

Disability Visibility Podcast

Episode 24: Disability Justice and Community Organizing

Guest: Sarah Jama

Host: Alice Wong

Transcript by [Sarah Blahovec](#)

For more information: <https://disabilityvisibilityproject.com/podcast/>

Introduction

[radio static, voices singing with hip-hop beat]

LATEEF: This is the Disability Visibility Podcast with your host, Alice Wong.

ALICE: Hello, hello! My name is Alice Wong, and I'm the host of the Disability Visibility Podcast, conversations on disability politics, culture, and media. Today's episode is about disability justice and community organizing with my guest Sarah Jama. Sarah is the founder of the newly formed Disability Justice Network of Ontario (DJNO) and Co-Chair of the federal New Democratic Party (NDP) Persons Living with Disabilities Committee. You'll hear how Sarah became an activist and how disability justice informs her work. Sarah will also talk about some of the major issues facing the disability community in Canada. Please note there will be discussions of eugenics, sexual assault, violence, and institutionalization. Are you ready? Away we goooooo!

[electronic beeping, computerized voice counting down to 5, 4, 3, 2, 1]

ALICE: Thanks. So Sarah, welcome to the podcast today.

SARAH: Thank you. I'm excited to be here.

ALICE: So Sarah, tell me a little bit about yourself, if you want, a little bit about your background, and whatever else you wanna share.

SARAH: Okay, so, I'm from Hamilton, Ontario, sometimes called the armpit of Ontario, but it's not true. We actually have 72 waterfalls. I think the city's very underrated. I do a lot of disability justice activism and anti-racism activism. I started my organizing in the student movement before moving out into the city. I'm 23, I'm still afraid of the dark, I'm just listing off random facts. I kinda depend on what you want to know. I work for the Hamilton Center for Civic Inclusion and for Councilor Matthew Green, who's the first Black city councilor in Hamilton. So he's helpful with intersectional learning about racial justice work within systems and outside of them.

Disability community and affordable, accessible housing in Hamilton, Toronto

ALICE: And tell me a little bit about Hamilton, because I think when we think about Ontario, we think about Toronto.

SARAH: (laughs) Yeah. True.

ALICE: But can you tell me a little bit about where Hamilton is in relation to Toronto, and tell me a little bit more about the disability community in Hamilton.

SARAH: Mm-hmm. So Hamilton is around 40 minutes away from Toronto. It has the largest population of people with disabilities in the entire province. We have a fully accessible transit system that's free for people with disabilities, so I think that's part of why we have such a large population of people with disabilities. We also have a pretty adequate mental health sort of community there, in terms of service providers. In terms of organizing, there's not a lot of community being built between disability justice organizers, though that's starting to be built up. There are a lot of services in Hamilton for people with disabilities, but again you see the intersections of poverty, hate crimes, and disability. We have some of the largest poverty rates in Ontario in Hamilton, and our city has the second highest hate crime rates, which seeps into rates of violence against people with disabilities. Human trafficking against people with intellectual disabilities is currently being investigated in our city as well. So though we have like a lot of positives, there's a lot of work that needs to be done in our city, too, so it just depends on how you look at it. And in terms of Toronto versus Hamilton, our city is currently being gentrified by people who are moving out of Toronto who can't afford to live in Toronto anymore so people are coming in and what's happening is you're seeing a lot of people who can't afford to live anywhere else because they're on social assistance and other things or maybe can't work, are being pushed out because of the rent prices moving up since people are moving from Toronto. Yeah, these are just some of the issues I can think of on the top of my head.

ALICE: So with so many people with disabilities in Hamilton, is there any issue with housing? Because I know that in most cities and towns, there are people with disabilities who really struggle with finding affordable and accessible housing, so with such a large population in Hamilton, is that an issue as well?

SARAH: Yeah, social housing is hard to find when it comes to accessible places. I'm lucky because the place I live in currently is a rent to geared income, which is like it's not market rent, it's based on the income that I'm making, and it's actually the first accessible place that I've ever lived in. It's a building with like buttons and bars in the bathroom and things, but throughout childhood, I grew up in community housing in Toronto and it was never accessible, the bathroom was always on the second floor, and so that's something that you don't really even think about accessible, affordable housing or social community housing in Hamilton. Yeah, it's not easy to come by.

[techno instrumental music]

Community Organizing

ALICE: And you're a community organizer. How did you fall into that, and like why do you love being a community organizer if I may ask?

SARAH: Okay, so how I kinda got started was always told this story about me being in grade twelve. I met a kid in grade nine, his name was George, and he was in a wheelchair and he told me he wanted to be an actor and he applied to attend this public, or he wanted to attend this public school called the Etobicoke School of the Arts, but he didn't apply because they didn't have an elevator and when I heard that story, it was like the first time I had ever like thought of oppression against people with disabilities in a sort of systemic way. Up until then, I thought yeah, I had barriers of my own, teachers called me a liability, one teacher called me a fire hazard, one teacher didn't let me go on a field trip. I had my own barriers, but at the same time it was always individualized. People with disabilities often think that our struggles are just our struggles and that is just something that we have to deal with because of the cards that we were dealt, right? But hearing George's story was the first time I ever thought wow, that's actually really shitty that he's going through this so I took a bus downtown to delegate in front of the

Special Education Advisory Committee in Toronto at the time, and I remembered the chair of this committee, I'll still remember his name, I'll tell it today, his name is Chris Bolton, he laughed in my face and he said "Who do you think you are to come and delegate here, try to delegate. You don't have speaking rights. You're not anybody on this board. If the student wanted to attend the school, he should've applied. How do I know that people with disabilities even want to act?" He started saying all these things and was laughing at me and I think that was the first time I ever really learned to not internalize the oppressions I was facing and really see it in the structural way where it was people in positions of power who had the ability to make decisions choosing not to because they didn't think that the idea of somebody else's quality of life being hindered by barriers to access was a problem. And so from that point on, I graduated high school, got accepted to McMaster University, studied school there and my math class was inaccessible. So at that point I got really frustrated and I decided okay, I'm gonna just run for Student Council. I had never done anything leadership-oriented in my entire life. But I was angry because it took weeks for my classroom issue to be dealt with because the professor didn't want to change rooms. So I decided okay, if I'm not gonna have any student representatives who are gonna try to help, I'll run myself and I campaigned on a platform of accessibility and I got elected by the skin of my teeth by my faculty, and within a year I was able to create the first-ever accessibility policy of the Student Union, and within two years I was able to push for the creation of a service on campus called Access for students with disabilities, by students with disabilities that was meant to teach advocacy skills. Not just like the standard accessibility centers run by people with disabilities that are supposed to help you access services, this was supposed to help you figure out okay, what do we do when the services that are supposed to provide for us fail. Where do we go. What can we actually organize around or what sort of power do we have as a community of people with disabilities here? And so I think that's how I started organizing and learning about organizing with the disability justice community, and then I became the Ontario Director for the National Educational Association of Disabled Students and then started to expand my work around intersectionality and do a lot of work around racism and sexual assault and various issues relating to other communities that also intersect with disability justice.

ALICE: And what would you say are some of the lessons that you've learned in community organizing that you wanna share in terms of what works or what are some of the strengths and you know, what are some of the most important things when organizing around a community and about an issue?

SARAH: I think one thing that I learned was the importance of coalition building, not just sticking to your one issue or your one cause because you care about it, but the idea that the indigenous community and their struggles, and the struggle for indigenous sovereignty can intersect with disability justice, can intersect with issues of anti-Black racism and police brutality, or the fact that a lot of the victims of police brutality are people who are racialized, are people with mental health concerns and disabilities. A lot of indigenous communities who do face struggles around disability and poverty also need that sort of advocacy as well. So coalition building, the idea that we have strength in numbers and that we should be coming together to fight what often is a common enemy of a system that exists that was created around us and for us instead of like with us. And I think that organizing in silos is exactly what these institutions want us to do, right? Not figuring out a way to organize together but apart from each other, so that's one lesson. Another lesson is the lesson of tactics. So one quote I really like is "you can't take down a building without understanding a blueprint of the building first" because if you try to do that without understanding the blueprint, it can fall on top of you. And so the idea of looking at organizing like building a skill set, understanding and studying when it's important to use a protest as a method, when it's important to use policy work as a method, when it's important to

use your powers in media or online activism, and understanding that all these ways of working and organizing are different and they have different pros and cons that can be used in various contexts and not just sticking to one singular method, but understanding how to organize as a science, right? And building your toolkit that way I think is very, very important.

[techno instrumental music]

Disability justice and finding leadership from disabled women of color

ALICE: I've noticed a lot of your tweets, you tweet a lot about disability justice and I learned about disability justice mainly through Sins Invalid and the writings of Mia Mingus, but I first really started getting an introduction to what that concept is. Say something I guess about how you understand disability justice and what you, how would you describe it to somebody who really has never heard of that concept.

SARAH: Mm-hmm that's cool. I learned about it through reading some of Mia Mingus's stuff too because she came to campus and I had no idea who she was but everybody was like you need to meet this person.

ALICE: I am a huge fan of Mia Mingus!

SARAH: Me too! And we got to eat together, it was really cool. I think what I like about the disability justice framework is it frames disability rights in terms of being intersectional. So talking about things like community-oriented justice and reconciliation but also like talking about issues around what I was talking about with regard to race and disability or the fact that there's such a huge proportion of people with disabilities facing sexual assault. Looking at the right to exist from a justice framework instead of just like inequality framework and that's it, because oftentimes the disability narrative is following a white, cisgender, man, and that doesn't really apply to everyone, right? That image doesn't speak to equality in my mind and so yeah, I think that's why the disability justice framework resonates with me as well. It's more about building community power and community as opposed to just fighting for the rights of a few kinds of disabled people, right? And I think it balances out the fact that even within own community, certain disabled people are given more speaking rights than others, so you very rarely see people fighting for equal representation of people with intellectual disabilities in media or academia, but you'll see often a certain kind of white disabled person in a physical wheelchair fighting for these things, right?

ALICE: I mean I think in the United States, we've had similar issues where the pervasive, the leadership of most quote unquote disability rights, you know, established organizations are really not by women, people of color, much less women of color. So what does it seem like in Canada? Even though I know it's a huge country, and it's hard to generalize, but would you say that as a disabled woman of color that Canada is pretty darn white?

SARAH: Yeah, Canada is also very white in leadership. I think even in the disability justice framework or disability movement, whatever you would call it, is still mainly made up of white individuals, though there are a lot more women involved, it's still majority not people of color, Black individuals. I think, I was making this joke with a friend the other day that like I didn't really know that there were other Black people with disabilities for a long time and it's not that it didn't exist, but they weren't accessing the same spaces I was, right, for various systemic reasons and barriers, but I think yeah, Canada's also very white in the disability community in who has access to power and speaking rights and it's often still one kind of disability, though mental health and mental illness is starting to take up a large space in community, like regaining that

space in the disability justice framework. Though I think there's a lack of understanding in our communities today, especially coming from the outside of the disability community, of the difference between a mental illness and mental health, the fact that we all have mental health, but then that doesn't mean that everybody's technically disabled by it, and so I think a lot of people are now occupying spaces that they wouldn't have occupied before and gaining access to the rhetoric of disability justice without having lived it. But these are all contentious so we could have a longer conversation about it.

ALICE: It might be another episode or two.

SARAH: Yeah.

Disability justice conference in Hamilton

ALICE: So you just, we're talking today in early December 2017. Just a few days ago, you were the lead organizer of a really important disability justice conference in Hamilton. So tell me a little bit about the theme and why you organized this conference, and if you could also tell me the title of the conference as well and the mission of it.

SARAH: Cool. So on December first, there was a disability justice conference called Momentum, and my friends and I decided to run it because we realized not a lot was happening in Hamilton for International Day of Persons with Disabilities despite the fact that we have the largest population of people with disabilities in the entire province. So we came together and talked about what we could do and we decided to run an unconference instead of a conference, so not the sort of suit and tie event where people show up to network but we actually wanted to skillshare and build a community, And what we did is we put a call out for proposals for workshops and accepted anything anybody submitted and also covered their transportation fees. So we had people coming from Ottawa to present, Montreal, it was really, really interesting. And some of the topics were around the history of mad justice, we had people talking about struggles in Huronia. So there is an institution set up there for people with disabilities with mental health concerns and the community there was fighting to stop a pipeline that was going to go through a mass graveyard that where people were numbered off and buried, if you had a disability, and they talked a little bit about that history in Canada that normally doesn't get talked about. Another presenter talked about the rates of sexual violence against people with disabilities in Canada because 83% of women with disabilities are likely to be sexually assaulted at least once in our country, so talking about that. And also, they talked about sexual health curriculum. We had a bunch of intersecting topics which is what we wanted to cover. So not taking like a one lens approach but talking about various modern issues that we're facing in a way that includes everybody in the community. And so what happened was you saw organically people from across the city but also various provinces coming together to talk about work that they've done and ways to help support each other in the future. So the last part of the conference was a smaller community forum where people could share ideas about what to do next and actually the Laidlaw Foundation, which is an organization in Hamilton, announced at our event that they created a pop-up grant that's going to close on January 15th for organizers to apply for \$500 just to run an event or something and it's possible for that to be scaled up if people use up these funds, and these funds are specifically to go toward disability justice activists and organizers.

[techno instrumental music]

Access, inclusion, laws, and healthcare in Canada for people with disabilities

ALICE: You know a lot of my friends, you know since we have our current president, there's been a lot of talk from people like, "Oh, the disabled Canadians have it so good!" And there's a lot of disabled Canadians are like "No we don't!" And what do you think are some of the biggest misconceptions that people outside of Canada who are disabled have of Canada in terms of how accepting or accessible, whatever you wanna say, inclusive they are of their people with disabilities?

SARAH: I don't think people in America know the history of eugenics in Canada against people with disabilities, the fact that a large population of people with disabilities in Canada were also forcibly, sorry, institutionalized, so we had the Orillia Asylum of Idiots which took thousands of people and children with disabilities, cognitive, developmental, but also even if it was mental illness and basically locked them away in these institutions. There was a lot of abuse, emotionally, sexually, physically. We even had like the Ross Macdonald School of the Blind in Ontario which was recently, recently the school lost a settlement and had to pay \$8 million toward fees for students who were also physically, emotionally, and sexually abused up until early 2000s so it was very recent. Our history of abuse is very recent and that \$8 million settlement wasn't enough for all the people who had already passed away, it was only enough to cover the people who were still survivors. Other than institutions, I think people also don't realize the amount of hate crimes that people with disabilities face in Canada, the fact that nothing is secure. 75% of women with postsecondary degrees if you're disabled are not employed, and that's with a degree, after all the hurdles that you have to face.

ALICE: And people also think the healthcare is fantastic.

SARAH: That's true too.

ALICE: Well I think it is better in some ways but it's not perfect.

SARAH: In other ways it's not, like a lot of the funding goes toward children which is good, children are cute, right? Who doesn't wanna make sure that children with disabilities are not living life to the fullest, but as soon as you turn 17, a lot of those, that access to support is cut. So you'll have a hard time finding surgeons to specialize with your disability. I actually said no to a surgery when I was 17 'cause I wanted to graduate high school on time that I needed, and I still haven't gotten it and I'm 23 because I just cannot find a surgeon who knows what the hell they're doing, who specializes, right? It's also very hard to find access to other resources like sexual health things or education and things like that. If you're disabled, a lot of the funding gets cut, you don't have access to physio and things like that so it's nice for a time, but it's also not. I think like in Canada, there's also the known fact that Down syndrome for example, more funding goes toward the prenatal screening of Down syndrome than there is toward the quality of life of children with Down syndrome, which means you have like doctors pushing people into aborting as soon as they realize it's a child with Down syndrome or another form of disability. Whether you're pro choice or anti choice, it's problematic because it's perpetuating a hidden history that no one wants to talk about of eugenics, saying that certain people don't have the right to exist. I think, yeah, there's a lot going on and I wouldn't go base opinions off of our healthcare system...

ALICE: And, you know even though in the United States, we all like to kind of complain and talk about the weaknesses and limitations of the Americans with Disabilities Act, but that is a Federal law and that's something that doesn't exist as a counterpart in Canada but there is an

AODA. For people who don't know what AODA stands for, can you tell us what it is and what you think of it?

SARAH: Yeah, so right now there are three provinces in Canada that have provincial legislation, though we don't have a federal act. Ontario's legislation is called the Accessibility for Ontarians with Disabilities Act, and basically the goal of it is to make sure that society's seeing people with disabilities as viable consumers, so making sure that we have access to stores, and the ability to move on our purchasing power, right, because the argument is that it's better for the economy.

ALICE: Capitalism!

SARAH: Yeah. Which I was gonna say.

ALICE: Yay capitalism! (laughs)

SARAH: Yeah, it grinds my gears because it basically is saying that to me, it says that if you can't execute purchasing power, if you're disabled to the extent where you can't work or go to stores.

ALICE: You have no worth.

SARAH: Yeah, you're worthless. I don't think our focus as a society should be on like how much people with disabilities are able to spend or produce. I think we should be talking about real issues like violence, like parenting, like healthcare, like sexual assault, and not just creating legislation around our ability to enter stores, though it's important, it shouldn't be the end-all be-all of some sort of legislation and I think my main problem with it is it proclaims that Ontario's gonna be accessible by 2025 but the Liberal government, as a Liberal government does, made all these promises without putting funding toward making Ontario accessible. So as though it's just going to appear accessible.

ALICE: But it better be by that date, right?

SARAH: (laughs) yeah. So I think, I think that I'm excited to see what 2025 will look like because when we wake up that morning and not everything is accessible I think it's gonna light a fire under everybody's butts to start organizing.

ALICE: And you'll already be organizing!

SARAH: Yep (laughs) yep.

What do you want to see for the future in Hamilton and across Canada?

ALICE: So I guess the last question I like to ask is what do you want to see for the future in terms of your local community in Hamilton but just also you know in your province and for Canada in terms of people with disabilities?

SARAH: I wanna see people with disabilities being taken seriously as a group of people that are civically engaged, that's gonna get up and vote or rock some votes if things don't go our way. I wanna see people delegating in June when the Federal Accessibility Act is finally released and it's not up to par, I wanna see people going to Parliament and saying hey, this was not the way we wanted it to be, and also they're two years late. Yeah, I want to see people practicing running for office, building power and community power and local power, but also institutional

power in a way that doesn't currently exist and I wanna see like hopefully more youth involvement in the disability justice movement because a lot of the people who were responsible for moving it along and sort of creating it in Canada are still alive, which says how new the movement is and I think there's a lot of room to start mentoring people that are younger in the movement, teaching them about things that have been done in the past and working together to build a future in a way that I don't think is currently being done.

Wrap-up

ALICE: Well thank you so much for being with me today.

SARAH: Thank you!

ALICE: For anybody who wants to learn more about you, how can they find out more about you?

SARAH: Okay. You can find me on twitter @SarahJama_ and you can find me on Facebook at the same name, Sarah Jama.

ALICE: Thank you so much, Sarah.

SARAH: Thank you for having me.

["Dance Off" hip hop song]

This podcast is a production of the Disability Visibility Project, an online community dedicated to creating, sharing, and amplifying disability media and culture.

All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast.

You can also find more information about Sarah on our website.

The audio producer for this episode is me, Alice Wong. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

If you liked this episode, subscribe to the Disability Visibility Podcast on iTunes and if you can, support the work of creating disabled media at our Patreon page at Patreon.com/DVP. That's p-a-t-r-e-o-n dot com, slash DVP.

Well, thanks for listening, and see you on the Internets! Byyyeoooo!

["Dance Off" hip hop song]