to Gippsland from Melbourne It took me over two years to find a regular doctor locally. So for two years, I traveled back to Karim, which was two hours on the train just to see my GP. But what I found, when I first got my disability, I didn't even know where to look for help and, but for me, what helped most was getting connected with Disability Advocacy Services in person. Brain Injury Matters in Melbourne over the phone and online. They pointed me in the right direction and New Wave in Gippsland pointed me directly to services that other people that had good experiences with. So I didn't waste my time going to lots of services. And the good thing about disability self advocacy is we're not professionally obliged to say that services are good if our experience was not good. So I eventually got to find good services that are available in my community by going to my local self advocacy group. What needs to change?

**Lisa:** Oh, I don't know. Brand new [inaudible]. That's the biggest one for me.

**Skye:** I think it would be good to have someone whose job it is to connect people with different services, I feel like.

**Lisa:** I think it would be better if people with a disability were recognised as people. As human beings, with every choice that they make being regarded as a choice. And every decision they make being regarded as a decision.

**Skye:** Because we're, in Victoria, we are governed by the human rights legislation in Victoria.

**Lisa:** Yes, but I'm thinking on that. I'm thinking it's there as legislation is there, but in practice, where is it?

**Steve:** Yeah.

**Heather:** There should be more disability awareness. And just common respect. And disability awareness everywhere, in every medical field and being out in the community. Definitely for those people who are starting out at a new job, whether they're being a doctor, working in a grocery store, driving the bus, everywhere. They really need disability awareness because I've had so many shocking experiences that shouldn't even have been here in the year 2023.

**Lisa:** Yes.

**Steve:** Yeah, so that's about all we have to say, I think.

**Lisa:** Thanks for listening to Raising our Voices on 3CR 855AM. Today we shared our experiences navigating the health system as people with a disability. This show might have brought up some difficult feelings for some people listening today. For support, you can call Beyond Blue on one three hundred twenty two forty six thirty six, or Lifeline.

**Lisa:** On 13 11 14, we are run by people with a disability and we give people with a disability a voice on the airwaves.

**Speaker:** You've been listening to a 3CR podcast produced in the studios of independent community radio station 3CR in Melbourne, australia. For more information go to 3cr.org.au