

Ep. 08 - Dignity Through a Disability Lens pt. 1 Transcript

Music

Maigan 0:10

Welcome to Dignity During a Pandemic: No One Left Behind. My name is Maigan van der Giessen.

Wen 0:16

And my name is Wen Chan.

Maigan 0:18

And we'll be your hosts.

Wen 0:20

The Dignity During a Pandemic Podcast is a community project of the John Humphrey Centre for Peace and Human Rights. This podcast is part of our YEG Dignity campaign in which we engaged with the lived experiences of folks in our community during a global pandemic; to open dialogue about the impacts of COVID-19 and how each of us navigates the struggles that surface. and find hope and strength during these challenging times.

Maigan 0:49

In this week's episode, we hear from members of two local organizations working to support and connect folks with disabilities: Gateway Association and The Self Advocacy Federation. Gateway is a family resource centre and employment centre that provides education, support, mentorship and inclusive employment for the disability community. The Self Advocacy Federation is an organization made up of people with disabilities, that works to help people understand their rights and show them how to stand up for themselves, through education and advocacy.

Wen 1:26

In this week's episode, we have Heath Birkholz interviewing his peers about dignity through a disability lens. This is part one of that conversation. Now, let's hear from Tara Mitrovic, Amy Park, Jesse Andrew, Julie Heffel, Kristen Bolduc, Barbra Oseemeemow, Daisy Stacey, and Sara Symington.

Music

Heath 2:01

My name is Heath Birkholz and my pronouns are he/him. So, what does dignity mean to you?

Amy 2:11

My name is Amy Park. Dignity to me is feeling accepted in my community, and being included in the day to day life, and having the same opportunities as everybody else.

Heath 2:26

Thank you. Okay. What is your name first and last?

Kristen 2:32

Kristen Bolduc.

Heath 2:34

Kristen, what to you is dignity? What does it mean to you?

Kristen 2:42

It means community.

Heath 2:45

It's being part of your community?

Kristen 2:47

Yes. Outside.

Heath 2:53

How so?

Kristen 2:55

All the trees.

Heath 2:58

Oh, so you like the open space? And being able to go out and walk and?

Kristen 3:07

Yeah.

Julie 3:09

She hasn't been out in (*pauses*) ages.

Kristen 3:12

Yeah (*laughs*).

Heath 3:15

How would it mean for you?

Kristen 3:20

My mom would be happy for me.

Julie 3:26

Your mum would be happy for you?

Heath 3:27

Your mum would be happy. Aww. Thank you, Julie. For Sara, what does dignity mean and look like for you?

Sara 3:39

For me, dignity means belonging in society not being forgotten about. Making sure that I can be myself and do things on my own. For instance, being able to book DATS (*Disabled Adult Transit Service*) online, instead of having to force my grandma to do it morning after morning. Having the DATS people ask the COVID questions of me instead of grandma (*laughs*). Even though grandma is the one who makes the booking -- sometimes I don't always tell grandma the truth, because she presumed one thing in yet there's yet another thing going on in this house sometimes (*laughs*).

Heath 4:28

(*laughs*) Sarah, what is the swimming class you normally take?

Sara 4:35

I play water polo, and it's normal water polo in every way (*laughs*). And just being included in the class without having to have an assistant on deck because of my disability means the world to me, like people think that people with autism have to be supervised full time. That is not true! We do not need supervision. We can follow rules just like you. We just may take a little bit more time to understand them.

Heath 5:17

That was wonderful, Sarah. Thank you. So, Barbra, what does dignity mean and look like to you?

Barbra 5:28

Dignity to me and that all is uh people have to be educated sometimes and that all to know what disability is like.

Heath 5:38

Tell me about your writing and your storytelling.

Barbra 5:44

Well, my book and that all is uh, well I'm writing a second book as well. Um well, I'm just uh going to uh sell my book in that all. My first one.

Heath 5:59

When you were writing it, was it making you feel more dignified? Did it look like you were more equal with your peers?

Barbra 6:13

Yes.

Heath 6:14

That's amazing.

Amy 6:15

That's amazing I wouldn't write a book. That's awesome.

Heath 6:20

Absolutely, it's really, really good. And, Julie?

Julie 6:26

Yeah?

Heath 6:26

What is your first name, and last name? And if you want, what are your pronouns?

Julie 6:34

Julie Heffel, she/her.

Heath 6:37

What did the dignity you felt look like to you with our inclusive dance group CRIPSiE (*The Collaborative Radically Integrated Performers Society in Edmonton*)?

Julie 6:47

With them, they always felt like I could move in some way, even ways that I wasn't familiar with. They would push my boundaries and come up with something that (*pauses*) I didn't think was possible to start with, or ended up looking way more beautiful, and artistic, and creative than I could ever imagine.

Heath 7:08

Which was even more awesome, because that came straight from you.

Julie 7:12

Well...

Heath 7:13

(*laughs*) It was essentially coming from you. And you are the one who made that magic possible.

Julie 7:20

I'm not sure which piece you're referring to, so you'll have to call me later.

Heath 7:25

Any of them Julie, any of the pieces you were in and the occasional one that I thought you were in, but you weren't actually (*laughs*).

Julie 7:34

(*laughs*) Okay.

Heath 7:35

Alright. Who would like to go next?

Jesse 7:39

I guess I will.

Heath 7:41

Alright, what is your first and last name?

Jesse 7:45

Jesse Andrew.

Heath 7:49

What does dignity mean to you?

Jesse 7:53

I think to me, in terms of everyday life, it means being able to do and be able to achieve everything, uh, as everyone else does. In everyday life, for example, there are times when I- I place an order at a restaurant, and they will bring me something completely different. So dignity for me is having the ability to- to have my thoughts- my thoughts expressed correctly. So having the ability to communicate is a big part to me.

Heath 9:23

Thank you, Jesse. So the first question Daisy, what does dignity mean to you?

Daisy 9:30

Dignity means- looks like for me is uh having respect for me, accepting me for who I am, and not judging me for what I do and accept my disability and all that.

Heath 9:48

Excellent. Okay, Tara, I think you're the last one to answer the question on dignity and what does it mean to you?

Tara 9:57

My name is Tara and last name is Mitrovic. Due to my disability, I would see people accommodating me in a respectful manner. And also including others who have disabilities in society and activities, and thinking about their needs before, say, continuing on with the activity. Asking questions first would be a good start. Um, they see you as a person, and as a whole, and not just say a person who uses a wheelchair, or just the wheelchair, or just the crutches. Um they uphold your self worth. And of course, don't put you down.

Heath 10:50

I'm thinking about how it looked like to you. When we were in the Justice4Reel, and you were making films.

Tara 11:00

Okay, I was involved in a wonderful program called Justice4Reel: Media Advocacy School. I initially was thrilled to learn about its existence, because I've always wanted to make films. And it sounded like a wonderful project, because you got to make public service announcements about things that you feel are important. Initially, I went in thinking, it would be just like every other place. Because when I go to say, wanting to take a course, whether it's online, or in person, or any event, I asked for accommodations for my hearing disability, which would be CART, C A R T (*Communication Access Realtime Translation*). And it's basically live captioning. So

somebody's sitting next to me and captioning every word typing very quickly. And usually, the answer is flat out no. Because it costs money, and that's the main factor for nearly every organization or facility that I've asked. So um, when I asked, the reply email goes like, "Yes, we can do that!" So, I went from being what would I say, meek and scared, to feeling totally wonderful, included, empowered. And just it was a wonderful experience, because somebody actually cared, that took the steps to include me in the event that basically, the whole world has said no to for many years. So that raised my self worth and dignity. And I would highly recommend asking, even if you've had many no's for accommodations, just keep asking and keep your dignity levels high, even if you don't receive a response that is ideal. Maybe the next person you ask will say yes.

Heath 13:22

Awesome. So, Amy, how has your experience of dignity been affected during this pandemic?

Amy 13:33

Well, one um, I would say that my sense of dignity has been impacted, because of people in my community who refuse to you know, learn math, and to not social distance, which is causing the cases of COVID-19 to once again go back up, which is putting myself and my family at risk of contracting it. The second way, is that because I'm working from home, I have had to go and pick up boxes of files from my work place downtown, and I've had to rely on my dad or my girlfriend to drive me to my workplace to pick up the files, uh whereas before obviously I could just go to the office uh on public transit, and do the work from there.

Heath 14:43

Thank you, Amy. That's really good.

Tara 14:47

My dignity has been affected not only in a negative way, but also a positive way. The negative is, the government is giving uh what would you call- is the federal government is giving able bodied people money every month, because obviously the pandemic is affecting a lot of people, well everyone, financially. Unfortunately the government only sees people with disabilities at a value of only receiving a one time payment, which is kind of interesting because we are human beings too, and we are also financially hurting. But on the positive, I find that magically accommodations that I've been refused for many years by government service providers and many other things have magically started accommodating my needs, such as um, say medical facilities have started using emails instead of phoning, which is perfect for my hearing disability, and what I'd been

requesting for years. So I kind of find it wonderful and ironic that it took a pandemic to be accommodated, I only hope that the facilities that are doing the accommodating in a positive way are going to continue should the pandemic disappear.

Heath 16:33

Thank you.

Julie 16:34

I find I'm really fortunate that he moved in when he [Jesse] did, because without him, my independence would be zero- actually, my independence is zero, but without him I would get nowhere. Cause I take the bus very rarely.

Jesse 16:54

So what does that have to do with dignity?

Julie 16:59

Well, I- I'm a very independent soul. And so to have to ask someone to do things (*pauses*) I haven't had to do that in a while. Like there's very few things that I need to actually have to ask someone. It took me forever to ask for help in the first place. If I can do for myself, then I don't have to worry about having to have someone around. Which makes things so much easier. And gives me dignity, I find.

Heath 17:36

How is it felt for your- your dignity, Jesse?

Jesse 17:40

Well, in relation to dignity, there's a need to support each other. I think it is important to be there for the other person in the relationship. Particularly knowing that they're deserving of dignity -boundaries [inaudible 18:15] they don't tell you um. That kind of support.

Heath 18:31

So Kristen, how has the COVID-19 world that we live in, how do you think differently about dignity?

Kristen 18:42

I need my family more.

Julie 18:46

Oh, you need your family more?

Kristen 18:48

Yes. Yeah.

Heath 18:50

So you miss seeing your family more?

Kristen 18:52

Yes.

Heath 18:53

How often do you get to see your family?

Kristen 18:57

In entirety, my brother has been cut off of.

Heath 19:04

You've been pretty much cut off?

Kristen 19:07

Yes.

Julie 19:08

Well, except for mom and dad. Right?

Kristen 19:11

Yeah, but as well my brothers.

Heath 19:15

And your brothers?

Kristen 19:16

Yes. I already had [inaudible 19:18] brothers.

Julie 19:22

Oh, you have a little brother.

Kristen 19:24

No. Uh [inaudible].

Julie 19:31

I should stop translating for her.

Heath 19:33

I think that it's actually something like-

Kristen 19:35

Help.

Heath 19:37

Do you find it helpful, Kristen, when Julie helps you out?

Kristen 19:42

Yes.

Heath 19:43

Yeah, I think that- if I can interrupt-

Kristen 19:47

Yes.

Heath 19:48

I think that it actually helps her dignity. Being able to have people help make it so that other people can understand what she's- what Kristen is saying. Because what Kirsten is saying is really good stuff, it's just unfortunate that a lot of us can't always hear what she's saying. So it's actually really helpful that you're here, Julie. But Kristen, I would like to hear more about how COVID is affected. your dignity as well?

Kristen 20:21

I cannot go out. I don't go to the mall no more.

Julie 20:26

Oh, yeah, she can't go to the mall anymore, which is something she used to do quite frequently. Sometimes with me!

Kristen 20:38

Yeah! *(laughs)*

Barbra 20:40

My experience of dignity has been affected by the pandemic and all, because someone said that um we are the blame and that all, and we were like the carriers and that all of the pandemic and everything. And I didn't know that I believed that! I seen it all the time on Facebook, and I've seen it all the time on news and all that and it's ridiculous.

Heath 21:05

Do you talk to anybody about it?

Barbra 21:07

Yeah, I did.

Heath 21:09

That's good. I'm glad to hear that.

Sara 21:12

I find that during this pandemic, I'm being forgotten about being looped in with the vulnerable when I'm not. Or at least not as vulnerable, as you would think.

Heath 21:28

How are you being forgotten about?

Sara 21:31

Well, there are a bunch of top down decisions going on, like they're taking the baskets out of the grocery store, in favour of carts. Because it's easier to clean a cart than it is to clean a basket. I need a basket to shop. I can't steer a cart with a walker for darn.

Heath 21:53

Do you approach the manager to see if they can give you an extra basket?

Sara 21:58

Sometimes they do often they don't. Often they argue with me. And they tried to basically say, why don't you shop somewhere else? Or why don't you order your groceries online?

Heath 22:11

Mmm.

Sara 22:12

Like everybody else with your disability is doing it this time. They don't understand that, because I'm on a very special diet, and because my animals on special diets too, that

grocery shopping online is a basic no-no for me. People don't understand that, just because I need certain things at the grocery store, doesn't mean I need them all the time, like Grandma will sometimes try to push me to use what is available at the grocery store and I'll say, "Gram, that's ableism!" (*laughs*). Because I feel safer using what I have used for multiple years.

Heath 23:02

Yeah.

Sara 23:03

I often have to resort to bringing my own basket.

Amy 23:07

Agh. Yeah, that's unfortunate.

Heath 23:10

Hmm. That's interesting.

Daisy 23:13

My experience was before the uh- dignity during the pandemic has been very stressful. I haven't been able doing much. I don't work. I don't see my friends as much as I want to, before this came- came along. It's just very frustrating. And stressful.

Heath 23:38

Thank you. So because of COVID-19, how has the changes in being able to access your supports- your natural supports been changed?

Tara 23:54

First of all, please, could you define natural supports?

Heath 23:58

That is a good question. So natural supports can be basically whatever you feel is within your inner circle of things that you know that you can go to if you're in a situation or that if you need to vent or bring up something that those are the resources that you go to. So it can be family, but it could be friends or whatever structure you want to make it.

Tara 24:28

Okay, I kind of would include my medical supports since the pandemic, all my medical appointments are basically canceled. However, I was not notified at all! So I was still making the effort to go to the appointments, arrive on time, wearing appropriate safety,

masks, gloves, etc., only, um, to discover after traveling for over an hour to get to the appointments, oh, your appointments being canceled because of COVID. But nobody took the time to message me even though this has been going on for three plus months to inform me, my appointments have been canceled. So that's been a huge issue and has happened multiple, multiple times. Also, I've had many medical appointments that I frequently attend, such as physio, etc., permanently discharged me because of COVID. Because they don't deem it necessary, even though I was referred by a doctor. I can understand safety precautions, but procedures and support such as physio that I do need can be done safely with say masks and gloves. I can understand the worries, but I think they are kind of going a little overboard in certain areas. I know safety is very important. But I also have a huge major issue with, um, communicating with uh medical individuals. Initially before COVID, but now even greater, such as booking appointments. Um, I'm severely hard of hearing, so I require support help to make phone calls. Of course, I only have supports during certain timeframes. However, when we make the phone call, we get the automatic messages, which is okay, but we're then informed that they're only taking phone calls or even messages between certain hours. And of course, they're never the hours that I have support in. So that's been a massive barrier.

Kristen 27:11

And I fail to take DATS.

Heath 27:17

Yes, DATS.

Julie 27:18

She hasn't been taking DATS.

Kristen 27:21

Yeah.

Julie 27:22

She hasn't gone anywhere. She was sometimes- every day of the week you were out with DATS, right?

Kristen 27:31

Yeah.

Amy 27:32

Um, for me personally, it- it hasn't impacted my natural supports, because my girlfriend and I live together, and I still see my dad, and I'm still able to take the Disability Assisted Transit. So it- I mean, I- I consider myself very lucky that it hasn't really affected me in that way. But I know for a lot of people it has.

Music

Wen 28:10

Thank you to Heath, for leading that discussion amongst Tara, Amy, Jesse, Julie, Kristen, Barbra, Daisy, Sara, and Brienne from the Self Advocacy Federation and Gateway Association. It was fantastic to get so many voices on to discuss dignity in the lens of disability during a pandemic. We want to send a shout out to both of these organizations for partnering with us from the beginning of YEG Dignity back in 2015. To follow SAF and Gateway Association's work, you can visit their respective websites.

Maigan 28:50

For full transcripts of this interview or to view past projects of the YEG Dignity Campaign, please visit our website at jhcentre.org. Thank you to our funders: the City of Edmonton and the Family and Community Support Services program, who have made this podcast a reality. And huge thanks to CJSR 88.5FM for airing our podcast.

Wen 29:16

We produced this week's show on amiskwaciwâskahikan, also known as Treaty 6 Territory and as Edmonton, AB. We recognize land acknowledgements are only a small part to engage in ongoing reflection, practice, and action against the legacies of colonialism that impact us today. Thank you for supporting this project through your own engagement and reflection. To follow SAF and Gateway Association's work, you can visit their respective websites. We hope you have a lovely rest of your day whatever time it is for you.

Music