Mob Dreaming Up Podcast

**Elena Macdonald**

Yah everyone, my name is Elena McDonald and I welcome you to "Mob Dreaming Up: Yarning, Sick Disabled Realities". This is a group yarn with a bunch of mob all around the country and we're talking about the realities of being disabled and sick within the colony from the perspective of mob in all our lived experiences. So I'm Elena, I'm Paredarerme mob from the southeast coast of Trouwunna/Lutruwita, that's Tasmania, to the rest of you. I've struggled with a lot of illnesses and the inaccessibility that comes with my disabilities for a long time now, and it's something I feel very deeply about, which is why I was so honored to be able to help create this show and invite everyone that's here today on it. So Tabitha, if you want to introduce yourself.

**Tabitha**

So, ngata everyone. My name is Tabitha or as my ancestors know me, (insert name here) I'm a Gunditjimara woman born and raised and currently living on Gaurna??? country. I'm a formerly incarcerated woman, having spent almost two years in Adelaide's prison for (inaudible) women and an accumulate two years on home detention. I'm still tethered to the state on parole for a further two and a half years.

**Tabitha**

I suffer significant mental illness. Mainly major depressive disorder, anxiety and post traumatic stress. And in fact, it was my illness that led me to both my offending and subsequent incarceration, as well as those illnesses being exacerbated and worsened the carceral state. And I also have chronic illnesses that I manage day to day. Thanks for having me.

**Renay**

Hey everybody I'm Renay. I'm a Biripi-Dunghutti woman on Woiwurrung country. I was raised on my country and then spent a long time going everywhere else. I finally reached a diagnosis a few years ago. I've got something called ankylosing spondylitis. And another thing called sporadic arthritis. A bunch of autoimmune diseases and mental health issues. Major depressive, post traumatic, you know, a bunch of other things. They love to travel in pairs, so. I'm just happy to get my lived experience out into the world and share it with people so. Also I feel it's really important that other people, especially Aboriginal women, find that support within their culture as well. So wherever I can do that, I will.

**Mali**

Hey, everyone, I'm Mali. I'm a Wiradjuri woman, and I'm living on Ngunnawal and Ngambri country in Canberra right now, but I was raised and grew up in Murwillumbah which is Bundjalung country. I live with several autoimmune diseases, including Hidradenitis, which is a skin condition, and suspected Crohn's and a lot of gastro issues, as well as inflammatory arthritis. Yeah, I have lived experience of both disability and caring for my mum, who's also an Aboriginal woman who was killed by medical negligence, and has definitely caused both her and myself quite complex trauma and PTSD around the healthcare system.

**Samia**

Hi, I'm Samia and I'm a Bundjalung woman and I was actually born in Canberra. I was removed from my mother and spent a lot of time in institutions and juvenile justice, and on the streets pretty young. I've had an eventful life [laughing] good and bad.

**Samia**

Since I was very young, I had a diagnosis of Crohn's. So very ill for a lot of my 20s and 30s, long periods in hospital, very long periods in hospital. And I also now have secondaries which is arthritis and some neurological autoimmune dysfunction. I have bipolar affective disorder too, and post traumatic stress syndrome. Currently, I'm recovering from a nightmare of a broken back and mistreatment and then resulting in negligence at the hospital that resulted in shoulder surgery and further negligence that resulted in being in intensive care with acute liver failure, all caused by the hospital.

**Samia**

So I've become pretty much completely disabled and can't walk properly and sometimes can't word find and I now can't work anymore. We were just talking, the hospital is completely lying about it, covering up their tracks. The reason I got poisoned was because they did an incorrect discharge report with someone else's name, information, medications, etc. So they gave me the wrong medication which nearly killed me. So I'm having a really fun time, not! [laughter] Yeah.

**Hannah Morphe-Walsh**

Oh, gee. I'm Hannah Moprhe-Walsh. Taungurong, from Central Victoria basically. I don't know where to begin describing most of... I mostly identify as a deaf person in this world. But I do have a number of other congenital abnormalities and various health conditions that I think add up to one disabled person?

**Elena Macdonald**

Yeah, well, um, I didn't say my conditions, but at the beginning, but basically, I have endometriosis, fibromyalgia, and gastroparesis, for which I currently have a semi permanent feeding tube, medical device to keep me alive, which was a very long process to obtain. Which I nearly didn't obtain in time because the medical system refused to believe that I was sick, and that I couldn't just "force myself to eat", in inverted commas. And as a result, I have Post Traumatic Stress Disorder from the trauma of battling doctors who just didn't give a shit. So, yeah, we all have a lot of really important and horrible. And what's the word? I guess?

**Elena Macdonald**

Well, yes, important experiences, I can't think of the right word. That are not heard enough. That's something I'm so excited to yarn about today. Because so often, how illnesses and the reality of being black in the colony intersect are just not acknowledged or even talked about enough, even within communities. So I'm really happy that we can do this today.

**Elena Macdonald**

I think I want to start with talking about the ways in which we are locked out and cut off from the support and connected connections we need. I don't know who wants to start. So I might just share a bit more about my experience, for example, the racism, even as someone who is white passing, fair, I have red hair. You know, eurocentric appearing features. He didn't within the medical system, it didn't matter. Although I of course, acknowledge that mob who are of darker skin are also discriminated explicitly for that reason, because of the racism within the colony.

**Elena Macdonald**

But I'm speaking, I can only speak from what I know of it. And even with my fairer skin, the racism, our experience with the medical spaces, and the medical industrial complex, more widely, has been horrific. And I wish I could just escape to country and live there for the rest of my life and never have to go into a medical space. Again, no doctors, nurses.

**Renay**

Yeah, absolutely. Sorry--

**Elena Macdonald**

Nah, you go.

**Renay**

Oh, I just wanted to mention that one of my first experiences of going to an Aboriginal Health centre was really impacted by a white person's view of how, because I just expect to walk in there. Because when I grew up, you know, we had all of my extended family were there, you know, you could walk down the street and say, people would know who you are, or, you know, you'd know their cousin or whatever.

**Renay**

I walked into this Aboriginal Health Center having just moved interstate and knowing no one. They were all asking me for, you know, "where's my paperwork"? And I'm like, "well, nobody's ever asked me for paperwork before". So already, you know, I'm walking in the door and I'm getting these boundaries and these walls put up. I'm already reluctant, you know, to go in there. Because it's having to deal with that, you know that history that you have of medical stuff and then to be put with that, I was really taken aback. So I think that put me on the backfoot already.

**Elena Macdonald**

Yeah, sure.

**Renay**

And that was, you know, I was like 12 years old or something. I remember being 12 and having panic attacks. I've got a kid that's that age. I'd had an experience of I was home alone and the cops knocked at the door and came in and raided my house when I was there alone at you know, 11 or 12 years old, and I remember just sitting on the couch just feeling like I was gonna die because I was just so panicked about this.

**Renay**

Then yeah, in this new place where I didn't have access to, I didn't have that extended network anymore. So I couldn't just go down the road and talk to someone and so yeah, I'm having this really intense thing that I wanted to reach out and get help with and then already those barriers are up.

**Renay**

I remember, and Mali, I have a similar experience, in caring for somebody, you know, from the age of 10, or 11. I was caring for an adult. So it's hard enough for grown powerful, you know, empowered women to go out there and do it, I kind imagined how this, this little girl would have been able to do it.

**Renay**

But yeah, it really was a case of, if you haven't got the piece of paper saying you're an aboriginal, and the government says you're an aboriginal, you're not welcome here, and just, I don't think I've ever had that experience if I've walked into a room full of mob and had people there, but no one's ever said to me "can you show me your paperwork? Can you show me that you belong here and that you can access this community?"

**Tabitha**

That's the thing I find with mainstream health services in hospitals is they play gatekeeper. I found that even coming home from prison where I was released onto parole under mental health orders and I needed to access my medication. And I went to the chemist with the scripts my doctor prepared and which had Close the Gap on them as part of the Close the Gap thing and I'm a fair-skinned woman as well. And immediately he said to me "where's your card?" and I said "what card?". He said "Oh, your card that says you're Aboriginal". I said "Bruz, we don't do those these days".

**Elena Macdonald**

[laughing] Bizarre!

**Tabitha**

So there's me coming home from a really traumatic two years inside, where you're absolutely brutalized and have subpar healthcare if you could even call it healthcare. Coming out on mental health orders, not being able to access my medication. You know, he refused to give me my medication until he could get in contact with my doctor to confirm that I was aboriginal. Looking at this stuff that these organizations do right about gatekeeping. And there's this whole rhetoric in the health system about self managing your illnesses and putting that responsibility on us. But we've almost got to go cap in hand begging for this stuff from fellas these days. That impacts us and impacts your health.

**Renay**

Yeah, the carb line, I tell you, at my I'm married to a whitefella. And so I send him in. And I've had people looking over his shoulder like. Where is she, you know? Where is this this brown person is supposed to be caring for. I've had even people who work at the pharmacy. If you're coming from, medical trauma is another layer on top of this, that you know, Tabitha, you're coming from this prison, you know, literal prison and trying to take care of yourself from that. And then being met with that just... and the gatekeeping, it seems to be everywhere in the medical community. Taking my children into a specialist and you know, I'm sure you guys have had it happen where they don't ask you the question, if you identify.

**Renay**

They choose that answer for you. And yeah, that's one of the most insulting things to me. You don't get to choose that answer. I get to identify, and especially I don't know, maybe some of you might relate towards that. Because you can pass as white, I find that it's more important to introduce my culture into that situation. Because for me, it's like a win. If you don't say, "Hey, this is what I'm entitled to, this is what you're giving to me, this is what you need to do for me". You know, it's like forcing their hand into doing that.

**Hannah Morphe-Walsh**

Yeah, it really is some kind of motivation to keep blackfellas off of their list somehow?

**Renay**

Yeah.

**Hannah Morphe-Walsh**

Every time I have to call into the hospitals, which is a nightmare already. They always just go ahead and assume like when they're doing that, check off of "these are your details, please confirm it". Like they always just go, they always just automatically say, "oh, you're not aboriginal". Despite the fact that it is, it must, it should be on on my file somewhere. And the fact that if I walk in, physically walk in, like it is 50/50, they will definitely have to ask.

**Renay**

Yes.

**Hannah Morphe-Walsh**

It's so blatant, that they just like they just don't want to think about it. They don't want us to be there.

**Renay**

Yeah. They feel like it's pandering.

**Elena Macdonald**

Yeah, I was just going to say, and then one of the consequences, if you finally get that, "oh, yes, you are aboriginal". Then they start looking at you and going. "But like, how can I be sure, because I've got this essentialised idea, and if you're saying you are, then you must be lying to me. So everything you say, after this, I'm not going to believe you, because you've lied to me from the beginning. I'm never going to listen to anything you say, because you said you're aboriginal, and I've been taught this essentialised idea from media, from school, from my own family, and so I'm not gonna listen to you."

**Renay**

It's so loaded too, that whole... behind that is not just, "I don't think you look like an aboriginal", it's like, "I don't think you deserve this treatment, I don't think you should access this health care, I don't think you should get this". You know, it's so loaded with all this even unconscious bias that they have towards aboriginal people that... you know, I remember being in pain all night, one night.

**Renay**

Because I didn't get diagnosed for a long time. I had a lot of other symptoms that sort of just happened and got worse and worse and worse managed, because I wasn't getting treatment. But standing in this, this dentist's office begging them to see me because I was in so much pain. And them saying to me, like, "Oh, no, you have to pay the $20 to get in", or whatever it was, I didn't have the $20 man. I didn't, I just didn't have it. I'm trying to beg them and say, you know, "but I'm an Aboriginal that means I get free treatment here." It's not that. And, you know, him arguing back and forth this person with me. And in the end, I said to him like "Do I have to come in, in the bloody lap lap and with my face painted? Or some crap, like? Is that, what level do I have to meet of, to be able to access this thing? And I think Hannah was it you that said that it's... now I'm just rambling. But you know, it's a mental block that they add to that access. That you know when you go in there, you're going to have to face that. And you're going to have to deal with that.

**Elena Macdonald**

And then you're not worth that care. Like the moral failing. I mean, the thing that's, oh, no, you go Tabitha.

**Tabitha**

I was just gonna say that, that moral failing stuff is like that in prison. So for mob inside, we don't have access to Medicare funded health services. So for example, you know, we know that something like 90% of women who are in prison present having had mental illnesses or active mental illness. Yet we don't have access to Medicare funded psych services.

**Tabitha**

So there's no access to psychiatrists and psychologists and counseling. They act then, as gatekeepers and when we go in and we're upset where, right at the end of it, you might be having a little [inaudible] and not sleeping. When we go in as black women we're seen as difficult, hard to manage, not able to look after ourselves, attention seeking. Actually they pathologize us when really they should be looking at the system and going "you know, we know that this person-

**Elena Macdonald**

 Exactly.

**Tabitha**

"We know what the statistics say about mob entering prison. I mean, reality in this country is that people with a mental illness comprise of a disproportionate number of people who are arrested who come before courts and who are imprisoned. And yet [inaudible] to support them, because again, the system gatekeeps, even when they've got us behind their gate.

**Elena Macdonald**

And I mean, I didn't realize until I had to engage with the medical space as a, as they call it a "complex patient", the moment you don't have a broken leg or something, they can slap a bandaid on, you're a complex patient. I didn't realize how easy it was for them to cut you off and say, "we're just not going to do it". With my gastroparesis, that means the stomach is partially paralyzed, it just the food sits there, it doesn't get moved down very well into the next stage of digestion. I nearly died from it. I became very, by the time I had a tube placed, I was about a week away from death.

**Elena Macdonald**

But even that, even saying that, within the medical system, "Oh no, you weren't". But I was because mentally and physically my body had had enough, I'd been battling for two and a half years to even get the diagnosis of gastroparesis, let alone the nutritional care. I remember a really horrible memory. Before I finally got diagnosed in Naarm, Melbourne, I was at the hospital back in Trouwanna and care outside of the major cities just abominable in hospitals, there's nothing.

**Elena Macdonald**

I was desperate, I was like, "I can't eat, I can't like there's nothing I can do. I can't put more in and I'm barely eating and I'm barely drinking". And I'm ending up in here every month from dehydration and malnutrition. And my parents were there and they just they were so hopeful. They were saying "surely I mean, you're so sick, you need that care", and the doctors came in and they said to me, "You just need to try harder. You know, you're not doing it, you're not doing it hard enough. You know, you can get it in, you're just not trying hard enough".

**Elena Macdonald**

The thing that sticks with me the most that day seeing my mum in tears because she thought I was going to get that help. Because she's a nurse herself and she herself is within that system. She thought despite how hard it is, I was that bad, that surely I'll get care. They just didn't. They didn't care.

**Elena Macdonald**

I'm only here today because I had a doctor who is an expert in the gut, in the field of the gut conditions that I have. If I hadn't seen him I wouldn't be here today. Even that acknowledgement, the medical system doesn't even want to admit. And to care, every time I go in, it's a battle. If it's anything more complex, then you know, I have an infection or something, I just need antibiotics.

**Elena Macdonald**

It's every single time it's a staying back and forth. I had to go to the hospital today to pick something up. But I realized that last night that I had to go home and I had to pick something up and I just started crying because just the space of hospitals alone that impersonal... they don't care. If they don't want to offer you care they're not going to offer it it doesn't matter if you're about to die or you're already dead. They're not going to take responsibility.

**Tabitha**

That's for mob in the colony isn't it?

**Elena Macdonald**

Yeah.

**Tabitha**

Having to appeal to the colonizer in these medical institutions for our own humanity. A basic human rights which is documented by the UN yet every day when you front up at hospital at these medical places you've got to beg for that.

**Renay**

 Yeah.

**Tabitha**

Your friends who are having to go for flour and sugar, and insulin and ventolin and medical treatments.

**Elena Macdonald**

Yeah, exactly. The constant the constant drain that puts on you and the mental strain and then having to go back home and trying to be something for your community as well. While also battling all this and then you think you can, I think this is something Hannah can speak to. Sorry, Hannah [laughter], the moment of panic there!

**Elena Macdonald**

But I think you can speak to it, is you're facing all of this so surely, you know, mob were disabled before colonization, mob were disabled during colonization, mob were disabled on the missions, mob were disabled everywhere. So you think "surely there must be some kind of network of support to help disabled people" but you go and look for it. And it doesn't exist. You were talking about it the other day Hannah, I think you spoke really well on that if you want to.

**Hannah Morphe-Walsh**

Um, yeah, no, it's, it's really stark actually, I think as an adult with disabilities. Because I mean, I was a disabled kid, like I was literally born with a hole in my head. So like, right from the beginning, it was sort of very clear that I had to be fairly able, like I could be different, different is fine, different is very accepted. But not being able to physically match up to other people is still scary, there's still like a lot of fear that, I think there's a lot of fear of the sick person. But there's also a lot of fear of the consequences of what sickness, perceived sickness can bring.

**Hannah Morphe-Walsh**

I have, like, a lot of my childhood stories, I'm like, "this is a funny story", and they're actually really traumatic. [laughter] One of my funnier stories is about how, and again, I was an asthmatic from pretty much the time I left the hospital. One of the memories that like sticks in my head of my father, he's stolen gen, so he just doesn't engage with government institutions, anything he perceives as it doesn't like it. And I remember, once I must have been using my inhaler, more than normal. Just like, with the little ventolin puffer. And I remember him saying that it wasn't good that I was using it so many times. Because I might, I might become addicted. And when I need it later, it's not going to be there. And I don't know, that, like, just sort of scarcity, mindset about, you know, supplies to Blackfellas and our health is just... yeah.

**Renay**

That threatening of that as well, like the constant threat of... you can be taken away, this can be taken away from you. If you, you know, become the difficult, quote, unquote, difficult black woman. And I think they don't, "they" being most of the population don't acknowledge that inherently Blackfellas come with a giant, giant... not necessarily like a mental illness, but they come with a giant lot of sorrow. That they're just carrying as people.

**Renay**

Well, I mean, I don't think I've ever met anyone who doesn't have that, unless they're severely get disconnected from their culture, I don't think that I have met one aboriginal person that does not have that heaviness within them. I think, you know, if you've got to look at health care, that's appropriate for us, that needs to be taken into account. And we do need to have these barriers removed. Otherwise, it's going to be our experiences, time and time and time again.

**Elena Macdonald**

Yeah. Mali, Samia, do you want to speak to any of the stuff we've been talking about? I know your experiences have both been very traumatic. So feel free to say no, but.

**Samia**

Yeah I do. So I'm in an interesting situation. Because my background started as an aboriginal health worker when I was in my early 20s. I'm now 61. And so I've worked in health for 30, 40 years. And my most recent job has been as an associate professor, teaching Indigenous Studies at University of Canberra. But before that, it's all been in health, population health, public health, Indigenous health, HIV, medicine, etc. Community Health.

**Samia**

My last job before this one was teaching aboriginal health to medical students. So all of the things we're talking about, I've watched over the whole of my career be issues and trying to address them, and trying to make a change in the system. And even going back to like, I can remember a time where there was nothing around collecting data for aboriginal people accessing health care.

**Samia**

We had big, you know, promotions. This is 40 years ago about that people needed to ask us those questions so that we could get proper care before and now they're back. They're kicking back on us almost. So it's like, I go in to hospital. A recent experience. Okay, so I go in, doctor comes to me, it's on my file that I'm aboriginal.

**Samia**

So he says to me "Oh, so what do you do?". In this tone that's already patronizing. And then he says "Oh so like, do you have a job?" And I go, "Oh, I'm an associate professor". Oh, attitude changes. Completely 150%. "Oh, you must be intelligent. Oh, okay, I need to treat you differently now". But then as soon as I start asking questions and going, "Well, no, you shouldn't be doing that. Or, actually, this is the way it should be done". I'm a, like you said angry black, difficult black. Yeah, problems that shouldn't be there, thinking I should have special treatment. You know, "Oh, complex needs, probably a drug addict. She's in pain and saying she's in pain. Must be a drug addict."

**Samia**

I've heard a nurse say, while I came out of recovery, and my arm was in agony, walk past and then say to another nurse, 'cause I was saying can they get the Aboriginal liaison?

**Samia**

"Oh, no, they're busy". I said, Can I get the social worker? "Oh well the social workers for other people not for you?" Then you know, I'm going "excuse me?" Then she goes up and I can hear her at the nurses station. So she goes, "Oh, you know what these people are like". Then now, because they've made all these errors? Of course, it's because I'm aboriginal and I'm imagining it all.

**Elena Macdonald**

Oh yeah.

**Samia**

I'm a mental health patient and I'm imagining it all. And I've also been told, "Oh but you should be going to your own services, it's about time". I'm at the point, like you said, about being afraid to go to hospitals. You know, I grew up with my mom being terrified.

**Samia**

A lot of my generation of the stories of, you know, having your kids taken. So we had, I grew up with a lot of stories about, you know, the fear of hospitals. And after what I've just been through, which has just been like... I have shoulder surgery as a result of the negligence of going in for different treatment that they lied about.

**Samia**

Then I wake up in intensive care, because they given me the wrong medication. Then they're standing there telling me "oh, well, you might die in a couple of days". As if I'm a piece of meat, that doesn't even matter. And then I was saying to Mali, like last weekend, I started vomiting again, and being really scared that my liver enzymes were going bad again. And so I got a taxi to a different hospital because I was terrified to go back to the same hospital. And I got there, and I sobbed and sobbed and sobbed and was having a constant panic attack. And just saying to myself "why have I even come here? Like, I'd be better off being dead than being here". I'm at that point, it's like, I'm terrified now to go to hospital.

**Samia**

I don't know what to say about it, because I'm rambling a bit. But, you know, it's so interesting to have been someone who's worked in all those health care settings. I've even been an advisor to the minister on mental health and suicide for Aboriginal people in the ACT, like on the advisory contacted them about this.

**Samia**

 None of them want to hear. None of these people hear. None of the complaints procedures, no one wants to do anything. So I think what is happening here, even though I didn't know what was going to happen, and I was going to be a part of it, is really important, because unless our lived experience starts being heard -

**Elena Macdonald**

Exactly

**Samia**

- no one's ever going to take it seriously.

**Elena Macdonald**

Yeah.

**Samia**

Like it has to be challenged, the system is broken. Absolutely, utterly broken. And not just for us, but for the nurses and junior doctors as well.

**Samia**

Yeah, that's also... I have Aboriginal student doctors who I taught, who have suicided because of the treatment they got in hospitals, you know, who've been molested by senior surgeons. You know, who are afraid to say that they're Aboriginal. Because they'll get treated differently.

**Elena Macdonald**

The way they would get treated, yep.

**Samia**

But then they want to take you and be the poster girl. [laughter] You know, the poster girl, Aboriginal doctor and they're so groovy. They speak four languages and, you know, stand on one leg and they can do dance as well as like, do, you know, do surgical procedures, and guess what? They just look like white people almost except they're Blak. Like, they want us to be what they want us to be.

**Elena Macdonald**

Yeah.

**Samia**

I spent all day yesterday sobbing because I feel so hopeless about the whole situation. I've just been approved for the NDIS and I came home from hospital early because I was so afraid of being there. And I was deathly ill and I live alone. I spent literally two weeks before someone showed up so I could even have a wash you know?

**Elena Macdonald**

Yeah.

**Samia**

It was meant to be after hospital care but they couldn't get it together. So I just sat in my same clothes. I was so sick, I couldn't even make my own food. Luckily, I had some friends who dropped in, but like people are dying.

**Elena Macdonald**

Yeah. And, all the way across the country, it's not just one group of people, it's everyone.

**Samia**

And it's not only remote communities, we're in Canberra, we're on Ngunnawal country. We've got the worst hospitals in the country and we're in the capital.

**Tabitha**

And you persist, like that makes me think the system isn't broken. I think the system is working exactly how it is intended.

**Samia**

In that way, yes!

**Tabitha**

Because this colony is designed to erase and kill us. I think that these institutions that are supposed to be 'health care', and that's, you know, an oxymoron, isn't it? Like it's institutions caring for us, I don't think they are. I think they're deliberately working as the colony needs them to. That's a really kind of jarring thing to think, right? But much of the performing for them, you know, when you talk about the doctors and that "they can also dance" and stuff, like, exactly. They want us when we can perform for them. But when we need something, that's when we know our place.

**Samia**

And you're right, because I remember, Foucault, you know, without getting academic that prisons, institutions, they're all based on the same format which is power based and oppressive.

**Elena Macdonald**

Control.

**Samia**

So we're victims who've made ourselves sick, it's our fault. If only we did the right thing, we'd be better somehow, you know? That's how those systems work. Hospitals are based on exactly the same system as prisons. Exactly the same?

**Mali**

Sorry. Yeah, I was going to say I find that discourse when I have been trying to get a diagnosis, it's always like, "well, do you know good nutrition? Like are you eating properly?" Two years being referred to dietician after dietician, just with them trying to get me to lose weight before I was able to see an Aboriginal dermatologist who was like, all of your conditions are connected, you need to see a gastroenterologist, why has no one met with you? It comes down to that, you know, that discourse of like "Oh, you don't know how to manage yourself, you don't know how to look after yourself".

**Mali**

My mum dealt with this to where one of the most insidious examples is, after she died of medical negligence, and we went through the coronial inquest, they changed her cause of death on her death certificate, from respiratory failure and pneumonia, to including chronic pain, diabetes, all that. That was not, you know, related to the negligence that killed her, but for them it was to paint a picture being like, "Oh look -

**Elena Macdonald**

Anything to cover up.

**Mali**

"- your body was unruly, you weren't looking after yourself, it was things that killed you, not us."

**Renay**

I think we've got that double crossover of being someone who's chronically ill, and facing these cultural things as well that, some days, like you guys are saying before, having to spend so much time at a hospital or going to an appointment. For someone who's got a chronic illness, whether that's physical, mental, or whatever, you just run out of energy. Then on top of that, you're forced not only to advocate for yourself as a chronically ill person, but also as an Aboriginal person on top of that. I had someone say to me recently, another Aboriginal person say to me, you know, I went up the Northern Territory and went out on country with people. They were just so happy and so wonderful.

**Renay**

They said to me, they didn't understand why all us mob down in the cities were all unhappy. And I said, well, mate, if I had freedom to go out on country, whenever I felt like it, and was surrounded by my community, I'd be happy as Larry as well. You know, we'd have so much more of that. Those things that nourish the other part of us, that is not just, "your gut has this inflammation" or "your spine is wrong with this". So, if we had those things, I'd be pretty happy about that too! It seems like we're running a race with no one, yeah.

**Hannah Morphe-Walsh**

Also, like the idea of like, you know, it's there's this dichotomy between like the "happy go lucky aborigine" out like, in some remote location, doing whatever they want, and like the "urban aborigine" whose like sick or their favorite is "anxiety", or "chronic presenter". I hate that that term exists. I hadn't known it exists, but it does. And I think I'm going to start to sound conspiracy theory-ish here, but I promise it's not. I think a lot of problems have come with.. exactly, like you said, can't remember who exactly, who said that (I'm so sorry, I'm so sorry).

**Hannah Morphe-Walsh**

But there's been a lot of data gathering over the last 50ish years. A lot of it does not change the actual outcomes for Blak people at all because the systems themselves are so fucked up. So what happens is, these, we see all of these statistics about like, Black people dying, young Black people will more likely have this disorder, this disease. Or they are more likely to present in severe distress.

**Hannah Morphe-Walsh**

Or the popular one about alcohol, where we are less likely to drink overall but when we do we are more likely to be problem drinkers. These things are used against us. They are perceived as personal faults instead of being because the system is so geared towards the individual being responsible for the individual. That instead of seeing all of these awful gut wrenching statistics from one particular place, or seeing just an absolute lack of information from, say, the regional and remote areas, which are so deeply underfunded, like, how would you, how would they know they're happy? It becomes a way to obscure the bigger picture that they're actually supposed to be gathering this data for, like, instead of fixing the problems, it instead becomes about identifying the problems, and then turning it on them.

**Renay**

Yeah, instead of actually dealing with the problems.

**Elena Macdonald**

I mean the funny thing is, another reason why there's so many mob in the cities who are sick and they're struggling, is because they have to go there to get treatment. I had to come to Naarm, to see a doctor who would believe me because there was nothing in Truanna. It's so underfunded, the moment you step out of sight, outside of those major areas, it's just not there.

**Renay**

Yeah.

**Elena Macdonald**

Another thing - Samia, when you were talking - that often drives me absolutely... I get so angry, is the restriction in medical spaces. On how you can be and how you connect. You cannot - it didn't really fully be realized to me, because I'm in a lot - I have these complex illnesses. So I'm on a lot of Facebook groups to learn from other people and find out lots of things I wouldn't otherwise know. It wasn't until I was on those groups that I realized how different the white person - and specifically the white woman, because it's often white women in these groups - what the white woman's experience is. They go and they say, "Look, if your doctor is not listening to you - because, yes, there's also the phenomenon of doctors not listening to white women.

**Elena Macdonald**

I mean, that's all the books we ever read. "My doctor didn't listen to me. So I've written a book about it. I've got one sentence about nonbinary, queer/trans people and non-white people". One sentence covers it. They say, "you've just got to be angry, you've just got to argue with the doctor, you've just got to say it". I have never felt more powerless or out of control than I have in medical spaces. It doesn't matter what I say, if I argue, I make it worse, they will put on my notes.

**Elena Macdonald**

"She is a difficult patient, maybe we should call security". I don't get angry because I'm protecting myself from the consequences of me being seen as an angry black woman. If I get angry, they're going to call security. And I will have, you know, permanent notes on my file that I will never be able to erase saying "she didn't respond. She didn't listen. She was wrong".

**Elena Macdonald**

But if a white woman does it, and bizarrely, I mean, I just don't understand. They argue and the doctor goes, "oh, the white woman's tears phenomenon. Of course, sorry, yes, you're upset". When a white woman is emotional, they say "yes, you're upset. I understand", when a black woman is emotional, or a black person, a nonbinary person, or genderfluid person is, or if a black man is emotional. They say, "that's why you're sick. You're sick because of whatever mental thing you've got going on".

**Tabitha**

And we can never just be angry or dissatisfied.

**Renay**

Exactly. You're just not allowed to.

**Tabitha**

"You have mental health, you are psychotic", and it's like "no I'm just actually not happy with the service I'm receiving right now" - and it's that stuff, what you said Elena about them putting it in your notes, and forever pathologizing us. So, it's like what Hannah was saying, they're looking for problems with us. So making it our individual fault that we feel this way or behave this way, or have this illness. You know, it must be something our parents did or our mothers did while they were pregnant. Never does the mirror turn back on state or back onto colonisation about why are we in this situation? Why are we presenting really complex needs that don't just relate to health but relate to our whole way of living? And everything that means for our wellbeing?

**Tabitha**

Why is it that I can't go back to country? Okay? I can't go on to country and for me country is medicine. My stories are medicine, that's what's going to heal me. But what does that mean for us? Because it's only the medical system telling us what health means. They're the ones who've set up all this deficit language about how many percentage of us have diabetes, and how early we're going to die compared to whitefellas. No one ever asked me. What does it mean to be well, to you Tab? What is it going to look like? You know, we have to orbit around and their notions of health and well being and behave in the way that they want us to behave as patients.

**Samia**

This is what I'm getting to, like. So because I've taught in those spaces, decades, all of what we're talking about. I've taught, you know about deficit discourse, about the stories beyond the statistics. What's really good, you know. All of that. How to interact with people as human beings, like what's the first thing you do with someone, you know?

**Samia**

Well, yeah. If you've got time, you're going to say, "are you Aboriginal and Torres Strait Islander, blah, blah, blah". Maybe. But, you know, someone comes into intensive care, the first thing you're going to do is, do what you have to do to save their lives, doesn't matter who you are, right?

**Samia**

But then I'll go, what's the first thing you can do that is going to make a difference to a person, is to actually touch them or get down to their level, and tell them, "you're okay, you're safe, I'm going to take care of you". Like, regardless of who you are, you know. So you can do all of this. And I've had students that go "I'm completely changed, I feel, you know, my whole worlds opened up, and I really want to make a difference in Aboriginal health, and yada, yada, yada". But like, as soon as they walk into the hospital, that goes out the window, because the system doesn't allow them to do that

**Elena Macdonald**

That to happen.

**Samia**

It's systemic and it's from the top down. So they can come - I've been in hospital, this time I was in hospital, I had doctors treating me that had been my students. And they knew what I taught them but there's no way they can practice that in that system, because they're basically told off by senior doctors who haven't been educated in any way to behave differently. Who say, "oh, look, you know, just get on with it. There's no time to go into anything else with them, they just think they're special" or whatever.

**Elena Macdonald**

Yeah.

**Samia**

And that angry black thing, like I was just - when I was in hospital, so two and a half months I was there. The same registrar, who came and said, "oh, well, so you're a professor". Suddenly I was of interest, because I was 'intelligent', you know having intelligent 'blacks', 'educated, black people'. So at one point, they were sending me off for all these scans. And I'm going, I said to him " what's this scan for?" "Oh we don't know, we just get told that the scan is at two o'clock and to send you over" and I'm going "No, who ordered the scan? What's the scan for?" "I don't have that information".

**Samia**

I'm going "well, you should have that information. Why don't you have that information?". "Oh Samia, you're being difficult". Then I go, "I'm health literate, like you know? Then he goes, "well, everybody has a right as a consumer to have health information". I'm going "yes, and I'm asking you for it". And then he finally goes, I go, "well, who wrote the order", and he goes "doctor so and so". I go, "oh, so he's the gastroenterologist. You know that he's the gastroenterologist, right?" He goes "yeah", and I go, "so that means it's for a gastro condition doesn't it? And he goes "yeah". And I go, "so you did know the information the whole time. You knew what the scan was about. You knew all of that. You know, so -

**Elena Macdonald**

Why aren't you willing to share it?

**Samia**

They're making us crazy.

**Mali**

Yeah.

**Elena Macdonald**

Mmm.

**Samia**

You know, they're making us like, like Rosalie Kunoth-Monks said. We're not the problem. You know, I'm not the problem. I'm not an illness. The colony is making us again and again, torturing us. Torturing us. Making, I feel like I'm crazy now. In my file, every time I go in, it's got somebody else's name, diagnosis, medications, and if I go in there unconscious, they're going to kill me. And I can't get that off my record. And it probably, all of us, also will have things saying, "oh, we're difficult. We're angry, we're mental health cases. You've been in prison. You're stolen generation. Like, "oh, you're too complicated, too complicated. Don't want to deal with you.

**Mali**

And trying to - Tabitha, what you were saying before, trying to hold that mirror back to the state. Like, it's not possible. You were talking Samia about complaints process and things like that. I've had people, I've had the hospital close my complaints.

**Samia**

Yeah.

**Mali**

Like just continually gaslight. Continually ask for extensions. There's no accountability whatsoever.

**Samia**

They lie.

**Mali**

They lie their fucking faces off to you. They know that they hold the power in the situation and no one will ever believe you, because you're angry. You're black, you're disabled. How could I ever trust you? I've had my mom in tears be like, "I was sexually assaulted by a nurse". And they were like, "we changed our medications. That's what it was". Like... yeah.

**Elena Macdonald**

Yeah, change of medication does that all the time to me. [sarcasm]

**Mali**

And like, even in death, I think too. There's just no valuing of our lives whatsoever. Like, no, my mom didn't even get palliative care. Like, that's the kind of shit that we have to put up with.

**Samia**

Yeah.

**Elena Macdonald**

I'm just aware of time, I think. It's a good sort of time, I think, to move on to the sort of next. It's connected to everything we've been talking about, obviously. But I want to talk about like changing the space.

**Elena Macdonald**

Particularly, the thing I found most... well, aside from the violence and trauma and sheer horror, that the colony put me through. This other thing I found most devastating was the ableism and lack of even the effort to recognize our struggles by mob who aren't disabled. Or who aren't coming up against that every single day. Before everything started to become really, really difficult for me, I didn't fully realize how overwhelming that lack of recognition and the casual ableism within the community, which I know is driven by the colony.

**Elena Macdonald**

But the fact that mob will still, even after being told how damaging some of those things can be, will continue speaking and continue acting, because... I don't know why. But it's just, it's one of the most devastating things to me. I've tried to speak against it. And I've had to sit there and listen to mob debate, (trigger warning for eugenics against disabled people). But I've had to sit and listen to mob debate in front of me knowing I was disabled, the eugenics. Of "if I disabled baby, I'd kill it".

**Elena Macdonald**

Then I'm going, "well, I'm disabled, and I have a pretty full life. What makes you think you can decide that?". "Well, you're different, you know, you've just got X, Y, and Z. You know, it's not the same". And then "why do you think that's an appropriate thing to say?".

**Elena Macdonald**

Well, it's devastating how when I want to connect with community across the country, and I want to talk about my experiences, they're either ignored, completely lost, or I log onto different social media spaces every day to see mob across country and what they're up to. So much of what they post is just not thinking about the disabled or ill experience at all.

**Elena Macdonald**

Which to me is just so bizarre, because when you look at the statistics over half of us, and I'm sure it's way more, but all mob who no other mob know I'm sure at least five people within their lives, who have an illness or a disabled or do you care work or are themselves involved in care work. The fact that this lack of space exists, I mean, what about the rest of you? How have you found that within, not just, I'm not talking about individual community, but like, on more national scales as well. And when you've spoken to mob across the country on social media, or met them at various, you know, events or institutions or things like that.

**Renay**

I don't want to ramble on more than I already have. [laughter] But even things like I'm not making community events accessible.

**Elena Macdonald**

I hate that.

**Renay**

Like, I need at a minimum, I need wheelchair access.

**Elena Macdonald**

Right.

**Renay**

I need a toilet.

**Elena Macdonald**

Lift access.

**Renay**

Yes. I need somewhere comfortable to sit. This is just bare minimum. I've had the feeling before of people going like, "they're already acknowledging us just, you know, don't push it too much otherwise or they won't give us anything".

**Elena Macdonald**

Yeah.

**Renay**

It's all or nothing in all spaces. I think it's more about us having to, other people having to take up our plight.

**Elena Macdonald**

Mmm.

**Renay**

More than anything, and getting everyone.

**Elena Macdonald**

Yeah, and realizing how deep it goes. I think it's most crucially, the most could give so much more insight and give us so much more power to speak back. If we actually recognize the intersections illness and disability have in deaths in custody, for example. Mob will just say, you know, "the death in custody". But I think also looking at the intersections of how illness and disability played into that. And like Tabitha, you were talking about how much incarceration exacerbates illness, and how illness leads people to incarceration and cycles of incarceration and hyper incarceration. I think the fact that that's, um... I mean, it's starting to be more now. I mean, we have this opportunity for this podcast, which is amazing. But that has taken so long, it still so little heard. I mean, how have you witnessed it?

**Tabitha**

I mean, and what we know is that mental institutions or psych wards pipeline into prisons. Mob with mental health disorders, who might be presenting differently in community, the cops are always called on us. So this kind of idea of duty of safety is weaponized against blackfellas for simply being unwell. Then people put, having to go through court systems. And when you don't present in a way that people might think, quote "normal".

**Tabitha**

Then you don't go well in court either. So you end up in prison. Then when you get to prison, there is no support. There are no Medicare funded services. So you remain unwell. Then what's worse is your freedom is then weaponized against you. So if you want to go to the health service within prison and say, "look, I'm really struggling mentally. I'm down, I'm not coping, I'm anxious, I'm not sleeping". You're then put in solitary. You're not given care or support. Your conditions are exacerbated by the system.

**Tabitha**

And then even more, you can't speak up about the treatment you're getting by the health service. So medication mismanagement is a critical issue. I was given double the safe legal dose of the medication in prison, which has led to a chronic illness that I now suffer from. I can't speak up about that, because I'm on parole. So if I speak out against the system or I pursue them formally then my liberty is at risk.

**Elena Macdonald**

 Yeah.

**Tabitha**

The thing for blackfellas in the system, is that once we get in there, all of these agencies conspire. So healthcare practioners are absolutely part of the prison industrial complex as are mental institutions. So when I'm out there in community talking about abolition, I'm talking about abolishing all of these things that harm us and inflict violence not only on black minds, but black bodies.

**Elena Macdonald**

Exactly. Yeah, cuz that's the thing like when I say I'm angry, and devastated because of the ableism with mob, I'm not attacking mob. I'm saying, this is a thing the colony uses to separate us. If you're not being, if you can't acknowledge and work actively to unlearn the ableism from the colony, and how you ever going to be able to fully create a struggle against them?

**Elena Macdonald**

Because if it's not, that phrase. Nothing about us without us. We're never going to get that if we don't also recognize this. The colony uses ableism and the discrimination of sick and disabled people to separate us. I mean, in their imagined world, it works perfectly mob feel isolated and alone, and they sit and listen to horrible conversations when the problem is the problem is not, nothing to do with mob but the fact that there has to be an unlearning and recognition of the fact that this even is a problem.

**Elena Macdonald**

I mean, I'm here today speaking but I that was just luck. I I could have very well been dead. I'm only, I'm just one. I'm full aware every single day that I'm just one black fella alive on luck, that I didn't get killed by the colony and behind me and around me are all the mob that didn't make it and a lot of the deaths are never recorded. Because the hospital if I may use it. Yeah, as in Mali's case, they try to get Mali's mum's case. They try and get away with it.

**Renay**

I don't think the system, I mean, sorry -

**Samia**

They're trying to do that with me, that's what they do they wear you down. And then you've got non-aboriginal people say, "is it worth it? You need to let it go because here's this whole thing of, if you fight for justice, and for what's right that you've got to make a choice between that and staying alive. It's almost like it's that cut and dry, you know, and it's like, I'm going, "I'm trying to just stay alive right now".

**Samia**

But meanwhile, like you said, if they've lied to me, and they've treated me like this, and they've caused this kind of negligence. They're doing it to heaps of people, and they're getting away with it. Two and a half months, I was in a private psychiatric hospital, where this negligence happened that caused my surgery, and they've written complete lies, and they've treated me exactly as in prison and it was during Black Lives Matter. Wow, was it really clear that I was the only Aboriginal person in the whole fucking place I'm like watching the TV and watching Black Lives Matter? And even the other patients are going "oh, what's that about? Why are you watching that?". Like, immediately, right there, you're just in a completely, you know, non relatable space...

**Elena Macdonald**

Because you're forced to -

**Samia**

...with the people that are there. I just felt completelu isolated it was horrible, just horrible. The only nurses who talked to me were the black ones that came from other countries. [laughter]

**Elena Macdonald**

Because they understand a bit about what it means to be -

**Samia**

We had like little Black Lives Matter debriefs in my hospital room. All the nurses Black nurses would come in there, and we'd all have our debrief about white people. [laughter] That's a horrible thing to say but that's how it was!

**Elena Macdonald**

And I don't think, oh no, you go.

**Mali**

I was just going to say, where the importance of having other blackfellas in those spaces or having Aboriginal health care professionals, you know? [audio cutting out]

**Mali**

- psychologists and it was the first time I heard a health care professional be like, "you're mob", you know? Yeah. [audio cutting out again]

**Tabitha**

This is why we need our services. I finally was so desperate, I called [inaudible] and nobody cares, and I don't know what to do.

**Tabitha**

And since I've become so sick of it. It's like I've lost my whole identity, I don't exist anymore.

**Elena Macdonald**

Yeah.

**Tabitha**

Then immediately, I had a doctor and a nurse from the Aboriginal medical service, come to my house every week and do my bloods here and check me out because I knew I was too sick to even get to the practice. You know, that was never going to happen with any of the white doctors I went to see, or any of the clinics I went to.

**Elena Macdonald**

I think that's the thing. I mean, like Tabitha was talking about the part, how illness contributes to being poor, the colony driving into incarceration, and then the worsening of illness as a result of incarceration. It's like, it's that isolation, you get this isolation from the colony, and then lack of acknowledgement within communities as well of how pervasive and how deep discrimination, particularly within medical spaces, runs. I think because, I mean, for a long time, if you were sick, or what did you do? And so, there's the ethos, I mean, my Nana, my elders, you just get on with it, you don't talk about it, because what can you do? What else can you do?

**Elena Macdonald**

And within today's society, we're no longer within the missions and with the limited rations, but we're still facing like Tabitha was saying. I think that was really powerful about you know, the sugar has turned into asking for the ventolin and so on. Then basic medical treatment or even recognition that we are sick, and I mean, against all of that, how can we keep on going when it's no wonder that mob are being trapped by the colony and dying because so little space actually exists?

**Renay**

I actually feel really empowered by the knowledge that we are part of the oldest living culture in the world. You know, and while it may be a steaming pile of shit that we're dealing with.

**Elena Macdonald**

Yeah.

**Renay**

We've come this far. I think that's the only way I can continue. Otherwise, it would just be every day, that I'm sure you all know, that feeling of just sitting and crying and feeling completely hopeless.

**Renay**

But knowing that people who, especially the women in my family have gone through, and I've made it, and they've given me the power to express myself, and not take it anymore. They survived up until this long. Like you're saying before, disability is not a new thing in our community, so, we're still here, and we're still gonna continue.

**Renay**

I think doing things like this for me especially, just having that connection with another person that I may never have met before, or never even heard of, but then being able to say, I know exactly where you're coming from. That gives me more and more strength to say "you know what, it's like when you're the only blackfella in the room?" And you're like "oh, shit". Yeah. It's, um, I think that's what, for me anyway, that's what gets me along, knowing that there's been millions of us that have gotten to this point.

**Elena Macdonald**

Tabitha, you were going to say something before when I was talking.

**Tabitha**

I was just thinking about there's some of these kind of illnesses and disabilities that we have, have been like, in our communities since the very first sunlight but a lot of them were actually brought on by colonization.

**Elena Macdonald**

Mmm, exactly.

**Tabitha**

And so we are having to pay for health care for diseases that they gave us. [laughter] The irony of that is not lost on us surely but that just perpetuates the struggle that we have every single day in persisting to survive in the colony. It's like living has become an act of radical revolution and I think that's exhausting. It's exhausting for us to have to face that every day and it's exhausting for our families and our communities around us.

**Tabitha**

Then when you're raised from your own spaces, so Elena you were talking about the kind of lack of inclusiveness of our own mob, when they're putting on events and things like that, and making them accessible. And when you're asking for things you always seem to be begging around for stuff, and it does impact. It impacts our own well being.

**Elena Macdonald**

Yeah. Then you go to these disability networks that are already established, but you get there, and you realize they're only really for the settlers, and particularly the white people of the colony. Which I'm not, which is something I'm sure we've all come across. But um, Hannah you were speaking about it, too. If you want to, you can just, you don't have to talk about it. When you're talking about wanting to find support, but the inaccessibility of disabled networks that are already established within this colony, because they're mainly for people that aren't us and don't have our experiences and rife with assumptions of what our experiences are.

**Hannah Morphe-Walsh**

I mean Samia, you were talking, you were saying that you were in a psych where you were like, the only black person there. And I know we're like 3% of the population. So I think they think that by having a single black person there, they're like doing that job with representation, because that's how it works.

**Elena Macdonald**

 Yeah. True god.

**Hannah Morphe-Walsh**

I will say this. I've had chronic pain, pretty much, I mean, I assume my entire life, like it's gotten to the point where it's just, I do not notice it unless it's like a really bad day or unless, you know, I'm on the kind of drugs that take away pain, which is so rarely.

**Hannah Morphe-Walsh**

And the first time I actually I didn't even realize it actually. I went to an Aboriginal Health Service and was doing an hour long history as a first appointment and that was literally the doctor was the first person who had ever said "but doesn't that, like, that looks like it hurt". So I think, I don't know, I don't think the solution is for us try to make ourselves more prevalent in systems that are already not working. I think that the struggle that we have is when we, you know, when mob find each other.

**Elena Macdonald**

Yes.

**Hannah Morphe-Walsh**

Especially when we can advocate for each other. We can't often but two people can get a lot more done than one, like two very tired people can get a lot more done than one healthy person wit all the time in the world.

**Elena Macdonald**

Yeah. I mean, you've kind of like, just naturally kind of summed up like, the kind of way where we want to direct this kind of conversation, this kind of young, Hannah, is that. We - [laughing] - sorry, we have all these... We have so much struggle and so much pain and so much trauma and so much death weighing us down. And so many difficult things and trying to find access and space. But I mean, this year myself, personally, I found I was really despondent, especially with COVID because it brought up a lot of new like, a different kind of adaption of eugenicist language.

**Elena Macdonald**

"Why should we quarantine?". In the beginning it was assumed only the sick people would suffer, already sick people. Already different people, and so on. Why should we suffer? Even from some mob who I believe, I think just, were just not aware of, you know, the vulnerability of sickness, was saying "why do we have to do this? Why can't they just quarantine?". As if a lot of sick mob hadn't already been quarantining, hadn't already been doing that, and living in isolated positions for the most of their lives, and so on.

**Elena Macdonald**

And I started talking to Mali, I think that's how we initially started talking because we were bonding about feeling isolated, and the isolation of, that had been brought about by COVID. I started to feel hope, again, because I was able to connect and actually talk with someone. I think it was the first time I had a really meaningful conversation, with other mob, about illness, and about disability, you know, with mob that actually reflected my experiences. Like you were saying Hannah, and I think that, that is one of the most powerful things. You can't change institutions that, as Tabitha said, are born, to cut us to pieces, and snuff us out and never listen to us. We can only change things through speaking.

**Elena Macdonald**

I think of all the younger mob, who've never really been able to speak in a big group of lots of other mob like them who have disabilities or illnesses or yarn about, and have get back similar experiences with the violence of the medical complex and in the medical system, how much strength and support that would bring. I mean, I've found I've been able to go on this year, despite everything that's happened and nearly being killed by the medical system twice within the one year. And trying to do all the other things life expects of you. I found the ability to go on because I've been able to talk and connect.

**Elena Macdonald**

And even if the show was, I think the idea emerged in May or June, I can't remember when, but whenever it emerged, it just started giving me hope, I started thinking of all the mob I'd get to talk and the promises we could produce just from one yarn alone, because we've had so little chance to even have that one yarn and all the other yarns that could emerge from that. So I mean, I guess I'm trying to say like, what kind of visions do you hold and kind of hopes you have for a space and futures in which you know, mob like us, and all of our experiences, not just parts of our experiences are all actively considered and held as important, and the kind of things you want to produce? Samia?

**Samia**

So I didn't really know I was going to be doing this [laughter], this afternoon. And had just got home from literally from rehab. And just doing this, it's just made a huge difference. I think that's the thing that we're talking about is like, connection.

**Elena Macdonald**

Exactly.

**Samia**

 Connection. Connections are broken, we're sick, whether it's spiritually or like, I go... I can't leave the house, I can't drive, I can't do anything. Like, months and months. But I can go outside and I can listen to the birds, and I've got a nice tree I can sit under, and like, that's my country right now. That's the only thing you know. But in terms of people, I've been extremely isolated, and lonely, and like despairing and hopeless.

**Samia**

So just having this conversation is like "oh, I'm not alone, other people are going through this as well". There's similarities and differences. I don't know, I think coming from the plan of thinking I could make a change by being, you know, in the system, has been soul destroying, and the only people who survive in those systems are people who become co-opted into it. If you keep trying to change, like, I have and be on the ground and actually impact people. You get awards for teaching, but they don't really like you, and you don't really, you know, get any kind of reward for it. And you're kind of difficult, and you have to fight the whole time, and it burns you out.

**Samia**

So, I guess I think this is the only way to go. More and more, more and more, we have to go back to like, community making our own, making our own connections, supporting each other, holding each other up, you know, like being being what we need for each other, because no one else is going to do it.

**Elena Macdonald**

Exactly. And I mean, the idea of the podcast being in the form of just a yarn, a casual yarn. To me, it was so important, because, I mean, I had the privilege of being raised in culture and growing up, there was nothing more powerful, powerful than what was produced from having a yarn. And listening to the things my auntie's would say, just talking, you know, just talking to each other.

**Elena Macdonald**

And I thought of all, with Mali's help, we thought of all different ways, you know, how could we do this and best produce something that was really good? But the idea of the yarn was just the best thing. Because just by talking and just by sharing, I mean, like, you were saying to me. I feel so I mean, I feel sort of healed from even having to go into the hospital this morning. Because having to even be in that space. I felt after I left, I just felt so panicked and stressed and miserable. And this yarn alone, has done the world of good for what has been a horrific year of trying to stay alive. When the medical system was doing its best to kill me.

**Renay**

Yeah. You did it. I told you we did it.

**Samia**

We're here.

**Mali**

We are.

**Renay**

I completely agree I think that that's where our power is.

**Elena Macdonald**

Yah, I'm Elena McDonald. This yarn went for longer than the one you've just heard on the broadcast. You can listen to the full yarn on 3CRs Disability Day 2020 website. And I'm thankful to the Wurundjeri country for watching over me while I've produced this and spoken and existed within many medical spaces, and for caring for those who have passed on all countries and nations around this colony who have have looked over and cared for those who have passed on within horrific medical institutions and horrible circumstances. I think that's very important. I always hold them within my thoughts and hold respect to those who have passed on and the countries within which they now exist. As old people and ancestors. Thank you for listening. It's been amazing - Mob Dreaming up: Yarning Sick Disabled Realities. Let's hear more of it in the future because we need it. So thank you.