Transcript, Episode 4 | Season 1: Reimagining a Good Life: Disability Justice, Peer Support, and Housing

Welcome to Reimagining Disabled Futures, a podcast from Disability Advocacy Women's Network Canada. I'm Neshwalena Khan. On this episode, you'll be hearing our conversation with Dr. Jihan Abbas, a researcher, educator, and social policy professional who's deeply engaged in the disability and equity movement.

But first, on this inaugural season, we'll be exploring what feminist recovery looks like for women and gender diverse people with disabilities in Canada. We developed this limited series podcast with an understanding that disability justice is intersectional, and that we all live and experience the world differently. This podcast is produced in the traditional territory of many nations, including the Mississaugas of the Credit, the Anishinaabe, the Chippewa, the Haudenosaunee, and the Wendat peoples, and in unceded Yogyakarta.

We're grateful to have the financial support of Women and Gender Equality Canada. You can check out the show notes for other resources related to each episode topic wherever you found this podcast. Thanks for joining us on this journey.

Now here's the show. Today, Erin and I are joined by Jihan Abbas, who is going to talk to us a bit about disability justice, what a feminist recovery actually looks like, and housing and some of the work she's done, and some of the things she's been seeing in the disability justice world. Thank you, Jihan, for joining us today.

I want to know if you could introduce yourself to the audience a bit. Yeah, wonderful. I have a PhD in sociology, and the area I look at, I look at disability studies, a number of different holistic areas.

I do some community research, and I'm currently an instructor at Toronto Metropolitan University in the disability studies program. I teach two classes there. One is about social movements and change, and the other one challenges philosophical and theoretical questions about what is needed for a good life.

Yeah, so I'm happy to be here today. Thank you, Jihan. A lot of this work on rooting resilience is vital to our own understandings while creating this podcast.

Could you share some of your main findings? Yeah, absolutely. That was a really interesting project, I think, because it was so centered on peer support. I think peer support lends itself incredibly well to a disability justice framework because it's grounded.

It's rooted in lived experience. It gets away from the professional lens. It's people sharing what works for them individually, which is often very different than what the system would tell you would work.

It acknowledges, for me, the systemic barriers and the injustice. That's where it lines up for me to a disability justice framework. It feels to me a little bit like mutual aid because it's building community.

How do we support each other through community? I think models like peer support are increasingly important as well because they validate the experiences that people have. A lot of times in the field of disability, we don't talk about dismantling the systemic barriers and we talk about sort of individual fixes. I think what happens is people face so many barriers that if you take that perspective from professionals or other things like individually, what do you need to do differently, you're not validating ableism or racism or poverty or all the other experiences people have that go into these things.

I think the importance for me in rooting resilience is it demonstrates the importance of models like peer support, the importance of returning to community and creating community and how that is one of the ways that we can support and sustain our work. Thank you so much. One other thing as well I was curious about, you mentioned one of the things you're doing in TMU for your courses is talking about what's needed for making a good life.

I'm curious to see what your findings are there and how that might relate to what we do here with livelihoods as well. It's interesting because you start to think about what is a good life. Of course, here it's shaped by colonialism and white supremacy and capitalism and neoliberalism.

We have these ideas of this is what you need to have a good life. Fundamentally, a lot of those things are ableist. They're racist.

They're anti-Indigenous. They're anti-queer. They don't really work for a lot of people.

In that course, we unpack what has shaped our understanding of a good life and why is that problematic? Who does it exclude? Then we start to look from the perspective of lived experience and intersectionality and cross-disability and what does a good life look like if you don't have those parameters, if you get to reimagine what a good life looks like? I think one of the main takeaways for me and for the students as well is this work of dismantling what we think a good life has to be and reimagining what that might look like. We get into issues like intimate citizenship, which policymakers are never going to touch on. Do you want love? Do you want companionship? Do you want sex? What do you need to have those things? What do you need to have those things if your life is completely controlled? If you are an adult with an intellectual disability in a group home run by an organization that happens to be religious, how is that going to shape how you love and make connections and sexuality and things like that? We start to unpack what are the supports that exist, what shaped them, who was excluded, and how can we rethink what these things look like? I think fundamentally, and for me, moving to that systemic piece, and that aligns with disability justice as well, is let's reimagine what this looks like without capitalism and all these other things because it can look this way.

Thank you. Capitalism is something that a lot of our participants across Canada identify aspects and components of what would be called capitalism or overtly named it, and those become barriers. Aspects of capitalism become barriers like egregious housing prices, inflation, the amount of profit made for medication or public transit, pieces like that.

I wanted to ask from your research or experience and things you've witnessed, barriers like housing, for example, it's a cost of inflation or just the way things are designed, like allegedly accessible housing or community housing or cooperative housing. How do you speak to housing and disability and what that looks like in Canada? Well, I think we have to shift to think of it more holistically, and we need to start to think about what is housing, what is a home? Because right now under sort of capitalism and neoliberalism, it's just a bed. So it might mean you're in a long-term care facility.

It might mean you're in a group home, not of your choosing or some other institutional setting. It might mean to find something that's affordable and accessible, you're moved outside of your community where your family, your friends, and your supports are. So I think we have to critically unpack, we have to move away from what does the system offer to what do people need?

Because your housing is going to determine the care you get if you need care support or care labour.

It's going to determine if you're not close to public transit, what does that mean? If you're not close to places, if you want to work where work is accessible. So for me, we have to start by kind of unpacking housing and asking, you know, do people have choice and control? And I would say right now people don't. People, because the system, and like you mentioned, it's so expensive.

We've had the financialization of housing. We don't have the social housing that we once had. We're moving further and further away from what I think was traditionally the welfare state where the government saw, okay, we invest in these things towards neoliberalism where it's, well, let's let the private market solution solve this.

And I think it's meant that we see more, say, younger disabled people in long-term care facilities. We see more people who I guess would fall under what we would consider the hidden homeless. So not unhoused, but staying with the family member or friend, like they don't have secure permanent housing of their choosing.

So we have to look at all of those things. I think we have to confront capitalism and neoliberalism because we know, you know, and there's been multiple reports, including from Canada Mortgage and Housing, that we are in an affordability crisis. And we're, of course, not going to solve that if we turn to the people who make their profit on housing and say, oh, please solve this for us.

And we know the numbers of housing we need, I think by 2030, and I think it's something like 3.2 million accessible and affordable units. And we're not seeing that. And everything that's coming down at various levels of government like municipal, provincial, and federal is all very neoliberal.

It's all very much tied into the private sector. And even the measures they're using, I think, I don't want to be wrong, but I think it's about 60% of the average person's income goes towards housing right now. And that's, you know, 60% of the average person.

So that's not if you are on disability benefits, if you're not working, if you have all these other things. So the measure, and I see it here, I'm based in Ottawa for affordable housing is so far beyond reach of somebody who might be on ODSP, that it doesn't even meet the needs. So it's really hard.

And I think just last week, the Prime Minister made a comment. And I think the comment was something along the lines of, and it was dealing with younger people who can't get into the housing market that I understand that housing is unaffordable. But you know, for the older generation, like this is their investment.

And it's like, well, wait a minute, let's unpack that. Like, why do we have an aging population depending on owning a private home to be able to retire, like that is a gap in government support. So I think to get back to my point, I'm not sure I'm articulating it well, but there's so much we have to unpack because we have, you know, we're being driven by the private sector and profit.

And we have this lack of imagination to see anything outside of that as possible right now, we can't even go back to imperfect systems we had before with social housing, because we've moved so far away, even from the government thinking it's their responsibility, like to build those homes that they did post war and other things. Thank you. And building on this, you mentioned reimagining what this could look like and practical steps for confronting this.

Do you have any ideas of what the average person could do or different organizations that we might make steps towards with addressing this housing? Yeah, I think like, one of the things that I think constrains us is we've got to move within this imperfect system. So previously, I had done some research, it was on housing trust. And it was the feasibility of housing trust in the Ottawa Carleton area.

And the idea was, you know, we've got an aging population who do a lot of them own their own homes. And is there potential that people could put those homes and trust for for other people, sons, daughters, and I think it's, it's not systemic change. It's something that you could certainly do within the current system to maybe alleviate some things.

But one of the things that was really discouraging about that particular piece of research, and we talked to people, like housing policy, we talked to different agencies, we looked at different sort of promising practices from, you know, other places, is that we have an incredibly hostile environment, specifically here to sort of having the imagination for those types of things. So So one of the things I think we talked to somebody who was talking about, you know, planning in a city like New York City, and I don't want to say that that's perfect at all. But you know, they have some things in place for green space and affordability that we don't have here.

So it got really hard. So they were saying, you know, these programs that may work elsewhere, if you have different municipal policy here, a private developer doesn't have to do those things. And if they don't have to do it, they're not going to do it because they're going to see a cost associated and we, you know, less and less, we see this, you know, almost bankrupting of our municipal budgets.

And we have absolutely no money for that. So you can't even have a municipality step in and say, well, I, you know, we'll cover this amount. So we can do this project.

So I think there are things that have worked elsewhere. But I would say we have such just a hostile environment right now. And then you look at if somebody is on benefits, there's, of course, a cap in terms of what quote, unquote, assets they can have.

So there, you know, there were parents who wanted to leave a home. And if they did that, their adult child would lose
all their their their benefits. So there's sort of all these things at work.

And I think it's why we have to take an incredibly holistic lens to understand this. Because even these fixes that we have that we think, okay, we've seen it work here, we'll bring it here, we may have a policy in place here that we just find at the various levels of government, like we are not going to get movement on and I think we're up against something pretty big with capitalism, because and we really saw this. And we see it with COVID is we've now normalized, prioritizing private profit over everything else.

We saw long term care facilities, you know, despite not taking the measures they should to to protect people from COVID. And we saw I think, like in in Canada to in Ontario, I think we saw some of the highest deaths in long term care facilities like the world over. And somehow we came out of that without stronger policies, those private organizations are making even more money.

And a lot of them are sort of big, like multinational, they their own by conglomerates and stuff like that. And we saw the weakening of legislation to protect people in long term care facilities. So it's really, like, it's really difficult.

And I don't want to say it's impossible, like there are things we can do. But I think that's why we need to pair the individual and the systemic because it feels like in this environment, for every win, there are multiple losses. And unfortunately, I think for the wins we have, it's oftentimes maybe the most privileged people within the community were able to access those things.

And kind of going back to how those intersections happened, we had a number of participants who spoke about their experiences of domestic violence and with housing in particular, and with disability really adding an additional layer to navigating the system and what they have access to. Could you speak a little bit to gender based violence and housing in the intersection with disability? Yeah, so we know that's a considerable consideration that doesn't always get taken up in housing discussions. But we know you are more prone to various forms of gender based violence or intimate partner violence if you don't have choice, like if you're sort of forced to live in a place because it's all that's available.

We also know that, you know, in situations where there's more stress, that might increase the incidence of abuse. So in other research Dawn's been involved in, you know, we had looked at abuse within sort of families, and how family caregivers, because a person depended on them for housing and other things, were able to sort of exploit that situation and vulnerabilize that person. We also knew during COVID, with sort of shelter in place and some of those policies, that increased violence as well, because people couldn't leave, people couldn't get away.

And I think in every piece of research I have done in my career, it doesn't matter what it's about, it could be about employment, education, abuse, intimate partner violence, gender based violence always comes up. Like we know that for disabled people, that the stats are astronomical in terms of, you know, and I think that's because of ableism and other things. But then you add in, if you don't have choice and control over where you live, those things, you are going to experience them more, because you're going to be made vulnerable through the system.

Thank you. That was like a very full answer, because I found also when we were talking to people that even though we kind of switched the questions to not overly ask about gender based violence, it just comes up, like it just emerges. And you're not directly even asking about it, but it's emerging in other questions about life and how choices are made and shaped and navigated.

So thank you. And we heard from the Sustainable Lively Groups Canada, about different assets people have in their lives to live well. And you kind of touched on it a little bit earlier.

But I wanted to know more about peer support, because I don't think people always people are either like big proponents of peer support, or they don't know a lot about what peer support looks like. It's not just like, it can be like just having a friend that you can go to, but it's more, it's more than that. So I wanted to talk to hear from you about your work and, and work you've seen and what peer support looks like.

And why is it so good for people to live well and have those relations? Yeah, I think there's a lot of different models of peer support. And like you said, there might be more informal models, and then there's more formal models. But sort of what I've seen through my research and experience, it's incredibly important, like that lived experience piece.

And I don't think people understand the power of, you know, sharing stories with each other, and those stories being relatable. And one thing I'm always reminded of, and they talk about it when they talk about sort of disability arts and culture, and disability culture is that for a lot of disabled people, even within their own immediate families, they're different from their family members. So they grow up with this difference constantly.

So what their siblings or parents might be sharing is not relatable to them, that's not what it looks like. So connecting with peers who have lived experience for a lot of disabled people, that might be the first time that you meet people who share a perspective, and you can start to talk about those things to unpack them to understand, oh, it's not just me. You know, I'm not wrong, because that happened to me, that wasn't my fault, like that's a common experience for other people.

So I think that's incredibly important. And in my research, I like to do focus groups, because I think they build in an informal layer of peer support, where you get those conversations going. And one of the things that I've loved seeing in that process is that oftentimes people will come to a realization in those group conversations.

I have had people realize they have been abused, and they didn't know it was abuse until they heard other peers talk about it. I have heard people sort of make these breakthroughs and understand the importance of connecting. I did one focus group, I did it at an independent living center.

And we had advertised it really, really widely. So we got a lot of people who had never been to an independent living center in their life. And one of the people came to one of those sessions.

At the end of the session, she shared, I didn't even know this existed. And even though we were talking about work, like how much it meant to her to hear other people validate, like, I wish I just had enough money to get fast food, like that would be a real treat for me. So little things like that.

And then years later, I think it was about three years later, because I followed this independent living center. I got one of their newsletters, and she had written a story in it. And she had written a story about her journey in the last three years finding other peers who were like her making these organic friendships with people who had lived experience and how it had really changed her life.

And I don't think we talk enough about how isolating it is to be disabled. And then you know, you may be facing also racism and trans antagonism, like all of these other things like anti indigenous sentiment. And then you're sort of adding all that on and then you connect with people who can share that with you and can share their experience.

And it's it's validating. And I think as well within peer support, and self advocates, people find a way to create community and move through the system to keep each other safe. Because the system itself isn't always safe.

Like we make assumptions that if you access services or supports, your life is going to be better. And that's not always the case. So even people being able to share, you know, my caseworker did this to me.

And then other people saying, yeah, my caseworker did that to me too. And I lost funding. And then you can have these open conversations about the harm that we've built into these systems.

And I think that's really important for people because the tendency is to blame the individual and not interrogate the system. So even that space for people to know it's not me and I didn't do anything wrong. And this is unjust, I think can be really, really powerful.

Thank you so much. We've also run focus groups and we've seen the way conversation of sharing of resources or just validation is so affirming for people. And another piece we want to ask you about is this project is a project about a feminist recovery.

And a feminist recovery for us includes a disability justice lens. And also the idea of like a post COVID world when for disabled folks, that's very untrue. So I wanted to get your thoughts on what it means to have a feminist recovery with a disability justice lens.

And that's a question we've also bring to our participants. Yeah, I think I mean, I guess I would say, first of all, that COVID isn't over. And this sort of ties back to neoliberalism and capitalism, like we're, it's over, because we've stopped testing and acknowledging it.

But people are still getting sick with COVID. And there's sort of, for me, there's two things happening. One, it's a mass disabling event, which we're not looking at enough.

So we are creating an entire new cohort of newly disabled people. We also know that if you are already disabled, and you contract COVID, you are likely you're probably more likely to have long COVID or other complications, some forms of chronic illness and other things we know now, it can exacerbate those things. So we're learning all of this stuff as we go.

And for me, it all points to, you know, COVID being a pressing disability justice issue for us, both in terms of it being mass disabling, but also what it's doing to people who are already disabled. And we spoke, I think, previously about the isolation. So now that we've lifted, we're not testing, we're not masking, we're not, we're not even asking people to stay home if they're sick.

Like, what does that mean? If you have a compromised immune system, it means even more isolation for people who are already isolated. And then I also see this, and it was always there, but in terms of the way eugenics operates, and the way it's taking its hold, like we've gone from, we're all in this together to, you know, we'll just stay home, don't inconvenience us. And it's really, I think, a sad moment for a lot of disabled people, because it has been isolating.

It's validated the systemic ableism. We saw institutions move very quickly to move things online and make them COVID safe. And we know they can do what they have the capacity, but they've just decided not to anymore.

We see this with the return to work. I've done a little bit of research around that and what that means for disabled employees, going back into like this push, get everybody back into the offices, which again, neoliberalism, it's about sort of corporate real estate, and these buildings can't sit empty. But what does that mean? If you, you know, are a cancer survivor? What does that mean? If you are going through treatment? What does that mean? If you have chronic illness or long COVID or a compromised immune system? So those things, I think they're really important questions.

And I'm sort of learning more and more about that. I was diagnosed with long COVID, and I'm going through the process now. And as I learn more, it's like shocking, but not shocking how we've ignored it, because that's what we're like, we ignore the climate crisis, we ignore everything, right, genocides.

But you know, the more research that comes out, the more it validates that this isn't just going to go away. We can't just say it's going to go away. And what's like, what is that going to mean in terms of a feminist recovery? Because we already knew a lot of people probably had more caregiving obligations, maybe they were caring for older parents, maybe they were caring for children, maybe they were just taking on more labor in the workplace, because we know that women generally do get more of that more of that unpaid administrative labor.

But what does that mean now that we have to balance keeping ourselves safe, maybe newly navigating a disability without supports, because people with long COVID aren't getting any supports. So what does that mean if you used to work full time, and you can only work part time now, you were already pre COVID, not making, you know, a livable wage, you were carrying too much, you were burnt out, and now we're going to add this. And I think I saw research yesterday that was talking about the number of absences in schools and how it's skyrocketing, you know, and I'm thinking of all the informal caregivers that's falling to like, what does that mean if your child can't go to school, and you do shift work.

So I think in terms of this idea of a feminist recovery, like we needed these are things that we all needed pre COVID. But now that we're living in COVID, and I imagine it will be exacerbated by like the climate crisis and other things. What does that mean in terms of, of disabled women and what the world looks like for them.

And like you said, like little things like public transit, like, if you rely on public transit, and it's no longer safe. And you know, we've got this general attitude now of eugenics, like I think people are probably worse at covering their mouth now than they were before COVID. Like because there's this, it doesn't matter.

It's just COVID. And that's really unsafe for a lot of people. And we haven't spent enough time talking about how incredibly hostile the world is towards disabled people, disabled women right now.

Thank you. And I'm just curious to know if there's any books or anything you've been listening or reading or watching lately that you found really insightful and interesting that you would like to share. You know, I think right now in this moment, though, like the lived experience pieces is really important.

I've been sort of the places I used to traditionally go, maybe the academic sources and stuff, I've been increasingly disappointed with how quickly they move along with neoliberalism. So I absolutely love the disability visibility project, the articles they post, Alice Wong's work, the books, disability and intimacy and things like that. Like I find through a disability justice lens and through community, I think we're getting some of our most powerful resources because they're not speaking from a place of upholding the current system or excusing it.

They're challenging and interrogating it. And I'm finding more and more informally, and maybe this links back to the peer support piece, like those are the spaces where the system is being interrogated the most. Thank you so much.

And I'm wondering, where can people find you online if they want to engage with your work or see what you're up to and academic work you're doing and other research? I do have a, like, I think if you search sort of my name and blogger, I know blogging people don't use it anymore. But I, you can kind of find me there. You can find me through the TMU through their disability studies website.

Yeah, so I guess I'm around, I'm in some different places, because I wear a few hats. But yeah, certainly, if you search for me online, you should find a way to connect to me through the university or I try to if I'm involved in things, post them on the blog, just so people people know. Amazing.

Thank you so much. Thank you for listening to Reimagining Disabled Futures, a new podcast from Disabled Women's Network of Canada. We hope you enjoy this episode.

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Stay tuned for another episode of Reimagining Disabled Futures next month. Until then, I'm Neshalina Khan, Senior Research Associate at DAWN Canada. Thanks for listening.