**“Disability Royal Commission” from the program “Chronically Chilled”**

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Hosts: Naomi Chainey, Marijo Pozega

Guest: El Gibbs**

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GEMMA: Hi there. My name’s Gemma Mahadeo, and you’re listening to 3CR’s Imagining Disability Justice, a special International Day of People with Disability broadcast.

*[funky intro music playing]*

NAOMI: Hello and welcome to Chronically Chilled, where we chat about all things chronic illness. We’re an underrepresented community in the media and it’s good to take this time each month to discuss some of these issues that are important to us.

I’m Naomi Chainey, I’m here with my co-host Marijo Pozega, and we’re joined today by El Gibbs, from People with Disability Australia. And we're going to chat a bit about the Disability Royal Commission which is happening right now, and how chronically ill folks might benefit from engaging with that.

Before we get into that though, we'd just like to pay our respects to Elders past, present and emerging of the lands that we are respectively recording from. We're still recording from home, there is still a pandemic, and we're not in the 3CR offices just yet, so we're all on different parts of the country. So I'm currently on the traditional land of the Bunurong people. Mario is on the traditional land of the Wurundjeri people, and El is hailing us all the way from the traditional lands of the Darug and Gunda-raga people. Have I pronounced that correctly El?

EL: Gundangara

NAOMI: Gundangara, okay. We want to acknowledge that sovereignty of these lands was never ceded. They always were, and always will be Aboriginal lands. So El, welcome. How are you doing today?

EL: Thanks so much for having me Naomi and Marijo, I am really well thank you. Although I feel like being on a chronic illness show, it should be totally fine to say, but I'm pretty tired.

NAOMI: Yeah. So just just to clarify, all three of us here actually do have chronic illnesses, this is very much self-representation on this show *[laughs]*. So El, you work for People with Disability Australia, and...

EL: I do. So yeah, I'm the Director of Media and Communications, so my job is talking about disability and/or illness in public, in the media. I look after lots of things—our website, I work with a great team around our social media, and I help the rest of the fantastic PWDA team to talk about the things that they're doing.

NAOMI: And just for full disclosure, I should probably let the audience know that I am currently a part of that team *[everybody laughs]*, just so that people know what's up with that. So El, we know there’s a Royal Commission happening right now on Violence, Abuse, Neglect and Exploitation of People with Disability. Can you explain a bit about how a Royal Commission works and what we might expect the outcomes of a Royal Commission in this area to be?

EL: Sure. So one of the reasons that we campaigned for a Royal Commission in particular was that it's the kind of highest and best form of inquiry that we have in our political system in Australia. So a Royal Commission has a bunch of powers that different kinds of inquiries don't have. So they can call people before them, like a court does, they can demand evidence, they can force witnesses to come before them, all of that kind of stuff. So it's got a whole bunch of really amazing powers, and the reason that we campaigned so long for that particular mechanism—the Royal Commission—was that we know that for many people with disability, violence against us is really hidden, it is something that is really hard to talk about and to find information out about.

So for people with disability, for example who live in a group home or an aged care facility, it's incredibly difficult to talk about what's happening to people without having things like their housing being threatened or anything like that. So we wanted to have an inquiry that had the kinds of powers, as we always say, to shine a light and to open the doors, because so much of the violence and abuse against us is hidden away, and happens behind closed doors. So that was really really important.

The other really important part of the Royal Commission is that it's not just looking at, say, the disability service sector, so not just day programmes or sheltered workshops or special schools, but it's looking at all settings. So what that means is: abuse that happens against us, say, in hospitals or in the medical system, at school, people talked about it in sporting clubs, all of that kind of stuff. And I think that the hearing that's coming up on COVID is a really good example, because it's going to really cover a huge range of things that don't sit in what some people think is the traditional disability system.

NAOMI: So what are some of the things? I know that we’ve recently done a survey on COVID-19 and people with disability. What were some of the things that came out of that?

EL: Yeah, I mean one of the reasons that we did that survey was—I don't know about you two, but I had a pretty awful time during that first batch of the lockdown. Particularly when all the delivery stopped and lots of changes happened really quickly. And so all of the systems that I use to maintain my life, for example, just disintegrated. And I was hearing anecdotally from other disabled people that that was happening to all of us. So I really wanted to get a sense of how widespread this was, is this something that was happening to lots of other people?

So we did a survey, just a quick one, that asked 200 people with disability, what they said, and what had happened to them. And so people said that they faced enormous increases in expenses, for groceries, but also for things like medication and healthcare, as well as access to hygiene equipment, so PPE, the acronym that we've all come to know, personal protective equipment, but also that they’d found it really difficult to continue the supports that they needed. So I found the same; the person that comes and helps me at home hadn't been able to come anymore, and that had made it really hard for me. And so the same thing had happened to plenty of other people as well.

We also asked about telehealth, whether people had accessed telehealth. And yeah, they’d used GPs via telehealth and specialists, but also things like allied healthcare. So that was something that I was a bit surprised about, but it was great to see that people had still been able to access things like physio and OTs during the pandemic and hadn't had to stop using those stuff.

So one of the things just before I go on, I just wanted to be really clear about... I call myself a disabled person, but I am a person with chronic illness. And I know that that's not always something that everybody does, but I wanted to be clear that when I'm talking about disability I do mean the social model of disability. So I am talking about... not any particular kinds of impairments, I am talking about the barriers that we face as disabled and/or chronically ill people. So I just wanted to make sure that, because I think sometimes that disability language cannot always be as welcoming, I think, as it could be. And I just wanted to make it really clear that I was being as inclusive as I can.

NAOMI: Yeah, yeah.

MARIJO: Just a question El, do you think that that's got some implications in terms of how people have engaged with the Royal Commission?

EL: I do. I do, and I think it's a really important point to think about, like how for us as people with chronic illness, the things that we may have experienced as violence, that abuse may be different than other people with disabilities. So I know for me, I'm going to make a submission, and that submission is mostly going to be about my experiences in hospital. So multiple, multiple experiences in hospital for very long periods of time, and so a lot of my navigation of the medical system has been deeply traumatising.

And, I'm now a firmly middle aged person *[laughs]* but I got sick when I was 19, and going into a system like that 30 years ago as a young person was extremely difficult. And I still remember very clearly what happened to me and how terrible it was. So I think that they're the kinds of experiences that I want to share with the Royal Commission, because I know that for those of us who have to engage with the medical system over years and years, and in my case, decades, the medical system shouldn't be traumatising, but for far too many of us it is.

NAOMI: I've actually been working on my own submission. And a lot of it is also similar to yours, El, focused on health, not hospitals so much, but just GPs in general. Just my experiences around that have been very much that GPs can be gatekeepers to services for people with chronic illness. And this is something I see in support groups a lot as well, is that you see people having unfortunate interactions with GPs, who don't take things seriously or don't understand what the symptoms mean in a practical sense, in terms of the support that you need.

And yeah, there's a gatekeeping happens there that I think fits into what the Royal Commission is trying to get at, because it's basically neglected. It's financial neglect, it's neglect when it comes to the services that people need. Yeah, I think it's really important that people with chronic illness do actually engage with this, whether or not you identify as a person with a disability, which some people don't, and that's okay.

EL: Yeah, I'd strongly agree with that. And I think that the difference it makes having a decent GP as someone with chronic illness versus just an average GP is profound. And it shouldn't be like that. I think particularly if you live in an area where there aren't that many options when it comes to GPs, or it's very difficult for you as a person with a chronic illness to access GPs easily, or to communicate about this stuff in a way that GPs need to understand, like they have their checkboxes that they need to know about.

And I have found over the years that sometimes you need to use the right language, and you need to be able to, to phrase things in particular ways. And I mean, that is as you say Naomi, such a gatekeeping role, like instead of actually supporting and encouraging people to access things like chronic care plans or anything like that, you have to know that these things exist to be able to ask for them. Whereas it should be that if you have a chronic illness, we should be supported to actually access things like allied health as much as possible, because the preventative nature of that is so great, that there really shouldn't be barriers, particularly financial, to accessing those kinds of services.

NAOMI: So on that note, we're going to take a quick break. So you're listening to Chronically Chilled on 3CR 855am. We're here with El Gibbs from People with Disability Australia, and we'll be back in a moment.

*[community announcements play with background music]*

*[Announcement 1:]*

DR. MARK WENITONG: Hey all you mob, it's Dr. Mark Wenitong here. Coronavirus has certainly changed the way we live, work and connect. These changes can be hard for some of us, and can make us feel no good in our head or spirit, like sad or worried all the time. Some of us might already be dealing with other things like sickness, trauma, and this can make it really hard for us to feel good about anything at the moment. If you're feeling like this, remember it's okay to ask for help. Have a yarn to someone you trust, like your family or an Aboriginal or Torres Strait Islander health worker. You can also call Beyondblue, Lifeline or the Kids Helpline to talk to someone, or look at some helpful information at headtohealth.gov.au on the internet.

VOICEOVER: A 3CR supporter.

*[Announcement 2:]*

WOMAN’S VOICE: My name’s Jane Rosengrave, and you're listening to a Yorta Yorta strong powerful woman on Disability Day, on 3CR!

NAOMI: Welcome back to Chronically Chilled on 3CR. I'm Naomi Chainey and I'm here with my co-host Marijo Pozega and El Gibbs from People with Disability Australia. If you've just joined us, we're having a chat about the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. If this is bringing up any upset or issues for you, please remember you can always call Lifeline on 13 11 14 if you need support.

We've just been talking about how some people with chronic illness identify as disabled and some don't. And in that regard, it shouldn't matter, you can still engage with the Royal Commission. How can we actually go about doing that, El? If we want to let the Royal Commission know about some of the issues that have been affecting us?

EL: Yeah, I mean, there's quite a few ways of making a submission. So if you feel comfortable to make a submission on your own, you could just go to the Royal Commission's website, you could make a submission via audio—so you have audio recording or a video recording. And I think that's particularly important for people who have chronic illness that has any kind of energy impairment, I think being able to do it as an audio recording rather than having to write something I think is really important. And there's forms and details about how to do that in Easy Read, and Auslan and in plain English as well on the website, and in lots of community languages as well.

But there's also a whole bunch of funded supports through the Royal Commission that can assist you in making a submission. So there is free counselling available through Blue Knot service. There's free legal support through the Your Story legal service. And then there's support through disability advocacy services. So PWDA, we're funded to do disability advocacy around the Royal Commission in New South Wales and Queensland. But there's lots of other services funded to do Disability Royal Commission advocacy support in Victoria, and they can support you to fill out the submission form and to tell your story, but also—and what our advocates are often finding is—people are coming to them to say “I want to tell my story to the Royal Commission,” but it turns out there's a whole lot of other stuff going on in their lives that they can use some advocacy support around. And so people are able to get help on a range of fronts.

MARIJO: And what I find interesting about this Royal Commission is, one, it's dealing with disability, but it's also dealing with violence and abuse. And sometimes it can be really hard for people who are experiencing any kind of violence and abuse to actually be able to identify and articulate it. And I wonder if that's something that’s come up during this Royal Commission in terms of people making a submission and being able to say, actually, what's being done here, or what I've experienced is actually not okay, and it's this and this and this. Because I think people can find it incredibly hard to identify stuff for themselves.

EL: I think that is such a huge issue. For many people with disability, they may not recognise that what's happening is violence or abuse or exploitation. Some of that is because for many of us, the forms of abuse that we can experience can be different to non-disabled people. So it can be things like removing a mobility device… Sorry, I'm going to talk about stuff, I won't talk in lots of detail, but I am going to talk about stuff that's a little bit upsetting, so just giving you a heads up, and turn off here for a couple of minutes, but I won't go into too much detail.

… So some of that can be about, yeah, removing a mobility device, or removing care and support. It can look differently than abuse that happens to non-disabled people. And so exploitation can be things like removing someone's bank cards and having control of someone's money. It can be about removing phones or removing access, it can also be about not explaining things and not letting people know that they have rights and that they have support.

So yeah, it's a massive issue, and I think one of the things that we are concerned about, we have talked to the Royal Commission about that. There needs to be a really big outreach programme by the Royal Commission, but also by us, by a trusted organisation who can reach out to people with disability and talk about the different kinds of things that do happen to us. Like, when I talk about some of my experiences in hospital, people talk about “but I didn't think that that was about violence or abuse or neglect,” but it is, and it's really important that this stuff is counted. And that it's not just… we hear campaigns around domestic and family violence, for example, but we don't think about that happening in group homes or in boarding houses, and not necessarily by partners.

So there are a whole range of issues that are unique to people with disability, that I think need much more explanation and much more awareness, and much more outreach into communities to talk about the fact that a) this is this is an issue, this is actually violence and abuse, b) This is what you can do about it to stop it happening, and c) this is how the Royal Commission can help. I think that that's a really important next step that the Royal Commission really urgently needs to start taking, and I'm really hoping that when the interim report comes out in October, that the Royal Commission acknowledges this and acknowledges that they need to do a bunch of work around this, and making sure that people are understanding both what violence is, but it wasn't what our rights are. I mean, if you're a person with disability who has gone to a special school, or you've ended up working in a sheltered workshop, someone's probably never told you that you have rights and never talked to you about the fact that you could have control of your money, and you can make decisions for yourself. So I think it's really, really important that this kind of conversation around what our rights are, is part of the conversation around the Royal Commission.

MARIJO: Yeah. And, and to provide some kind of environment where it's actually safe to be able to speak about this stuff. Because it's so unspoken, yeah.

EL: Absolutely, yeah. And I also think that one of the things that it's going to be really important for the Royal Commission to understand is the huge power imbalances in our community. So for a person with disability who, say, lives in an unregulated boarding house, they live in a small room, they live with a whole bunch of other people. How safe is it for them to talk about being obese that they're experiencing? And if that's the only place that they can find to live, the only accessible place that they can find to live, the cost of them speaking out can be further abuse, but it also can be homelessness. And these are very real risks that people are being asked to take to talk to the Royal Commission.

So one of the things that we're really looking forward to is the government bringing in some legislation to basically make sure that people can tell their story safely, that can be confidential. And because we know that many people with disability don't feel safe yet to tell their stories, because they are worried about it getting out, and for the service provider that they’re talking about, for example, finding out that they said these things about them.

NAOMI: So in situations where someone's service provider is also providing their living situation, for example in group homes, is there a way for people—like if someone has that much control over every aspect of your life, basically, confidentiality is one issue, but also some people will actually need help to do things like access a phone or access a computer—is there any way at the moment that we might be able to reach people who actually can't access the technology to make a submission?

EL: It's such a great question, and I think it is really important that the Royal Commission acknowledges how hard it is going to be for some people to make submissions. So this is one of the roles that disability advocacy can play. And I know that some of our advocates are doing this exact thing: actually sitting with people and working through their submissions, making sure that they can get them into the Royal Commission, and making sure that they can do it safely and with the supports that they need. But we need way more of this to be happening. So this is only just the tip of the iceberg, if you like, what we need is for there to be much more of these kind of services, going in and doing a proactive outreach into group homes, into boarding houses, into caravan parks, into the places where people with disability who have the least are living.

MARIJO: Can I ask, so not all Royal Commissions are equal in terms of what resources are given to them? What are the resources like in terms of this Royal Commission? And do you think it's kind of enough?

EL: Yeah, and this Royal Commission has had quite a lot of resources put towards it overall, so the Royal Commission itself. And then there's been quite a lot of funding, gone to Blue Knot for their free counselling services, and to legal aid, I think it is for the Your Story legal service, which is free legal assistance. And then there has been some funding that's gone to disability advocacy organisations like ours.

But I think that in terms of the scale of the issue, one of my concerns is that the Royal Commission hasn't been given enough time to do their job. And particularly with COVID, I think it's like even the Aged Care Commission has been given an extra six months. And I think we really need to start talking around doing a bit more time for the Royal Commission to run, and therefore some more money. But I also think that we do need to do some investing in the outreach around advocacy, particularly to some communities.

So the Royal Commission has recently reported that only a tiny percentage of people with disability from culturally and linguistically diverse backgrounds have put in submissions. And same for Aboriginal and Torres Strait Islander people with disability. Now, this is not acceptable. We have to make sure that this Royal Commission has whatever resources that we need to do to make sure people can put in their submissions, and that they know about the Royal Commission. So I think that this is going to be the next steps.

I mean, if I was in charge of marketing of the Royal Commission, which I'm not, I know what I would do. But I think that this kind of stuff, where this outreach from everybody—so that includes disability advocacy, like PWDA—is going to be incredibly important.

But COVID, of course, has made things even more difficult. So many people with disability have much less supports, have got much less money, and are in situations potentially, where they're much less safe. So we heard a report this morning, of 1,500 women talking about the huge increase in domestic and family violence, and we know already that women and girls with disability are far more likely to experience domestic and family violence. So we can only extrapolate from those figures that this is happening to people with disability now, during COVID.

And so hopefully, there'll be some investing in finding that out. But I also really hope that people do tell the Royal Commission if this stuff is happening to you now, but also to talk about it if it has happened to you in the past. So, I think everything from not being believed, not being supported, not being able to access help, to talking about living in poverty, to talking about being on the DSP. I mean, I was on the DSP for many years, it's really difficult. And I think it's important for us to talk about the financial implications, impacts of having a chronic illness, of accessing allied health, those kinds of things. Because if the Royal Commission doesn't know about that they can't make recommendations about this.

MARIJO: And it's also just about if something just hasn't felt right. Like you might not know how to articulate it all and all that stuff. But just something that you've experienced, if something just hasn't felt right, that it's also important to contribute that to the Royal Commission. Or to be able to do that.

EL: Definitely, yeah. And even, take advantage of the services that are available through the Royal Commission, even if you don't end up making a submission. So there is free counselling through Blue Knot, and there is that free legal advice. And they will be able to support you to talk about this stuff, and to have a think about if making a submission is right for you.

NAOMI: So El, what are the outcomes that PWDA is actually hoping for from the Royal Commission?

EL: An end to violence against people with disability. I think, for me, one of the things around the 2015 senate inquiry—I watched and listened to all of that, and I read all of the reports from it—was how pervasive this violence is against us. And that one of the fundamental reasons for that is that we aren't valued for who we are. And I think that one of the things that I want to come out of this is that we start to connect these dots. That we start to connect that, you know, us not knowing our rights, us not being included in society, us not being respected as people with disability and valued for us as people, that that directly contributes to this sort of violence against us. And I want things like segregation to end, you know? That people with disability can live in the community just like everyone else, go to school, go to work, and have the same access to things.

So we've heard already in one hearing that people with intellectual disability die 25 to 30 years younger than other people, and don't have access to things like screening services, and are in hospital told that their lives aren’t worth living. And it's just, it's just horrific. So I want an end to all of that. And I want an end to people seeing us as somehow not real or whole people, because we absolutely are. And we have value and we have strengths and we have lots to offer, just as people, as we are, right now. Even if we are lying in our beds, even if we are like me, sitting here in my pyjamas at work *[laughs]*. I think it's important that us, as disabled people, as sick people, that we are included, and we have value.

NAOMI: I want to thank you so much El for joining us today and going through all of that. I'm sure that's some very useful information and a lot to think about for everyone at home. And I want to reiterate if this is bringing up any upset or issues for you, remember, you can always call Lifeline on 13 11 14, if you need that support. And El has talked about Blue Knot as well, which is a counselling service, which you can access as well that's for free.

To everyone at home you've been listening to Chronically Chilled on 3CR, 855am. And if you missed out on the beginning of the show, the podcast will be available at www.3cr.org.au. And if you enjoyed our show and you got something from it, and you want to support radical radio, you can always support 3CR by becoming a subscriber or by donating to the station appeal which you can also find on the website.

Chronically Chilled is on the air on the first Wednesday of every month. So until then, look after yourself. And we'll see you next month.

*[funky outro music playing]*

*[station announcements playing over music]*

*[announcement 1:]*

WOMAN’S VOICE: ‘Cause if we don't talk about us, everybody else is going to, and they're going to get it wrong!

*[announcement 2:]*

*WOMAN’S VOICE:* ***[28:53]*** *[speaking in a different language]* … You're listening to 3CR’s International Day of People with Disability broadcast.