Down to the Struts

Season 7, Episode 5:

Guest: Aine Kelly Costello

Host: Qudsiya Naqui

Transcript by: Qudsiya Naqui

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“it's important to value everyone for who they are, we all have inherent worth. We all bring different aspects of, our contributions and skills and are part of our communities in diverse and wonderful ways.”

**Introduction**

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Hi, this is Qudsiya Naqui—creator and host of Down to the Struts, the podcast about disability, design, and intersectionality. Today, we’ll be listening in on my conversation with Aine Kelly-Costello. Aine is a contributor to the Disability Debrief newsletter, a co-convener of the Inclusive Greens—The disability network of the Green Party in Aotearoa, New Zealand—and an organizer with Migrants Against the Acceptable Standard of Health Aotearoa. Aine and I talked about their work as a journalist, a podcaster, And an activist at the intersection of climate, migration, and disability justice. Aine and the founder of the Disability Debrief, Peter Torres Fremlin, who you heard from in Episode 2, recently launched a hub on climate and disability

As part of the Debrief’s extensive library of disability news from around the world. Aine has also created a resource guide to accompany their reporting, all available to you on the hub. Be sure to check out the show notes for links to these materials and much more. Ok, let’s get down to it.

Qudsiya Naqui:

thank you, Anya, so much for being with us today on the podcast.

Aine Kelly-Costello:

My pleasure.

Qudsiya Naqui:

I wanted to start off by asking you to briefly introduce yourself and tell us a little bit about your disability journey.

Aine Kelly-Costello:

Thanks, Qudsiya. Hi, everyone, my name is Aine. I grew up in Aoteroa, New Zealand, which is where I'm now currently based again. But also, I've lived in a few other places. I was born in Ireland, and then lived in Canada for a few years as a kid. And I've also spent the past few years most of it living a bit in Sweden, and then in Norway. In terms of disability, I was born blind, and realized in my early 20s, that I am self diagnosed autistic, so neurodivergent. And then also, when I was in Sweden, partway through a master's in investigative journalism, the pandemic came along, I got COVID. And subsequent to that, I got long COVID out of that. So I've had long COVID Now for the last almost exactly three years,. In terms of getting involved in disability community, I was really lucky that through some accessibility law campaigning and training around that, and having a job around that I ended up getting more connected with the like a wider sense of disability community outside of blindness community back in 2017 18, both in Aoteroa, New Zealand and internationally, it really like sparked my interest in wider disability advocacy. And I'm so thankful that I had that while becoming chronically ill, because I think that, in many ways helped with what was still a really difficult transition. And just a little bit more background that I'm I'm white, I have all the sort of places that I've lived in our global north high income countries, at university educated. I studied music and languages at university. And, in the last few years, most of my work has been around storytelling. So written and audio within the disability space and its intersections, in particular with climate justice, and migration. And more recently, independent living advocacy as well.

Qudsiya Naqui:

speaking of your work around climate justice, I'm interested to learn about what led you to bringing together your interest in disability, climate justice, journalism, and activism and how did you get into that work?

Aine Kelly-Costello:

I was at university when I first came across. So there was a guest speaker coming to give a lecture called Bill McKibben, who is one of the founders of 350.org, which is a grassroots climate justice organization. And Bill McKibben was talking about the need for our institutions to disinvest or divest from the fossil fuel industry to send a signal that they should have no social license to keep polluting our planet. That was back in 2013. And the next year, a few people were trying to get a campaign for Auckland University, the University that I was at a time to, to divest off the ground. I joined in thinking like, oh, I'll just say that maybe there might be something I can do to help wasn't quite sure how they would take that as a disabled person who had I've never been involved in campaigning before. And yeah, it turned out that it was the literal first meeting. And so because of that, I ended up getting pretty involved from an early point, as that movement grew on campus, and part of what 350 have been really great at doing in terms of their orientation to campaigning is also upskilling campaigners. So through being involved in fossil fuel divestment stuff, I had opportunities to, do trainings on campaign strategy and narrative and media and, practice facilitating meetings. And also, as I stayed involved with that space over those years and was lucky to have really good relationships within 350, and with the Coordination Group of the Fossil Free University of Auckland group, I started getting a little more outspoken about what would it mean to make campaigning more inclusive and accessible to disabled people more generally, and not just me. And so with 350, I started doing a little bit of training in that area. And I remember feeling like super self conscious about it, I was pretty new to the wider disability community at that point myself as well. And I was wanting to ground stuff in our disabled people actually impacted by climate breakdown. That was my introduction to combining climate and disability a little bit more. And then at the end of 2018, I ended up interning for a media outlet here in Aoteroa, and New Zealand, and from there, just got a bit more freelance reporting. And I did a master's in investigative journalism. My thesis was on journalism in relation to climate change, although it didn't have a disability angle. And then, about a year ago, my friend, who is also disabled, Peter Torres Fremlin, who produces a newsletter called Disability Debrief, which has these amazing roundups of curated world news on disability asked me if I wanted to write about disability and climate intersections for the newsletter. We still have way too few people writing about intersections of disability and climate within journalism.

[Breezy, contemplative beats]

Qudsiya Naqui:

what's still missing when it comes to disability and climate justice, both in terms of the substance of climate justice, activism and advocacy, and also in terms of access and inclusion of disabled folks in the climate justice conversations?

Aine Kelly-Costello:

I think that fundamentally disabled people are still pretty invisible. We have moved a long way in the last few years, but if we think about wider climate, justice, advocacy, it is still the case that disabled people are often just completely not there. And there are terms that come out of that, right, which, which generally would refer to as eco ableism. So, for example, in the transport arena, if you are advocating for cities, which are car free, or a cities with a lot of shared spaces, but if disabled people haven't been involved in designing those shared spaces, or thinking through the fact that some people actually rely on cars for independence for accessibility reasons, otherwise, they can't get around at all. We still need mobility, parking, we still need taxi drop off kind of spaces that are accessible for disabled people. We still need shared spaces to be designed in ways that separate out Micromobility and cycle lanes from the footpaths, so that footpaths are safe for, you know, wheelchair users for blind people for children and older people. In the environmental space one that comes up a lot as well as the way that single use plastics are being phased out and the particular focuses of those on things like straws, or even campaigns around, switching to other types of sanitary products, like cups and so on for people who menstruate. You know, disabled people having needs around medical waste and and those sort of aspects around actually what happens when a product that was mainstream, which was critical to disabled people's survival, such as some disabled people needing straws to plastic straws to drink to literally live. If you make that a specialized or a nice thing, you're making disabled people have to like explain themselves in order to get something that they rely on to survive. And then I think as well, within campaigning spaces in relation to accessibility and inclusion, when disabled people don't necessarily see a other disabled people feeling safe and comfortable within those spaces, but be any like actual information or like understandings from environmental and climate organizations around what is it that they are actually doing to try to make these spaces more accessible and inclusive? Have they actually written like a strategy about how they're going to change that goes across all levels of the organization with input, paid expertise, input of disabled people into those plans? when events are being advertised, is there actually information about different aspects of accessibility for events? Is there on the RSVP forums, a place for people to add in what are their access needs? And someone actually going to be monitoring that? Is there a functional feedback system so that if people give feedback on a lack of accessibility and some aspect of a campaign, that that will actually get integrated? Are we seeing images described on social media and videos captioned and also videos with Voicing so that there's not just a text on screen, and, you know, transcripts made available? And things like that? I think we often see some of the same thing, themes. I'll just also plug, one piece written by a friend, also disabled, Anna Maria Joseph called Cripping Climate Activism. And Anna interviewed me and to others, also disabled climate activists, for that piece. I think it's a really nicely put together piece.

[breezy, contemplative beats]

Qudsiya Naqui:

in addition to your climate activism, and its intersections with Disability Justice, you also are quite politically active, in New Zealand, can you talk a little bit about that and how those experiences have been for you?

Aine Kelly-Costello:

in New Zealand, our parliamentary system is mixed member proportional, and there's a bunch of different political parties with representation in Parliament and, and I am a member of the Green Party, which really aligns really well with my values in terms of fighting for social equity, for an end to poverty and things like that and also for a sustainable planet. So putting the social and climate justice aspects together. And within the Greens we have a disability network called the Inclusive Greens, which is a forum for disabled people to like together be able to have a safe space within the group, but also, for us to have a like a collective voice within different aspects of the party, right. So in relation to connecting with members of parliament, also in putting into policy. And yeah, just being more visible throughout all aspects of the party, really. So I've been co convening the Inclusive Greens, which is the Disability Network for the last two and a half years now. And it's yeah, it's been really cool to have that forum, I think. And a lot of us also do, and put into other committees, which I think is important to write to try to have the visibility of disabled people and our perspectives throughout throughout the party. But it's, it's good to be ourselves, like in community with the other disabled people in the party as well, because then we can let we have spaces where we can share if things are difficult. We also last year managed to get a lot of changes into when a constitutional review was was happening. So disability and accessibility, are now embedded throughout the Constitution. And the party is in a structure which is much more founded on Waitangi, which is New Zealand's founding document. So much more embedded in an indigenous worldview, which is also fantastic. So it was great at that, at the same time as making those changes to be able to get things like, you know, that we respect and honor the principles of the UN Convention on the Rights of Persons with Disabilities into the Constitution, for example. And also just having, yeah, having voice in in a lot of different areas of the party, and including working even with the party staff around accessibility of party processes, and providing trainings and tools and materials on on all kinds of different aspects.

Qudsiya Naqui:

it's, interesting how you describe that balance of having the inclusive space, that's just for you just for disabled Green Party members, where you can build the power that enables you to go out and infuse your point of view and concerns into everything that the party is doing. I think that's a really great strategy of both creating space and, disability community, but then also collecting power that is then deployed elsewhere.

Aine Kelly-Costello:

Another example of that would be like this year, we have an election at the end of what, in October. So this year, we're really focused on the party in general, and Inclusive Greens are really focused on election campaigning, of course. So, within Inclusive Greens, we've kind of talked about what are some different ways that people might feel comfortable and able to to be involved in campaigns. And we've also ran, and we will run some more trainings for candidates and any members of campaign teams, both around applying a disability lens on messaging, and also around making their campaigning accessible and inclusive. And we have multiple members of the network feeding into that training as well. So that would be an example of trying to build our own power, but also reach out and share expertise.

Qudsiya Naqui:

Have you met with resistance in doing the work that you're doing? What has the reception been to the Inclusive Greens?

Aine Kelly-Costello:

I think overall, there's definitely more that the party can do to make space for marginalized communities. I think that a lot has improved, dramatically over the past several years. And, the Inclusive Greens has actually existed since the early 2000s. And just a shout out as well to our first Deaf Member of Parliament, Mojo Mathers, who's in parliament from, I think, 2011 to 2017, who really did a lot to amplify disability within that space and within the greens. So building on very much building on that sort of legacy. But I think in general, we are making progress. Certainly now, in terms of having budget for having New Zealand Sign Language interpreters at meetings and things like that were never second guessed or questioned when we asked for budget for interpreting or something like that. So that's certainly good, but obviously we Can I think we can always do more, I think within election campaigning as well, you know, the more that we're able to really support marginalized candidates, the stronger those campaigns will be, and the more that we'll be able to reach out to a diverse constituency of voters across the country from those communities as well.

[Breezy, contemplative beats]

Qudsiya Naqui:

Aine, you do so much. But importantly, you also are a podcaster. And you, you have the blog and podcast and website, Disability Crosses Borders. Can you tell us a little bit about how you, thought through that project and what you've learned about disability migration and culture through doing that work?

Aine Kelly-Costello:

Yeah, so I was working on this and 2021. And at that point I had had, I had long COVID, for about a year, we were sort of a year and a bit into the pandemic, I was wrapping up my master's thesis, and I was living in Norway. So basically straight after the pandemic started, when I had been an international student in Sweden, my parents, two months prior to that had moved to Norway, because they'd been wanting to go move back to the northern hemisphere for a long time. So I ended up moving in with them in Norway, when all the borders were closing, and everything was a mess, and April 2020. And I really appreciated having their support as I ended up getting, you know, sicker because of long COVID. But I did not plan to move to Norway, that was not on the agenda at all. And so I felt quite dislocated. And I was kind of struggling to process that aspect. And so I think part of it was my realizing, you know, I was kind of keen to, to try and do some kind of media project, I had a bit of time I had the financial security, huge privilege of living with my parents. I this was something I kind of could do in the sense that it could be on a very time flexible timeline. And I had, quite a few friends, who were also disabled people who were either migrants or immigrants, or who just like, lived between cultures in different ways. So I thought, Well, why not bring those interests together and start a little podcast series, which also has, yeah, like write ups as a blog and had transcripts as well, on these intersections between disability migration and culture, and in terms of what I learned, like, I think just that it's, it's powerful for us to have these kinds of spaces which you you also have been so instrumental in creating and I really admire the work you do through through Down to the Struts and your newsletter, as well. So we're very much on the same page there but just for disabled people to be able to talk to each other. And also to be able to share our stories in a in a way which is on the terms that we would like to in a way that feels safe. So yeah, it was a privilege to be able to interview both friends and people that I hadn't hadn't met and didn't know before. And yeah, I really appreciated like for myself as well, like on a selfish level being able to have a lot of conversations about the those kinds of messy intersections around like, place and culture and, and disability that I think are just so underrepresented in. Yeah, and a lot of media and sort of mainstream platforms.

Qudsiya Naqui:

I absolutely agree and I very much hear you about the pandemic project being trapped in your home and thinking about what you can do with your time that is a is a positive contribution. And that was exactly, , my mindset in starting Down to the Struts. And I had no idea that it would become what it is. you have another, podcast project that you launched in the last year, would you like to share a little bit about that?

Aine Kelly-Costello:

So over the past couple of years, I've been doing a bit of work with the European Network on Independent Living, which has members, which are organizations and also disabled people And is a sort of umbrella body around Independent Living advocacy in Europe. And I did a podcast series interviewing five people about their experiences with independent living, which was called On Our Terms. And also if you if you look up the European Network on Independent Living, there's, there's so much material there from from disabled people in different forms. I have a YouTube channel, which has a ton of interviews, as well, and interesting webinars and everything. I think one of the threads that I was also really keen to make sure that I picked up in the interviews was trying to really hear from a diversity of of people and also talk about the fact that the independent living movement did start out with a real focus on on physical impairment, and how are we actually making sure that people with learning disability and people with other disabilities are actually included and and empowered through those movements as well, and people with other marginalized identities.

Qudsiya Naqui:

And I know, once you finally were able to return to New Zealand, you kept up your interest. And in this issue of migration, and were doing some advocacy around that in New Zealand. Can you tell our listeners a little bit about what that work entailed and what you were focused on?

Aine Kelly-Costello:

New Zealand has some horrific migration requirements, which, I mean, a lot of countries, coming from a sort of colonial eugenic backdrop here, have put barriers to people they have deemed unfit or unworthy or unwanted, around migration, and being able to come and settle or get visas for a really long time, right. But New Zealand and Australia in particular, both countries still have really horrific ly strict forms of these policies. So in New Zealand, we have the acceptable standard of health requirements. And under these, if you have a health condition or disability you are very likely to be deemed a cost to health or education services. And then you you'll get a letter basically telling you that you don't meet the acceptable standard of health and that there's a process for most people. There are there are limitations to this, which are really unjust, but most people are then able to apply for something called a MediCal waiver. The thing is that applying for a medical waiver is a usually a hideously long process, and it's no sure thing at all, that you will get a medical waiver. So one disabled person who I actually interviewed on the first episode of Disability Crosses Borders, Juliana Carvalho went through a really long battle with immigration over her ability to stay in the country and get visas and get residents. And she was very public about it and had made a petition to basically that New Zealand would follow what it signed up to in the UN Convention on the Rights of Persons with Disabilities around the right to liberty of movement and non discrimination and get rid of the acceptable standard of health requirements. So she'd made a petition around both kind of her individual case and that together and then from there, Giuliana and I and And, and some other friends and other people who had been impacted started forming like a community around this. So we formed a Facebook group and we try to sort of provide community and support. We're not immigration advisors or lawyers, but informal support to those facing the horrifically discriminatory and stressful impacts of those requirements. We work with MPs who support ending the policy at the moment the Green Party has been really, really supportive. So, Ricardo Menendez March who is a Green MP has been really good at raising these issues in parliament with us. So asking, asking questions within parliament, we've done further petitions, we have spoken to the media quite a bit. And we did a shadow report last year when New Zealand was having its review and to the UN Convention on the Rights of Persons with Disabilities. You know how well it's doing. So we wrote a report that fed into saying, actually, this is a really massive problem. And then we did get the Committee on the Rights of Persons with Disabilities to recommend that, that New Zealand ends the disability discrimination within the acceptable standard of health, which was a great outcome. But the government is still I believe in the process of figuring out what it will do about the recommendations. And given their past positions, There is a lot of attachment to the status quo. So our advocacy continues, you know, the the mindsets that disabled immigrants, immigrants with health conditions, also, immigrants with high BMI, which is particularly gross, are deemed basically unworthy are considered economic units that can just kind of be rejected. And we really find those narratives incredibly harmful, it's important to value everyone for who they are, we all have inherent worth. We all bring different aspects of, our contributions and skills and are part of our communities in diverse and wonderful ways. And our immigration policy needs to honor that. the campaign around that is called End ASH now. So ASH stands for acceptable standard of health. So if anyone wanted to follow us, we have a website is endashnow.org. Twitter is at EndASHNow. And Facebook, facebook.com/endashnow.

Qudsiya Naqui:

we can also include those resources in the show notes if folks are interested in learning more about the movement. So what's next for you, Aine? Are there projects that you're working on now that you're particularly excited about

Aine Kelly-Costello

I am working on another podcast series, this time with a podcast called Enabling Commons, which is run by the Disability Inclusive Climate Action Research Program, based out of McGill University in Canada. And I would again, encourage people to subscribe to that podcast, there's a first season which is up there already hosted by someone else, and it features interviews with disabled people who are working on climate action, climate justice, from all different perspectives. So scholars, activists, yeah, people sharing their own lived experience, big range. So I'm really looking forward to putting out the second season of that some of it may be out by the time that this podcast also comes out. I'm hoping to be starting a PhD through Otago University in the independent living areas looking at the living situations and the policies and mindsets that have allowed institutional thinking, and yeah, ways of regulating and upholding how disabled people live to continue in New Zealand, even after the formal end of institutionalization back in 2006. And, how is it that we can make a society where disabled people, especially people with learning disability, which is the terminology here for people with intellectual disability, can actually live with choices equal to everyone else, and with dignity, with choices about where they live, and who they live with, and what kind of support it is that they want to receive and who they receive it from? And you'd be able to just have choices about what their daily lives look like.

Qudsiya Naqui:

That's so exciting Aine, congratulations on both of those projects. And I again, look forward to reading your research and listening to the new podcast season. where can our listeners find you and learn more about your work.

Aine Kelly-Costello

On Twitter, I'm at AineKC95. So A I N E K C nine, five, yeah, always really happy to be in community and connected with people interested in similar things to me. Or yeah, just wanting to connect with other disabled people. So feel free to feel free to reach out. And yeah, thank you so much, Qudsiya, for the opportunity to be in conversation with you. And all the best with Down to the Struts, I look forward to hearing other episodes as well.

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Down to the Struts was produced by Ilana Nevins and me. Our social media manager is Avery Anapol. With special thanks to Claire Shanley for designing our logo, and to Eiffel Gangsta Beats for our theme music. Remember to subscribe, rate, and review the podcast on your favorite podcast platform, And follow us on Twitter and Instagram at Down to the Struts. You can also get the latest updates by joining our Facebook group, Down to the Struts Podcast, and by subscribing to our newsletter, Getting Down to It on SubStack. We also love hearing from you directly! You can always drop us a line at downtothestruts@gmail.com. All of these ways of connecting with us are linked directly from our website, downtothestruts.com. And of course, stay tuned for our next episode, so we can get back down to it!