

Dogs, Wolves, AI & Accessibility Episode 43 with Dr. Mahadeo Sukhai

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Persons with lived experience with a disability need to be involved in the planning of it, need to be involved in the design and the development of it. Otherwise, the biases of the non-disabled individuals working on this piece of technology are going to creep in and the next thing you know, the device is useless.

Cross-polliNation: Welcome to Cross-polliNation, a podcast about solving problems with creativity and innovation.

This week, we're talking to Dr. Mahadeo Sukhai, Vice President of Research at the Canadian National Institute for the Blind, CNIB, about technology and accessibility for persons with disabilities and in particular, a technology that's a hot topic these days AI or artificial intelligence: how it can really benefit persons with disabilities, where it can act as a barrier to access and how the technology can be trained.

The latest 2022 stats from Statistics Canada tell us that 27% or 8 million people in this country live with one or more disabilities. That's nearly one-third of the population. It also means accessibility and assistive technologies are likewise pretty important for a very large group of people.

As you'll hear Dr. Sukhai tell us, users of assistive technologies include pretty much all of us at one time or another. But it's a topic that not all of us know a whole lot about, which is one reason we wanted to hear about it on the show. Dr. Sukhai kicks



things off with his own story about who he is and the work that he does.

Sukhai: My favourite colour is blue. I'm a Trekkie. I love to cook. I love to read. I really love to watch my 15-month-old grow and develop. I love watching that. My second language is Spanish. I love warm beaches and I will emphasize the qualification, warm.

I love the sounds of oceans. It's very calming. I'm a son, I'm a brother, I'm a cousin. I'm a friend. I'm a husband. I'm a dad, I'm a scientist, an educator, a researcher. I am neurodivergent. I am a person who lives with a disability and I am South Asian. I'm Indo Caribbean ancestry. I'm a first-generation settler, a newcomer. I was born blind and today I live with low vision.

So I'm a scientist with lived experience with a disability and that, makes me somewhat unicorn-like, I suppose. And so I think it's actually really important to just establish from the get-go that yes, there's bona fides and we'll talk about those, I'm sure. But I'm actually also a person.

And that person has interests and things that he likes to do and things that he doesn't like to do. I hate cold beaches, right. And, you know, things that he appreciates and things that he doesn't appreciate and that helps people connect with me as a person as opposed to, you know, when one introduces themselves with one's identities or one introduces themselves with one's professions, I think all people hear in both of those cases is the word 'blind' or the word 'low vision', the phrase 'low vision'. They don't really hear who we are.

So when my colleague's sister introduced herself in a similar vein to what I just used, I realized, well, you know, there's a beauty in that, there's a power in that. It forces the audience to confront the fact that you're actually individuals. We're not our disabilities.



And as someone who is a scientist and an educator and a researcher and an inclusion professional but a scientist first who, who often is distilled down to, 'you're the first blind geneticist' or 'you're the first blind whatever', I think it's actually important to start that way.

Cross-polliNation: Like a lot of the guests on the show, Mahadeo's work has evolved and taken different twists and turns through his career. I asked how his work in genetics evolved into the work he and his team do today at CNIB.

Sukhai: In addition to being a geneticist, I had a very burning curiosity about something and it, it started when a genetics prof said to me, 'you're the first blind geneticist I ever heard of'. And remember I said before that, you know, I'm more than blind in front of whatever, right? But this person said that to me when I was 18 years old and in third-year undergrad in university and I was curious about it - actually 17 years old when they said that to me - and I was curious about it.

And so I explored it and I discovered that empirically, I actually was the first blind geneticist that anyone had ever heard of. Because I couldn't find evidence of another one, right. And I looked long and hard.

But I didn't fully really understand why that was the case and it didn't make sense to me that there was to my mind, nothing particularly unique about my knowledge, my education, my circumstances, anything like that, that would have made me the first to do that.

And I didn't think I would have been and I never conceived until that moment in time that was a possibility. And the thing is, I didn't want to be the first blind geneticist. I wanted to be the first to discover something. I wanted to be the first to learn something. I want to be the first to do something but not that



way, right. Because that's a trailblazer but it's a trailblazer of the wrong kind from my perspective because that trailblazing comes with baggage.

And so once I figured out that I was indeed empirically the first blind geneticist, my next question was, well, why? Why did that actually happen? And what were the reasons that led to me getting there versus no one else getting there before me and frankly, very few people getting there after me?

And so that actually kickstarted a parallel career that was academic adjacent. That was enriched by academia, that was very academic in nature but wasn't officially recognized as an academic career per se. And that experience was the experience of, you know, let me understand the quality of life and lived experience of. first, it was students with disabilities in higher education. Then it became persons with disabilities in education and employment.

And then it became persons with disabilities, more specifically persons who are blind, deaf blind and have low vision in their interaction with the world around them, period. Right. And so I spent years doing both of these two things together.

I was paid to do one and I was basically volunteering to do the other as what one might call, a citizen scientist. And then the opportunity actually came to take over CNIB's research department. And when that opportunity came, it provided a chance to meld these two worlds. And allow me to do the citizen science work for money.

That didn't mean I had to give up a scientific career because I simply translated a scientific career, right. I was at that point anyway, where I was doing a lot of population data science and starting to do a lot of health services outcomes work. And that



was verging on public health research and it was not as big a step as you might think.

And I translated literally from the job I had at the University Health Network in Toronto into leading CNIB's research department.

When I inherited CNIB's research department, we had no projects no resources, no staff, no money. And I had the chance to build it effectively from that point to today where we do person-centered research that focuses on quality of life and lived experience of the human being. The individual persons who are blind, deaf blind and have low vision.

But we also do systemic research that looks at and aims to unpack and understand the systemic barriers that exist within society, the things that are rooted in ableism.

And ask a fundamental question, which basically is: how do those things that are rooted in societal ableism actually intersect with that quality of life and lived experience?

And then knowing the answers to those questions, you can ask subsequent questions, which would include, well, what are the kinds of interventions that will move the needle on all of this to improve quality of life and lived experience?

Quality of life and lived experience we can measure really easily. Societal ableism is not measurable but it is tangible if you understand what I mean, right. You can feel it, you can taste it, you can experience it, but you can't quantify it.

But you can quantify its impact on how a person lives.

Cross-polliNation: Since we're talking about accessibility and technologies, it's also worth very briefly talking about how



disability is defined. What does it actually mean? The Stats Canada description we mentioned at the beginning of the episode uses one particular definition of disability and as you'll hear, it has limitations.

Sukhai: Many people will say, well, disability is a health outcome. A lot of other people will say, particularly those of us who were born with a lived experience or acquired it at a very young age and for whom it's a part of our lives, a lot of us will say, well, no, it's a demographic. Right.

It's part of my social identity, just like me being South Asian, first gen newcomer, cis, male, husband, dad. So, right, all of those things are part of my intersecting social identity. Why not neurodivergent, low vision, right. And I think that's the root of, how do you define disability in Canada.

Statistics Canada uses something called the Washington Group set of questions to ask people about something that has an impact on daily activities. And it's based on the premise that a disability limits your function.

And so the way that the questions are designed are really around functional limitation, right. And so people who identify as living with a disability identify as living with a functional limitation.

There's problems with that because it doesn't really account for things like neurodivergence. It doesn't really account for things like brain injury. And the model that is currently in use doesn't account for things like speech, communication disabilities. And so there's some challenges I think there that ultimately may need to be resolved down the road. But it's a loaded question, how does Canada define a disability.

Cross-polliNation: [Among many other important reasons] Those definitions mean something for, among other things, who



might or might not be counted or considered when it comes to interventions.

In going back to technologies and how an ableist world creates barriers to accessing areas like education and employment, how can that be measured?

How does a lack of accessibility show up in people's lives?

Sukhai: Employment rates would be a really good example, right. Or promotion rates of persons who are blind, deaf, blind and have low vision and by promotion, I mean promotion out of entry level, junior positions into management and senior, even c-suite positions, right.

Or job satisfaction rates or educational outcomes or educational attainment or you can measure things like access to health care. You can measure things like health outcomes, you can measure things like access to social services, you can measure things like access to technology, you can measure things like access to information.

So all of those things are quality of life measures. Some of them are social determinants of health, right. And so by understanding those things you can, in theory, understand how societal ableism influences them, right.

Because across the board, for all of those measures, persons who have lived experience with disability are often experiencing poor outcomes, literally on every measure you can think of.

And if that was solely due to individual causes and individual factors, then you can imagine that individual-level interventions that target individuals would actually have a positive outcome. The problem is that they don't, right.



And there's no good evidence that suggests that, if I were to design an intervention that was specifically focused on, and I'm going to use employment as an example, on coaching you through an interview, that intervention that coaches you through a job interview is more likely to get you a job, right.

Because there's the other side of that equation, which is the people on the other side of that job interview, the hiring committee who all have their own biases who have, who all have their own perceptions. Who are all ableist to some degree, whether they realize it or not.

And so employment rates in that scenario are only going to improve if, not only is somebody coached to handle a job interview properly, but also you've done something to identify and remediate ableism in the context of that job interview, right.

And so the intersection between the person and the systems around them are what really defines the outcomes that we care about.

Cross-polliNation: What's an example of an intervention that can help make the world more accessible?

Sukhai: For example, if you imagine that a smartphone is a powerful piece of assistive technology that can impact the daily living of persons with disabilities on a number of different fronts. Then an intervention could be as simple as giving somebody a phone, right.

And CNIB has actually done that with something called the Phone It Forward program where, thanks to the donations that we've received, people in corporations have given in phones to be recycled and wiped and basically reinstalled to factory specifications, then given to persons with vision loss.



But when you do that, you also have to make sure that phone comes with a data plan, right. Because not everyone may be able to afford a data plan. And you also have to make sure that people know how to use the phone, right.

Because if somebody is adjusting to vision loss, yes, they might know how to use the phone if they're sighted. But if all of a sudden they have lost a substantial fraction of their vision and they're older and this is all new, they won't know what to do with this thing. It'll be like a brick, right.

So an intervention in a scenario like that is, well, you give them a phone. But there's another intervention that's called providing a data plan. There's another intervention that's called smartphone tech training, right. And those three interventions might actually need to be packaged together in order to see any kind of meaningful difference in the context of, for example, giving somebody a phone.

So interventions could be frankly anything. It depends on what needle we want to move and how we want to move it.

Cross-polliNation: So here's another example of a technology based intervention related to vision that can help make things more accessible at a broad systemic level when it comes to employment and education.

Sukhai: Microsoft Word, the default fonts in Microsoft Word is Calibri size 10 size 11 or size 12, right. Which for somebody who like myself has difficulty seeing is very hard to read. I usually go into every Word document that I get from anybody and I change the font to Verdana size 14 just so that I can read it. And I have low vision. So I don't, I don't use audio, right. And thanks to an ancient distrust of screen magnifiers, I don't use magnification and so, you know, I make things big, right.



But if my employer - hypothetically because CNIB has guidelines around this already - if my employer, instead of generating everything in size 11, Calibri, generated everything in size 14 Ariel or size 14 Verdana, then my list of workplace accessibility solutions would not need to include large print, right.

So a systemic solution could simply be a policy that says that the documents that you produce as an employer are all produced according to these guidelines, to make them accessible by accessible by default.

The research that we do within CNIB's research team is intended to inform the systemic level research – [it's] intended to inform what guidelines can look like if somebody ever chooses to make them, right.

One piece of guideline that we actually created at CNIB was before my time where somebody did a piece of research on accessible print material and came up with a series of recommendations for what became known as CNIB's clear print guidelines. Which literally is how to make accessible print material to be readable for persons with low vision.

Cross-polliNation: So a couple of examples of technology interventions that promote accessibility and often also benefit a lot of people in different ways.

Which brings us to AI, the benefits it has for accessibility and considerations in making sure it's accessible. What is AI when we talk about it in this context?

Sukhai: Well I think that's a really good question. I think a lot of it really depends on, how are we thinking about artificial intelligence? Are we thinking about it, for example, in the Chat GPT kind of way?



Are we thinking about it in terms of machine learning and data gathering? Are we thinking about it in terms of pattern recognition and image processing? So there's a few different things, right. So you can use AI to do a bunch of things, right.

Artificial intelligence. We used to call it machine learning. And the even older name for it was an artificial neural network, right.

And the basic idea behind something like this is, you feed it a bunch of data and you ask it questions. And what you do is you train it by feeding it a bunch of data and asking it questions. But they are questions to which you know the answer, right.

And so, because you've given this thing a set of rules, hopefully it comes up with the same answers you come up with. And so you train this artificial intelligence to do that. And your gold standard for comparison is what a human being is going to say.

And so you're able to calculate something called sensitivity and specificity based on whether the artificial intelligence gets the same answer as the human being, right. And so you've got these things called true positives, true negatives, false positives, false negatives and the AI is going to hit those and you're going to determine, because you're comparing against the human, you're able to determine, did it get the right answer? Did it not get the right answer?

So you calculate how often it gets the right answer, how often it gets the wrong answer. And then what you do is you say, OK, fine, we've trained this thing to be accurate to within whatever 99% confidence, 98% confidence, what have you, so now we're gonna feed it new data to which we don't have an answer and have it actually predict stuff, right.



So you can use an artificial intelligence algorithm or artificial intelligence software to be able to do things like pattern recognition.

And so you can actually use this for, and I'll give you an example that CNIB and Vision Loss Rehabilitation Canada, particularly the VLRC have been working on, which would be diagnosis of retinal changes that might correlate with diabetic retinopathy or diabetic macular edema. Which are eye conditions associated with diabetes, right.

And so if you take an image of the back of the eye and you feed this AI engine the image, the AI can predict, is this likely to be, you know, an image that has retinal anomalies that suggest this person should go see an ophthalmologist for diagnosis of diabetic retinopathy, right.

And so you can use it as a screening tool. So that's one way it's potentially beneficial to persons with disabilities. You can also use it as a predictive algorithm.

So let's say, for example, you're using AI to help you with pattern recognition in the grocery store. And so, you know, the AI that you're using takes a - you take a photo with your phone of whatever you're looking at on the shelf. And the AI you're using scans the image and it says, this is pasta sauce, right. Or this is cooking oil, right. And so then you know it's pasta sauce versus cooking oil and you might need both but at least you know which one's which, right.

And so you can have predictive AI that actually does that kind of thing for you, which also becomes quite beneficial. You can have AI that that gathers information with respect to how you're learning how to do stuff in the context of, say, rehabilitation, right.



So there's a new piece of technology that was developed in the United Kingdom called the We Walk, which is a really fancy white cane for someone with vision loss. And I say fancy because it's got a whole pile of sensors that detect things about gates and how the cane is actually being used. And so all of those sensors actually feed into an AI support that will track in real time how you're actually using that cane. So how you're walking and how you're navigating the world around you. And so you could, if you so chose, get real time feedback on whether you're doing it right. And you're not causing a safety risk for yourself. And so that's fantastic but that's an excellent teaching tool, right.

And so you can also use artificial intelligence in that kind of setting where you're using it to train persons with disabilities and you really need that level of data to really walk and talk people through that, right.

And so those are in the context of assistive technologies. Those are the kinds of things where AI is really beneficial because AI as as a predictive tool, AI as a data gathering tool and a data interpretation tool, will help you understand the world. Will help you interact with the world in a way that is in theory going to make the most sense, right.

You also have artificial intelligence in the context of say natural language processing where you can actually have AI sort of transcribe and read things back to you, right. So think about Otter AI as an example. Think about the transcription tools in Google Meet, the transcription tools in Zoom, the transcription tools in Microsoft Teams, right. Those are all artificial intelligence based. They're based on something called natural language processing.

And so those things are great for persons who would benefit significantly from having those transcripts for whatever reason. And so those are spaces where artificial intelligence will do really



well, right. And the better it does in those spaces, frankly, the better, right. The better for everybody, not just for persons with disabilities because tools like that become very helpful for absolutely everybody, right. I mean, how many people have gotten away from taking notes because Zoom will give you a transcript.

Cross-polliNation: So what does it look like to have good data to train an AI model so that it gives results that are genuinely helpful?

Sukhai: It needs to have really, really good data, right. The best data you can possibly feed it with the highest fidelity and the highest quality. You know the saying, garbage in, garbage out? I took computer science in high school and we learned this all the time. It was abbreviated GI/GO. And effectively what it meant was, if you wrote crap code, you were going to get crap results. And it's absolutely true with training in AI. If you train it badly, you're gonna get the wrong answers.

Cross-polliNation: What happens when an AI isn't trained from a good data set?

Mahadeo mentions an example of a model developed by a USC student to train an AI to tell the difference, using photos, between dogs and wolves. The AI was able to do it but only because the backgrounds of the dog training photos contained grass and the backgrounds of the wolf training photos contained images of snow. Meaning it didn't learn to differentiate between dogs and wolves based on their characteristics, it learned to do it based on other elements of the photos, specifically, the backgrounds the animals were posed in [which would be ineffective in a real-world test].

Sukhai: So you really have to be careful when, when you teach the artificial intelligence something. You have to be absolutely



careful that it's actually looking at the right thing because an example like that, photos contain hundreds of information elements as opposed to just dog and wolf.

You've got to really understand that this isn't as simple as dog versus wolf because you're actually feeding that artificial intelligence a massive amount of information with differences that if you don't actually have those differences quantified yourself, then you've got a problem.

That's one way that you can actually really mess up an AI, if you train it badly, right. The other way you can actually do it and I'm gonna come back to the medical examples for a moment. So, remember I said that in a lot of the pattern recognition stuff, the gold standard is what the human would call something?

This is a few years ago. So hopefully things have improved since, but there were reports in the context of pathology where, for example, you had human pathologists calling lung cancer samples, right. As in, calling the percentage of tumour on lung cancer slides, right. They were looking at, under the microscope and comparing that to what an AI pattern recognition engine was going to do.

But the problem is that the humans get things wrong, right. And if the human gets it wrong, do you think the AI is gonna get it right?

So in those kinds of cases, if you had three pathologists look at the exact same slide from a lung cancer patient, one person might say, well, there's 10% tumours here. One person might say there's 90% tumour here and one person might say, there's 50% tumour here.

They'll all agree that there's tumour, but they won't agree on how much tumour. And the problem is that if they're not gonna agree,



then you don't know what the AI is supposed to agree to. Which is another way that the training can go awry if the human information is not high fidelity. So you have to be really careful about this sort of thing.

And then the other issue of course is that persons with disabilities are statistical outliers almost by definition, right. I mean, I'm a statistical outlier by definition because I'm the world's first congenitally blind geneticist. You wouldn't expect blind people in genetics.

So no AI would actually predict me, right. It feels nice to be unpredictable. But then if that's the case, then the behaviour of persons with disabilities, if you're using predictors and persons with disabilities are going to behave differently because of our own lived experiences compared to the other parts of humanity, right, then what's gonna end up happening is, either the experiences of persons with disabilities get thrown out because they're statistical outliers or the prediction algorithm doesn't actually know what to do.

And if you feed the prediction algorithm the experience of a person with a disability and it doesn't know what to do, it's going to throw out a nonsense answer, right.

And so you have to be mindful of those sorts of things. So AI in the context of assistive technology, there's lots of beneficial ways that you have to think about it. But you also have to be really, really careful because if the AI is built wrong, you've got a problem.

Cross-polliNation: So if you're designing software or other technology, what do you need to keep in mind so that it's inclusive to persons with disabilities?



Sukhai: First of all, the inclusion of persons with disabilities as part of the design and the evaluation of the thing is important, right. So, number one, what is this thing supposed to do? And number two, how are people intended to interact with it? And number three, what if any benefit will this have for persons with disabilities?

And if you can answer those three questions and then you will have - and you don't have to answer them perfectly. You just have to answer them to a reasonable first approximation because once you have a reasonable first approximation you can then say, OK, fine, let's go consult with persons with disabilities about this thing, right.

And then as you're designing the AI, as you're training the AI, persons with disabilities could be engaged in that process. In order to make sure that it's learning what you really want to learn and not learning something else by accident, right.

Like you really don't want - and you know, we didn't talk about things like applicant tracking systems and applicant screening for employment and other ways to use AI that interface with persons with disabilities in terms of how we interface with the world.

But you really don't want a system that artificially excludes or artificially minimizes persons with disabilities because it doesn't know any better.

Cross-polliNation: Is there an example of something like that?

Sukhai: So let's say, for example, you have a job that you're having people apply for and that, that job is, I don't know, you know, this person is going to work in an office. Travel is required and so you – and it's, it's travel sort of within a region, a geographic region. You don't have to get on a plane but you do



have to move around within the boundary of about 200 kilometers, right.

And so you put in that job description, this person must have a driver's licence and you flag it with the AI as, this is an absolute requirement. Now I don't have a driver's licence and so, should I apply for that job, an AI is gonna screen me out because I don't have a driver's licence.

Now, there is, so let's take that and run with it for a moment. So again, you've told the AI to do something because you as a human being, you have a bias and you've translated that bias onto the machine.

So at the end of the day, humans, in order for AI to really do what it needs to do, humans have to check their biases and then make sure that the AI doesn't inadvertently develop a bias because of the way it does math. In order to do that, you still have to check your bias.

So you know, there's, there's something for example, called the Meiorin test. And the Meiorin test is a legal way to determine if a job requirement like, 'must have a driver's licence', is it - which on the face of it is discriminatory - actually is discriminatory with a purpose, right.

So if I was hiring somebody to be a truck driver, right, for a regional trucking company, then must have a driver's licence will pass this thing called the Meiorin test because you cannot be a truck driver without having a driver's licence, right.

On the other hand, [in] the example that I gave you where this person is supposed to work in an office and they need to regionally travel within a boundary of 200 kilometres, they don't need a driver's licence. They can get around using transit public or regional, they can get around using taxi, Uber, they can get



around using rideshare, they can hitch a ride with a colleague. They could do a whole bunch of other things. They don't need a driver's licence, right. But the default thinking is, everyone has a car, so everyone should have a driver's licence, which is stupid, right. But it's the way we think about things in North America.

Cross-polliNation: So how can you write a job ad like the one we just heard about in a way that reduces the chances of including biases that will make it harder for people with various kinds of disabilities to be considered for that job?

Sukhai: There's, there's a trick that I've learned and it basically comes down to what a five year old would do. Ask why. So, ok, so I need a driver's licence for this job. Why do I need a driver's licence for the job? Well, I need a driver's licence in order to travel. Why? Right. Can I not travel some other way? Oh no, we, we expect you to travel by driving, right. Why do we expect you to travel by driving?

And at some point you realize you can't answer that question, right. I mean, at the end of the day, if you cannot answer the simple question, why, or the answer is what, 'Just because', right, then you know, it's the wrong answer.

Machine learning has a lot of beneficial applications, right. Machine learning is a great way to manage large volumes of data, right. And ask questions that will give you reasonable answers in a shorter period of time.

The thing is though that if you teach that AI badly, you're going to get a bad answer, right. So and one of the challenges with something like Chat GPT is Chat GPT is being taught by the World Wide Web and the World Wide Web is full of fluff, right.

There's, there's a whole pile of stuff on the internet that I mean, you think about it, doesn't make sense, right. You know, there's



conspiracy theories and there's, you know, flat earth hypotheses and there's all sorts of things that are - there's no information filter, right. Humans have an information filter, we can apply an information filter. Yes, that filter is called a bias sometimes. But we have the ability to exercise judgment to realize that it is a bias, right.

We haven't necessarily taught AI how to recognize what a bias is, right. And you know, it, at the end of the day, it's, the AI is operating according to rule sets and if we give it the wrong rules and we train it the wrong way, it's going to learn the wrong thing.

So you know, the power of artificial intelligence to be integrated in or be assistive technology for persons with lived experience with a disability is great. But in order for that to work, persons with lived experience with a disability need to be involved in the planning of it, need to be involved in the design and the development of it.

Otherwis the biases of the of the non-disabled individuals working on this piece of technology are going to creep in and the next thing you know, the device is useless.

Cross-polliNation: So, be thoughtful about design and include the people you're designing for.

That's it for this episode on technology's AI and accessibility. If you'd like to know more about this topic, Mahadeo was kind enough to contribute to an article I wrote for Science Borealis, a Canadian online science blog, that you can find online called <u>Good</u> <u>Ingredients For Assistive Technologies</u> where he talked more extensively about assistive technologies.

[That article talked about] How we're all in fact users of assistive tech, about universal design and what it looks like to design products and technologies with full accessibility in mind. It's



creative and imaginative product design and I'll include a link to that in the show notes along with the transcript of this episode.

If you'd like to find out more about Mahadeo's team and their work, you can find CNIB at <u>www.cnib.ca</u> and you can find his book on <u>accessibility in the sciences</u> online.

Thanks for listening. If you enjoyed this show, we'd be thrilled if you shared it with other people, you think would also enjoy it. And we appreciate your time in listening to this episode.