

[Transcript of Mind the Disruption podcast Season 2, Episode 3 “Disrupting for Disability Without Poverty”]

[Collage of Quotes from Season 1 Guests]

Jennifer Scott: I think if I go to work today, I'll die.

Paul Taylor: There's been a series of injustices that have allowed some people to have food and allowed other people to struggle for access to food.

Samiya Abdi: People are stuck in this powerlessness paradigm.

Harlan Pruden: Always ask yourself why?

Sume Ndumbe-Eyoh: There were times when I would think maybe I'm going to get fired. Right.

Sarom Rho: It's the moment of refusal.

Heather Lokko: If we're not intentional about creating some discomfort, things won't change, it will stay status quo and that's not okay.

[Season 2 Introduction]

Bernice Yanful (narration): Hi. Welcome to the second season of Mind the Disruption. I'm Bernice Yanful. I'm a knowledge translation specialist at the National Collaborating Centre for Determinants of Health, an organization that moves knowledge into action, with the goal of better health for everyone. I've also worked as a public health nurse in an Ontario public health unit, and I recently completed my doctoral studies at the University of Toronto.

This season, we're talking about social movements for social justice; groups of people working together to build collective power for change and health for all.

We'll dive into a range of topics with people from across Canada. We'll talk about the environment, immigration status, food, birth, disability and poverty. We'll talk about racism, ableism, and colonialism. And we'll talk about solutions, and the power of collective action.

In each episode, you'll hear from a disruptor – someone who refuses to accept things as they are. They see something that is unfair, or unjust, and they take bold, courageous action, often in the face of active resistance. They work with others to disrupt the status quo because they

have a deep shared conviction that a better world is possible. You'll also hear from a second guest, someone who will reflect on how public health can do things differently and better. At the end of each episode, we'll name some concrete actions that public health can take to work, with others, in service of social movements for social justice.

Rebecca Cheff (narration): This podcast is produced by the National Collaborating Centre for Determinants of Health. We support the Canadian public health community to address the structural and social determinants of health and to advance health equity. We are one of six National Collaborating Centres for Public Health working across Canada. We're funded by the Public Health Agency of Canada. We're hosted by St Francis Xavier University, which is located on Mi'kma'ki, the ancestral and unceded territory of the Mi'kmaq People. This podcast is part of our organization's commitment to confront intersecting systems of oppression and reveal concrete opportunities to disrupt racism and colonialism. The views expressed on this podcast do not necessarily represent the views of our funder or our host agency.

[Episode Introduction]

Rabia Khedr: As a disabled person, I cannot watch my fellow disabled person beg for somebody to buy them food. There's no place for this kind of poverty in my Canada.

Bernice (narration): That was Rabia Khedr. Today I'm speaking with her about Disability Without Poverty, a vibrant movement led by persons with disabilities to end disability poverty in Canada. Let's start by learning more about the movement.

Rabia: Lifting disabled people out of poverty has to happen because disability poverty is a national emergency requiring an intentional and immediate response to get money to the people with disabilities who need it most fast so that it doesn't cost any more lives.

Bernice (narration): Poverty is a significant and well-documented social determinant of health that disproportionately impacts people with disabilities in Canada. Elisa, a member of Disability Without Poverty, describes the injustice of this reality.

Elisa: I'm just going to put it like this: it's not fair. It's not fair that we must fight to have enough money so that if we lived on our own, I would not have to choose between food and university.

Bernice (narration): Supporters like Jen from the Women's Legal Education and Action Fund agree.

Jen Gammad: Disability poverty is a vicious structural cycle that contributes to their substantive inequality. Without financial security, disabled women and trans people are deprived of and further excluded from a range of cultural, economic, educational, political and social activities and exposed to more violence. Poverty takes away choice, and it is policy failures that create and exacerbate such conditions.

Bernice (narration): After years of tireless advocacy by people in the disability community and their supporters to address this injustice, the federal government promised to create a new monthly Canada Disability Benefit in 2020. Minister Qualtrough, who has a disability herself, talks about the significance of this announcement.

Minister Carla Qualtrough: In the recent Speech from the Throne, our government committed to a disability inclusion plan. This will include a Canada disability benefit.

The disability inclusion plan is an important next step in advancing the rights and inclusion of person with disabilities.

Bernice (narration): Disability Without Poverty was formed to make sure the government delivers on this promise quickly and with meaningful involvement of people with disabilities. Advocates call this “nothing about us without us.”

Realizing the benefit is about more than money. It's about addressing ableism: the systemic belief that not having a disability is normal and best.

This belief results in discrimination and barriers for people with disabilities that contribute to health inequities.

Ableism is at the root of why disability poverty persists in Canada.

As a poverty reduction strategy, the Canada Disability Benefit has the potential to deliver dignity, autonomy, inclusivity and independence to disabled people living in poverty.

Here is Disability Without Poverty co-chair Michelle Hewitt speaking about this vision for change.

Michelle Hewitt: We are united in fact that there needs to be an end to disability poverty and the time is now.

[Interview with Rabia Khedr]

Bernice (narration): Since 2021, our main guest Rabia has been the incredible National Director of this movement. She brings to this work more than 30 years of experience as a dedicated equity and justice activist and community organizer. She has advanced disability justice at the local, provincial and national levels. And she draws on her lived experience as a Muslim blind woman and as an advocate for siblings with intellectual disabilities.

Later, I'll speak with my colleague Jonathan Heller about how public health can build community power and support movements like Disability Without Poverty.

Bernice: So Rabia, you are the National Director for Disability Without Poverty. Tell me about Disability Without Poverty.

Rabia: Well Disability Without Poverty basically came to being as a result of the promise in the Throne Speech of September 2020 by Prime Minister Trudeau. He announced his government's commitment to the Canada Disability Benefit. And people who had been working in disability space across the country at the grassroots level particularly disability community and caregivers out in British Columbia and elsewhere said, "Wow, okay, this is a huge opportunity." This government is committing to a Canada Disability Benefit that will lift people with disabilities out of poverty. We have the commitment from the top. We cannot count on government alone, that means parliamentarians and the public service, to bring this to fruition the way we need it to be, and therefore, we need to begin building a movement to end disability poverty.

So we began a journey, a number of people. I got invited to host a series of webinars by Al Etmanski, who was involved in bringing a number of people together and felt that it was time for new leadership, new lived experience coming forward nationally in the disability space advocating.

So I hosted a series of webinars and then in 2021, we ended up more formally organizing Disability Without Poverty and I ended up becoming its national director.

Bernice: That's incredible. So take me back to before you became the National Director. So you mentioned that someone yielded their leadership roles that you could take over or fill that space. Can you tell me a little bit about how that came to be?

Rabia: Well, historically and to be honest with you this is why I moved away from the national disability space a couple of decades back there wasn't a lot of diversity when it comes to people talking about disability issues nationally. And this one individual who had done a lot of work advancing financial security and rights alongside others, leveraging his white privilege over the years, felt that it was time to make space for others.

And as I've always said, if people in positions of power, if in particular white men and white women in positions of power don't make space for people like me, I can knock on the glass ceiling as much as I want and I will not break through. So it's really about sharing power and creating space and opportunity for racialized people with disabilities to be engaged at a level that they are more than qualified for.

Bernice: Absolutely.

Rabia: And that's one of the reasons, one of my other involvements through my other 365 days a year commitment to spiritually and culturally relevant services through DEEN Support Services and the establishment of Race and Disability Canada as an initiative, bringing together a number of grassroots disability groups of people with disabilities who are racialized are working to create tools and resources and opportunities to bring about that kind of structural and systemic change in the national disability landscape.

Bernice: Yeah, absolutely. I'm wondering if you can speak to a little bit about why the benefit is so important and how you're hoping it will change the lives of people with disabilities.

Rabia: Well, we're learning today out of the most recent stats, hot off the press a couple of weeks ago, that 27 percent of Canadians live with a disability. That's about 8 million people. Previously, we've pegged disability poverty at 23 percent of that population. So 1.4 million people.

I think that's definitely gone up with that 5 percent increase in the occurrence of disability in this country. In terms of general population, we went from 22 percent to 27 percent. We know that over 41 percent of people living in poverty are disabled. That's a disproportionate amount.

We know that out of people who face food insecurity, 50 percent are disabled people. So about 50 percent or more of disabled people living in poverty are depending on food banks today.

And we see more and more that disabled people are going online a few days into receiving their benefits from provincial sources or other sources of a fixed income saying, "Hey, I've paid my rent and my bills and I have no money to eat. I have no money for other necessities. Please help me." So they're raising their own funds using crowdsourcing. And yet, we're also seeing disabled people on the street asking for money.

Rabia: After I came back from Ottawa in 2022, having some conversations and meeting people and impressing upon them the importance of the Canada Disability Benefit becoming law, I went shopping.

I needed to replenish my produce and necessities and I went to a major store to shop with a friend of mine and we came out of the car and this gentleman approached us and he said, "I'm waiting for my social worker. She's not here yet. I'm really hungry. I need food, but I can't go into the store because it's a membership-based model. I have a transit ticket I can give you. Can you buy me the chicken wings on special today? And a drink?"

And I said, "okay."

I checked with my friend because obviously I couldn't see him and I said, "Is he legit?"

She goes, "he's in a wheelchair. He definitely has a disability."

And we said, "Okay, we'll get you food."

We went in there. The store was very busy. We waited like a half hour. We picked up some fries. We made it a combo. And we walked out without having shopped yet, saying, "I wonder if he's still there in the parking lot waiting for us. He probably gave up on us."

And I cracked a joke with my friend saying, "Darn, I can't have the chicken wings because they're not halal, they're all yours, but I can have the fries and the Pepsi."

And there he was still waiting.

And I said, "My friend, I thought you would have given up on us." Because we took so long.

And he goes, "I knew you'd come back."

We gave him the food and he said, "I'm sorry, I can't hold all of that. So keep the fries." Because of his wheelchair. He could only hold the container of the chicken wings and the drink.

And he offered us the bus ticket again and I said, "I'm sorry, we're not going to benefit from it. It's okay."

And I said, "Have you heard about the Canada Disability Benefit bill and the work that we're doing on disability poverty?"

And he goes, "I heard something about it, but is it really going to happen?"

And I took his name and I said, "W, I promise you that it's going to happen." And I meant it.

I meant it, because as a disabled person I cannot watch my fellow disabled person beg for somebody to buy them food. There's no place for this kind of poverty in my Canada. Not in my Canada. Not in this country of abundance.

Not in this country that we have occupied, which was entrusted to our Indigenous peoples, share in its abundance with each other, who openly shared with their colonizers and were taken advantage of. To me, truth, reconciliation, and disability justice goes hand in hand, locally and globally, and I want to see an end to disability poverty in this country. We are on the brink of an opportunity for systems change. Addressing disability poverty head-on through a national top-up benefit that lifts people to the poverty line. And the poverty line today nationally sits at about \$2,300 roughly.

Bernice: That's per month. Monthly?

Rabia: Per month. And disabled people on fixed benefit amounts receive up to 30 percent below that poverty line.

Bernice: Wow.

Rabia: I can speak to Ontario. My brother has an intellectual disability, you know, I come with all this lived experience of not just myself, but my siblings, and he lives in a group home, and his ODSP rate in Ontario with a couple of increases since last year sits at about \$1,305.

Bernice: Wow. And how do people live on that?

Rabia: Well, his group home room and board cost is \$1,143 now. So it's a thousand dollars below the poverty line. Now, he has family to support so he doesn't have problems getting clothes and shoes and gloves and hats and shampoo and toothpaste or having a birthday party.

Bernice: Right. What if someone didn't have that family?

Rabia: When there are people who don't have that family support, or don't have family members with at least livable income to also help them out. Through no fault of their own.

Many disabled people living in poverty are not choosing not to work. They just can't work due to the barriers that they face related to their disability.

Bernice: And you've mentioned seeing examples of people having to crowdsource to be able to afford their basic needs and often we think about crowdsourcing for those types of things, in my mind, I automatically go to the United States, right? Where because of a lack of healthcare, benefits, etc. a lot of people are having to crowdsource for healthcare, or crowdsource for what have you. And that's not something that we typically think of happening in Canada, but from what your experience and the people that you struggle with, that is not so uncommon, where people are having to reach out to these other sources to be able to survive essentially.

Rabia: Well, a very prominent story is that of Madeline on the west coast who every month struggles to make ends meet and every month struggles to cope with her disability related needs, and every month finds herself falling further and further behind, reaching out for help and support financially. And says, "Is this the month that I end my life because of the poverty I experience?" So she has her medical assistance in dying application ready to be executed.

That's how desperate people with disabilities are in this country, that the basic necessities of living with their disability cost at least 30 percent more than the official poverty line and their benefits sit up to 30 percent below that poverty line.

Bernice (narration): This is an important point. There are essential costs associated with having a disability that Canada's Official Poverty Line doesn't consider such as accessible transportation and housing or personal care and assistive devices.

Existing provincial and territorial programs do not meet these needs. For example, the monthly ODSP or the Ontario Disability Support Program barely gives Rabia's brother the income he needs to cover the cost of his group home.

In 2021, when Rabia became the National Director of Disability Without Poverty, the movement's goal was to ensure that the federal government followed through on their promise to create the Canada Disability Benefit. They wanted to make sure that persons with disabilities were at the table to shape the bill in a meaningful way.

Just two years later, the Canada Disability Benefit, also known as Bill C-22 became law.

I was curious to learn about how they achieved such a monumental win.

Bernice: Can you take me between 2021 and 2023? What did that organizing look like to get to that point in June 2023 when that bill received royal assent?

Rabia: Well, it looked like and again I go back to relationships and power. Philanthropy and folks involved in incubating this concept of disability without poverty invested in us building a movement. And invested meaningfully.

I had the opportunity to have the supports I need to do the work that I need to do. I had somebody supporting me in managing my schedule, in formatting documents, in generating alternate formats of documents, in finding information for me.

I was able to build a team, and within that team I was able to also have the supports I need. So my strength isn't those little tasks, very important tasks, but very time consuming tasks for me when it comes to accessibility. So I was able to focus on what I do well. And what I do well is pushing out the messaging, crafting messaging, building relationships, talking to the world in whatever format necessary, in person or online, bringing folks together, tapping into a variety of networks. So, I was able to do all that while learning and be mentored by people who knew how to build a movement.

So the first year was about bringing in experts, tapping into expertise to design the benefit, preparing modeling data that could inform bureaucracy on what the benefit could look like ultimately, what it might cost. Sharing our modeling data with senior public servants.

Learning to leverage the media was huge for me, creating and co-authoring op-eds with recognized personalities.

Leveraging the concept of an open letter that we had signed by 200 prominent Canadians with and without disabilities.

And we engaged artists with disabilities. In fact, our original co-chair Luca Patuelli otherwise known as Lazylegz. He's a world-renowned dancer with a disability.

So, we pulled out all the stops. We were organizing in a space where everything was virtual initially. We had to leverage every online platform possible. So, webinars, podcasts, any and all social media, pushing out messages.

So, we established a diverse, and again, I would say, quite refreshing and new leadership table that brought forward people from across the country with lived experience of disability different types of disabilities, intersectional identities along with a couple of caregivers, just to make sure that we weren't leaving anybody behind. So we had this rich new diversity at the table talking about disability again, which I think is second to none.

And even now the world had opened up, so we started to do lunch and learns and community meetings, and we even went and rallied on the Hill in the fall of 2022, and that's when this bill was tabled for second reading, and we saw unanimous support emerge taking it through the various processes in Parliament. We participated every step of the way from the Parliamentary Committee hearings, to the Senate hearings and so on and so forth.

And finally, finally, we even launched a Disability Poverty Report Card in June of 2023 and went to Ottawa to rally government again. And finally, C-22 became law at the end of June of this year.

Bernice: That's incredible. It sounds, when you say, oh, 2021 to 2023, that's not a long amount of time, but when you talk about the story and all the different strategies, all the people that you brought together and how you were working in collectivities, it's a massive amount of work and a massive undertaking. Of all those strategies that you talked about, do you feel like one was the most effective or more effective than the others? Or do you believe it's like all of those different things in combination that really made a difference?

Rabia: We have to work in every way. More and more, we're working on the ground because there are always people that we're not going to reach through online space. So we had to be meeting people where they're at in community. And we brought together a really rich table of partners.

And some of the incredible, incredible ideas that emerged, emerged out of that group. For example, Dana Milne, she said, "There's an effective campaign that we ran before. We need to try this campaign. This will help conquer the digital divide. This will involve people on the ground." And that was our Budget the Benefit postcard campaign.

Previous to that we were running a campaign called Where's the Bill? And we even had a jingle by Jay Ross produced for that. It's actually really cool.

Bernice: Oh do you remember the jingle?

Rabia: It was just, you know, "Where's the bill? Where's bill?" It was really nicely done.

♪ *Where's the bill? Where's the bill? By word of mouth, we're going to bring it to the House.*
Where's the bill? Where's the bill? ♪

Rabia: We kept talking about where's the bill, now it's second reading, now it's before committees, now it's in the Senate, right? It needs to pass. So we were, talking about all that and keeping the pressure on to budget the benefit.

And in spring of this year, we launched our postcard campaign. And over 70, 000 postcards have been distributed across the country in various communities calling on the Finance Minister to budget the benefit. And one of the learnings was, "Hey, postcards are great on the ground." People get excited. We can use them at events. We can collect them from people, or people can individually mail them off, and they go free to Parliament Hill.

People in rural and remote communities have been able to participate, who may not have the same level of online access or access their local MP.

A beautiful story that emerged was that of a gentleman, a senior in his 80s, who's a father and a grandfather and because of his lived experience as a caregiver of a person with a disability, he was very passionate about this benefit to support his family members. He's like, "I'm not a technology guy." He met our communications person Amy Ma, based out of Montreal, and he said, "Give me 1, 000 postcards. I'm going to get them signed and sent off."

So we really saw passion and possibilities of people who wanted to participate because this was so personal and real to them.

Bernice: Yeah, absolutely. I love that, passion and possibilities. That's such a neat and powerful way of framing it.

What was like for you when you heard that the bill, after two plus years of organizing, had finally passed? What was that moment like for you?

Rabia: Well, for me, for all of us, it was “Yay, it's time to celebrate. Let's pause and let's party.” And, you know, party for me doesn't mean alcohol. Party for me means just, “Yay! Let's make noise like we do in certain cultures”, right? And it was really, “Let's celebrate.”

Bernice (narration): The Canada Disability Benefit Act became law in June 2023. But the work, Rabia told me, is far from over. People with disabilities have yet to receive this benefit.

Why? Because the law that passed only provides a framework for the benefit.

This framework gives the federal government up to two years to figure out the details of what the benefit will actually look like, who will be able to access it, and how much the monthly benefit will be.

These decisions are critical and will be the difference between a benefit that meaningfully addresses disability poverty and one that falls short.

Rabia and Disability Without Poverty from experience know that people with disabilities must be involved in a meaningful way in these decisions.

Nothing about us without us, as they say.

To do this, Disability Without Poverty launched their initiative to shape the Canada Disability Benefit called Shape the CDB.

Rabia: So, we took on Shape the CDB, asking Canadians with disabilities and caregivers 75 questions in its first phase. Reaching people who are racialized, people of color, Black, Indigenous, formerly incarcerated, currently incarcerated, institutionalized, Francophone, communicating in American Sign Language and in Quebec Sign Language. Tapping into a rich diversity of people and also members of the queer community, tapping into everyone and anyone with lived experience to give them an opportunity to have their voices and views heard.

Through that survey, we gained 4,537 responses with a over 90 completion rate. Majority are people with disabilities and a small percentage are caregivers. And there's a healthy overlap of caregivers with disabilities themselves.

So we really, really are proud of whom we've reached and heard from in this process and we have a couple of more steps in this process where we are having peer to peer interviews because not everybody can participate online.

And then we will definitely use this data and offer to brief provincial and federal governments, as well as bureaucrats so that they are well aware of the spirit of nothing about us without us, being engaged in this entire process.

Bernice: Is part of the work in terms of how you're trying to shape the benefit about how disability is being defined and understood. Do you think there a disconnect between how Disability Without Poverty, for example, understands what a disability is and how policy makers understand it, or is there alignment there, would you say?

Rabia: Well, we don't embrace a shared definition of disability. The medical community still looks at a medical model, still looks at rehabilitation. It doesn't look at the disability justice approach or human rights model or social model of disability that the barriers that disabled people face the consequence of their disability, but are socially constructed.

Bernice: Yeah, absolutely. And you mentioned that bill that was passed, it's a framework bill. And now you're organizing is focused on ensuring that the actual benefit provides support to the people it's intended to provide support to. What are some potential areas of focus in terms of how that benefit's designed?

Rabia: Well, everybody needs to work together. That means all levels of government, all programs and supports. That means, a federal benefit kicks in, the province shouldn't claw back on the supports that they're giving people with disabilities right now.

Bernice: So that means, so let's say you're in Ontario and you are receiving ODSP. Because of the federal benefit, they might take away some of that ODSP funding. Is that an example of a clawback?

Rabia: That would be an example of a clawback.

Bernice: So no clawbacks, that's a critical part of what you would like?

Rabia: Well, no clawbacks or rather harmonization.

Bernice: Oh, okay.

Rabia: So let's harmonize everything so there's no consequences to the programs and supports that people with disabilities are getting that leaves them worse off. The whole principle behind accessibility legislation provincially and federally is to not to create new barriers of sorts, right? It's to reduce or eliminate existing barriers and prevent new barriers.

To me, the spirit of that legislation needs to be honoured once the Canada Disability Benefit is introduced. That there aren't new financial barriers or systemic hardships inflicted upon disabled people when it comes to them accessing personal care services that are brokered within their provinces, that comes to them accessing subsidies for rent, accessing special diet supplements, accessing assistive devices program funding, accessing funding that pays for incontinence products, for example.

Bernice: Yeah absolutely.

And last question for you. How have you seen yourself be changed in the work that you're doing?

Rabi: I feel that I've grown. I've always spoken truth to power and been quite diplomatic at dealing with difficult situations, but I've sharpened some of those skills. I've strengthened my ability to orate my thoughts.

Bernice: We see them on display today!

Rabia: I've definitely gained a much stronger network of people that I've learned from. And it's restored my belief in the fact that there is power in coming together, in building a movement, in sharing a disability justice language that can make local change and spiral into national and global change.

You know, it's been 30 years since I got my undergrad and walked down Convocation Hall and decided that that was a turning point in my world that I was politically changed in those years of being in university and seeing what was happening around the world and the othering that I was experiencing, not so much as a person with a disability, but as I was a Muslim brown girl who was blind, and I felt I needed to rise up and be clear about who I am, and that's when I started to wear hijab, and I said, "In your face, Canada, I'm Muslim too." Because of the global situation. And that global situation hasn't changed. In fact, it's gotten worse and worse.

In the nineties, it wasn't called Islamophobia, today it is. And I face it in many spaces. But the fact that I dare to speak truth to power today in a variety of spaces also dispels the myth around a Muslim woman with a disability.

I appreciate the privilege that I have as a Canadian citizen, being able to rally on Parliament Hill and walk through the halls of Parliament, talking about the issues that matter to me.

And yet, at the same time, I know that there are aspects of my identity that are oppressed, that feel that they can no longer speak truth to power and that also makes me very uncomfortable.

So there is a lot of work to do. I have changed. I have gotten, you know, a lot more in some of the language I use about my power. I used to say I'm a *-bleep-* disturber and I adapted to white-privileged language saying I'm a systems disruptor and a social entrepreneur.

Bernice: Oh social entrepreneur!

Rabia: So yes, I think I've grown. I've changed.

And I really, really believe that if we work together, recognizing and appreciating our differences, discovering our common values, and talk to those values appealing to the hearts and souls of people in positions of power, we will see the change we dream of for disability justice in this country.

♪ *Where's the bill? Where's the bill?* ♪

Bernice (narration): Rabia's journey with Disability Without Poverty has restored her belief in the power of coming together and building a movement led by persons with disabilities. Our conversation left me with some questions: Where is public health? How can we use our power to support this vibrant intersectional movement to end disability poverty in Canada?

To reflect on these questions, I talked to my coworker Jonathan Heller. Jonathan is a visiting scholar with the NCCDH focused on redistributing power for health equity.co

Before joining the NCCDH team, Jonathan co-founded Human Impact Partners, a US non-profit bringing the power of public health to movements for a just society. He was the co-director for 14 years. Jonathan called me from his new home in Vancouver.

[Interview with Jonathan Heller]

Bernice: Jonathan, I know you as the power guy at NCCDH. How did you first become interested in community power building for health equity? Is there a story that illustrates that?

Jonathan: Yeah, I learned about power from community organizers. And so back in the early 2000s, I was at a non-profit in the United States and we were doing a bunch of health impact assessments and we were doing them on a range of issues from housing to transportation.

And we had two kinds of partners that we were working with on those health impact assessments. Some of them were government organizations. And we I did a lot with community organizing groups who were running campaigns on these issues for more affordable housing or paid sick days or all these other social justice issues. And those organizers would take our health impact assessments, take the data and do a lot of advocacy around them. And when we stepped back and we saw where our health impact assessments were being effective, where they were actually contributing to change, it was not, maybe unsurprisingly, it was not with the folks who were working in government. They pretty much took our data and shelved it. You know, the evidence wasn't convincing anybody to do anything different. But when we were partnering with organizers, they took our data and they integrated into their campaigns and they've actually used it to advocate with policy makers and they were able to change laws, change policies, change projects.

So we continued working with organizers and they are the ones who really I would say enlightened me about power. We started seeing that the reason why they were able to make change is that they had a lot of people organized and they could show up and kind of almost force policymakers to look at things differently.

I would say even at the beginning, I came into doing health impact assessments thinking that the evidence was going to make a difference, but it really wasn't at all, and it was really hard for

me to understand. In fact, when the organizers were first telling me about power, I kind of blew it off at first.

Bernice: What were these organizers telling you about power that you initially brushed off?

Jonathan: I think really I just wanted to believe that the evidence was going to make a difference.

Bernice: Don't we all?

Jonathan: And that's what we're taught. When we go to school, we're taught that it's about evidence-based policymaking. Whenever I think about that phrase, I think about somebody who told me that it's not about evidence-based policymaking, but it's actually about policy-based evidence making. That people basically create evidence to back up their policies.

I wanted to think that power wasn't part of it for whatever reason. It was really hard for me to take in. I've noticed that that's true for others, like I think in public health, we don't really own our power, we think of power as something that's kind of yucky, that we don't really want to engage in. And I think we really need to change how we think about power if we want to be able to make the equity and justice kind of reforms that we talk about.

Bernice: Yeah. I think that's a really important point. Typically, power can have some negative connotations, which you've written about. Tell me about what power means to you.

Jonathan: Well, so we're actually recording this on Martin Luther King's birthday. I'll go back to him and he said: Power is the ability to achieve a purpose, whether or not it is good or bad depends upon the purpose, right?

And so, achieving our purpose, which is advancing equity and justice is really important.

And then the other way I think about power is I think about community power building and there's a definition that Manuel Pastor put out there a few years ago that says that community power is the ability of communities most impacted by structural inequity to develop, sustain and grow an organized base of people who act together through democratic structures to set agendas, shift public discourse, influence who makes decisions and cultivate ongoing relationships of mutual accountability with decision makers that change systems and advance health equity.

Bernice: So it sounds like you're saying that power isn't inherently bad or good, but it depends on how that power is being used and for what purposes. Do I have that right?

Jonathan: Exactly.

Bernice: Why does power matter for health equity?

Jonathan: So I think advancing health equity requires us to change systems and to change policies. And, in my mind, there are reasons why inequities exist. They're not just a natural

thing. It's because a group of people who has more power is setting the agenda and creating the structures essentially that advance their interests.

So we have to actually build our power so that the people who are making decisions listen to us rather than listen to the few individuals who are trying to advance inequity essentially, right?

I think that's an important thing for public health to think about and realize it's not just happenstance that we have these inequities, there are people who are actually benefiting from them and want the status quo and their interests are what policymakers generally listen to.

Bernice: I think that's such a good point, Jonathan. I don't know that in public health we take enough time to think about how inequities aren't just by chance or random, how they're intentionally created and reinforced. Because I think having that understanding would really probably shift the strategies that we implement in public health in terms of advancing health equity.

Jonathan: That's to me, one of the things that's most important about looking at things through a lens of power is that it does lead to a set of strategies that we can actually implement that are concrete, that allow us to do something different that will advance health equity and justice.

Bernice: So let's talk a little bit about those strategies. I was reading a document you wrote on power and health equity, which is fantastic, by the way. And it discusses the three faces of power framework. Tell me about that framework.

Jonathan: Yeah. So there are different ways of thinking about power and I'll start by just saying there is no one right way. The one that I find most useful and that leads to the best strategies in my mind is this three phases of power framework that was developed in the early 1970s by a guy named Steven Lukes, a social theorist. And he was building off of many other people's work. And people before him had described the first face of power, which was what people think of as a visible face of power.

So who's able to influence city council members to actually vote a particular way. So it's really visible. You can see the results in the vote by the city council members.

Then people went deeper and said, "Well, that's not the only thing that's going on. How does something get onto that city council agenda?" So who's influencing things a little bit more behind the scenes in a less visible way, a hidden way in those back rooms. So that's the second face of power: the ability to actually get something onto a decision making agenda.

And then what Lukes did is he extended that even further and he said "Well, we're kind of trapped in our worldviews and in this particular way that we know the world and that limits what we even think of as possible,." So we don't even know what to ask in many cases.

Bernice: From what you're saying, the first face is that visible face of power. What we can see in terms of the actual votes that are being made, etc. Second face is who is exerting influence

behind the scenes. So would those be things like taking a particular member of parliament out to dinner or those types of things, or what would be an example of the second face of power?

Jonathan: Yeah, I think that's kind of an example of it, that definitely is part. Another way of thinking about it is having the infrastructure in place in order to influence those members of parliament. Like business groups, for example, are organized. They're not speaking as individuals. They're speaking as a collective. They've come together in chambers of commerce and in other formations for the specific purpose of doing lobbying and advocacy, right? And so they've built massive infrastructure to influence the decision makers at all levels of government, right?

When we organize in our communities, deciding together what to do and what to advocate for and doing their own lobbying, that's the second face of power.

Bernice: Okay. And then the third face is about the power to influence wider world views and narratives about a given issue.

Jonathan: Exactly, right. We can think about that as an invisible face of power because we don't even know what's going on. So there's the visible, hidden, and then invisible.

Bernice: Let's apply that framework to thinking through the story that Rabia told about the work of Disability Without Poverty when it came to mobilizing for disability benefit. How does the story Rabia told apply to these three faces of power?

Jonathan: Yeah, so she started talking about power immediately and early in her comments she started talking about some basically white guy stepping aside and allowing become a leader. And I think that's a great example of somebody sharing their power and their privilege. I really appreciate that. And it's so nice that someone recognized that that was the right thing to do and actually did it. And I think that that's not the norm. I think people tend to hoard power.

And so in most cases, we people who advocating for equity and justice are going to need to build our power so that we can force our way in.

She talked a lot about this campaign that they were running around federal legislation for the disability benefit, and she talked about working with experts to write legislation, to do advocacy, to get this open letter signed by over 200 people.

She talked about developing a diverse leadership table, issuing a report card. Uh, she talked about a postcard campaign. All of those things are part of influencing a decision that was being made at the federal level. And so I would think of all of those things as being part of that first face of power.

She talked about infrastructure they built. They built an organization, Disability Without Poverty. They brought coalitions together. They organized people. And they essentially got the disability benefit onto the agenda and got it passed, right? And so building all that infrastructure, I think of as that second face of power.

And then more towards the end, Rabia was talking about the way they talked about all these issues and leading with values and talking about how the current situation is not who Canada thinks of itself as, who we want to be, and those are narratives, right? The campaign and Rabia were trying to change how people saw people with disability.

She was pointing out dominant narratives out there like the lives of people with disabilities are just not as valuable, not worth as much as people who do not have disabilities. She was talking about people's value. And she didn't talk about capitalism per se, but she talked about how people's value is thought of as being directly proportional to how much they can contribute to the economy, right? And those are really problematic narratives. And so I think the campaign tried to start shifting those narratives. And that's examples of face of power.

Bernice: And it also sounds like some of the work of the campaign is to shift how people understand disability itself. She mentioned concerns with medical definitions of disability, which can really exclude people from entitlements that they should have rights to. So it sounded like part of that work is shifting how we understand disability and removing it from those medicalized, narrow definitions that can be really restrictive and not encompassing a full understanding of what a disability is.

Jonathan: Absolutely I think we have this biomedical view that a disability is something that needs to be fixed or cured or eliminated or erased, that it's like abnormal, that it's a problem, right? I think that then leads to this view that disabled people are the problem, right? And that's absolutely something that we need to shift if we want justice and equity people with disabilities.

Bernice: Yeah. And also understanding it more broadly that disabilities aren't necessarily just things that you can see, for example.

Jonathan: Absolutely. 100 percent.

Bernice: Absolutely. In your view, how can public health support the work of Disability Without Poverty at each face of power?

Jonathan: I don't know how much public health has really been involved in the campaign to date. But I can think about how we can get involved as things move forward or get more involved as things move forward.

We know that the disability benefit that Disability Without Poverty has been fighting for would improve health, right? I think that we have that evidence already. We know that it would benefit the people with disabilities, it would benefit their families. It's pretty intuitive. And I would say that we have a lot of evidence that that's true about the health impacts of poverty, for example, and how much poverty negatively it affects our health.

We could gather that data, create reports about the likely health impacts of the disability benefit, write op-eds, we could help organize folks, we could potentially testify.

There are decisions that Rabia was talking about that while the federal decisions have been made, they won the campaign, there's now a bunch of implementation to happen and she was talking about wanting to make sure there aren't any clawbacks. Well, public health could get involved at this point and talk about why it's so important and what the right thing to do is the provincial level. We can bring all of our data and our reports and we can partner with all those people who are organizing to help contribute to the provincial wins essentially.

I think that's an example of what we can do around the first phase of power is just to weigh in on those provincial fights that are coming up.

Bernice: Yeah, absolutely. And I think from my conversation with Rabia, it sounds like public health hasn't been very involved at all. And in my view, just in terms of my experience as a public health practitioner, I think that sometimes because what we consider a public health issue is so narrow and outdated. And we're not really in the spaces that we should be. We espouse values of health equity, but in our actions, I think we still have a long way to.

So thinking about 10 years down the road, 15 years down the road, what are your hopes for public health in terms of action to build community power for health equity?

Jonathan: So, the first thing I think we need to do is understand power, understand organizing, and start building relationships with community organizers, right? No matter where we are or what issue we're working on I would bet we can find some people in the community who are organizing around those issues and developing those trusting relationships is really what's going to pay off in the long run.

Bernice (narration): What a privilege it was to speak with Rabia and Jonathan and learn about how Rabia is working with others to build a national intersectional movement to end disability poverty through a new federal Canada Disability benefit.

There is much to be done to make sure this benefit becomes a reality. To get involved, check out disabilitywithoutpoverty.ca.

Jonathan talked about how public health can use our power to support this movement. He shared some practical strategies that we can use to understand and redistribute power.

For related NCCDH resources about power, check out the links in the episode notes.

Production for this episode was led by Carolina Jimenez and Rebecca Cheff, with contributions from Pemma Muzumdar and Bernice Yanful.

Pemma Muzumdar (narration): Thanks for listening to Mind the Disruption, a podcast by the National Collaborating Centre for Determinants of Health.

Visit our website nccdh.ca to learn more about the podcast and our work.

This season of Mind the Disruption is hosted by Bernice Yanful, and is produced by Rebecca Cheff, Carolina Jimenez, Bernice Yanful and me, Pemma Muzumdar. The Mind the Disruption project team is led by Rebecca Cheff, with technical production and original music by Chris Perry.

If you enjoyed this episode, leave us a review! And share the link with a friend or a colleague. Hit the “follow” button for more stories about people working with others to challenge the status quo and build a healthier, more just world.

[Episode Credits]

[Production for this episode was led by Carolina Jimenez and Rebecca Cheff, with contributions from Pemma Muzumdar and host Bernice Yanful (NCCDH). The Mind the Disruption project team is led by Rebecca Cheff, with technical production and original music by Chris Perry. Promotion by Caralyn Vossen (NCCDH). Artwork by comet art + design

Sound credits: Clips used from [Elisa in Disability Without Poverty Youtube Video](#), [Where’s the bill? Youtube Video](#) and from House of Commons proceedings including [Jen Gammad](#), [Hon. Carla Qualtrough](#) and [DWP Co-Chair Michelle Hewitt](#).