Queer-Trans-Health-Disability-Day-Iris-Lee-03-12-2023

**Iris:** You're tuned into Radical 3CR Community Radio, 855 AM, digital and online. As part of 2023's Disability Day broadcast, themed Health Sovereignty, in the next half an hour, we're going to be talking queer trans health. I'm Iris Lee. We hear from Farida and Stephanie about some of their experiences navigating their health in this messed up system, touching on long COVID to hospitals to autism and imagining beyond where people's needs are actually met. First we'll hear from Farida.

**Farida:** Well yeah, I guess a long term activist. I currently have long COVID and I've had it for just over a year. I guess having long COVID significantly impacts my capacity to be politically active. However having long COVID, I feel quite angry about the situation of people with long COVID.

**Farida:** I feel that the government is not doing its job to either protect people or to educate the public about long COVID, or do any of the things that a decent government would be doing about long COVID. So I want to be politically active about it and I'm sort of just starting out.

[ There is] inactivism again with the campaign for disabled accessible public transport stops along Sydney Road. I'm getting a little bit involved in a couple of other things too.

**Iris:** Yeah, a number of threads in there we'll speak about today. First, would you like to speak about your experiences navigating health and long COVID in recent times?

**Farida:** Yeah. Well, like probably most people who have long COVID, I have had a pretty terrible experience with a doctor the first time I tried to seek medical help. You hear real horror stories from what people have been through. The doctor I saw, he tried to figure out all sorts of ways to dismiss my claim that I had long COVID. Like, he basically believed that I had long COVID, right?

**Farida:** But he also tried to weasel his way out of properly diagnosing me because he didn't want to write a medical certificate. It felt very like a gaslighting sort of situation. At one point he told me "you don't have depression". He didn't ask me, do you have depression? He didn't read the literature on long COVID that would have led him to the conclusion that pretty much everybody with long COVID struggles with depression.

**Farida:** He just told me straight up "you don't have depression, therefore I'm not writing you a medical certificate" sort of thing. So that's the sort of thing we've got to deal with. There's no national standards for healthcare. That's one thing the long COVID community is pushing for. A national framework for medical professionals to address, yeah, about how they should treat us.

**Farida:** To give them guidance and also set some basic standards. That's our main problem, but we also have other hassles. Like public transport is really not accessible in Melbourne. I wasn't aware of this when I was able bodied, I never even thought about it. But yeah, it's something I've become aware of now. We can't hop on the tram basically. People with disabilities can't hop on the tram very easily.

**Farida:** Because there is a real lack of accessible tram stops. Like you think about it, a lot of trams have stairs. And if stairs are an issue, if you're a wheelchair user, if you get fatigued easily like me, or even just elderly people, or people on crutches. They can't hop on a tram with stairs.

**Farida:** And this is a problem that could be quite easily fixed by having low floor trams and tram stops that are level with the tram so you can just go straight from the tram stop onto the tram. And that's what the SATS campaign is pushing for, the campaign to make accessible tram stops on Sydney road. I'm doing the social media for that by the way. I'm doing the instagram account

**Iris:** So while we're on the campaign for Sydney road accessible trams, is there anything else you want to touch on around that campaign and demands around that and how it's going?

**Farida:** Yeah well that campaign started just this year. And it has had three protests so far. Two of them were just on Sydney road itself. A bunch of people with disabilities and allies blocked the road. Marched down the road, filled up the road. It was pretty cool. I wasn't able to physically go on the march myself with long COVID, but I'm glad they did it.

**Farida:** And I listened to the speeches and they were good. We handed over a petition to the federal government and not federal government, the state government. That attracted, I think it was 3, 242 signatures, something like that. It was over 3000. So pretty good.

**Iris:** Cool, it definitely feels like there's some momentum there and taking direct action there in terms of yeah, on Sydney Road.

**Iris:** It's really like a powerful way of making change and doing all the different work around petitions and demands and building that campaign. I'm thinking now of turning a bit more back into talking about COVID and what would you like to see around activists to queer circles around the practice of going about things in terms of the needs of people with long COVID?

**Farida:** Well first of all I think the long COVID community itself needs to be more organised. Self organisation is very difficult for us for obvious reasons. A lot of us are bedridden. A lot of us struggle to function, let alone get politically organised.

**Farida:** However, we are, we have been getting organised slowly. And there are some people who, at risk to their own personal health really are doing a tremendous amount of work to fight for our rights. But if we are able to get more organised and have a more public facing campaign then that would be great for... I think we will get more organised and we will have a more public facing campaign. We already have a petition out . And so the petition is for us to have access to antiviral drugs. There's a bunch of people, like categories of people that the government has decided are eligible for antiviral drugs. But people with long COVID ridiculously are not one of those categories. Which is so bananas. We can't catch COVID again!

**Farida:** For me personally, it's debilitating enough to catch it the first time, let alone the thought of catching again. And a lot of people are getting reinfected actually in the long COVID community with this, the current wave of COVID going on now. So we've got our petition. I'd like people to come behind that. If you google search that petition about access to the

**Farida:** antiviral drugs for people with long COVID I think you'll be able to find it. It's got heaps of signatures. I think it's got over 10, 000 signatures or something. There's that. We have been talking about doing some sort of protests at parliament house. The global day of action about long COVID is the 15th of March.

**Farida:** So keep your eyes peeled for something around about that date. There are things people can do just to help us. Giving us lifts to places is one basic example because like I said, we can't easily use public transport necessarily. Basic practical help like that would be good. As far as etiquette around activist circles goes, I appreciate it when people mask up, and it's sort of become the norm that people don't. And I would like to see masks provided more at political events.

**Farida:** However I think with the whole vax versus anti vax or mask versus anti masking arguments that have gone on in society, I think that that sort of created a dynamic of people fighting each other instead of the government and letting the government off the hook. So I think. Yeah, I agree with more masks. However, it's not the first point I want to push. The first point I want to push is that we have got to come together and hold the government accountable for this complete mess that it has gotten us into around long COVID.

**Iris:** Yeah, definitely around 10 to 15 percent of people who are infected by the Omicron, one of the first few waves of Omicron did end up with long COVID.

**Iris:** So it's a very widely spread thing, that capitalism is just asking us to privatize the costs of it in terms of the government's not accountable for this mass disabling event.

**Farida:** Hmm. Yeah. One thing I think we can all come behind is that the government has to just fund health care! Our health care system is gutted and it's showing. And this is not just impacting people with long COVID. This is impacting everybody. Mainly it impacts the poor. I guess the wealthy have access to proper health care, but we don't. You got to pay for any decent medical attention around long COVID a lot of the time. We got to pay for all our medications.

**Farida:** Clinic 19, the clinic that I'm seeing about long COVID, they're really good by the way. I recommend them to anyone who has long COVID,. But yeah, they're no longer able to do telehealth. Soon they won't be able to do telehealth appointments for the first appointment a person has. And that will rule out a lot of people from being able to access that service, which is a damn shame. So the government's just got to take it seriously. Yeah, we got to be able to have telehealth appointments.

**Iris:** Yeah, definitely. It's pretty shocking what's going on now in terms of how much things have been wound back. And the already existing austerity and organised abandonment there. It's pretty shocking. Thinking about also what has been the other aspects of, I guess, finding community with other people with long COVID and what has that been like for you?

**Farida:** Wonderful. We have our Facebook group, the Australia Long COVID Community. If you have long COVID, totally get on that.

**Farida:** I got more advice, good advice from there than from anywhere else, just from being able to talk to other people with long COVID. And I found a quality GP through that network. I found sound advice about how to manage symptoms. I found just moral support, you know, like people who are going through the same thing and being able to not feel alone.

**Farida:** There's thousands of us in that group. It's a pretty big group, so totally get on that. And also friends who have long COVID have reached out to me and I'm really grateful for that. There is sort of a people coming together aspect of what's going on with long COVID, which is nice. In as far as we're able, because we can't hop on the tram.

**Farida:** Farida laughing

**Iris:** Awesome. I also know humour's played a role as well in those groups. I've seen you post online.

**Farida:** Yeah there is a, I forget what it's called. The COVID long haulers humour therapy group, I think it's called. Yeah, there's lots of hilarious memes. It's good. They help us get through the day. It's pretty dark. Probably people , who don't have long COVID don't find these memes funny, but to us they're hilarious.

**Iris:** Definitely. Would you like to sketch out any thoughts about what health and care would look like in a radically different society where people's needs were centred?

**Farida:** Well, I think this is not just imaginary. There's other parts of the world where we can look to concrete examples. I did a bit of reading in one of the COVID waves about vaccination. About which countries had the highest vaccination rates and why, which countries had the lowest vaccination rates and why.

**Farida:** The countries with the highest vaccination rates were Cuba, United Emirates, Bhutan, countries like that. Vietnam also had, didn't have a high vaccination rate because they weren't able to access vaccines, but they had the lowest rate of anti vax sentiment. So countries with a high rate of vaccination were places where people were able to trust the health system and the government and that was trust that was built over time.

**Farida:** These are places where stuff functions. Where health is actually funded properly. But also just trust between people would be good. I think having a base level of care in society that yeah, we just mask up because that protects people. That would be nice. And I think that isn't really possible in our current society here because we just don't have a basic base level of care for each other.

**Farida:** It's too like, I don't know, it's not nice, the society we live in. It's competitive. It's ruthless. It's selfish. A more collectivist society would mean there'd be more potential for more measures.

**Iris:** You have just heard from Farida. We will put links to Sydney road accessible tram stops and the petition for access to antivirals for people with long COVID in the show notes on the 3CR website. You're listening to 3CR 855AM, Community Radio's Disability Day, under the theme of Health Sovereignty. In this part, we're talking queer trans health. Next up, we'll hear from Stephanie.

**Stephanie:** Hi, I'm Stephanie. She/her pronouns. I've been transgender for about two years, transitioning. And I was very sick before that happened. And, yeah, I've had to navigate things as I've transitioned from one person or being to another while still in the medical system and trying to recover and get access to help and support, especially mental support seems to be very difficult.

**Iris:** Yeah. I know you spent a lot of time in the health care system and in hospitals. I guess you don't have to go into all the harrowing stuff at all that I'm thinking about. Could you talk about your experiences a bit around navigating the health care system? What has it been like in terms of the difficulties of it, and the challenges?

**Stephanie:** I don't think anybody really spends the time they need to educate what sort of services and support that you really need. When you're going through something as harrowing as some of the medical conditions you can be diagnosed with. So they don't really tell you that you should really have a good mental support.

**Stephanie:** They might mention that "oh, we have a psychologist as part of the team", and I ignored it for a long time. And when I finally did need one, he goes "oh, you can find a local one". I was like "well, how come, you have one on staff? And I now I need help for processing a lot of the things I went through for so long".

**Stephanie:** And then you go see a local one and this is during COVID. So it was quite difficult to access in the first place, let alone trying to navigate and find one that was good for me. Rather than for somebody else because you can't just get one straight away that might be good for your needs

**Iris:** Yeah, definitely I think there is a disconnect there in terms of there's this like my body mind's like Teetering dualism would be a term for it and it seemed like the healthcare system sees like the body and body and mind is separate when they're interconnected.

**Iris:** And I guess I kind of relate to like my more limited time in hospital. It's also, it's also like a time that is mentally very difficult, but that's kind of like not seen as something that you get support on. It's just seen as like, there's this thing to like fix or depending on why you're in there. And it's like the other aspect can be completely.

**Stephanie:** Yeah, it was, yeah, it was, it was really difficult because that's the first time I've explored mental health and I wasn't getting any support with members of my family and any friends or anything like that. So they were never going to understand what I've gone through. I also put a lot of things on the standby as far as my trans journey.

**Stephanie:** I put that aside for a fair bit because I wanted to deal with the immediate situation first, but I knew I'd have to find the right thing. Psychology for that, which means I had to look for more than one. I'd have to sort of look at one local service, wait until I could see them in person, and then I'd wait until in person before I brought up something important, such as my gender journey, or gender questions, I should say, and other things like that that are more important and a lot more I suppose private, to bring up with anybody, even a medical professional for the first time.

**Stephanie:** It makes it real, I guess.

**Iris:** Definitely. What were your your experiences around being In and out of these healthcare systems and also coming out as trans at the same time and also having to put off coming out as trans. What was that like for you?

**Stephanie:** It was hard for... the main thing is that I'd been seeing the specialists and all the different professionals, you know you go through different people every time you have a clinic appointment and things and all of a sudden, I knew there's going to be a point of no return. Where I'm gonna have to come out and all these people that know me for such a long time I would have to get to know me as somebody else. And at the same time hopefully, it wouldn't affect my care, or the duty of care that they should be having for every patient. So that was very difficult to have that, and almost having to compartmentalize my medical stuff, my mental stuff, it wasn't easy to not have it all together. Each individual element was dealt with separately, and not under an umbrella of, you know, this is all part of what you've gone through and all part of you. We're not treating it that way though. Whatever you decide to deal with it is how you decide to deal with it. It wasn't really, we're part of it. So you sort of have to navigate it on your own and, you know, you fall and die by the sword on your own steam, whether you have education on what's out there and what's not, so.

**Iris:** Yeah, it's a very intimidating place to be in and I think only times I've heard good experiences from friends with navigating healthcare system really is when they've had some sort of peer navigator or some sort of patient advocate. Because there's a lot of work in terms of speaking to doctors and dealing with some oppressive dynamics and like you're saying the splitting off of different aspects of yourself yeah it's just doesn't really seem like a holistic way to go about the different needs that many people have. Yeah,

**Stephanie:** I mean, even the day to day of doing treatment at home when I was doing that, they don't tell you about all these little bits and pieces. Like, there's one thing doing things in the medical conditions, there's other things when you have to do treatment at home.

**Stephanie:** Even simple things like, where do I throw which rubbish and stuff from all the medical supplies I have to go through? Luckily, I was able to talk to somebody before they finished their training for doing home treatment. If it wasn't for that, then this is where you learn these little tricks.

**Stephanie:** This is what you do with this, you need to get a sharps container, you need to get this, this and that. And they don't tell you this information. It's almost like somehow you have to struggle and find out. Or somebody's got to tell you from somewhere else, even though there's a few organisations out there.

**Stephanie:** Unless you know they exist in the first place you're kind of on your own, and you're lost. And it takes a lot out of you, as well.

**Iris:** Yeah, it's very exhausting. I guess another aspect is yeah, the system's not very good at centering people that don't fit the white cis, neuro normative, straight, male norm. Body and mind. Do you want to speak at all about what it's been like navigating these systems as an autistic person, or?

**Stephanie:** The autism part of things didn't come until fairly recently as far as being diagnosed. It was definitely a block that I knew there was some issue that I had with not being able to connect to people. But not being in any sort of social system for a long time, especially when all my life for quite a while was all about treatment, I only had to deal with other medical people and nurses and things like that.

**Stephanie:** So it was just translating the information they needed from me and then translating it back. So there was no real warmth or social interactions that were anything less than superficial, which made it really difficult to navigate who I was as a person being so removed from society. And also questioning a lot of what I thought was definites and they end up not being so definite as I was sort of exploring and questioning my gender and identity.

**Stephanie:** Because I lost a lot of that before I even started. And then I had to find a new one while also fearing that I need to catch up and get my life back, and that life was not going to be the one I had before. And I didn't want it to be either, to be honest. But I needed to figure that out and without any help or guidance, it's like having one paddle on a river and going well, which way should I paddle? I've got no idea which will get me to where I need to be. And where do I need to be? It was really, really difficult without anyone cheerleading you or giving any guidance. So I had to push myself and luckily with everything I went through, I had a strong sense of self enough to get by where I think some people may have struggled, but I'm still a little bit lost trying to navigate forward. Yeah..

**Iris:** Yeah. I think the system leaves... disabled people with organised abandonment. I mean I know even trying to navigate and access supports like the NDIS is just a nightmare.

**Stephanie:** Yeah, you don't know what they're looking for. You know what you need, but you don't know what they're looking for from their end, especially when you read so many stories, but you don't know what they're doing behind the scenes as far as how they're qualifying people.

**Stephanie:** Yeah, I've applied a few times. I didn't know what I was doing. The doctor didn't know what I was doing, or what they were doing. I just tried to get whatever I thought they needed. So you don't want to do that. You want to say, this is what's going on with myself. This is the support I would hope would be most beneficial to me.

**Stephanie:** And then from there, hopefully they can say, "this is what we can help you with". Not just profiling everybody that they're out to get. You know, and use whatever sense from the system, especially in light of not having alternatives. The alternatives are very disappointing and there's not enough mental professionals out there to help people, especially that don't fit into the exact niches of where some people actually live.

**Iris:** Yeah, definitely. That's just designed to fail people and to just really... in the logic of seeing people as disposable. Which is really gross and ableist, and causes so much suffering in the society. And in terms of coming into trans communities, what was that like as someone who's disabled and a woman of colour? What was that like for you?

**Stephanie:** It's been very difficult. I know a lot of people's experiences are quite different. But I guess, not being anywhere near the situation with my upbringing, it was also seen to be quite a negative, being brought up in a very religious home. Very religious parents, very strict upbringings, migrants from another country.

**Stephanie:** So we didn't have flexibility to explore or anything like that, ask questions. We were just told this is the way it is, that's it. I tried to integrate into groups and things like that, but I don't know, I don't know if I was too different, or. Yeah, my upbringing was quite sheltered I guess, in some sort of ways.

**Stephanie:** But I have very much struggled with trying to enter any sort of community. I'm too used to being invisible and unseen, and I'm sort of too considerate I guess. Because I know that I've been hurt a lot of times and not been seen. And I guess I've fallen suit on that. Trying to be reasonable, trying to be nice, trying to be patient, and not advocating for myself that way, which nobody else is willing to advocate for me. So I ended up unfortunately falling to the side. So I'm still very lonely and not part of the community.

**Stephanie:** The ASD is also a problem. Because I don't know how I should be acting or communicating with people. So it's been very lonely. I hear the 'community' and things, and I get disappointed because I don't feel like there is one. Not for me, anyway.

**Iris:** Yeah. I hear a lot of hardness and pain and that. And I think that's also an experience unfortunately, that is kind of common. Because there's lots of ways in which trans communities fail people because of ableism, racism, trans misogyny. And it's something that, depending on where we are in those systems, we need to have a responsibility to change so that more people are welcome into different spaces. So there's more spaces to open up, and we can push back against some of the isolation that's a part of this capitalist society, I guess.

**Iris:** In terms of thinking more radically about different society, what would health and care look like for you if people's needs were centred? You didn't have to struggle for NDIS, struggle for money, struggle through the system, struggle making connection.

**Stephanie:** Ideally, I'd be looking for more things to get upset about, because all of them would be gone.

**Stephanie:** But I'm always worried about one thing or another. Which is not great. We have enough things on the planet to worry about, and unfortunately looking after our fellow person. Which I wish it wasn't that way. We should value each and every person to their own ideals and to their own benefits and wonderful things that they offer.

**Stephanie:** I think that's really important. And if people don't see it then unfortunately they get left behind, which is not great. But yeah, I'd like to see people accepted as them. Not to have to create labels or dramas or angles or bias or anything like that. There's no easy solution to anything I guess. But the conversation needs to be opened up a lot more rather than just giving a few crumbs here and go "this is good enough for you". It's not.

**Iris:** You just heard from Stephanie, part of this Queer Trans Health segment of this Disability Day Health Sovereignty Broadcast. This program was produced on the stolen lands of the Wurundjeri and Bunurong peoples. Sovereignty was never ceded. Finally, a thanks to 3CR and to Pauline Vetuna for coordinating today.

**Iris:** Stay locked to 3CR 855am. Digital radio, streaming online and your community radio app and podcasted at 3CR.org.au

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