

Voices of ABLE2

Episode 3 - Nothing About Us Without us; Centering Lived Experience in Building Inclusion in Communities

EMELOU

[00:00:00] Welcome to Voices of ABLE2, where we share real conversations about disability inclusion and community.

I am Emelou Porquez, and today's episode is called “Nothing About Us Without us: Centering Lived Experience in Building Inclusion in Communities.”

For far too long, decisions about accessibility and inclusion have often been made without the people most impacted at the table. The disability rights movement has pushed back with a powerful message— nothing about us without us. True inclusion can only happen when people with disabilities lead the conversation.

In this episode, we speak with disability rights advocate Michael Lifshitz about why lived experience must be at the center of every decision [00:01:00] and how communities can be stronger when all voices are heard.

Known in Ottawa and across Canada as an advocate for the disability community, Michael Lifshitz is a savvy businessman, an insightful motivational speaker, and pretty funny when he does his stand-up comedy gigs. Michael was born with a condition called multiple congenital musculoskeletal abnormalities.

While he wears an artificial leg, aging has resulted in Michael walking minimally with the assistance of a walker or cane and using an electric chair most of the time. Contrary to what many would have believed possible, he became a chartered public accountant, and also obtained an MBA from Edinburgh Business School.

Today in addition to continuing a successful career in finance and accounting, a CFO and co-founder of Breakaway Experiences, a gift experience company, he uses speaking, comedy and writing to not only educate people as to what people with disabilities [00:02:00] can do, but to also inspire them to overcome their own challenges and live their life to the fullest of their abilities.

Michael has been a dedicated supporter of ABLE2 for several years, serving as the honorary chair of our signature fundraising gala, Evening in the Maritimes.

I am pleased to welcome to Voices of ABLE2, Michael Lifshitz. Thank you so much for joining us here today, Michael.

MICHAEL

Thank you for having me.

EMELOU

Let's get right to it. So, when we say nothing about us without us, what does that really mean and why is it so important to think about this when having conversations about inclusion?

MICHAEL

I honestly love that saying nothing about us without us. And I think it goes for everybody in every group. I think often we make assumptions. And there's an acronym that if you make assumptions, you make an ASS of U and Me.

[00:03:00] And I always, uh, like that. But I think it's true.

Someone like an able-bodied person can have the best intentions in the world to be helpful and inclusive, but they may not have, and of course they don't have the same experience as someone who lives as a person with a disability. I say nothing about us, without us, having others, or being at the table, I think it's important to have, uh, well, section of folks with various disabilities because it's not a one size fits all approach, right?

I will be the first to admit that even myself, I consider myself an advocate and there's times I don't think of something simply because I'm not aware of what it is to live with a visual impairment or hearing impairment, whatever the case may be. [00:04:00] Uh, so I think it's important to that cross section because we know what we need and what would work and because of our lived experience.

I mean, I've, I've lived with a disability my whole life. We're talking 50 years of experience. I got experience knowing what works and what doesn't. I always joke when I go to a doctor. And the medical student comes in and I'll, I'll listen, but I have a general, uh, policy that if I've been disabled longer than you've been alive, probably I know a little bit more than you about disability.

Uh, so I think it's important that we are there to share our experience and that we know what we need. And who better to say that than the people impacted by it?

EMELOU

Yeah. Yeah, absolutely. And um, I was just writing a spiel about inclusion and it talks about [00:05:00] people with disabilities, often facing barriers like exclusion to systems like healthcare, education and things like that.

Um. And it's true, like if you truly want something to be inclusive, you have to include everyone's voices at the table, especially those who are often facing the barriers to accessing services. Right? Um,

MICHAEL

Absolutely.

EMELOU

So what happens when decisions about accessibility or disability inclusion are made without people with disabilities at the table?

MICHAEL

I would suggest that if it does happen, it usually has to be redone. Uh, because, and I could give you an example, the McDonald's near me. And the first time I, I went there, I was coming back from a show and it's one of the 24 hour McDonald, which is very dangerous. That's when you're coming back from a comedy so late, it's way too tempting to just stop and pick something up.

[00:06:00] Uh, but I, I went, I, I drove. There's um uh, accessible parking right next to the ramp. A good place to accessible park. I get to the ramp, the door doesn't have a button, and I'm like, okay, well we can't get perfect. Okay. So I open the door, wheeled through, I placed my order, and then I notice the door door with a button on the other side.

Mm-hmm. And that's at the top of the stairs. I'm willing to bet that that was built by a person who was not disabled. I just imagine the architect doing, the architect, doing the final walkthrough and here we got, and just going and looking at that and going, oh man, come on. Um, but yeah, I think that is a funny example of what happens when someone's not included and the counter to

that is I was working at a university in the library department [00:07:00] and the director of our library's office, and there was no button on the door, so they got a button installed and when they came to install it, they had me come out, uh, and they said, okay, where would be the best place to put it?

And the result was that there, it was placed in a place, on a place where the door would open without slapping me in the face. I always like the button, but you have to hit the button and then like move before the door hits you. Uh, I think that's what happens when they don't have person with, uh, who's actually going to use it, consulting on what is the best course of action.

EMELOU

Yeah. Many DEI committees include people with disabilities, . What should leaders be doing to ensure that representation becomes real influence?

MICHAEL

I think the important thing is that when you are going to consult [00:08:00] people with, uh, disabilities on an issue, you, you listen to them. Uh, and the reason I say that is I can think of some city initiatives where they're, they have people with disabilities on the committee.

Wonderful. But then if what they say, it's not brought forth to council to make the decision, uh, uh, there, that kind of becomes a problem. And I'm trying to remember what the issue was. I think it had something to do with Para. The users told the counselor representative one thing, but that wasn't brought forward to council.

And it was like, well, it's more just of an advisement. And I'm like, okay, well maybe you should listen to the people uh, who are using the service. [00:09:00] Like, it's great to say we have this much success getting people on time. Okay. But if, uh, like I, I, I kind of was laughing because there was one point I was having had an issue with my pickup, with Para. I mean, uh, Para was priding themselves on 90% of the time we pick people up on time.

And the person I spoke to at Para told me, he goes, I realize it's kind a 50-50 with you. I'm being picked up on time. And I'm like, Hey, well is it just like, how is it that you have a 90% success rate of picking up people on time? If I'm only 50-50? Yeah. Like should I be taking this personally, that I'm the only one?

Or I'm guessing that I'm hearing stories from other people. Um, so I think the important thing I would say is that if you're going to have a user input or a person with disabilities' [00:10:00] input, it's not a question of that we have a person with a disability on the committee. It's actually listening to that person, uh, as to what, uh, issues they are facing.

EMELOU

Yeah, and I, I feel like, you know, uh, places that do that. Like just simply a check mark of, oh, we have a person with a disability on the advisory committee seems performative to me. Right. Like it doesn't, it's just for show.

MICHAEL

Exactly.

EMELOU

Uh, they're not really listening to the things that actually matter.

And so this segues into my next question, which is what are some of the barriers that still prevent people with disabilities from having their voices heard in meaningful ways. So, um, like what I said, getting them on the committee, but not actually listening and implementing what they're trying to suggest is, I guess, one of the barriers.

Um, anything else that you can think of?

MICHAEL

Absolutely, and I think [00:11:00] inviting people to the conversation. So the, the, the example as I was thinking about the question. Example that popped into my head was there was a photo on the, uh, that one of my friends shared, uh, that he was honored to be invited to share his thoughts on the future of the city.

And I'm looking at the picture and I can't help but notice now maybe there was someone with an invisible disability. There was no one with a visible disability in that picture. And I kind of, you kind of start to feel like, okay, well do people with a disability have a future in the city because we're not being invited to the conversation.

And I'm like, given the challenges that we've seen with, uh, transportation. Uh, so I know, speaking for myself in terms of transportation in the city. [00:12:00] Uh, there's been times I'm on the bus and people are upset that the wheels are taking up space and I should be using Para Transpo, I'm like, well, no. People with disabilities can still take the bus because, I'll be honest, a lot of the time I take the bus and when I need it, when I'm able to just to free space on adaptive transportation for people who really need it and can't take the bus.

Um, or just from a flexibility thing. So I, I think part of the barriers is physically being able to get there.

EMELOU

Yeah.

MICHAEL

So if I get invited to an event, often I may not go for the simple fact, I don't have the energy to put in the effort to start looking. Is it, uh, is the place accessible? Can I, is there parking?

Can I get there Easily? Um, if I'm driving, is there a parking lot where I can park with street parking? Uh, often [00:13:00] could be challenging because my wheelchair gets out of the van, uh, out of the side of the van. Uh, so those are some of the barriers I think. Um, um, even something as simple as when you're doing an event and invite people, a little line, this venue is wheelchair accessible would be helpful.

EMELOU

Yeah.

MICHAEL

Uh, so I think that there's the physical barriers, there's the, uh, almost assumption that they're not gonna come. Uh, and I think just, I'm not entirely sure that the, a lot of the programs are that are there to help and, uh, in some ways prohibit participation.

Like, I know I've had, uh, people tell me that they can't come to say a comedy show because their caregiver is set to come and is just in time to help them get

ready [00:14:00] to bed. So they have to be home by a certain time right. So I think some of the supports do limit that independent living to a degree.

EMELOU

Yeah.

MICHAEL

Um, so I think there are still those barriers.

EMELOU

Yeah. And, and I can't believe that in this day and age, we're still experiencing so many barriers that exclude people from participating.

It certainly doesn't take much to add an an accessibility clause in events, right? Like, this event has an accessible washroom, or, you know, it just, it takes less than a minute to add that in or let potential attendees know how accessible the place is.

MICHAEL

Exactly.

EMELOU

Yeah. Uh, you mentioned earlier about that image of the City of Ottawa's plans for the future, and not having a person with a disability part of that picture. In relation to that, do you think representation, matters for you to know if something is, you know, [00:15:00] truly accessible or truly inclusive?

MICHAEL

A hundred percent. I think representation matters. Uh, so for example, I, I do comedy. Mm-hmm. Uh, I think there's something to be said for the fact that, there's a lack.

Like I, I watch tv. There's a lack of character with disabilities. Yeah. And often it could very well be like, I'm thinking of the show Superstore. They had a guy

within a wheelchair. It's an actor. Basic. It was not actually someone with disability it, just him sitting in a wheelchair as a prop.

Uh, which is kind of unfortunate. Uh, or like, I, I was thinking about the show, Fred. Out of six beds, could one be in a wheelchair? Maybe. I don't know. I'm just saying. Uh, so these are kind of the things that popped in my head. Because I look and I'm like, okay, well where, where do I fit? [00:16:00]

Or even just I was talking to someone. I'm involved with an organization, our annual conference, and I'm like, you know, it may be nice, I, I guess not everyone needs it, but when you set up a stage of a ramp, 'cause as someone sitting in a wheelchair, I'm like, okay, well, being in a position where I would go on stage.

I don't see it as a possibility because how would I get up there? Um. Now, yes, of course, if I had to would be a wheelchair. But it's the fact that I have to make that effort to do, like, to me, if we're renting a stage, why not just have one side stairs, one side a ramp.. Yeah. Problem solved.

Um, that's just one of the things, but it, it, it does impact on a psychological level if you don't see the possibility of you doing that. Mm-hmm. What happens, right?

EMELOU

Yeah. Yeah. And that's so,

MICHAEL

So yeah, I think that's an issue.

EMELOU

Yeah, that's really [00:17:00] powerful to have representation. I don't know if you've seen the movie Wicked.

The actor who plays Nessa Rose is an actor who was a wheelchair user, including the younger, like kid version of her role. So, it was just really powerful to see that representation to have someone actually with lived experience, and it kind of shaped how they did the production.

Like they had to make sure the filming was accessible, right? Because they had an actor with, and so I think that's very powerful to show people the possibilities, right. And just to have that representation of people with disabilities in mainstream media.

MICHAEL

And actually, I'll be honest, I did hear about that and I wanted to actually move on and see the movie more because I just want to support the fact that I'm like, alright, it's, I, I, I even, I forget her name, but I followed her on Instagram because I was so excited that a person [00:18:00] who actually uses a wheelchair was in a movie. I was pretty excited about that, uh, It does not happen nearly enough.

EMELOU

So, for listeners who want to be allies to people with disabilities, what's one practical step they can do to make sure they're amplifying the voices of people with disabilities?

MICHAEL

I think by sharing the messages, people with disabilities share. For example, I can talk to politicians till I'm blue in the face about accessibility. If other people start asking about it, I think it'll become a bigger, um, question. Uh, so for example, I know like when very simple example when the disability benefit came out.

Uh, the \$2,000, uh, year, um, and. I only really heard either people with disabilities or organizations like ABLE2 that work with people with disabilities, [00:19:00] like people directly in the space talking about it. It would be lovely to see the rest of the politicians because I mean, yes, we are 20% of the population, but I don't necessarily feel politicians always listen to it.

The example I'm gonna give, uh, I had an argument with, uh, the Quebec government about funding for my adaptive van. Uh, and I won't go into the whole story. But, uh, in Quebec the case, of adaptation, every five years I had a Lemon and need to replace it.

And we were trying to figure out how to do this. Uh, and I was getting the runaround from the government. So I finally decided, okay, I'm gonna go public. So I went on the video, uh, and the, I started a petition. I think I ended

up with like 3000 signatures and I actually had people [00:20:00] contacting their M and H telling them what they thought and echoing the statement.

And uh, uh, it ended up getting settled the Friday before they called the 2008 provincial election. Because I guess “person in wheelchair who's trying to work and needs van” doesn't make a good election headline, so they kind of wind down. But that's an example of other people amplifying. Like, it's great for people with disabilities to advocate for them,

Uh, and another example. Um. One year, a friend of mine mentioned, uh, Evening in the Maritimes, as I think was mentioned in the introduction,

I'm the honorary chair and one of my friends asked me, how come there's not more politicians at the event? Because largely speaking, we're in Ottawa. Uh, we have municipal, we have our M and H, MP. They go. [00:21:00] That's a question you can ask them. Yeah. I, because that was the year I actually tried to invite a whole bunch of politicians and so I, I think it's asking them the question, making accessibility and inclusion, uh, an election issue.

When you're talking to your candidates, ask them what they think. So I think that's where people can be an ally, by asking the question about what are you doing for, um, because ultimately, this may sound cynical, but politicians care about keeping their job to a degree as much as they may have some good attention and that, yeah, I wanna win my feedback or my whatever.

So I think having more people having the conversation means how they can be an ally.

EMELOU

Yeah. Yeah. And I think that's an important conversation [00:22:00] to have because I don't think a, a lot of people realize that disability can happen to anyone at any point in their lives. Right? So, definitely they should have these conversations with politicians, with community leaders and ask them what they're doing to get people with disabilities more involved.

MICHAEL

Yeah. It's funny you say that because I always, I hope everyone one day has mobility issues and the reason why it's, and I'm not saying that to be mean because the reality is what I'm basically saying is that you live long enough, but you, when you age, yeah. It will be more difficult to do those things.

You need accessible, you're gonna need accessible housing. You're gonna need a coffee shop that you walk up the three steps to go to. Now, will you always be able to do those three steps? Maybe not. [00:23:00] So that's where I think, and I know the argument about accessibility is always the cost. We don't have the money to do it.

If we keep on saying we don't have the money. We're never going to get there. Because statistically, I, I don't remember the exact statistics, but we're an aging population, right? The, the older age groups are becoming a greater percentage of the population. What are we going to do when there's not enough accessible housing?

There's not enough. Uh. accessible activities or whatever. Um, it's gonna, if, if not for the moral issue, think about the economic progression of our society, we're gonna need better accessibility.

EMELOU

Yeah. Yeah. That's, that's, that's true. Wow, this has been just very insightful and very, eye-opening. Thank you again so much for [00:24:00] coming on to our brand new podcast and sharing your insights today, Michael.

MICHAEL

Thank you for having me. This is fun.

EMELOU

Today's episode reminds us why nothing about us without us is a call to action, not just for disability advocates, but for everyone in the community. Inclusion is recognizing that it is a collective and shared responsibility because it benefits everyone. And when people with disabilities are included in decision making tables or lead these conversations, inclusion becomes real and decisions become stronger, and communities become fairer for everyone.

Thank you for listening and for joining us in amplifying voices that must always be at the center of building a truly inclusive world.

We would like to thank our presenting [00:25:00] sponsor, Sequence Marketing. As one of ABLE2's most trusted partners, Sequence Marketing has played a vital role in amplifying ABLE2's mission, connecting with communities and sharing stories that matter. Known for their creative and people-focused

approach, they bring a commitment to storytelling and brand excellence that makes a real impact. Their generous support has made this podcast possible. Thank you, Sequence Marketing for helping us make inclusion heard.

If you'd like to learn more about what we do or how you can get more involved with ABLE2, visit able2.org.

Thank you for listening to Voices of ABLE2. If this episode moved you, please share it with someone who needs to hear it.

Join us next time for another story that deserves to be heard.