National Collaborating Centre for Determinants of Health

Centre de collaboration nationale des déterminants de la santé

Mind the Disruption

PODCAST EPISODE TRANSCRIPT & COMPANION DOCUMENT

SEASON 2 | EPISODE 6

Disrupting for Reproductive Justice

Episode released on:
May 7, 2024

Mind the Disruption is a podcast about people who refuse to accept things as they are. It's about people pushing for better health for all. It's about people like us who have a deep desire to build a healthier, more just world.

In the second season of Mind the Disruption, we explore **social movements for social justice:** groups of people working together to build collective power for change. Throughout the season, we delve into approaches for advancing racial equity, applying intersectionality, building community power and working together. In each episode, we name concrete actions that public health can take to work with others in service of social movements for social justice.

This episode companion document, available in English and French, provides a different way to engage with the podcast. It includes a written transcript of Episode 6 with key quotes, related resources and discussion questions to prompt reflection, sharing and action.

EPISODE 6
MAY 7, 2024

SEASON TWO

HOST

BERNICE YANFUL

Bernice Yanful (PhD) is a Knowledge Translation Specialist with the National Collaborating Centre for Determinants of Health (NCCDH), and she previously worked as a public health nurse in Ontario. Bernice is dedicated to advancing health equity with a particular focus on food systems.

PODCAST GUEST*

DR. SARASWATHI VEDAM

Dr. Saraswathi Vedam is Lead Investigator at the Birth Place Lab and professor of midwifery at the University of British Columbia. For over 38 years, she has been a midwife, educator, parent and researcher. Her scholarly work includes several community-based participatory action research projects on health equity. She has worked with service users to develop new quality measures of autonomy, respect and mistreatment in perinatal care. These accountability tools have now been applied in 65 countries at institutional, health system and country levels.

* Guests have provided the content for their introductions.

EPISODE DESCRIPTION

Many public health practitioners provide a range of supports focused on sexual and reproductive health. Explore this episode to learn about how Dr. Saraswathi Vedam and her team at the Birth Place Lab are disrupting the status quo for reproductive health research in Canada by intentionally centring the voices and priorities of communities who are under-represented and excluded from health research. Saraswathi speaks with host Bernice Yanful about how she works with others to bring the Lab's vision for "reproductive freedom, safety, and justice for every person" to life.

EPISODE 6
MAY 7, 2024

SEASON TWO

IN THIS EPISODE

SEASON ONE

QUOTES FROM SEASON 1

JENNIFER SCOTT

I think if I go to work today, I'll die. (Season 1, Episode 1)

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. (Season 1, Episode 5)

SAMIYA ABDI

People are stuck in this powerlessness paradigm. (Season 1, Episode 3)

HARLAN PRUDEN

Always ask yourself "Why?" (Season 1, Episode 6)

SUME NDUMBE-EYOH

There were times when I would think maybe I'm going to get fired, right? (Season 1, Episode 2)

SAROM RHO

It's the moment of refusal. (Season 1, Episode 4)

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 1, Episode 8)

INTRODUCING SEASON 2

BERNICE YANFUL (NCCDH)

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 (NCCDH)

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'kmaw People. This podcast is part of our organization's commitment to confront intersecting systems of oppression and to 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.

CONSIDER THIS!

Before reading or listening to this episode, think about your current understanding of reproductive justice.

- Have you heard of this term before?
- What barriers exist to reproductive justice in Canada?
- What have you learned about this at school, at work, in your life or in the media?
- How has your work intersected with this issue?

INTRODUCING THIS EPISODE

"Centring the service user's priorities and preferences and cultural context — that's how you get to reproductive justice."

SARASWATHI VEDAM

BERNICE (NARRATION)

That was Dr. Saraswathi Vedam, our guest for today. Saraswathi is the lead investigator of the Birth Place Lab and professor of midwifery at the University of British Columbia. She's been a midwife for close to 40 years. She is also an educator, parent and researcher focused on reproductive justice. Let's pause for a moment to learn more about the reproductive justice movement in North America.

1994, Chicago, United States: A group of Black women gather and coin the term *reproductive justice*. Building on the work of other advocates, they disrupt the mainstream, White-dominated women's rights movement because it does not represent their realities or the needs of their communities. Later that summer, they launch a movement for reproductive justice and, after gaining over 800 signatures, take out a full-page ad in the *Washington Post* and *Roll Call*.

Their ideas travel with them to Cairo, Egypt and are shared with delegates to the International Conference on Population and Development. This brings more attention to the power dynamics that influence access to services and individual choices. And the conversation about reproductive health needs shifts beyond contraception and family planning.

1997, Southern United States: SisterSong, a collective of community organizations focused on reproductive justice, is formed. This collective brings together 16 organizations led by Black, Indigenous, Latina and Asian American women.

2023, Atlanta, United States: A group of reproductive justice leaders meet to envision the future of the reproductive justice movement. Through the SisterSong website, they share this declaration:

PEMMA MUZUMDAR (NCCDH)

> We choose us. We invoke the spirit of our ancestors who cleared the path for us, the comrades who fight alongside us today, and those who will fight beyond us, who will become our greatest dreams.
>
> We reclaim the demands of Reproductive Justice that our Black foremothers named nearly 30 years ago:
>
> - The human right to own our bodies and control our future
> - The human right to have children
> - The human right to not have children, and
> - The human right to parent the children we have in safe and sustainable communities.
>
> We are still fighting for these rights to be real in our lives; we know things are not okay.
>
> We have a lot of work to do.
>
> We need you to join our fight so we can make this dream a reality.

BERNICE (NARRATION)

Just like in the U.S., the Canadian reproductive justice movement is concerned with a wide range of interconnected issues, many of which we have discussed during this podcast:

- food justice
- caring for babies and their parents, no matter their immigration status
- disability without poverty
- living in a community that is free from the effects of environmental racism
- being able to access health services

These are all inextricably linked to reproductive justice.

In a 2022 report, the Women's Legal Education and Action Fund, or LEAF, describes reproductive justice issues in Canada. Some of these include:

- barriers to education, services and culturally safe care, for example, policies that force Indigenous pregnant people to leave their families and communities to give birth in far-away hospitals
- barriers to accessing the resources and supports necessary to parent with dignity, for example, how Black and Indigenous parents face anti-Black and anti-Indigenous racism within the child welfare system, housing and employment

On their website, LEAF state:

PEMMA

"We cannot have substantive gender equality for women, girls, trans, and non-binary people without reproductive justice."

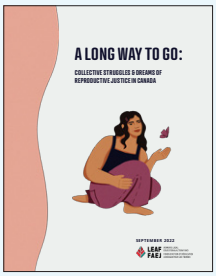
Beyond complacency: Challenges (and opportunities) for reproductive justice in Canada

Women's Legal Education and Action Fund. [2022].

Reproductive justice is deeply interwoven with countless other health equity and social justice issues. This report by the Women's Legal Education and Action Fund brings together a wide array of research, key informant interviews and community perspectives to provide an overview of the barriers that limit the ability to have or not have children across Canada, and the ability to raise children with dignity — key tenets of reproductive justice. The report describes legal and policy areas where reform must happen to achieve reproductive justice in Canada.

A long way to go: Collective struggles & dreams of reproductive justice in Canada

Women's Legal Education and Action Fund. [2022].



The struggle for reproductive justice is one that is longstanding, and those that have been impacted most continue to speak up and use their voices to advocate for more equitable experiences in reproductive health. This anthology, a publication by the Women's Legal Education and Action Fund, explores the experiences of many touched by this issue, through paintings, poetry, essays, collages and interviews. It is a thoughtful collection that highlights the struggles and inequities faced, along with the resilience that blooms and radiates in this space.

These two resources equip public health practitioners, scholars, students and policy-makers with a strong foundation to understand reproductive justice in Canada and begin the conversation on it in their respective spaces.

TALKING WITH DR. SARASWATHI VEDAM

BERNICE (NARRATION)

Back to my conversation with Dr. Saraswathi Vedam. Saraswathi is a trail-blazer. She and her team at the Birth Place Lab are working with others to bring the Lab's vision for "reproductive freedom, safety, and justice for every person" to life.

They are disrupting the status quo for reproductive health research in Canada by intentionally centring the voices and priorities of communities that are under-represented and excluded from health research.

The Lab describes itself as facilitating "multi-disciplinary and community-based participatory research on high quality maternity health care across birth settings."

Knowing that many public health practitioners provide a range of supports focused on sexual and reproductive health, I spoke with Saraswathi to get a sense of what the Canadian public health community can learn from her work.

BERNICE

All right, so just to start off, I understand you've been a midwife for over 35 years, which is incredible. Can you tell me the story of what drew you to midwifery?

SARASWATHI

I grew up in central Pennsylvania at a time when there were very few Indians in the United States. My father came to the university as a postdoctoral fellow in 1956, my parents came. And at that time, before 1965, there were only 100 visas available to people from India coming to the United States a year, across the United States.

BERNICE

Wow, how many did you say, 100?

SARASWATHI

One hundred until 1965. So there were very few Indian immigrants at the time. I was the first Indian baby born in the little town where I was born. My mother normally would have had been in the lap of her family. In the tradition in South India, you would go home to your mother's home 3 months before, 3 months afterwards, and be looked after and be taught. And the community would sort of rally around that pregnancy and birth.

And my mother didn't have that when she had me. She was really alone. So as the South Asian Indian community started to grow in the university town where she lived, she took it upon herself to mother the other new moms and new parents. There was this whole transition, you know, how do you cook Indian food here? How do you keep your traditions? When their babies were born, often those families would come and stay with us for a couple weeks afterwards. So I grew up in a house full of mothers and babies, and I guess that would be one sort of route to where I went.

I was exposed very, very young to what professional midwifery was because my mother's older sister was a teaching nurse midwife in India and had been trained in England at Addenbrookes. She was one of those *Call the midwife* midwives, you know, she literally went on bicycles and went all around like that show.

I also had three aunts who were obstetricians. When we would visit India later as we were able to, I would speak with them. I was influenced by them. My aunts would do a lot of service work also in the Bombay slums and places where there were very few medical and health facilities, and they would do volunteer and extra work there and take me and take whoever's around to help. So as I became a teenager, I was exposed also to care to marginalized populations and the social sense of social responsibility in health care.

I would say those threads also have come through my life. I actually went to college to do English. I wasn't thinking myself of becoming a health care provider.

BERNICE (NARRATION)

At college, she was exposed to ideas and organizing for social justice and reproductive rights.

SARASWATHI

I had had friends who had been involved in the social justice or, I would say, the feminist movement to expand options for care at a time when birth and pregnancy had become very medicalized. But that was sort of periphery to mine. I was exposed to it in part because I went to Amherst College in the first year they went co-ed, so I was in the first class of women. And I was the only woman of colour who was admitted, the only Indian woman there. When I was at Amherst, there was a lot that needed to be transformed to make it truly a welcoming space for women.

I learned from a lot of very vocal and impressive women who had been admitted. I wouldn't say I was any kind of leader at the time. But I was exposed to having to lobby to get reproductive services. There were no reproductive services or contraceptive services on campus, of course, because it had only been men before. And so we had to lobby to get a nurse practitioner.

It was at the time when there was a lot of discourse in the world about things like the medications that were being given to prevent preterm birth but actually were causing birth defects and also causing cervical problems. The DES [diethylstilbestrol] exposure, all of that happened during my time at Amherst. So I was exposed to truth-telling, I would say, or the lack of truth-telling and its consequences in health care.

"I was exposed to truth-telling, I would say, or the lack of truth-telling and its consequences in health care."

SARASWATHI VEDAM

These were the sort of ideas that were all percolating. And along the way, totally serendipitously, I met somebody who was a professor at Yale University in the midwifery program. We were at a party together, and she started talking to me about midwifery. And she told me that Yale was for non-nurse college grads and there was a direct entry program and that you'd end up with a master's. And somehow I applied, and I got in, and I feel so fortunate because it was truly what I was made to do, I think.

BERNICE

That's so interesting. It sounds like it was kind of in your blood, but then it took a party and a chance meeting to draw you in that direction.

SARASWATHI

Yes, exactly.

BERNICE (NARRATION)

And so began Saraswathi's journey into midwifery and working with others to bring different approaches and lenses to reproductive health. After having that conversation with the professor, Saraswathi did indeed go on to train as a midwife at Yale.

SARASWATHI

At Yale, we were certainly taught as midwives to think about physiology and think about the science we know about physiology or didn't know. And to have an appropriate use of, a judicious use of intervention, that understanding birth as a physiologic process that requires intervention only when things vary from normal. And that essentially that there is an innate ability for the human body to give birth, like any mammal.

BERNICE (NARRATION)

She told me about what she learned from mentors.

SARASWATHI

The care is best when it starts closest to where the family feels and the birthing person feels comfortable.

BERNICE (NARRATION)

And she told me how she brought this into her practice, offering both hospital and home births and working closely with families who experienced racism and other forms of discrimination.

SARASWATHI

Over time, I began to realize that I was an unusual practitioner because most nurse midwives only offered services in institutional settings. I spent almost 20 years in clinical practice. After I graduated from Yale, I practised as a midwife. I raised my own family, I have four daughters, and we lived across the United States so I was exposed to a number of different ways that midwifery was practised in upstate New York and California and Indiana, Connecticut, Michigan. And so very different places for practice and very different ability to provide care in the community and to diverse populations depending on things like insurance reimbursement and who can access the care.

As I told you, there were very few people of my age who were Indian, even fewer in the profession of midwifery. I didn't really know I would go to those conferences and I would be the only one. In many of these settings where there was a group of Black midwives, they would welcome me into their conversations, and they would have small caucuses of providers of colour. And then as it became more apparent that, because I was a person of colour, I also often cared for communities of colour and cared for people across the spectrum of access and resources.

The Birth Place Lab

BERNICE (NARRATION)

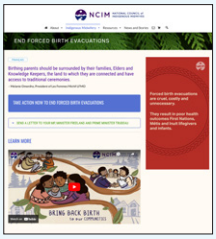
Saraswathi continued to practise as well as teach midwifery across the U.S. Eventually, she was asked to come to the University of British Columbia to lead their midwifery program. There, she established the Birth Place Lab. She now works closely with students, other researchers and systemically marginalized communities "to promote reproductive justice through inclusive, participatory research and transform policy, practice, and experiences of care through knowledge transfer."

BERNICE

So you established the Birth Place Lab about a decade ago at the University of British Columbia. I would love to hear about the creation of the Lab and what the Lab is aiming to do.

End forced birth evacuations

National Council of Indigenous Midwives. [2024].



"Birthing parents should be surrounded by their families, Elders and Knowledge Keepers, the land to which they are connected and have access to traditional ceremonies."

— Melanie Omeniho, President of Les Femmes Michif Otipemisiwak

Saraswathi discusses how the health of a birthing parent and infant are deeply connected to their familial environment and the culturally sensitive care they receive. Yet in Canada, many Indigenous families are forced to leave their homes, culture and support systems to give birth in areas foreign to them. This is what the movement to end forced birth evacuations by the National Council of Indigenous Midwives is all about. This website lays out the issue of forced birth evacuations, shares perspectives on the harm this practice does, and provides tools and steps to support and advocate for the return of birth to communities.

SARASWATHI

The research work I'd done at Yale and through my life was around place of birth. And as I came to Canada and started to understand the relocation of Indigenous families and how place and community were so important and yet so inaccessible for Indigenous communities and marginalized communities, immigrants and refugees, and those were the communities I had been serving for a long time, then I was more motivated to understand the impact of place on experience of care.

And then then I got a grant from the Vancouver Foundation to do a participatory action research project. And that's what really brought me to the Birth Place Lab. Because I would say the participatory action research model brings together all those threads of how I had practised as a midwife, the questions I had as a person of colour, as a provider of colour, as a provider that worked with historically marginalized communities.

For the first time, we had the opportunity to have funding to ask the service users what they thought was most important. How did they define quality and safety?

And so that first study we did, which was called Changing Childbirth in BC, was a step into asking different questions, measuring things in different ways.

BERNICE

I love that.

Defining reproductive justice

BERNICE

And I know the Birth Place Lab has a focus on advancing reproductive justice. What does reproductive justice mean to you?

SARASWATHI

Oh, that's a great question. Within the context of the work that I do, I think it is that every person who experiences pregnancy, whether or not it ends up in a childbirth, experiences pregnancy, birth, postpartum, newborn care, should have the right to decide who to give birth with, how to give birth, in what setting to give birth, in what ways to do that.

> *"Every person who experiences pregnancy, whether or not it ends up in a childbirth, experiences pregnancy, birth, postpartum, newborn care, should have the right to decide who to give birth with, how to give birth, in what setting to give birth, in what ways to do that."*
>
> **SARASWATHI VEDAM**

It's very wrapped up in the concepts of personal and bodily autonomy but also human rights. It's the rights to be treated with respect, dignity, kindness, compassion, which we know now from the global attention to what they call respectful maternity care or respectful care connects absolutely to medical outcomes also. Because if people don't trust the system, they won't access the system and will not access things that might be helpful to them.

And if the system doesn't trust the community, then the community knowledge that has served the community well for generations gets lost also.

And so to me, reproductive justice is inextricable from things like environmental justice or food justice. It's all connected as we form families.

And as our identity and our cultural context of where we are brought up — as you can see from my story — for providers and for service users, you can't just peel off, you know, who you are when you enter the work.

Reproductive justice to me is centring the service user's priorities and preferences and cultural context — that's how you get to reproductive justice.

> ***"To me, reproductive justice is inextricable from things like environmental justice or food justice. It's all connected as we form families."***
>
> **SARASWATHI VEDAM**

BERNICE

I think that's so powerful. So bringing the service users at the centre of decision-making about their own care, essentially. And I like how you made those connections to other forms of justice, food justice you mentioned, environmental justice, they're all intertwined and interconnected, so I appreciate you making those connections as well.

I know as part of the work to advance reproductive justice, you've spoken about redefining the perinatal period. I'm wondering if you can talk to me a little bit about that, how the perinatal period is typically defined and how you're seeking to, you know, redefine it or facilitate other meanings of the perinatal period and why that's important.

SARASWATHI

It's more the word perinatal, so I would say most people will understand the perinatal period as being before, during and after a birth event. But perinatology as a field and perinatal care has really focused more on at-risk newborns or at-risk pregnancies with a focus on the child, right? As opposed to the person who's carrying the baby. We think of it as a mother-baby unit or a parent-baby unit.

And I think that's what perinatal, the word perinatal can remind us, that it's a continuum from preconception through early parenting. And at every one of those cut points, we can affect people's outcomes, experience, justice.

Because you can't wait till the moment of birth and focus just on that. It is about: does that person have resources to get to clinic to have prenatal care? Are they far away? Are they close? Do they have safe and healthy foods in their area? Are they living in a safe place? Do they have a safe environment? That will, of course, affect their pregnancy, which then ultimately will have an impact on preterm birth, or on whether or not they can care for the baby, whether or not they are able to do things like breastfeed and care for their other family members. It's the whole continuum.

BERNICE

Yes, so reclaiming that word so it's recognizing the whole continuum. Would you say typically, perhaps, contemporary uses of perinatal tend to constrict its meaning so that it's about the period immediately before birth and following?

SARASWATHI

I would say yes. And again, focused on the baby, not on the parent.

BERNICE

High risk?

SARASWATHI

And on high risk, I mean, perinatologists usually look at at-risk pregnancies, yes.

Participatory action research

BERNICE

I know the Birth Place Lab focuses on participatory action research, and you spoke a little bit about your journey of getting into participatory action research. I'm wondering if you can tell me a little bit about what participatory action research is and what are some elements or qualities of good participatory action research. What does that look like when done well?

SARASWATHI

If you bring communities to the table, you can somehow get solutions that work and that are long-lasting and that you get buy-in to, so that bringing everybody, the whole system in the room, what's really important. And sometimes you can achieve something that is not just actionable but that is effective.

And so community-based participatory action research, the part that adds to that, is that it's the service user or the person who's most affected that tells you what questions to ask, how to ask them, what kind of measures to use. They're the ones who lead the interpretation of the data that you get, who maybe collaborate on unpacking the results, on telling the story and who should hear those stories. It's from the beginnings.

"It's the service user or the person who's most affected that tells you what questions to ask, how to ask them, what kind of measures to use. They're the ones who lead the interpretation of the data that you get, who maybe collaborate on unpacking the results, on telling the story and who should hear those stories."

SARASWATHI VEDAM

And in our work, it's from even before we get the funding, we ask the questions of the community, "What is it important to study? Help us. Collaborate with us." And then, especially when you're working with communities that have historically been unheard — Indigenous communities, Black communities, people who live with disabilities, people who have history of housing instability or substance use, or people who are immigrants and refugees — there are many subpopulations that we don't know that much about their lived experiences.

Participatory action research takes the lived experience of whatever topic you're on and centres that. So again, it talks about centring the person who's experiencing the care or the outcome, and have them be at a central, maybe even a leadership role in deciding all of those things. What kind of funding you seek? How do you ask the questions? Who do you ask? How do you recruit those people? When you do it that way, it's really transformative.

Doing participatory research helped us move further faster.

BERNICE

Oh, interesting. Because people might push back and say, "No, in fact it takes longer," but I think that's such a good point.

SARASWATHI

Well, it does take longer. It does take longer to go from idea to output, absolutely. And that's a challenge because you can only go as — and the Indigenous people have taught us that a lot in Canada, how relationship making is important and how waiting for ceremony, for doing work in a good way, doing research in a good way, means that authentic partnership.

But at the end of it, then you come out with a product that's actionable in a way that, often when you take small pieces of the story — you just look at Apgar scores or how much bleeding someone has or just look at whether they like this medication or not — you're not really considering all the conditions.

We found this in TB care in low-resource countries where you can have all the great drugs, but if the bridge is washed out and the person can't come in to get their prophylaxis, then it's useless, right? So you have to fix the system around it and the entire approach. And you can't do that without everybody at the table.

So that's why I'm saying you actually get further faster because, while the process takes classically longer from conventional research, which expects you — you know, the first participatory research grant that we got from the Vancouver Foundation was a 2-year grant.

It was very modest, now I understand. And they wanted us to do the study in the first year and the knowledge translation in the second year, which is impossible.

BERNICE

That's not enough time! I know that from personal experience.

SARASWATHI

It took us a year just to collaboratively build the survey. And then we had massive uptake of the survey because things were being asked in a different way from the perspective that hadn't been.

But then in the last question of that Changing Childbirth in BC study, we asked, "If you'd like to tell us something more or detail what you've told us through the survey, you could join a focus group." Well, 1,100 people signed up to join a focus group. We didn't have the time or funds to do that. So then we had to decide: do we convene some portion of these focus groups or do we do the knowledge translation? We decided to convene the focus groups, 33 of them that were led by local community members.

The RESPCCT study: Community-led development of a person-centered instrument to measure health equity in perinatal services

Vedam S, Stoll K, Tarasoff L, Phillips-Beck W, Lo W, MacDonald K, et al. [2024].

This journal article by Saraswathi and her colleagues describes the participatory methods used to develop and implement a person-centred survey on respectful perinatal care in Canada, and it summarizes responses from 6,096 service users who experienced pregnancy across Canada in the previous 10 years.

And that, again, it taught me a lot about how to set up funding in a good way, and now it's taken me several learning — you learn as you go.

First we got that [funding], then we got funding to work in the U.S. with communities of colour and people who had community birth. That was the Giving Voice to Mothers study.

BERNICE (NARRATION)

This was a landmark study of almost 3,000 people from across the U.S. about their experiences of pregnancy and birth care. Here are some key findings from a Birth Place Lab video:

TATYANA ALI (NARRATOR) | One out of every six of us experience mistreatment. Among those of us of color, double — one in three of us experience mistreatment — including being shouted at, scolded, ignored, or threatened by their providers.

The type of care provider we have matters. In this study, about half were cared for by physicians and half by midwives. We found large differences in the amount of autonomy, respect, and mistreatment that we experienced, depending on who cared for us.

And place of birth matters. People who gave birth in hospitals reported more mistreatment. (Birth Place Lab video: *Giving voice to mothers*)

The Giving Voice to Mothers study revealed a lot about how race and ethnicity affect pregnancy and birth care in the U.S.

Recognizing significant research and knowledge gaps in Canadian context for this topic, the Birth Place Lab is now engaged in the RESPCCT study, which stands for Research Examining the Stories of Pregnancy and Childbearing in Canada Today.

SARASWATHI

Because of what we learned there and the measures that we developed, we were able to bring it back to Canada. And in 2018, we got funding from CIHR [Canadian Institutes of Health Research] to run a national study about experience of care with a focus on respect and a focus on marginalized communities.

And we then had enough funding to do it right. So we took 2 years to understand how to ask those questions in the best way. What were those validated measures, person-centred measures that existed already? Which ones did we have to design? And then we were finally ready. We then mounted it on a survey. We content validated, we piloted, we did all the steps that conventional research wants you to do.

And we were ready to launch in April of 2020, which, of course, you know, where the world fell apart. And so we had planned to do a lot of community-based data collection with what we call data doulas, so community members who would be alongside these communities who normally weren't engaged in research. But, of course, because we had to do everything remote, we had to shift to an online survey. And we extended our data collection period so that we could give people during a very stressful time — it was not just the pandemic, but it was in the aftermath of George Floyd's murder, it was when the discovery of unmarked graves happened — so it was a very challenging time for these communities to do things like participate in a survey. But we eventually closed data collection in February of 2022, and we got 6,096 responses from all across the country.

BERNICE

That's incredible.

SARASWATHI

And it took us a year just to clean the data, to make sure we didn't have bots answering, to make sure that we understand who had responded and what the data set was, and to do it carefully and do it in collaboration with community members. But in the last year now, we've been working with these different communities to start to unpack and analyze the results.

BERNICE

What I'm hearing from what you're saying is that other forms of perhaps more conventional research might help you go through those steps quicker. When you do participatory research, it might take longer in terms of those steps, but it's actually more relevant. The results are more relevant, which allows it to be more actionable and can get you to solutions and interventions faster in the long run.

SARSWATHI

That's my belief. I'm sure there's always a role for other types of empirical and research that is, you know, the classic randomized control trial, but there are some things you could never study with a randomized controlled double-blind trial. For example, place of birth, people will not agree to be randomized to place of birth. They tried. They tried and got, over a number of years, got 11 people to agree.

So some types of questions that we ask have to be asked in different ways. And that's why I think it's so powerful to have what now is being termed person-centred research or person-centred metrics — measures where people report on their lived experience.

Lessons learned

BERNICE

I just wanted to pick up on something you mentioned earlier about learnings that you've gained throughout the years around participatory action research. What would you say has been the biggest lesson that you've learned?

SARASWATHI

Hmm, that's a tough question. I've learned a lot, and I'm constantly still learning.

BERNICE

Or just a highlight.

SARASWATHI

I would say that it's okay to take the time you need is one of them.

And it's most important to pause when a stakeholder, particularly if it's a stakeholder with the lived experience, has a concern.

It's important to have the right people at the table when you're making key decisions or for them to lead decisions, and take your ego and agenda out of it.

BERNICE

Which can be tough.

SARASWATHI

Yeah, absolutely.

And modulating your own anxiety.

I remember the first time we did the Changing Childbirth in BC study, and all of these five different communities came up with an hour-and-a-half-long survey, and I thought, "No one is going to fill this out." And they also wanted the people to be able to report on not just their last birth, but they wanted people to be able to report on up to three providers and up to three births so that they could tell us about different

"It's important to have the right people at the table when you're making key decisions or for them to lead decisions, and take your ego and agenda out of it."

SARASWATHI VEDAM

experiences. And I was worried about that because one person could then give you nine rows of data potentially, right?

As I've learned, there are brilliant statistical programs that can accommodate that. As the field evolves, there are things like intersectional analysis and that can account for — people are always trying to figure out causal relationships, and they de-emphasize things like associations. But associations sometimes can lead you to causal relationships if you ask the questions the right way.

So if I don't know how to do that, if you collaborate with other people, somebody will know how to account for that and to control for it. And then you can be transparent about what the limitations of your findings are too.

I do think that my trainees and doctoral students have taught me a lot about theoretical framing and, you know, whether it's feminist or critical theories that help you think about research and findings in a different way.

I think the Indigenous ways, doing the OCAP [Ownership, Control, Access and Possession] course and understanding other ways of knowing and elevating them as having validity has been very influential.

It's a journey. And definitely we make mistakes along the way, right?

BERNICE

Of course, of course. It sounds like a lot of lessons learned.

I liked your point about taking the time you need. I think that's so critical, especially with the ways funding cycles work, and it can seem like there's a lot of pressure to produce, produce, produce. But I think to your point, the type of research that you're doing, it needs to be collaborative at every step of the way, and that can just produce such richer and transformative work. So I think that's a key point about really taking the time you need.

SARASWATHI

It's a challenge because, of course, in academia and in the world, funding is real. And you have to also fund adequately to compensate the time of the community members who are leading or on your steering council. Because this isn't their work, right? They've lived it … they shouldn't have to do it free. They're not getting any — you know, as a professor or as my doctoral students may benefit from getting a getting a manuscript out of it, but they don't. So compensation and getting systems and funding mechanisms. I think they're starting to get there, that community partners have to be acknowledged in that way. I think that's been changing even in the decade that I've been doing this, and that's helpful.

"When I talk about taking the time, it's not just taking the time to produce the results, but it's also taking the time for that authentic engagement and exchange."

SARASWATHI VEDAM

I think what authentic engagement means is the other challenge because it's not okay just to have a single person. And when I talk about taking the time, it's not just taking the time to produce the results, but it's also taking the time for that authentic engagement and exchange.

BERNICE

Right, relationship building.

SARASWATHI

I never thought I would be where I am today, not just me personally, but the Lab. I think what's helping a lot is that there are many more people with lived experience and identities, unconventional identities in the academy who are now entering the academy or who are joining that. So I feel a lot of hope that racialized and queer and trans and people with disabilities, under-represented communities, Indigenous researchers, there are more and more who are emerging. And I think they will lead us to a different way of doing things where this becomes the new normal.

BERNICE

And it's a journey, like you said, right? It's a journey and a process. And it's encouraging to hear that, even in those 10 years that you've been working with the Lab, you see a change and a difference. I think that's so great.

Person-centred measures

BERNICE

I wanted to transition now to talk a little bit about the various measures that you've developed. What intrigued me in particular was the Mistreatment Index that has emanated from the work that you're doing. I'm wondering if you could tell me a little bit about the Mistreatment Index and where the felt need for such an index came from?

SARASWATHI

So MADM and MOR came from Changing Childbirth in BC where people told us they wanted us to study how decision-making happened and how comfortable they felt and respected in those conversations.

BERNICE (NARRATION)

You might be wondering what MADM and MOR are:

- MADM is the Mothers Autonomy and Decision Making scale, which assesses women's experiences with maternity care.
- MOR is the Mothers on Respect index. This index assesses the nature of respectful patient-provider interactions and their impact on a person's sense of comfort, behaviour and perceptions of racism or discrimination.

SARASWATHI

In the Giving Voice to Mothers study, they loved all of those questions. But they said, "It's not just enough to talk about if we were comfortable, but what about when someone shouted at us or scolded us or withheld treatment or threatened us or physically or sexually abused us." They said, "You need to talk about those more egregious human rights. Those are happening in our worlds."

And so we named it the Mistreatment Index and then used it to evaluate that care. And in that study, we found, and this was a high community birth, high midwife-led birth population, which we know that both community birth and midwife-led care is associated with higher levels of reported respect and autonomy. But even in that population, we had one out of seven, one out of six people, sorry, 17%, one out of six people who experienced some sort of mistreatment, one of those real egregious human rights violations.

And I'm sad to say that we have just been unpacking that in Canada. It's over 22%, 25% in some places, these interactions that are truly interactions that we would not tolerate with strangers in any other walks of our life are happening. And they're happening more with marginalized, racialized, Indigenous populations.

Some people call it obstetric violence. That's the same concept. I think at the time the mistreatment typology was developed, there was more of a feeling that nobody wants to believe that they are being violent or abusing human rights, especially if you're a health care provider. So they felt the acceptability of the term would be better if we called it mistreatment to educate health care providers. There's a lot of debate on this — we won't solve that in this podcast — about what terms to use and what's most effective and what's confronting.

But in our current discourse around anti-racist and dismantling White supremacy, there is more calling a spade a spade, I would say, than when I was being socialized. So I'm again on a journey to learn what we need to do to draw attention to things, even things that we don't believe that we participate in.

BERNICE

How does racism harm pregnant people, babies, their experiences and outcomes?

SARASWATHI

Do you have 3 more hours? There are so many. That's a very big thing.

To me, racism is violence. And when people are harmed by racism, by stigma, by discrimination, they are less likely to trust the health care system. They're less

likely to access care. They're less likely to reveal things that are happening with them. They are personally and mentally traumatized or historically and over generations, there's tension, there's physical effects. We know that, whether it's structural or interpersonal racism, that there are actual physical effects on that too. There are many, many consequences to that.

I would say that the Mistreatment Index is not precise enough to capture what you would call racism. Dr. Dána-Ain Davis has a beautiful framework on what the domains are around obstetric racism.

I think that there are many researchers now who are looking at how do we measure and bring some accountability to this conversation. Unless you measure it, you can't say that it happens and you can't then link it to things like outcomes and experience.

"Racism is violence. And when people are harmed by racism, by stigma, by discrimination, they are less likely to trust the health care system. They're less likely to access care."

SARASWATHI VEDAM

Opportunities for public health

BERNICE (NARRATION)

Public health practitioners have a clear role in understanding and addressing structural racism as a determinant of health. So understanding how racism harms health for pregnant people, babies and their families is really important. I wanted to know more about what public health practitioners could learn from the Birth Place Lab.

BERNICE

A lot of people in public health, we have different roles as it relates to prenatal nutrition, education, breastfeeding support, healthy mothers, healthy babies, etc. What do you see as opportunities to use some of these measures that you're developing within the public health context?

SARASWATHI

That's a beautiful question. And thank you for that.

The other thing that I should have said I've learned is that it's really important for us to shift the conversation and start focusing on things like measurement and accountability towards community-driven solutions. So it's one thing to measure it and to say it's happening, but it's another thing to be accountable for what you do. As I said, mistakes will be made, but what do you do after the mistake? And how do you prevent it from happening again?

So to me, some of the measures that we've developed and other people are developing should be implemented. But the important thing is to find measures that have been validated with the input of the people most affected. So Indigenous people, Black people, immigrants, refugees, whatever it is. And then apply those measures at the points of service so that you cannot just see and track its incidence, but also work with the service users in that setting to see how can it be turned around.

"It's one thing to measure it and to say it's happening, but it's another thing to be accountable for what you do. As I said, mistakes will be made, but what do you do after the mistake? And how do you prevent it from happening again?"

SARASWATHI VEDAM

And communities have been navigating — and even Dr. Davis's work talks about racial reconnaissance, which is how do people who know they're entering a racist system or discriminatory system, how do they navigate it to protect themselves and to avoid or to preserve what they want? There's a lot of community knowledge about how to do that and what we could do differently.

I think what we have to do is there has to be more conversations across from communities with health systems about how do we redesign our system? How can every birthing family have a debrief after their birth and be able to be at the table and heard and listened to? How can they contribute then to what happens the next time? And their ideas?

How can we bring — and in some settings you'll see it — how can we make sure there's always a space for Elders and Knowledge Keepers to come to the care points and offer and be respected for what their input is for what might work for this family or person?

How do we marry traditional knowledge with modern allopathic knowledge or with other systems, whether it be Chinese medicine or Ayurvedic medicine? There are lots of systems of knowledge that we now understand are more efficacious than we previously appreciated.

"Having the baby is a moment in time, but who's going to look after that family afterwards, right? The community. And in our studies, we found that people rely more on their communities and family members than they do on the health care system."

SARASWATHI VEDAM

Even when you talk about food justice, right, communities have been feeding each other, have been growing things, if they can preserve that knowledge and have the land and access to their community. You know, having the baby is a moment in time, but who's going to look after that family afterwards, right? The community. And in our studies, we found that people rely more on their communities and family members than they do on the health care system. So I think maybe we need to also.

BERNICE

When you talk about the continuum of care, it's not just that moment in time, to your point, it implicates all health-related systems, including public health and public health practitioners. I think that's such a great and powerful point.

I'm curious from where you sit and from your perspective, what do you think that the public health field can learn from the work of the Birth Place Lab? What are some learnings for public health in terms of the work that you've been doing?

SARASWATHI

That takes a bit of hubris for me to say that they should learn from my Lab.

BERNICE

Or implications for public health, if that's a better way of putting it.

SARASWATHI

I would say that my hope is that the approaches that we've taken, the participatory approaches, being unafraid to ask questions that haven't been asked before.

And the follow-up, so working — what some people call integrated knowledge translation — starting on those solutions while you're on that journey and not being afraid to work with that thing.

Often our service users will say, "We don't need to be told that mistreatment or racism or exclusion happens, that's our lived reality, but what are you going to do about it?" They're tired of waiting and tired of another story that talks about that research. So I think to be responsive to communities, we have to get going on those solution-oriented strategies in collaboration with communities.

BERNICE

You mentioned your journey over the past 10 years and more broadly 30-plus years as a midwife—

SARASWATHI

Nearly 40 — 1985, so 39 years now.

BERNICE

Thirty-nine! That's amazing. So thinking, you know, 10, 15 years down the road, what are your hopes for reproductive justice?

SARASWATHI

Well, I guess I hope that as I transition into a different phase of my life and career that there are enough other people working in the field of reproductive justice that there can be this groundswell. And I see that coming. I see amazing early career scholars and trainees.

My hope is that the work continues on the path that it's now on. I don't think it will happen in my lifetime. I'm old enough to understand that. But I do think that we've already seen more awareness, more attention to it. I hope it's not just a moment in time, and things tend to go in cycles, but I think that to diversify our workforce, to diversify our research workforce as well, that itself, I think, will help. That's what I hope to see.

And then more communication from conventional health systems with communities in authentic ways where communities can determine and self-determine what works for them.

EPISODE TAKEAWAYS

BERNICE (NARRATION)

It was such a privilege to hear about how Saraswathi and her team are working in partnership with communities so that research findings and measurement tools are more meaningful, unmask inequities and can be used to drive change. Learn more at birthplacelab.org.

Our conversation made me think about how taking a reproductive justice approach in public health and health promotion means understanding the experiences of racialized pregnant people, their families and their communities during the entire perinatal period, from preconception to early parenthood.

As we've heard so many times throughout the season, communities know what they need. We need to listen to them and be accountable to them.

Believe it or not, this is our last episode of Season 2. On behalf of the Mind the Disruption team, Rebecca, Pemma, Carolina and me, I'd like to take a moment to thank all of our guests for sharing their ideas, approaches and stories with us. And thanks to all of you for joining us on this journey.

Has listening to this podcast made you think about a topic differently or given you ideas about how you can advance health equity? Do you or someone you know have a story of disruption that we should feature? We'd love to hear from you. Please write us at ncccdh@stfx.ca. And stay tuned for Season 3.

This episode was produced by Pemma Muzumdar, Rebecca Cheff, Carolina Jimenez and me, Bernice Yanful.

PEMMA

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.

REFLECTION QUESTIONS

We encourage you to work through these questions, on your own or in a group, to reflect on this episode and make connections with your own context.

INITIAL REACTIONS

- What is something that surprised you in the conversation with Saraswathi? How did you feel as you were reading or listening to this episode? What prompted these feelings? How can you use them to fuel action?
- How are reproductive health and reproductive justice connected with other social and structural determinants of health and social movements that have been discussed on this season of Mind the Disruption, such as food justice, disability without poverty and environmental justice?

CONNECTING THIS TO YOUR CONTEXT

- How do reproductive justice, food justice and environmental justice intersect in your community and your work?
- What barriers and gaps in services and/or policies related to reproductive justice exist in your community?
- If you are a service provider, how do you ensure that the cultural and personal preferences of service users are centred in decision-making? What are obstacles to achieving this?

DISRUPTING FOR A HEALTHIER, MORE JUST WORLD

- Reflecting on participatory action research, how can public health practitioners shift their focus to community-led solutions in their work? What are the challenges and benefits of adopting this approach in your current role?
- How can public health systems create people-centred indicators and accountability mechanisms that address reproductive injustices, particularly in the areas of mistreatment and autonomy in care?

FINAL QUESTION OF THE SEASON

- Has listening to this podcast made you think about a topic differently or given you new ideas about how you can advance health equity?

CONTACT INFORMATION

National Collaborating Centre
for Determinants of Health
St. Francis Xavier University
Antigonish, NS B2G 2W5
nccdh@stfx.ca
www.nccdh.ca

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The NCCDH is hosted by St. Francis Xavier University. We are located in Mi'kma'ki, the ancestral and unceded territory of the Mi'kmaw people.

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La version française est également disponible au www.ccnds.ca sous le titre T*ranscription de l'épisode du balado et document d'accompagnement : Disruption en matière de justice reproductive* (Mind the Disruption, saison 2, épisode 6).