



The Shared Mic is inspired, recorded, and produced on Treaty 6 Territory. Treaty 6 Territory is the traditional territory of the Plains Cree, Woodland Cree, Beaver Cree, Saulteaux, Blackfoot, Metis, Nakota Sioux and many others whose footsteps have marked these lands for centuries. We are just beginning to understand the significance of the land and want to ensure we honour the people and place. Today, this land is still home to many Indigenous people from across Turtle Island whose histories, languages, and cultures continue to influence our vibrant community. We are grateful to have the opportunity to work on this land.

Eric:

Hello, I'm Eric!

Salima:

And I'm Salima! Welcome to another episode of The Shared Mic!

Eric:

Today, we've got two very good guests. Bean is a local disability advocate who was left paralyzed from the waist down after an event in July, 2012. And Cindy is the Executive Director of the Canadian Hard of Hearing Association, the Edmonton branch.

Salima:

Bean and Cindy will be discussing how to navigate the world with a disability.

Cindy:

Maybe I'm going to start Bean...with just asking you to give a little bit about how, how you ended up with your disability?

Bean:

Sure. Well, I was in Las Vegas and it was Friday the 13th in 2000--July, 2012--and I was supposed to go to the pool that day, but it was raining outside. And so I went to the bathroom, brushed my teeth, washed my face and stuff, went over to the window and saw that it was raining, walked over to the bed and laid down. And that's when I experienced, like, the worst pain I've ever felt in my low back. And after that, I wasn't able to move my right leg. And so I was laying there trying to move both legs, but



only my left leg was moving. And then a few minutes later it went prickly from my hip all the way down to my toes. And within 10 minutes I was left paralyzed from my waist down. And so I'm diagnosed with transverse myelitis and basically it's inflammation of the spinal cord at T10-T11.. And I believe it was caused by the Epstein-Barr virus that attacked my spinal cord.

Cindy:

Wh-why do you believe that?

Bean:

Just from the research that I've done over the last eight years and seeing how the Epstein-Barr virus acts. It's super common within the human population and there's four stages to it. Most people, it stays in stage one or stage two. I'm one of the "lucky ones" that it got to stage four, which is where it attacks your central nervous system. So I am quite lucky that it didn't attack my brain or higher up in my spinal cord, but I do wish that it attacked like my fat cells or something less vital than my central nervous system. But here we are.

Cindy:

So is this permanent then?

Bean:

Nope, it's not. I've regained a lot of mobility and function over the last eight years. And because of that, I've opened, like, a nonprofit here in Edmonton called "ReYu Paralysis Recovery Centre" where we help other people retrain their nervous systems using activity-based training. A lot of people think that the central nervous system damage is permanent, but there are lots of studies done in the last few decades stating that the central nervous system can regenerate and you are able to bypass spinal cord injuries and even brain injuries to retrain your nervous system, which is really cool.

Cindy:

That is really cool. So do you think then--so you're able to walk again right now?

Bean:

No. So I can ambulate a bit. And so that's with a Walker. It's really slow and it's--I'm not very coordinated yet--I really have to work out my coordination, and I have a lot of spasticity too, so that really, like, slows my walking down and makes everything a lot harder. And I exert a lot more energy, which makes me more tired.



But, yeah, like I do stand to brush my teeth every day. I drive my car with my foot. I try to do functional things with my body and hopefully, you know, one day for sure, I believe I'll be walking again. I don't know if I'll look like an able-bodied person walking, but I do believe I will be.

Cindy:

That's pretty amazing.

Bean:

Thank you. Cindy. I'd like to ask you a bit about yourself, too. So how did you fit into the world of disability?

Cindy:

I've lost most of my hearing, but I was born with hearing.

Bean:

Okay.

Cindy:

But contracted chickenpox as a child--as a baby, actually. And the virus, of which can be very harmful to some people, was harmful to me and damaged my hearing.

Bean:

Okay.

Cindy:

So over the course of time, the virus remains active with you. And for some people like myself, it becomes active during different times of my life. And it has to this point of my life killed most of my hearing. So in a sense in audiological terms, I would say I am deaf, but because I use my speech to communicate and use a cochlear implant and a hearing aid to hear, I consider myself to be hard of hearing. With devices on I'm hard of hearing and with my devices off, I'm totally deaf.

Bean:

Wow.

Cindy:

But because mine was a progressive loss, I've been for most people, that's an easier navigation because I've been able to adapt and change as my hearing got worse.

Bean:

Right.

Cindy:

As a child, I didn't actually notice the hearing loss and nobody actually noticed it. It was quite easy to adapt to it without knowing. And it's easy to be able to follow your parents and know what they're saying or your siblings. So no one really recognized it. And even in my elementary school years, it was easy to get by because you have one teacher and you get to know that teacher. And if you like school, like I did, you kind of just follow your teacher around and you know, what's happening and you're kind of in with things. It was all good. We didn't really notice the hearing loss at all much. It wasn't 'til junior high where you start switching, going from class to class and teacher to teacher and the noise level changes. And of course it becomes not cool to sit in the front, which I typically did before and stopped doing. And that's when the challenges started to present itself where I wasn't hearing quite the same as everyone else. I was getting a different conversation than what was being had.

Bean:

Right.

Cindy:

And it became quite comical actually. But not to me. It was then that my mother also noticed that, you know, unless I was really looking at her, I didn't seem to be paying attention, which I'm sure she thought was just being a teenager and not paying attention and listening. But it was then that my mother finally, you know, said, "you know, we got to get your hearing tested." This has gone on too long and (she) carried through with the threats and found out that I had a very significant loss by that very first test I ever. And was told that I did need hearing aids.

Bean:

That's really cool. Can I ask...so when you first got your hearing aid, you said you were 13? What did it look like? How big was it? And, like, did you wear it every day or, like, did you resist it?

Cindy:

Definitely resisted it. It wasn't an "in the ear" hearing aid.

Bean:

Okay.

Cindy:



So it was rather large and it fit the whole internal part of my ear.

Bean:

Okay.

Cindy:

You know? It wasn't really fooling anyone. We think we are, but we're not.

Bean:

You know, we're our own worst self critics. Right? And I can only imagine being a teenager and having to have some sort of different disability that makes you different from everybody else. I mean, I was 30 when I was paralyzed. And so, I mean, there's pros and cons to everything. And I don't think that there's a right age to get a disability....

Cindy:

No.



Bean:

Right? Like there's no good time to be disabled, but I just, I find it interesting to hear other people's experiences and their perspectives because it does--it does make a difference at what age you are, you know, disabled. Right? Because of your coping mechanisms and how you're able to... and maturity levels and stuff, too. Right? So I just think it's really interesting to hear other people's experiences. Can I ask you about the cochlear implant and what was that surgery like and how has it helped?

Cindy:

So that the cochlear implant is, is considered a type of brain surgery. It is working very, very close to your brain and while it's become quite safe over the last year, there's, there's certainly still considerations about that type of surgery that people would have. It's probably what put me off of it for a long time. There's a chance that they will hit your facial nerves. You can be paralyzed in your face.

There's a chance it could not work, but the surgery itself, they have to place a little type of computer with electrodes and they thread it through your cochlea to stimulate it. Because when you get to this point--the cochlea is our, is our "brain of our hearing" in a sense, and it's not stimulated anymore. It's not getting the same message. So it can't send the message to the brain. So these electrodes are implanted through and threaded right into the cochlea to replace the hair cells that have been damaged.

It's pretty amazing that they came up with this stimulation to act like the hair cells. It's a faster input straight to my cochlea than the natural hearing process, even. So you, you talked about, you know, surgery and regeneration and things like this, obviously going to be able to help you, too.

Bean:

Oh yeah, of course. I mean, you know, our brain is considered to be the most complex thing in the universe. Right? And we, I mean, scientists have been studying it for decades and really, we only know about 10% of what our brain is capable of the power that our brain has to rewire our body. It's incredible, but it truly works.

Cindy:

But having said that, and even with technology, and even with our mindset saying, "we can do things," there's some, certainly some limitations out there. So what do you find is the biggest crutch out there, to say that word, but what do you think is the accessibility? It isn't great still.



Bean:

No, it's not great. And physical accessibility. I mean, living in Edmonton, which is a winter city, we're already isolated for pretty much six to 10 months of the year because of snow and ice. But I feel like bigger than the physical barriers, it's the attitudinal barriers here in Alberta.

Bean (cont'd):

They are really strong against people of any minority and disabilities is included in that. So me being an East Indian woman, born and raised here in Edmonton, and now having a disability, I have faced more than my fair share of discrimination and racism.

And so that just lets us know that, "okay. So we're not thought of. We are completely an afterthought. We're not thought of for accessibility or inclusion." And so, you know, that needs to change. It's 2020, it needs to change.

Cindy:

And, and so like with me, we have the Canadian Hard of Hearing Association and that's where I work and that's where I feel like I belong because I have other people to be a stronger voice. That's where I get my support from. Do you have something similar? Is that...do you feel that having other people, like, who know what you're going through...is it is a great support system for you?

Bean:

Yeah, for sure. I call them my "wheely awesome peeps" and they're just my "wheely" wheelchair friends. Right? And I like to have a lot of people around me. And so I started creating a friend group of people with disabilities, and you didn't need have to have a spinal cord injury to be included. I didn't, you know, it doesn't really matter, but like I just wanted to be around other people who understood what it was like to be different.

Cindy:

And that, and that's what bonds you, I guess. And it's what spurs you on because you know, other people are also going to benefit.

Bean:

Can I ask you...so with COVID happening and having to wear masks, how has that impacted your ability to communicate?

Cindy:



There's been a huge impact! So much of what I understand or anyone with hearing loss is through what we see. Now, people aren't proficient speech readers, really. You can only understand about 40 per cent of the English language, and that's, if you're a really good speech reader too. So the other 60 per cent, you're just guessing, but your facial expressions give us those other clues. You're, you're, you're--what you're doing with your mouth. What you're doing with your eyes. When we only see the eyes, it's really limiting. What we're hearing is a little bit more muffled through the mask. So it's been a huge hindrance where we're selling lip reading face masks right now. A big goal of ours is that everyone try and get these face masks so that, you know, we can see you. We can see you smile. We can know that you're not angry.



Cindy (cont'd):

It's still muffled, but at least we see your lips, we see your eyes. We're pushing this campaign, trying to sell these out here. I really have to say, though, schools really picked up on it and the teachers are getting them and I've been floored with how many people are ordering them. So in just the last couple weeks, we've sold over 700 of them.

Bean:

Oh my goodness. K. send me the link afterwards. 'Cause I want to buy some. I've been looking for clear masks because, I mean, I. I don't have a hearing impairment, but I read lips so much and I never realized how much I read lips until I couldn't see people's lips anymore.

Cindy:

Well, that's, what's happening with everyone. We get a lot of people calling saying, "I think I lost my hearing." People do rely on that face.

Bean:

Yeah. So much. And you don't even realize it until, until it's taken away from you.

Cindy:

Well, how about yourself? What, what's something really positive. That's come out of this for you?

Bean:

A lot of positive has definitely happened through the creation of "ReYu", right? We really have been able to instill confidence in a lot of people and to really have them believe in themselves and in their recovery. That's honestly been one of the biggest positives that's come out of my paralysis. And then also like my mental health and my awareness of self as has, I've definitely worked on that so much over the last eight years.

And that's something I didn't do prior to being paralyzed because I just thought that I didn't need help. I don't need therapy. I don't need self-reflection and to do self work, but in order to be truly better, you have to work on yourself all the time. And seeing a therapist has been the biggest saving grace of my life, post paralysis, because she's really given me the tools to work through what I've gone through and what's coming ahead in my life. Cause I'm sure the adversity isn't done yet.

Cindy:



Again, you mentioned just, you know, that support of your group. That is, that was amazing. They gave me the Canadian Hard of Hearing Association. It gave me a lot of friendships along the way. It--I just think if other people could join something and do that, the mental health aspect does, it just does improve. We don't understand that unless you're going through it, but you need that connection.



Bean:

Yeah. And how do you handle people staring and their questions?

Cindy:

You know what? Ours is really the “invisible disability”. And so a lot of times people don't know that we have hearing loss. And so when we're missing something, it's not like you can obviously see the hearing aids or a lot of people's hair covers it. Right? It's not that I'm trying to hide it. If they see it, I'm, I'm perfectly fine. But a lot of people aren't. I can tell you that is one of the biggest things is the embarrassment factor. Literally the hearing aids, but I'm okay with it. Cause it just, it gives me a chance to correct the problem. Let them know what happened.

But you know, when I know they're staring, it's obviously I know that I've missed something. They're wondering, “why the heck is she--why isn't she answering me?” Or, “this isn't what I asked her at all. Why'd she say that?” I mean, I know I've gotten it wrong, so that gives me a chance to clear the situation up. For sure. For me, it's a good thing when they're staring 'cause then I know I'm out of their ball game there. I didn't get, it might be a different, a different thing. How do you handle that yourself?

Bean:

That's kind of evolved over the last eight years when I was first paralyzed, I was very insecure and I hated everything about my life and about myself. And so I didn't want anybody to look at me, but of course people stare and they're curious. Some people have a look of pity on their face and that doesn't make you feel good ever. So please don't ever be that person to anyone who's listening. At first I was really insecure and my mom could tell that I was, I would get upset. And so my mom would often yell at people and be like, “what? You never seen a girl in a wheelchair before??” Like, “what are you staring at.” Right now it's all, it's definitely evolved. I'm way more confident in myself. And now when people stare, I will look back at them and I'll smile.

Cindy:

You ever use it as a teachable moment? Oh yeah.

Bean:

Oh yeah. A hundred per cent. For sure. And it's all on their reaction. Right? Sometimes people will, like, I mean, I can see them staring at me. So if I turned to look at them, you know, either they will keep engaged with me or they will just look away and pretend they weren't staring at me. You know, people react in different ways, but if they smile at me you know, some people will just come up to me and ask me like, “what happened?” And I'm more than happy to answer. And I'm more than



happy to share because, you know, if it can happen to me, it can happen to anybody. And that is an educational moment where you can change the stigma. And like, one of my goals with “ReYu” has been to change the world and people often laugh at me, but like, that's how you do it.



Bean (cont'd):

You do it one person at a time and you tell them your experience. And especially, like, in my culture. So being East Indian--having a disability is thought of as shameful. And it's not just the Indian culture. It's a lot of other cultures around the world where having a disability brings shame upon your family. And so these people are often hidden. They don't go to weddings, they don't go to parties, they don't go to funerals. And so it really increases your sense of isolation for sure.

But for me, it's a great experience to tell like parents and tell people that, like, you know, I didn't want this to happen to me, but it happened to me. And because it happened to me, you're now going to treat me very differently and that's not right. I didn't do this. I didn't want this. I didn't deserve it. But here it is. And so I'm still a regular human being. I think I still deserve respect and dignity just like anybody else. And just because I'm sitting, doesn't make me any worth less than you.

Cindy:

That's exactly the assumptions people make. That's what we got to clear up.

Bean:

Yes. Agreed.

Cindy:

When I miss something, or it's different than what they asked. It's their assumptions like, "oh my gosh what's the matter with her?" Those things you have to clear up at just forefront and say, "I didn't hear, I'm hard of hearing." So, yeah, we have to use those as teachable moments.

Bean:

Oh yes. A hundred per cent.

Cindy: And I think we will change the world, still. I have seen change. I'm not saying I haven't seen change. Slower than I would have liked, but it certainly changes.

Bean:

And I mean, this year has really catapulted change. And you know, as these next generations are growing up, they're way more inclusive. You know, like my nephews see me in my wheelchair and they're more cognizant of wheelchair parking spaces of curb cuts, of wheelchair buses and stuff. Right? And so you know, just as these next generation of kids are growing up, we're going to see a lot more of this change. And as you, know, as we fight the patriarchy--patriarchal system, we're going to see



you more change happen. But like, it, it took us this long to create this problem. So it's going to take us a long time to fix it, too.



Cindy:

That's correct. That's correct. Yeah. But like I said, it's mostly the attitudes we've got to change.

Bean:

Yeah.

Eric:

They both had so many interesting things to say, but what resonated for me was the discussion around the support systems that they talked about and how important they were to preserve the mental health and their wellbeing. And thinking about that, we also--in the aging community--support systems are very important. And particularly the times of COVID, having those people who you can check in on, they can check in on you, really promote better mental health and better physical health as well.

Salima:

And I think when we talk about relationships--so, I'm a speech language pathologist--and I always think about the link between relationships and communication. And I think in this time of COVID, Cindy brought this up, where masks are really hiding a lot of those communication cues that we need people who are hard of hearing or deaf and even people who can hear and don't have that disability. It's harder to communicate with something over people's mouths.

So what I loved was that Cindy talked about the "Share Your Smile" campaign and these innovative new masks that have kind of a little window where you can see people's faces. And if any of our listeners are interested, you can pick up your own mask with a window from the COMO foundations, [C O M O foundation.ca](http://COMO.foundation.ca). So you can help promote that communication accessibility in your community.

The other part of this that I took away was the intersectionality of identity and how being talked about being a woman of color AND having a disability. And those intersections are often not thought about. We often, we like to put people in one category, but people can bridge and people exist in this intersectional world. And I think it's important that we identify that and talk about that. Especially with advocacy movements.

Eric:

The Shared Mic is an initiative of Age Friendly Edmonton, which is a project between the City of Edmonton and the Edmonton Seniors Coordinating Council.



Salima:

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Eric:

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Salima:

And of course stay tuned for our next episode.