

Audrey:

Let's start with introductions and your thoughts on the language of disability and the term itself.

Participant 'N':

Can you hear me okay first of all? My name is N. My indigenous name is _(Indigenous Spirit Name). I am registered with X First Nations. And I'm X (Indigenous Nation), Bear and Turtle Clan. I'm a social worker and I've been blind or visually impaired all my life. It's not a hereditary blindness, it's from when I was born, I was premature so it's retinopathy of prematurity. And so, for me, I think that 'disability' term has always been there throughout my life because that's how I've identified. I think for me, it's been more around actually finding space as an Indigenous person that I can be allowed to be in. Because for those that may or may not be able to see, I don't look indigenous. I have the higher cheekbones and all that and many people say when I'm speaking, I certainly 'sound indigenous', whatever the heck that means, but anyway. So, for me it's about trying to find spaces as a person; that is indigenous, that's blind; to be able to, like, learn my traditions because I wasn't raised with them. And I've been slowly taking that decolonization work on myself and praying to find people to work with. And, you know, people have come my way which is amazing. So, it's, I'm really glad that you're doing this work. I, myself have been trying to do this work for quite a while and I've done quite a bit of work with expanding the circle with Marsha Renu. I'm doing another project around the accessibility, accessible Canada Act, where indigenous peoples are concerned. And just really want to live and work in my community, I'm in Toronto. I'm a parent, a grandparent. I think that's it for now, I'll pass it to someone else, is that kind of what you wanted?

Audrey:

Yeah, that was awesome. Thank you. Miigwetch.

Miigwetch.

T would you like to go next?

Participant 'T':

Hello, my name is T. I live in Brampton. I'm from X and I'm a mother of three son, two twin daughters that were born three months premature. I am mixed native and black culture and I am suffering with, I'm in my final stages of kidney failure. I also have arthritis in 14 joints. So, to me when I hear 'disabled', because I was an able-bodied person and now, I'm in the category of disability; when I hear the word 'disabled' to me it means like I no longer can function at what people expect of me. Oh, starting to cry.

Wanda:

Alright T. you go ahead right now.

Participant 'T':

The hard part for me too was being in touch with my culture because my family, like most we weren't aware of a culture. The X culture, being of mixed Aboriginal descent because our

families didn't talk about it. So, for me to just find centres in which I can learn about it is a difficult task. Because in Brampton, there's not too many. I have to go to Toronto, or the Greater Toronto Area in order to go to these centres. Also, I find being in and out of the hospital, when I'm in the hospital there's a prayer room but you can't smudge - you can't. Yep, all there is a space for meditation. Like I am not included with what my traditions are. Okay, thank you.

Audrey:

Thanks, T, I appreciate that it's difficult to share and if anybody ever needs to take a break, also Wanda's here and can light the medicine again. I really appreciate you all having the courage to join us. L.?

Participant 'L':

I'm here, my name is L. My spirit name is ____ I'm Deer clan and I'm from the X nation, which is in the Arctic area. I damaged my spine. I basically collapsed in an apartment building in 2005 and it's taken me five surgeries to rebuild it so I'm able to even sit up in bed and I'm now able to walk around with a cane. I'm not someone who was born disabled physically. I do suffer from mental health conditions as well. And the last hospitalization I had at St. Mike's, I had to fight very, very hard tooth and nail going up to the ombudsman, ombudswoman for access to the prayer space and the ability to smudge. And in that process, it really taught me how to advocate for myself. My partner was bringing medicines in and they were saying I couldn't have them on the floor. And I couldn't have loose tobacco around in case I had the urge 'to smoke it' even though I was using it as offerings. So, that was a very difficult learning process for me about how to advocate for myself when I was really, really, really, really ill. The word 'disability' to me, has always been used towards me as a slur. Especially by a former employer of mine, who didn't respect my rights at all as someone who needs accommodations. So, I'm learning more and more how to advocate for myself and I've spoken at length with X (Toronto Agency) about my accessibility needs when it comes to accessing a sweat lodge.

Audrey:

Okay, miigwetch. I actually forgot to introduce myself, which is rude, sorry about that. I am Audrey Huntley, co-founder of No More Silence, I go by she/her. Yeah, I do use the term 'disability' to describe mental health challenges that I have when I need to get accommodation at work and in a legal sense. But I also feel like it's most often used as a slur. And I'm finding that I appreciate it more when people use language like 'differently-abled' to describe themselves. Do you want to introduce yourself Wanda?

Wanda:

So, yes, my name is Wanda, Mi'kmaw individual from the East Coast. I guess it was just over two years ago, January 2019, I lost the use of my legs. Before that I was an able-bodied person I would, well it wasn't so great but I got around on a scooter. I could move around, get around. I had spinal cord surgery and as a result of that, when I woke up in the ICU, I didn't have the use of my legs. So, I've been struggling with what that means. When one day I realized; and I was in rehab when I realized this; because they wanted me to stand up and I wanted to crawl. Because I wanted to be able to crawl into a sweat, but I can't. And so, then we talked about what an

'accessible sweat' would look like and that's when the dream occurred. To see we can possibly build an accessible sweat. Well, one that welcomes everybody not just, not just those that don't use their legs as we've been hearing from people around their different disabilities. I'm sorry, that wasn't a term I should use. 'Differently-abled' is how some identify. It's been really nice to learn that people need more room in the sweat, they can't sit up, some have claustrophobia. I mean, I've always made accommodations for people in many areas. I'm a harm reduction person. If somebody wants to abstain from the use of drugs and alcohol then I support that too. But there's some who can't, there's some who don't want to do that. There are people who smoke medicinal marijuana or eat marijuana, there are so many ways now in which the medicines we use for our own healing. So, that's where I'm at and I'm happy you're all here. Please feel safe in what you need to share and if you don't want anything at all posted on our webpage, then that's absolutely okay. So, thanks.

Audrey:

So, our second question ties into the idea of what 'disability' means and we understand you're not historians but we'd like to know your thoughts on how that concept of 'disability' aligns or doesn't align with indigenous culture and tradition? Is it something that you think existed prior to colonization? Or what do you think was the case for people who were 'differently-abled' prior to colonization? Do you think that there was that concept?

Participant 'N':

It's N, I can go if you're going in the same order, or I can let someone else go doesn't matter to me. Okay. So, I think that before colonization we were all in community. That's my belief. I believe that someone like myself, that would be blind, would be welcomed into the community - would be supported into the community because it would be a healthy community. There wouldn't be addiction, there wouldn't be generational trauma and so on. So, I would like to think that someone like myself would be supported.

However, I think the bit of work that I've done with some Elders is that my blindness for example, is a gift, that this is the life I've chosen for myself. There's that thought that I've been taught, and I do know it, it seems to change depending on which Elders you speak with it, it shifts a little. And I'm probably not giving it justice by any stretch of the imagination. I think the thing for me though is if I don't name my blindness, so I don't personally love the 'differently-abled' language because I feel like it labels me even more. Like I'm "different or quote-unquote "normal" quote-unquote. So, it's kind of, sometimes I struggle with what words to use and so on, depending on the spaces that I'm in, I may say 'a person that's blind', because then it gives a different a clearer picture. I've never in my life, gone to a sweat, which I would love to do. And I will name X (Toronto Agency) absolutely, they have some amazing Elders there for sure. And I know we're going to get into this but I need to use this as an example because I find sometimes when I say things, if I use stories, then people get the picture clearer. So, there was a sweat and the organization I was working for at the moment was folding. This was just before the pandemic. And so, I was really struggling with 'I need - I need to do a sweat'. I smudge, I do prayers to Creator look for other ways in which to heal and so on and move through the world. And I get there and Knowledge Keeper that was leading the sweat came out and he said, "Well, you can't do it, we don't have anybody to support you. You know, you didn't bring extra clothes

with you," you didn't do this, you didn't do that. I'm like, "well, first of all, I didn't know I needed to and second of all, I was told that the sweat was open to anyone. So, are you then saying I'm now not 'anyone' because I can't "see" to navigate within the space?" I was devastated. Because here I am, as a social worker that's worked in a community for many, many years in Ottawa and Toronto. Honestly, struggling with trying to learn my own traditions, as much as I possibly could and yet another barrier. And at a time in my life that ... I was like, "Are you kidding me?" And my facial expressions give me away like I, so they knew I wasn't happy. Yeah, he knew I was not happy and I said, "I'm going to take this to 'name of different knowledge keeper'. This is not okay." And so, then it becomes a conversation around, 'okay, how can we accommodate you to be in sweat in a good way? And it's going to take time and conversations.' It's like, are you kidding me now? Like, are you kidding me, like, so I can't do it when everybody else can and/or wants to? So, like, I think language is important but I also think that indigenous communities have to be open to us being there. Whether it's an education or training that I give them or anybody gives them or whether it's like the chiefs and so on from Assembly First Nations and doing it in a good way, in a respectful way. Rather than just being silenced or being told "No, that's not our way." Well, we need to make it our way. How can we do that in a good way? I don't believe for a moment that it can't be done. So, I'll just share that.

Participant 'L':

Thank you for sharing that. I'm sorry, that happened to you.

Participant 'N':

And that agency does do a lot of amazing work. I do want to be clear about that. They do. I think we can all do this learning, myself included. So, when I say "we can all do this work" I'm saying I can do this work too. And I'm happy to do it alongside and with folks.

Audrey:

Thank you so much for sharing that. Sorry, that happened, it shouldn't happen.

T, did you have thoughts?

Participant 'T':

To me, before colonization I believe everybody was accepted in that if anyone was slightly different it was considered a gift. Just like what I've been taught and what I've heard.

So, to me, I've always been; because our culture, being of indigenous descent; we've always been accepting of people different like two-spirited. I just naturally assumed the community would automatically accept everybody and no one would be left out in anything. We always took care of the people that needed care. That's just how from the stories I've heard from my family (and stuff like that) because we've had seven generations within Canada. And I, the stories that have been passed down with people with different situations, we've always taken care of each other. Yeah, that's about it.

Audrey:

Thank you. That was great. So, the principle of care and taking care of everybody, I think is really important indigenous value for sure.

Participant 'L':

I was just saying this is sort of a difficult question for me to answer because I want to paint a rosy lens that my community would have supported me not being able to walk. But I also know the reality of how harsh it is up there and how everybody has to contribute. So, I'd like to think that my community would support me pre-colonization. Having me do a different sort of task as opposed to taking on the hunting role. Because in my communities (it's) the women who would hunt alongside the men but the women would be the ones who be taking in charge of the hunt. So, I'd like to think that I would be supported and not expected just to go and there's a concept that when people are disabled and they feel like they're a burden to the (I think this might be post-colonization). But, this idea that if you're a burden to the community, it's best to remove yourself from the community and go off 'into the storm' and never come back. I'm not sure where that story came about, or that idea, that if you're a burden to the community you should remove yourself from the community. I'm not sure but I'm pretty sure that it sounds like something that would have been a post-colonial idea. That if you can no longer contribute, you are expected to sort of remove yourself from the group because you're not able to contribute just because the conditions up there are so harsh and it's so difficult and being nomadic. I'm not trying to paint my people as 'bad' I'm just accepting the reality of some of the stories that have been told down to me. But I also know that my community is extremely caring and there's been stories of elders who've been hitched up to sort of like wagons and dragged alongside, along with the group, as it migrated from place to place along with the reindeer herds. So, it's a difficult question because I want to see it as like "good" or "bad", like 'pre-colonization we were awesome'. And then, suddenly 'colonization' happened, everything fell apart. And I know that it's not that black and white. Regarding X (Toronto Agency) I felt a lot of the burden for advocating for people with disability; especially considering that the elevators don't work sometimes in the buildings, you know. Let alone like access to ceremony; a lot of the burden fell on me to have to advocate for myself and for other people. It was difficult to be put in that position. Sometimes with the Elders having to explain this idea that "well you should have notified us in advance", or "we don't really have a policy in place for this." But the Elders when I worked with them one on one, the lodge keepers, they were really willing to be accommodating. It was more like 'the bureaucracy' was stuck on this idea of like, 'Oh, we're going to have to change everything. And we're going to have to change the way we do ceremony.' So, the bureaucracy was different than the individual practitioners, who I felt were very, very welcoming and willing to accommodate me. So, I'm not sure if that's a, that might be a systemic issue that needs to be addressed, that maybe some agencies are afraid to take on people who are differently-abled, or clients who are differently-abled, because they bring 'extra work', or 'extra burden' or 'extra thought' into how they do their traditions. That's really all I have to say.

Audrey:

Okay, thanks for that. Our next question is, kind of like some of you've already started to answer it, is: "Have you experienced barriers when in or 'in accessing' cultural spaces or ceremonies? So, some of you have already touched on it, have there been barriers, like N described,

basically not even being allowed to access the space or that have made it difficult to access a cultural space or ceremony?

Participant 'N':

I think barriers are attitudinal barriers. And to the person that just spoke about "systemic barriers", those are barriers too, like, barriers have such a wide range of scope that it's incredible. But when I do training at shelters and so on. And or I'm doing what I call 'disability awareness training', I always say that the biggest barrier is the attitudinal barrier because it's the policies and procedures that are in place that that create barriers. So, for me, oftentimes for example, people speak about barriers and they talk about a ramp or they talk about an automatic door opener or elevators. That's one level of barriers but for example when I signed up for some cultural, workshops through X (Toronto Agency). I specifically asked them for a Word document, because I use a screen reader as a blind person, they sent me a PowerPoint of a presentation. So, then I requested a Word document again because I can use a PowerPoint with my iPhone sort of, because my iPhone speaks to me, but to read it in a wholesome way from beginning to end without it breaking up and getting the content it's not great. So, it's about accessible formats. It's about kind of always having to ask "can I have a Word document?" And then I got to say, "I'm blind, I use a screen reader." Or I'll say, you know, you know, I want attend, I want to attend a powwow at Ryerson. And they're doing a really amazing thing where they have peers now and for the first time ever when I went to a pow wow two years ago, I was able to go to the pow wow with the person and that was amazing. But ten other pow wows previous I couldn't participate, right? Unless someone was with me. So, there's so many barriers that are hard to name. But with the barrier comes the voices that, the voice that I constantly need, to have to ask for those barriers, and it does get exhausting. It does get, it's kind of like, 'okay, I get this part of my lot in life but holy crap.' It's a bit annoying.

Audrey:

Thanks. Who else wants to add to any barriers they've experienced?

Participant 'L':

Wanda if you could explain a little bit about the barriers that you have faced? If that's ok?

Wanda:

That's a really good question. I think that I'm not even sure if I faced any barriers because when I lost the use of my legs, I certainly felt that I wanted to learn to crawl versus walk to get in the sweat. So, I haven't tried to access anything. Except I know I wouldn't be able to get in a sweat. I don't see that there's anything else that you couldn't access with any disability other than the Sweat, the Sundance or the Shaking Tent. It would depend on the ceremony and I mean, you could access the Sundance I mean, I don't see that being a barrier. So, the one that, the thing that I'm trying to do, or what I realized was that if I want to sweat, I'm going to have to build it. And I'm going to have to build it so that it can accommodate me in a wheelchair or some other form of transferring because you can transfer without the lift so, I don't know. Good question though I don't think I've thought about it. I guess because I'm like a bull in the china shop if you

say no to me, you don't usually get away with it. Good question. Does that answer your question?

Participant 'L':

Yep, thank you for sharing that.

Wanda:

Okay. I appreciate you asking. Good question.

Audrey:

And T, did you want to add anything?

Participant 'T':

To the barriers mine's being in and out of hospitals because of what I am dealing with the kidneys and that. My problem is that once you're in the hospital the prayer and meditation rooms are very difficult to access because some of them are locked up. Some of them you can only use them during certain hours and we all know, culturally, I can wake up at two o'clock in the morning and I need that time. And I need to go into the room and possibly smudge or do whatever I want but you can't do it within a hospital setting. And just for them to be open to different cultures and their practices some of them are not accepting. That's about it.

Audrey:

Okay, thanks. Well yeah, we certainly know, more recently, it's become even more obvious like how deep the systemic racism runs in health care. With the experience of Joyce Echaquan who actually live streamed her own death while she was being mocked by nurses.

Participant 'L':

Can I add something about disability accommodations?

Audrey:

Our next question is: were you able to achieve accommodation and can you describe it, who assisted with that? Did you want to speak to that L?

Participant 'L':

Yeah, sure. Somebody out in Manitoba, his name is Dave Keshane. He invented a little stool that I can use when I'm inside the sweat lodge, it helps me sit better. It doesn't change my position in the sweat lodge, its makes me a little bit higher up so I get a little bit more of the steam. But I bring it everywhere with me, and I sit down with the person doing the sweat. And I explain to them what the stool is and how it helps me and my partner actually built it for me. And I find that, at first, people are really skeptical about bringing 'outside things' inside the sweat lodge. But when I actually get a chance just to show them how it improves my ability to sit in the sweat lodge, I find that people are really open about allowing me to bring it in as long as it's like "prayerfully" brought in. So, that's something that I've just sort of had ad hoc. I've always wanted to show people it and explain how to build it so other people can maybe build it and make it

easier for people who have disabilities regarding their functionality of their legs. But I found when I've been proactive about that kind of stuff, people are more willing to, I guess because when I show up there and I'm like, 'I'm coming in and I've got this thing and I need this thing in order for me to be able to be comfortable in the sweat lodge'. There's a lot of skepticism at first but it seems like maybe I'm just a good talker, I don't know. But I'm able to sort of convince people that even though this isn't traditional, like this is something that was invented just maybe a couple years ago now, it can be allowed into a sacred space. So, I've been really lucky that I haven't faced any, no sweat lodge leaders deny me access with my special little stool. So, but the process is you know, it's nerve wracking to like, go up to a sweat lodge Elder and the person's eating and be like, "can I have five minutes of your time? I know you've got like 1000 things going on but can I just have five minutes of your time just to try to, maybe change the way you've always done things? I hope you don't mind." And because you don't want, you don't want to face rejection, right? Like so I was like, 'Can I smuggle it in?' Should I try to like, you know, leave it outside the sweat skirt where I'm sitting and reach under the tarp and pull it in? Or, or what? Right? Like, but I guess I've been really lucky because it's - and it's made out of natural materials it's not like I'm bringing in a plastic chair but it'd be fine if I had to, right? Like, it's just a process of like, not a lot of people have the ability to advocate. Or maybe they, or they're you know - cause that's asking a lot of people in the middle of a ceremony to be like 'I need some extra support'. You don't want to take away from the group, you don't want to bother the Elder, you don't want to upset the routine that the Elder's had. So, like, I guess what I'm just trying to get as I found a 'workaround' but I do appreciate that not everybody has the ability to even advocate or ask- if it's a first time at a sweat and you don't know anybody and you can't be like, "hey, Carl vouch for me," or something right like, it can be very difficult and intimidating and I can, I can appreciate that. But I have luckily found like, at *Toronto Indigenous Agency*, the sweat conductors, conductors that I've worked with, have been willing to give me extra time to get myself settled. And when they open the door between rounds like they give me extra time, so I do feel accommodated by the individuals who are putting on the sweat lodge. Like I said it's more like changing the way that people with disability or people who are 'differently-abled' are viewed in our community that it's not - we shouldn't be felt like it's a burden to ask for extra support. And we shouldn't feel like we're changing the way sweat ritual or ceremony is done because we need extra support. And I just wish I didn't have to feel that way when I'm asking, like a new sweat conductor, like "is it okay for me to bring my little stool in?" But like I said, overall, I've had more success when it comes to just speaking with sweat conductors personally as opposed to going through like the bureaucracy of asking for change and that's unfortunate.

Audrey:

Okay, thank you. I think that is a good example of an 'attitudinal' barrier. So, basically, you know, if there was more of an openness and not such a rigid kind of approach to how ceremony is done then there'd be room for that. It should be perfectly acceptable for people to ask for accommodation, I think.

Participant 'N':

I've advocated, very strong, like, I am very clear when I ask for what I need. I think there is certain voices that are heard "over others" and, or if- if, you know if I say went to Alderville First

Nations where I'm registered and I'm with my sister, or maybe one of my brothers, and I'm participating in a pow wow, there's no questions there like I just go. The accessibility piece though, is like, where can you go and do Sundance? Who can do a Sundance? How can you get access to that information? I've, you know, lived in Toronto for 14 years now and piecemealing things together is an access issue, like I've been told by Elders and knowledge keepers, "well, we don't know how we can help you walk up a hill to do a Sundance." I'm like, "my legs work very well, I'm very, very privileged that they do and I can tandem cycle and do those things it's my eyes that don't work. I just need to be guided. You know, so I think it's a very complicated conversation because there's many moving parts that need to be addressed and while I know that not everything can be resolved in one conversation or so, I do hope that offering suggestions like, yeah, I want to do a sweat and if it's a matter of being a matched with someone to do it with a peer for the first time I'm okay with that. But give me that option, like like, someone that can guide me through it, right? Like I know you're in it, so I don't see, right? So, I, what I know, by pictures and what someone have said to me because they've described it, you're kind of in a tent, for lack of a better word, and it's really hot. And you have to know when to move and when not to move. So, it would be someone that would need to tell me when to go and which direction because I wouldn't want to do anything inappropriate. Is this is making sense?

Wanda:

Absolutely it's making sense. I'm somebody who does sweats and have been doing them up until two years ago. So, it's a dome-shaped structure that represents the womb of Mother Earth. It brings together the elements of fire, water, earth, and air which is connected to the creation story. So, once you get in there, I mean you crawl in there and so you would have to avoid the pit. Which, once you got in and you were sitting in the space that you were sitting in and you wouldn't have to worry about acts like falling in the pit or anything because you're not going to move. And it's dark in there, it's so dark in there that you can't see your hand in front of your face. So, you're used to that. So, I see that you have a 'one up' on most of the people who go in are afraid of the dark. So, I'm sorry those things have happened to you. I mean, I've always asked people what it is they need when they come to the sweat. What it is they need, it's good to know in advance but you don't always know. But, you know, because you have to accommodate everybody and knowing that, how much room, because sometimes it's a very small space.

Participant 'N':

So, the excuse that I got. That there were, that there are quote, unquote "sweat hogs" and we didn't know you were coming. So, therefore, "we can't accommodate you." But there was no option of maybe we could do another time.

Wanda:

Oh, I am so sorry. I mean, 'sweat hogs' are people who should know better. They should already be understanding the seven sacred teachings of love, respect, honesty, humility, courage, they should already be living that life. So, they should. I mean, as a sweat lodge

conductor if I had someone in my sweat that was averse to the fact that you were participating in, then I'd ask them to leave. Because they weren't being kind. I mean and the fact that one thing that could be very easily solved for you is that you need a guide. So, maybe you might need to bring your own and so that would be accommodated too, right?

Participant 'N':

But it shouldn't need to be 'bring my own'. I don't, if you're if you're talking about full inclusion then it's about being able to go somewhere and fully participate from beginning to end. Period.

Wanda:

Absolutely.

Audrey:

Yeah, people have brought up, it has come up a couple of times, not just for; like with a variety of challenges; the need for conductors, or helpers. And it's just I think, an option that some people might feel more comfortable with someone that they already know. And that they should have the option of bringing someone.

Participant 'N':

And a helper nearby that like Wanda gets the whole harm reduction piece, you know, or someone that is going to understand that emotions come up in various ways in which they do. So, when there's accommodation issues within our own culture to even learn them and the people that have that - that as their, whether they're an Elder or a Chief or w a grandmother or knowledge keeper, we need to start from all those places. I really believe we all need to do this work.

Participant 'L':

Were you not offered the assistance of an Oskebewis?

Participant 'N':

No, no. No. I, I was told very clearly that nope... yeah.

Participant 'L':

I'm sorry to hear that.

Participant 'N':

And you know, and I don't want to take up too much space for other people. It's one thing if it happens once but when you try to go and learn your own traditions and cultures multiple times and you're constantly trying to find people that will be willing to work 'with' you. It's exhausting. Like, I have a great deal of patience. So, it's hard.

Wanda:

Yes, it is.

Audrey:

It is really ironic. It's ironic when those spaces that are supposed to be for healing actually turn out to not be very welcoming and very healing.

Wanda:

And create more damage than they do help.

Participant 'N':

Yeah, exactly.

Wanda:

I have to say that I've done sweats in prisons and I had, in the youth jail, I've had both somebody who has no sight. But the one that I had was also someone who couldn't hear. So, we had a sign language interpreter, who was a staff person, come with them. And the only time this individual, I forgot I just remembered, it was that this individual couldn't hear the prayers because it's dark inside; and we do ceremony but she was told what to expect; and then when the door opened, the interpreter and her would have a conversation. And then she could say her prayer so that we could hear it. Because of course, it's in her heart, she knows so I, I'm so sorry. Like, it just goes beyond anything I believe that we do.

Participant 'L':

And as Oskebewis we were trained to help. Like, that's part of your role so I'm just surprised that nobody saw that gap or that need.

Participant 'N':

The conductor overruled them....

Audrey:

He just lost all my respect.

Wanda:

Damn.

Participant 'N':

Well, it's a learning curve and I'm willing to work with him for sure. So, I think it's going to be like, so he just pushed it back to the Oskebewis, and I guess will work on it.

So, did you say the conductor refused to?

Participant 'N':

Yeah.

Audrey:

I mean it is one of our, the goals of our project will be to develop guidelines and then present these to the agencies, all the agencies.

Participant 'N':

So, I hope when you do that, we can all be a part of that.

Audrey:

Yeah, we can certainly run that by everyone who participated.

Participant 'N':

Yeah, great.

Audrey:

That's whenever we do this kind of work it's always very participatory, so we're getting your feedback now. I mean, we're consulting with you at the very beginning of the project and every step of the way we will touch base to let you know.

Participant 'L':

Can someone light some medicines, please?

Audrey:

Sure.

Participant 'L':

Thank you.

Participant 'N':

I know I don't need to apologize for this being really heavy, I just want to name that it is hard. Right? So, just, I'm just appreciating that however I can name that for folks so thank you for having space to say that because I, this is to be honest, Wanda like this is like one story of many. Yeah, so if I can find an Elder to work alongside with I would be so happy because the stuff I've been told is, yeah, anyway I'm going to let other people speak.

Wanda:

You're going to be okay, L?

Participant 'L':

It just really hurts me to know like, I wish I would have been there that day. Like, I'm not sure when this happened but like when I was affiliated with them like I, I just took, you know, I guess maybe because someone who, like myself is differently abled, I sort of always keep an eye out for it. But when they can't even get their elevators to work, you know, like, in a building, and that's not considered an issue, let alone like accommodating someone for a sacred ceremony? It just sort of really shocks me and I, I don't really know where to put this information, because ..."

Participant 'T':

I just have a question because I've never really participated in a sweat lodge. And depending on my illness, at what stage I am, I'm about to be fitted for dialysis, but I'm using the portable process.

If I'm doing my treatment; because you can walk with it and do whatever you have to do through the day and it gives you more accessibility; would I be able to carry that within the sweat lodge?

Wanda:

I don't see why not. I don't think it's a really big contraption that you'll have?

Participant 'T':

No, it isn't.

It's about the size of a carry-on.

Wanda:

Okay my concern would be, and I would - you would have to know that is that you sweat a lot in there; so if that doesn't interfere with your dialysis in any way. Like, you would then have a PICC line, would you not?

Participant 'T':

Yes. Yes, I would.

Wanda:

Of course. Are you attached to the machine 24/7?

Participant 'S':

No, it's just at certain times you have to do your treatment.

Wanda:

Right, so and the way that I see is that we would do it, you would come at a time after your treatment.

Participant 'T':

Okay.

Wanda:

And the reason why I say that is then you will have done your dialysis and you will feel better. My only concern would be, when you detach all of that equipment, do you cover? What do you cover your PICC line with?

Participant 'T':

There'll be, it comes with - well, there's the process while I'm waiting; and presently I have a low function; but by the miracles that they say I'm still not needing dialysis, because I'm at 9% and I should have been already hooked to dialysis but I'm walking around. And that's the spirits that are helping me but once they're going to place it in and under my skin until I need it. So, when I do need it, now they're going to take it out and then it's going to have its own little like cap and dressing type of thing. That it's covered when you're not using it, it's covered. And then you have to be loosed up yeah. And it'll be at my stomach.

Participant 'L':

I think it might be bringing the machine in too, right?

Wanda:

Yeah, I wouldn't bring the machine in. I would say the best part, the best way to do it is after you've had your dialysis and it's been un-attached to your body, that you wrap that area in terry cloth.

Participant 'T':

Okay.

Wanda:

Or cotton or something. Because it's going to get hot in there.

And I don't see any, I mean, your legs work really well whether you have dialysis or not?

Participant 'T':

I've got arthritis, you know I'm 55, a little stiff.

Wanda:

Yeah, well we're good with that. Yeah, no I don't see why you can't participate.

Participant 'T':

Okay. Thank you.

Wanda:

The thing that I see in talking with, I guess it's me as a sweat lodge conductor, but you know, it's not even a but, when we put the "guidelines" together or whatever it is, then we will put together best practices. So, they will know that if a person comes, that is on dialysis, peritoneal dialysis that the best practices would mean that after dialysis, they come to the sweat, before, you know like, you have a good day or two or however long before you need your dialysis again. So, I would think that the dialysis would have to be done and you'd sweat within the first few days of the dialysis being done. And then it would be stated that the area that we covered was something of a terry robe or a 100% cloth. And so, then they would understand what the accommodation was. Because the Elder may not know what that means. Now I know for a fact

that my teacher did dialysis at home. So, I'm quite familiar with dialysis, I would go and she would be doing it at home so she would still come to ceremonies with us.

Audrey:

So, we need to transition and slowly wind it down because we started a bit late, unfortunately, we don't have a lot of flex time. Fortunately, everybody has said a lot of really amazing, useful information and touched on the last questions which were how you want disability focused organizations to relate to you as an indigenous person. A lot was already said about hospitals there. And then the other question was, what would you want indigenous focus organizations to know about your disability experience? If anybody has any comments, on those points at this time would be great, if you could share.

Participant 'N':

So, I think that in both cases, whether they are a disability organization or an indigenous organization, I feel like there should be sets of questions to ask. Let 'us' tell you what we need, how can we best support you? What information do you need and what format do you need it in so that you can attend an event in a good way? The model of this project in terms of being inclusive, they could start to try to model that, in terms of whether it's someone that requires ASL or clear language documents, documents for someone that may have an intellectual disability. Or even if it's someone like myself, who would love to find an Elder to shadow or maybe even to be an Oskebewis. I've never been given that opportunity. How can I be in my community and work in my community and give the knowledge that I have, back? Some, some kind of like, I don't know if it's, like peer or if it's like, working with an Elder, someone said to me once, "Well, you have to find an Elder and work with them for five years. And that's the only way you're going to be recognized in the community." I'm like "Okay, so how do you get into the community when you're not - when it's not inclusive?" So, finding creative ways to work together with one another would be great, a starting point.

Participant 'K':

It might be a good idea to audit what they already have in place to see where their strengths and weaknesses are?

Audrey:

Yeah, that's one thing our partners on this project do, they are CILT (Center for Independent Living) and they do accessibility audits. So, you know, we don't have an endless budget to have them do an endless amount of audits, but we do hope that they'll be able to audit at least, you know, one community space.

Participant 'N':

That would be with Wanda or you, right? Because I worked at CILT for many years, they're not an indigenous organization.

Audrey:

We're partnering with them because they bring the disability lens. We're doing the project together so we would do that together. And the audit would be of an indigenous organization.

Participant 'L':

How's everybody doing? Is everybody feeling, okay?

Wanda:

Took the words right out of my mouth. The helper goes right into the role of a caregiver. Everybody, okay? You okay, L?

Participant 'L':

Yeah, I'm good. I'm just really excited I'd like to find out how I can help more. If there's like any way that you need, like somebody to help you out in your group and I would love to volunteer my time.

Wanda:

We will need to see your stool. Your chair or whatever it is when, at some point, you don't have to do it right now.

Audrey:

Not right now but in person hopefully in the spring when we can actually meet, hopefully COVID will allow. Those of us who've been vaccinated to meet in person and to build this lodge.

Participant 'L':

But yeah, I just want to thank you guys for putting this opportunity together. It's been something that's really been needed in our community but sort of bounced on but no one's ever actually landed firmly like with like, good 'eagle-claw grip', right, like so.

Audrey:

Well, thank you all for participating. I'm really grateful for your courage and sharing.

Participant 'T':

Thank you for putting the meeting on and allowing us to share.

Audrey:

You're welcome. Wanda, do you want to send us off?

Wanda:

Yeah, well first of all, I'd like to thank all of you for the courage that you've shown to share your words and your stories. It's going to help us to create a bigger dream. And understand what it is that we need to do, to put together a space where everybody is accepted and accommodated. Ancestors, Creator thank you for joining us here today and watching over us. It's not about a

closing or an ending but it's about a new beginning. It's about moving from this time and place and moving forward to another space and another another place. Because our ancestors know that wherever you are, that we're connected by the Internet. Ancestors, Creator if there's anybody here who needs that special touch, please wrap them in your arms, your wings, your paws. Let them know and feel, unconditional love, that the universe has for us. That as we lay our head down to rest, to go into that 'dream space', be kind to us. Send us dreams that comfort us. Send us kindness and happiness in those dreams. And when the night meets the day, at the crack of dawn, you can go home to that place that you call home and take with you those things that make us feel not really good. Thank you, Creator, Ancestors for filling our minds and hearts with what it is that we needed to talk about today. And if there are people who are hurting because of the words that we shared, that you need to let it go, because our words were not meant to do that. The courage that you had share, the way that other people has viewed your struggle, as painful as it was, it's going to be so helpful to us and changing the way that the world looks at all of this. So, thanks. This is one gift that we can give each other that we can never take back and that's the gift of time. We come to this 'Earth-walk' through the womb of the life giver. And we take that first breath, when we sing our first song, which is that cry that you hear. And from that moment on, we learn to communicate but most importantly, we keep breathing one breath at a time and that's what's important. Because that breath is what keeps us alive. And they always teach us that, you know, we 'breathe that first breath' as we walk towards breathing, our last breath. And today, we breathe life into each of us, as we sat together. So, thank you, all my relations, a ho.

Audrey:

Miigwetch, Wanda. Thanks, everybody.