

# Accessible Community Forum: Accessible Healthcare in BC

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## Forum Discussion Transcript

### **SUMMARY KEYWORDS**

disability, work, people, health, mental health, chat, call, doctor, ableism, support, sharing, access, speak, great, bc, services, find, healthcare

### **ACF Accessible Healthcare Forum Discussion Transcript**

29:56

Okay, just maybe make sure on YouTube that we are live. I'll check you. Welcome everyone. We will get started. In just a moment.

31:14

No. Here we go. We're just getting started right now and everyone can just keep themselves on mute. And I'll go over how we can raise our hands to ask a question and be a part of the conversation. So welcome to our accessible community forum. I'm hoping everyone can see my screen alright. Okay, so to begin, I would like to acknowledge the importance of the land on which this online event is taking place. The Disability Foundation works from the traditional territories of the Coast Salish peoples and in particular, the Squamish Musqueam and slaver tooth First Nations. This acknowledgement is a statement to reaffirm our commitment and responsibility in our own understanding of local indigenous peoples and their history. So thank you for joining us and participating in this accessible community forum on accessible health care in BC. My name is Emily Chambers and I am your Connectra Program Coordinator. The purpose of this forum is to gain insight and feedback from the community around accessible health care in British Columbia and healthcare as a whole in Canada. So here at connectra we value diverse opinions and perspectives. We want this to be a safe environment for everyone to share. So please be respectful of what others have to say. little housekeeping as we began just a couple of rules. This forum is being recorded and streamed to Facebook and YouTube so you are more than welcome to choose to have your camera on or off the Forum will live on our YouTube and Facebook channels after so you can share it if you have to leave if you miss anything you can come back and watch. All participants should be muted upon entry. I'm hoping Chloe can double check that. To ask a question. Type your question in the chat box or you can use the raise hand function under reactions in the bottom of your screen. We have Chloe who is monitoring the raised hands and we will try and get to everybody. Appreciate people not jumping into conversation so we can make sure that everybody is respected and heard. Okay, a

moderator will call on you and unmute your microphone so you can ask your question. Or if you'd prefer us to ask it for you. Again. You can put it in the chat. Use the chat for comments if you require a screen reader which I know there's some people here today that are using screen readers. We do recommend that you close the chat. We will be sending out a complete transcript of the chat after the event next week to all attendees as well as the actual transcript of the discussion today. We have automated closed captioning available so please go to the button at the bottom of the Zoom meeting. I click Live transcript and show subtitles to turn them on. Our agenda for today short welcome. We're gonna have panelists into task introductions. We're going to have just under two hours of discussion which I promise you flies by, and then we'll do our closing summaries. So, to begin, I'm just going to show a short video on some of our other programming offered by Connectra.

34:42

Connectra creates opportunities for people with disabilities by providing information resources and programming geared towards greater inclusion and quality of life. On service Mondays, we highlight a local organization or initiative on November 6, it's mashup labs and November 27, it's wavefront community center. Every third Monday is our perspective series where you'll hear from guest speakers on varying topics. Join us on November 20 to tune into a discussion about nap getting winter sports with a disability. Wednesdays Archer yoga with Bobby Seale Kaminski. Thursday's our adaptive fitness with ocean rehab and fitness. Fridays are contemporary improv dance classes with Janice Lawrence. Every third Friday is a global presentation by the disabled independent Gardening Association. This month we're learning about anti-inflammatory foods with Renee Chan. We have a new program starting this December creative writing classes will be online Tuesdays at 4pm pt. Join us for our connector holiday party at the Red House community arts and Recreation Center on December 6 Visit the events calendar on Connectra website [connectra.org](http://connectra.org). For more information and to register for events or find us on Facebook. All right.

36:13

Okay, and now we are going to introduce our panelists. If I can get to the next slide, which I don't seem to be able to alright. So I'm going to introduce our panelists briefly and then I will let them introduce themselves. That works. So today's panel consists of Charmaine neighbour Gall, the engagement leader on the patient and public engagement team at health quality BC Joanne Smith, a certified nutrition practitioner at fruitful elements nutrition. Her specific area of focus and expertise in nutrition is with individual sustained trauma cord injuries and brain injuries. Cassie Stark, who is an occupational therapist with tall tree integrated health based in Victoria BC. Her main areas of practice include concussion and mental health, pascals Jen drawl moving I said that okay is a program staff at pathways clubhouse working in the public education department and Heather Lamb, who is the info line services lead at spinal cord injury BC, Heather is visually impaired and handles calls with clients needing assistance over the long term or who are dealing with multiple issues related to employment, housing, or health. So welcome panelists, anything to add to your bios. Maybe you can just say hello so that everybody knows who you are. Awesome. Okay, great. All right. There's Heather. Thank you.

**Vanessa Lim, Tall Tree** 38:00

My name is Vanessa. Cassie wasn't able to make it today, but I'm another community occupational therapist. I'll be stepping in today to represent Tall Tree.

38:12

Oh, thank you so much for joining Vanessa. Sorry, I didn't let you in earlier in the meeting. I didn't I didn't hear anything. No, that's okay.

**Vanessa Lim, Tall Tree** 38:17

That's totally fine. Thank you. Welcome.

**Joanne Smith** 38:22

And Hi everybody. I'm Joanne, I'm calling in from Toronto. And I'm very thrilled to be a part of this discussion today and I have to say, I'm always impressed with what is happening out in BC I'm pretty connected with SBI BC. And you know, their their organs very advanced. I think in terms of services they provide and even just watching that video right now, Emily, phenomenal we don't have anything like that out here in Ontario. So this is just I will learn a lot today from all of you. So thank you for letting me be a part of this.

38:56

Thank you so much, man. Thanks for being here. Okay, so to start. I would love for each of the panelists to just define what accessible healthcare means to you. Maybe we can start with Joanne.

**Joanne Smith** 39:12

Sure. Um, so I think it's like universal design. It's just, it's a basic human right for all of us to have equal access to services, hence, universal design, and it's also basic human right to have access to accessible health care. And if we're denied that it's a violation of human rights, and it's just you know, everybody from visual impairment, hearing impairment, mobility impairment, everybody should have equal access to information services provided communications, you know, to accessibility when you actually get to a healthcare facility, I have a mobility impairment so that includes everything from you know, high low tables to help get you on to have examinations. And it really is just across the board complete and utter accessibility. Before I became a nutritionist, specifically looking and working with people with neurological conditions. I was actually a reporter and a producer and host a two national television shows in Canada on disability issues. And what I find frustrating and I think it's wonderful that you're

hosting this today is because when I did stories for CBC 25 years ago, on exactly this issue, we're still dealing with accessibility issues and health care today. So you know, we need to still obviously raise awareness about accessible health care. And it's just you know, it's disappointing and disheartening that here we are, 25 years later, still dealing with the same issues. That I covered years ago on television.

40:50

I agree, and I think there will be lots of gaps to be discussed in this confirmation and conversation and hopefully a lot of solutions mentioned as well. Heather, do you want to go next?

**Heather Lamb** 41:00

Sure. I'd like to agree with everything that Joanne said. I would add that when the general public talks about accessible health care, they mean that they can get the health care that they need. But for disabled people, obviously there's other accessibility considerations. And those include accessibility of the offices, the accessible exam tables, but also knowledge from the practitioners about the person's specific disability. We certainly don't expect every family doctor to know every single disability diagnosis. That's not realistic. But we I think it's realistic to expect that we are referred to somebody who does know more about that particular condition and we shouldn't have to wait for years to get referrals to specialists.

41:47

Absolutely. Great points across the board. Oh, no, Cassie is not here, it's Vanessa.

**Vanessa Lim, Tall Tree** 41:55

Yeah, that's me.

41:56

Thank you, Vanessa.

**Vanessa Lim, Tall Tree** 41:58

Thank you, Joanne and Heather. You guys really? Like hit the nail on the head there? Um, yeah. For me. When I think about accessibility and healthcare, it's making sure that everyone has accessible access to the health care that they need and in a timely manner, irrespective of any of their circumstances or personal characteristics. So that like, aside from the physical aspects of things, but it's also socio-economic factors, their gender, sexuality, the way their communication, preferences, those are really

important as well to be considered. And I sometimes find that those sometimes do fall short within the healthcare system, particularly in my work in the private sector. We oftentimes are advocating and having to bring up these situations or factors to adjusters and funders because they're not aware of it. Well, I'm really glad that these conversations are occurring so we can have open discussions about it and I can learn about different perspectives outside of my own.

42:55

Awesome, yes, this is gonna be a learning experience for all of us. And that's why they're always really important to feel heard by the community as well. Sure, main, would you like to go next?

**Charmaine (she)-HQBC** 43:07

Absolutely. Thanks so much. Thanks so much, Joanne, Heather, and Vanessa, for that. I'm going to take just a quick moment to add a bit of introduction to myself, I'm calling in from a traditional unseeded territories of Songhees and Esquimalt nations, colloquially known as Victoria and I work for health quality BC and through high quality bc i also especially work a platform that we have called Patient voices network so I will speak to that more as we go forward. And before I was at health quality, BC, I worked for Island health, and I mostly ran the acute volunteer programs and like the hospitals, so very much kind of like a focused on community as far as being an island health and before that I worked with the MS Society of Canada. Um, I if you hear background noise or see anything it is my very chatty coworker, my cat is that person because I do work remotely from home. And this is not if you if you're seeing my background that has very pretty foul vibes. That's not my actual home. This is just a zoom background. Yeah, I really appreciate us asking this question about accessibility. I think it has a lot of different interpretations and means different things to different people. I think that our personal experiences often are the ways that we have these definitions. So for me having friends and family with both visible and invisible disabilities, that means that they have access appropriate quality access to health care, that meets their needs, and it's something that I especially witnessed with a parent with a disability, several different disabilities all the time daily and see a healthcare system that does not always meet their needs. So so that's something that's very important to me just to see that around learning. I just want to quickly touch on always, always learning just the conversation. I've seen a little bit in the chat this this afternoon, around for some folks the real importance of having an ASL interpreter. I really appreciate hearing that kind of conversation and different angles and views for folks. So thank you for that as well.

45:17

Yeah, absolutely. We are seeing what is happening in the in the chat here. so I do appreciate, Scott, your comment and Vinu, I do apologize for us not having an ASL interpreter here at this meeting today. That's not something we have done with our online forums in the past and this is the first that I've heard that that would be very helpful outside of our closed captioning. So we will definitely put that into our future plans. And again, I apologize and appreciate the feedback is important that this is a consistent learning

process. And that's why we have conversations like these. So thank you Pascal, do you want to talk about what accessible health care means to you?

**Pascale (she/her) - Pathways Clubhouse 45:58**

All right, thank you. I think others have kind of covered the majority of it so far, but I'm coming from the lens of working alongside people with mental health concerns. So a lot of the resources we're trying to access are those mental health professionals. And yeah, it's definitely not accessible. And what is available is very short term or really long wait lists, and the options that are available just aren't I feel like sometimes they're doing more harm than support for a lot of the people that come to Pathways clubhouse. Just for instance, when someone is in a crisis, you know there's the crisis line or there's the hospital and those are the options and given some of the backgrounds that people have, they've had traumatic experiences and so having that be their resource, or what's accessible to them for their health just really isn't a good option. So I think from the work that we do here at the clubhouse being able to access more mental health resources that are long term and specialize and can really meet the needs of the people here would be amazing. So and not just to the community at the clubhouse, all Canadians so that would be ideal.

47:32

Absolutely. And if you have any resources that you know of this goes to everybody panelists and attendees and want to share them to chat again, have a transcript going out after this meeting next week of everything that was mentioned. We'll also add the resources to our connector website. So hopefully we can leave here with more resources than we knew of before. And, and yeah, be sort of moving in the right direction. Speaking to what Pascal said, I want to go to some of our findings from the survey that we that we launched at the beginning of this month. So 81% of our survey respondents agree that ableism is an issue in the healthcare industry. 63% of respondents say people with disabilities do not receive the same level of care as people without disabilities. 51% of respondents say that medical professionals have made them feel like a burden for seeking care with their disability. Can we talk about maybe we can go to Charmaine first how our health care providers being held accountable for discrimination. And where do you go if you feel like you've been discriminated against in the in the medical system?

**Charmaine (she)-HQBC 48:42**

Yeah, I mean, I can't speak to uh, specifically around discrimination, but around absolutely the accountability piece. I mean, first of all, each UBC just so that you know about the work that we do and I'll throw our our website into the chat so that folks can see what on earth I'm talking about when I say h qv C, which stands for health quality BC. We are leaders in the health system and provide guidance to the Ministry of Health. It's a it's a relationship they find us but we also give them guidance on on projects and provide leadership or especially around quality. A big part of like I said, the work that we do is to the patient voices network, which I can speak to later but that's also around that accountability in regards to

involving what we call persons with lived in living experience, which is all of us we've all experienced access to health care, either ourselves or through friends and family. And by having that patient voices network, we bring in those voices to improvement projects in health care. So that's one way that we do work around having that accountability, especially around improvement. Now when it comes to the pieces, and I'll have some of the links I'm going to put into the chat here. When it comes to pieces around concerns you have around access. Any concerns honestly, the main way that we usually recommend folks go is through what's called PC QIO or patient care quality office. Some of you might be familiar with that. So every single health authority is required to have a patient care quality office and they are legally required to follow up on every single complaint that comes through. Patient Care Quality offices also accept compliments. So that's another thing if you do experience, really great care. That's another way that you can also shine a light on that but that that's where you can formally lodge complaints that are legally required to be followed up through the system. And it's like I said health authority based. So depending on what region you're in, it would be you'd find the office at that link. The other way that you can also and I don't love the word complaints, but the other way that you can also lodged complaints, and I'm putting the link in here as well in the chat is directly to the Ministry of Health. So I put that link in there. And at that link, it also shows you all the different kinds of areas of health that you might be trying to identify a concern and then the last one I wanted to share was also the BC M splits person, so their website as well. I'm just gonna put that in the chat as well. So those are all different areas. You know, avenues as far as lodging complaints and concerns. I'm also just going to show this one, this is only one of many, but there are a lot of advocacy groups as well, who do wonderful work and a lot of the times this one is BC healthy living, and there's lots of advocacy groups who really work side by side with the health system to really, to really push change around policy and, and procedures. So that's just an example of one and and like I said, there's also the patient voices network who, which is where which is you know, a lot of the work that I do, where we bring again, side by side, bringing your patient partners together with healthcare partners to work on improvements. Someone else on the panel here can maybe speak to other ways like I believe there is you can reach out specifically to different colleges. Vanessa, she's nodding your head yes. I'm not sure if someone else wants to speak to that.

**Vanessa Lim, Tall Tree** 52:36

Um, so I can I can touch on just for occupational therapists and for other allied health professionals. So each of our professions has a governing college or body that this is where we usually apply for licenses and within those governing bodies as well. As a client you can also file any complaints or if there's any discrimination that you're facing, you can actually file complaints directly to the governing college each province will have their own governing body for their profession so exempt for example, we have an a college for occupational therapists in British Columbia, but there will be an equivalent for Ontario Alberta in any of the other provinces. So if you do need to make a complaint about a specific condition under those governing bodies, you can always just go on websites and find links for those specific colleges and then they'll be able to lodge a formal complaint there.

53:38

Okay, wonderful. We had a comment in the chat just had a question. Is there a time limit for submitting a report? I think this is kind of more to Charmaine about the recording.

**Charmaine (she)-HQBC** 53:51

I don't know that I can speak enough to the reporting that would be something because I don't work for the Ministry of Health. I'm not too sure how that works. And I don't I don't work with our our systems analytics closely. At HTPC. We do have folks that work on that, but I don't know that I can speak to how that works from the data that standpoint.

54:17

Okay. Does anyone else on the panel want to speak to this issue, how health care providers are being accountable for discrimination?

**Heather Lamb** 54:23

I can jump in here. I'd like to take a step back and acknowledge that there is a lot of ableism in the system, which is not surprising given that our society also has a lot of ableism one of the best ways that I think we can counter the ableism in the system is to better educate the next generation of doctors, nurses and all other medical professionals. And part of that involves going into the schools and making sure that they have a full understanding of disability before they graduate. One prime example I often speak to classes at the University of Northern BC in Prince George where I live. And a couple of years ago, we were speaking to a Health Sciences class. It was a fourth year class. And these are students that are going on to they're in nursing or they're going on to medical school or occupational therapy, those types of things. And one of the students commented that it was the first discussion of disability that he had heard in four years of school, that's concerning. So I think as a community, we need to be stepping up and doing as much as we possibly can to make sure that our voices are heard in the education system, in hopes that we can reduce the number of people who have to put in complaints down the road.

55:38

Prevention. Yes, absolutely. I think that's a great point. Heather. Pascale Duan, do you want to jump in on this at all or should we move on to the next question?

**Pascale (she/her) - Pathways Clubhouse** 55:49

Just go off of what Heather said in terms of the education side of things. That's primarily my role here at the clubhouse is going into the community and connecting with people and just trying to reduce stigma around mental health and what different diagnoses might look like. We also have sub programs. We have staff that are of a younger age that go into the high schools with other members living with a mental



illness, to have those open conversations and talk about what mental health mental illness looks like and create a space where they can ask questions, gain information, and also just come into the clubhouse space here and learn a little bit more about what that looks like. So I definitely agree, starting younger and providing the information and access to people who can openly have those conversations is a great starting point.

56:49

This was an overwhelming response in our survey of ways that ableism can be mitigated in the healthcare system. The number one response was education for healthcare staff. So I would be interested to hear for the healthcare professionals on the panel. Can you speak of the training that you did receive around disability and ableism in your professional practice, and some of the gaps that were maybe missing? Maybe we could start with Joanna?

**Joanne Smith 57:18**

Sure. I also just want to reinforce what Heather said to education to physicians is absolute key. It's shocking how many positions when you roll into their offices, their or their examination rooms. You can see the discomfort that they're just not a lot of experience interaction with people with disabilities. And again, the stories we did 25 years ago it's often the same because you have a disability or sick and it's trying to you know, really divide that as well as unlimited stability can be very healthy, but they seem to always assume you're sick and then you have to you know, clarify and advocate for yourself while you're there. And so education for physicians, absolutely. For me, in terms of my education, I was the first person with a disability going into nutrition school to specialize in people with neural auditions. I knew I was taking a huge risk of depression before I was actually injured. And then when I What point because the awareness so I really had to advocate for myself and push this as wanted to do a piece in the kind of holistic approach to recover what I based my business on my nutrition field. And so there has been great acceptance with it. That being said, you know, ableism on the flip side of being a healthcare provider, I work with anybody I specialize in neurological conditions but when I have able bodied people who see me on Zoom or talk to me on the phone, have no clue I have a disability. They roll in and when they see me in clinic in a wheelchair, some of them will walk right back out. Like it's quite shocking. So there is awareness it has to go on with physicians health care, but also just you know, the society as a whole. So there ableism on both sides, but when it comes to my own health care when it comes to practicing as a health care provider, advocacy, you have to break remain calm and advocate for yourself. It's just part and parcel of unfortunately, where our system is still functioning. And so no matter what, what environment I go into, whether it's my own health care or working with any kind of, you know, clients, it's snowing the back of my mind, I'm going to have to do a lot more education here to lay the groundwork and make people comfortable. And that's just it's part of my acceptance and what I do and what I have to put out there in order to be taken seriously as part of a health care provider in this in this field.

59:47

That's fantastic work that you're doing. Charmaine, you have your hand up.

**Charmaine (she)-HQBC 59:51**

Yeah. Thanks for that. Joanne that's super, super interesting to hear and good to hear. I just wanted to share around the the education piece for healthcare providers. I am seeing in recent years a change towards a more patient and family centered approach in the teaching and I know about this because schools like UBC medical school as well as the medical imaging programs here on Vancouver Island, like como Sen. BCIT. And I know there's others, they make a very, you know, conscious effort to bring in what we would call the you know, patient voices and patient partners and caregivers. Now they're not specifically always looking for folks who have disabilities, but the being able to bring in those voices hopefully can give that kind of patient centered lens that often will include those experiences of accessibility and and also, I'll add that there's a the ideology of what we call, what matters to you or the framework called what matters to you, which I can also add that in the chat, just realizing I could do that. It's a framework that HTPC pVn provides education to the system. About and we do know that that's happening in a lot of schools. And it's this reframing of making both the education but also the the health care practices to be focused on what matters to the client. So root matters to that person in that moment and under their context and story. I just put that link in the chat just more about the what matters to framework that's also being taught and yeah, I just I just wanted to add that.

1:01:44

Thank you for that. That's great. Does anyone else want to talk to the educational training that they received or think to be implemented, more ways to advocate for that? On my channel

**Heather Lamb 1:01:57**

about that? So I went through my social work education and there was one class on disability issues. It was an optional class. I chose to focus most of my projects in other classes around questions of disability. And I had a couple of profs inform me that they were actually learning from me during that process. I also did a practicum in hospital social work, and I had some pushback from not from social workers, but from other medical professionals about whether or not I belonged in that space as a low vision person. I proved I proved that I did belong obviously, but it was shocking to me at the time, so I did some research about it, read some literature and discovered, not the what I shouldn't have been surprised that ableism is so common in the medical field, but at that time, I was younger and a little bit more naive, and I was surprised, which is why I say we need to improve the education that people are receiving, so that it's no longer surprising to other professionals. To have a disabled colleague.

1:02:59

Very well said. I'm glad that you could have be of educational value to some people that you were with at that time. We did have Leslie's got in the chat. Say my concern relating to hearing loss whether

captioning or ASL interpreting for extended health services, including dental eye care, physical therapy, massage, nutritionists, etc. Outside of the hospital setting, these services are not included in access and requests to the service providers to pay for. And it's often it's often denied this also came in from are 66% of our survey respondents don't believe that the provincial government slash government of Canada provide suitable assistance for people with disabilities to access health care services, and 51% of respondents don't know which healthcare services in BC are free and which are partial costs. So there's some obvious gaps here. I know also in the mental health space of things not being covered. Heather, I feel like I would go to you first on this about maybe speaking to some partially covered services and what this looks like.

**Heather Lamb** 1:04:10

Sure this is a challenging one because our system is very patchwork. We are told from a young age that we have universal health care. That's actually not really the case. We have universal access to certain parts of our healthcare system, but not all of them. So there's things that are covered for some people such as home support for people who are on PWD, provincial disability assistance or other very low incomes. But for people who are kind of on that line between having just enough money to not be covered, but not actually having money to pay for the service, that's where it becomes quite problematic. With accessing home support or catheters are a big one. They're not covered in our system except for people on PWD. So people are literally paying to urinate. And that's a real problem. There's a lot of things that are like that in our system. So if people aren't sure what's covered or what isn't covered, that's actually one of the services that my organization provides. We have information about who is covered for which things if you're not sure, give us a call. And we can help you navigate through what you might be eligible for. And I'll put that information in the chat.

1:05:21

I was gonna say maybe we could post that information in the chat. That's fantastic. Does anyone else on the panel want to jump in on that? things outside of the regular scope like nutrition, counseling, mental health not being covered?

1:05:45

I do see a hand up from an audience member. Amelia?

**Amelia Cooper (she/her)** 1:05:53

Yeah, I was just wondering if we are going to have a participant discussion as well. Or if it's just a panel speaking because I think it might be helpful to hear what people with disabilities like in the participants have experienced as well. Yeah, I

**Sandra** 1:06:11

agree. I agree.

1:06:13

Absolutely. Yes. This is where we have the raise hand function for sure. If you have something to share, we'd love to hear from you. This is also why we send out the survey in advance so that we can get feedback from our community and why we all want you to be here. So, Amelia, if you want to start off I just do ask that. Everyone if you're not speaking to continue to keep yourself muted so that we can give the speaker the floor. Did you want to share something in particular Amelia?

**Amelia Cooper (she/her)** 1:06:43

Yeah, I was just thinking too, that we need funding for things that prevent health problems as well. Such as housekeeping stuff. There is no funding for that, to have my house clean so that I don't become sick from air quality issues and germs and stuff. And I have a difficult time cleaning the house by myself due to being in a wheelchair and being a little person and such. I have brittle bones disease. And someone mentioned earlier about seeing physicians that specialize in a person's disability. However I find in BC there's no there's no doctors that specialize in Oli, like even mostly candidate doesn't even have a wi specialist. And I think a lot of people with disabilities have a hard time finding doctors that specialize in certain disabilities. So they have to just go with whatever they can get right whatever the government provides. them with. And, yeah, I find a lot of doctors are also like discriminatory due because they think that because you're a person with a disability. You don't need a certain medical treatment or service. Even though you do you know and I just wanted to mention that.

1:08:07

Thanks. Thank you so much. Yeah, I think this is going to be an enlightening conversation for lots of people. I did make a note of the housekeeping in particular. And like I said, we do send a transcript of this discussion with questions and comments that have been brought in by you and we do send it out to a list of government officials and health care officials that can instigate real change to make sure that you feel heard. So thank you for sharing.

**Amelia Cooper (she/her)** 1:08:34

I can't get funding to get help or to do exercise to like to go swimming or to go to the gym. It's really difficult for me to do it by myself. And because I can't go by myself, I feel like I'm not getting proper exercise and stuff as well, which is also like a preventative thing, or health problems. I could mention that previously.

**Heather Lamb** 1:08:56

Absolutely.

1:08:59

Good. Points. Okay. I'm trying to make sure that I can see whose hand up is, is up first. So I see two participants have raised I see Patricia, Patricia, would you like to add or comment?

**Patricia G** 1:09:12

I don't know your thank you. I wanted to speak further to what Amelia was saying. So I have a genetic condition called Ehlers Danlos hypermobility type. And so, similarly, I've had referrals declined, because the specialists do not see Ehlers Danlos patients and I find that very shocking and wrong because I feel that no matter what your health, you should be able to access a physician. So like if I were to compare it to say cancer, if if someone was referred to cancer clinic and the doctor there said, well, we don't deal with bone cancer, we only deal with breast cancer. It would be you know, people will be up in arms of it. Whereas with things like Ehlers Danlos you know, I've been referred to cardiologist and then the cardiologist says no, sorry, I don't take Ehlers Danlos patients. And then I've been referred to a rheumatologist and told sorry, I don't deal with Ehlers Danlos patients. And so then I just get referred back to my GP, because there is no one in BC who specializes in Ehlers Danlos. The only thing I've been able to access is going to medical genetics, where they rule out Marfan and then refer you back to your GP. So I just wanted to sort of reiterate what Amelia was saying that if you have something that's not as common, there doesn't seem to be much. And then there's also this lack of diagnostics, where even with Ehlers Danlos it's like is it even rare? Or are people just not able to get testing? So you know, there's that whole piece too. I just wanted to mention that

1:11:07

is a great point. Patricia, do any panelists want to jump in and speak you this discrimination? And then we sort of addressed some of the gaps in those barriers before we do have a dynamic mg with their hand.

**dynamicmg** 1:11:30

Yeah, that's me, Monica. Yes, thank you. So I've had the worst experience in my life. In Indian ICU this past summer. I'll go it's a little bit of a long drawn up story, but I'll, I'll give you the cool version of it. Basically, my lungs collapsed from a pneumonia and I was on a high powered BiPAP machine in the hospital and the doctors. The one ICU doctor showed me my lungs and of course they were differently shaped. I have osteogenesis imperfecta as well, like Amelia and and he basically told me that like he wasn't sure what was going to be the future because you didn't know if my lungs were going to reopen again. And how far do I want to go? At that point he already convinced me not to have a do not

resuscitate order. And at the time I said yes. Because I was so freaked out. And the way he described it literally was you know we have to push really hard on your chest and you'll break your ribs and you know, there might be nothing left. Another words that might not be any organs left. And that's ridiculous. I talked to a nurse afterwards. I find that you don't go that deep into the chest cavity wall that you're touching other organs. But yes, your ribs could definitely break and mine would. That was number one. Number two. He said I said well if I need any more option and what about a tracheotomy? Oh, tricky. I don't even know if you'll survive the tracheotomy. And if you do, you could be in a coma. And if you're in a coma, and you really want your family to make that decision to take you off. of life support. And and I'm like, well, nicotine. I won't show by that. I mean, a bad show you before. And then he said to me, well, you'd have to be on a ventilator as well and then you'd have to live the rest of your life in the jail facility. And I'm like, No, you don't you can live at home with a to N and no, you can't. You need special treatment for that. And you would have to hire special people, nurses for that and you can't afford that. So he was putting me down left, right and center. He was using emotional blackmail and manipulation. He basically the underlying tone was while you're here now, but you may have to either live the rest of your life in the hospital, or you know, kind of mindless well just give up. So he's not offering me anything. And it was extremely disturbing. And anybody else I tell the story too. They say the exact same thing you didn't want you to live. And as an West Detroit, the next day came up to me and said to me, Hey, your lungs are really weak. How about you try exercising them? And we went through that what that was, was even on a different machine so that I can eat during the day because when you have a BiPAP mask, it covers your entire nose now. So I said sure. Okay, sure. Hours later, he basically came and said, Oh, why don't you try this little exercise or just at least 10 minutes a day only if you can, not encouraging whatsoever. And he went away for five, six weeks. He comes back he never wants a bye now. I am in the recovery ward. I no longer in the ICU. I don't have the BiPAP mask on I don't have the high flow mask on just a regular nasal mask. Do you think he came to me and said congratulations. And one of the major reasons why my lungs collapse because when I went in the hospital they weren't collapsed. I just had pneumonia. They let leak for two weeks practically they made me lie down most of the time. Instead of me exercising trying to do as much as I can. No, they will doing passive restraint. Giving me Ativan day and night. So I was barely moving. I ended up having high blood pressure, edema. I personally really bad shape. But it wasn't big if it wasn't for my tenacity. And my sister being my advocate, my family being my advocate. And thank God my God given me strength, that's for sure. I might not even be here today. I could have died. And it was he didn't want me to have physiotherapy what's called Respiratory Care. We will not do that. Because your bones could break. I'm like, I know how much my body can handle. They did it once and I should come on. I knew that I needed every day. No, no, you we can't we can't risk it. My own physiotherapist I have more than one. And they were willing to come in and help me. But hospital said no. I had to beg them to let me get my tail givers back because they said oh can't pick you up. We can't pick you up your your you have to go in this thing. That actually was dangerous the way it was. They had no concept of handle a person with osteogenesis imperfecta Yes, I'm fragile and I break easily. But there's a way you can handle me and I don't break. So this to me, was outrageous. And I'm in the process of writing down all my feelings and perceptions and like everything that twice and then I have to take a step back. And I'm going to write a letter to the ministry to the to the end, your minister of health and all these people because this needs to change. Someone has said to me, nothing's gonna happen. Monique, you were the letter to the newspaper. Nothing will happen. But if we don't start speaking out, nothing is going to happen. You're absolutely right. We all need to start speaking out. And we all need for what's happened to happening to us. Because this should never have happened ever.

And and to Amelia I just want to say I do have a doctor for specifically for osteogenesis imperfecta and I'm happy to share that with you offline. And that's not a problem when you have a few few and far between but they'll always come out there. So anyway, for what it's worth. I say we need to be yourself advocates and if you ever go in the hospital you know you need to bring somebody with you. Because time and time again. They were asking me Oh, you live alone. How do you do that? Like they didn't know about the choices for supporting independent living program. And I even like the doctor was trying to convince me that my lungs are gonna get worse and I'll probably die from the anyway, at some point. But you don't know that. Yes, I know there are papers on this disease with a most people who died from the lung issue. However, not everyone does. And I even met a woman on online on Facebook who had a pneumonia who was on the BiPAP machine in the hospital and her lungs came back and I asked her well did they give you medication but she said no just time she even gave me the doctor's name and what how to contact them. Do you think anybody in the house leave? Me? Oh no, it's a different situation. And when my lunch was starting to get better, some of the fellow pets said Oh, will you remember what the doctor said? Just because it's a little bit improvement now, doesn't mean it's going to be later and I'm passionate about it because I find it's happening to me. It's happening to other people. And I'm sorry, I'm gonna have to bring it up. But this is why people are choosing to end their lives because they don't have access to medical care. Because their doctors don't believe in them because they think we're just using up space and we're using that class but

**Amelia Cooper (she/her)** 1:19:51

also I want to say to the love these like no offense to people in the panel keep saying they're gonna make changes they're gonna make changes all these health professional Kitson, you're gonna make changes, but we don't see any results. Yeah, they just pick things and say we're doing this business. But I've lived 33 years was a lie. And I have not seen very many changes.

**dynamicmg** 1:20:15

And in my 50s Yeah, didn't see much. If anything, it's gotten worse. Not better. It's gotten way worse. Not way with every since the pandemic.

1:20:25

Okay, that's an interesting thing to bring up. I so appreciate first of all, Monica, thank you for sharing that and I'm so sorry that that was your last experience does not sound acceptable in any way, shape, or form and no one should have to deal with that. So thank you for speaking and being passionate about it because this is a topic that you know affects so many people and it is important to share our stories. That's why we are hosting discussions like these so that you can be heard and connected with your community. I think that it Sandra I want to get you because if you had your hand up but I would like to circle back to some of the changes that have been done in an effort to improve the system Charmaine, maybe we can talk about that. Sandra. You should be able to unmute yourself if not Chloe can help you with that.

**Sandra** 1:21:13

Hey now Monica from way back. And also Amelia I also understand what it's like being misdiagnosed when you're born with a birth defect. I was born with scoliosis I was born with some mobility challenges are also want to let you know I'm also made tea. I'm Cree and French. And so the indigenous communities are often lacking services. And we have people that are living in remote communities that are not getting like the support they need, especially those with disability. I also wanted to mention you know, years ago, indigenous folks, women, especially like I said hormone scoliosis, and I had four children on pregnant and my very first one, they tried to actually tell me they can carry children they want me to actually have an abortion also to be sterilized. And I will tell you this was in Winnipeg Health Science Center. So the reason why I'm saying this because it goes all across the board across North America, much like kava to our digital people. I am glad to say I brought four beautiful children, all adults and I'm a grandmother. So I wanted to share that. Also, my biggest thing is I'm currently on ei on sickness and illness benefits. I had worked and I also spent a lot of ableism and the job due to PTSD and I'm also a survivor of the 60 Scoop generation. It would be nice if we can have affordable naturopathic services for summit but are not a fan of Western medicine. Or to have an A go on aim. Pain pills, right. I also I have osteoporosis, arthritis, degenerative bone disease. So all of that builds up and I'm also on my 50s but these are some of the things I wanted to express my concerns and I know that we have a huge shortage of physician in British Columbia and that is optioning causing a lot of service disruption for the patients that do require immediate care. And I also think that the physician needs to be having sensitivity training that is so crucial. One small piece. I was at Burnaby General Hospital one night and I have scoliosis when I was having severe back pains. I was walking and I have a lamp and you could tell my body's not properly alone. Due to my scoliosis. I was walking and the doctor I was there in emergency room. And here's the lady with a broken hip mocking how I walked. And I was just like the floor but I'm like what is going on? I didn't say anything. Everybody is Dara. Me. I'm Anca like I just kept quiet. I was just appalled by that. And that's an example of ignorance in the medical system. Doesn't matter disabled. Whether you're white, brown, whatever. Everybody is entitled to proper adequate, humane health care. And you'll wonder why our people indigenous folks don't like going to emergency because of this kind of stigma and having to deal with any kind of racism. Thank you. That's all I have to say.

1:25:54

Thank you so much, Sandra for sharing that. Does it do anything else want to speak to that? We also had a comment and question for Miss Sefa in the chat speaking to this, saying Canada is failing at its commitment to the United Nations Convention on the Rights of Persons with Disabilities. We need more advocacy out of political and legal space. Self advocacy is important but doesn't carry enough weight. We have systemic discrimination towards people with disabilities. What work are we doing or aware of to hold government to account and meet obligations? Where's the Canadian Human Rights Commission on this? It's only getting worse as a healthcare system is being under resource. This does kind of circle back to what Amelia and Monica were talking about before. Having felt like things have gotten worse since the pandemic. Sure, man, I don't know if you're the one to start this off, but maybe between you and Heather and some of the other panelists. Can we talk about some of the changes that are underway or have come into effect? In the in a couple?



**Charmaine (she)-HQBC** 1:27:01

I? I'd like to hear from Joanne Joanne had her hand up and wanted to Okay, awesome.

**Joanne Smith** 1:27:05

Thanks Jermaine. Monica, first I want to say I'm so sorry to hear what you went through that was absolutely horrific, and very much speaks to the prejudice that's happening still to this day. And what we just discussed a few moments ago about the absolute need to get better education in the training of our physicians, health care providers, nurses, whomever it may be. I do want to pick up on something that Amelia talked about, about having funding for whether it be helping clean someone's home for better health care. Having someone help you get to the gym to exercise absolutely speaks to better health care. And also Sandra, you mentioned about naturopathic services. All of them I believe in some way or another. Hopefully they can be funded in some way. Again, we have to advocate for ourselves or have someone advocate for you when you're in a hospital system, because of the that Monica described. And I hate to say it but so much of the onus is put on us and part of why I practice and do what I do for a living is prevention, prevention prevention. So whether it's kind of naturopathic dealing, were helping to prevent osteoporosis from getting worse. When I saw the early research of spinal cord injury and what it meant living with and the health secondary health complications that I was going to deal with and my community my demographic was going to deal with getting older and realizing that there was not a nutritional component to help maintain your health. That's why I went back to school and started to practice and what I do prevention is key just to put it out there as a stat spinal cord injuries. We on average live with seven adult health care complications every year. On top of our spinal cord injury. It can be extremely expensive, and once you're hospitalized, your health is going to deteriorate even more. And so for me prevention is key. So whether that means exercise, it means getting your house cleaned or having someone help you or eating well, all of these things. are absolutely critical. And I understand there is a financial component to this. And not everybody can you know say hire a naturopath, so often is not even including supplements in your diet. It's sometimes taking certain things away that can contribute to deterioration of your overall health. So prevention is absolutely key. So so much of what we're dealing with it is up to us to practice that. Unfortunately. Nutritionists aren't covered here. I do a lot of workshops to try and get the information out there to people. It really is the onus on us to help prevent a lot of what we're gonna face in the future. So I just want to speak I just wanted to support what Amelia and Sandra said about prevention and having people help you. I know right here in Ontario we don't have that kind of funding to help people. I don't know what the case is out there in DC. So as much as you can prevent things and this is what I preach to all of my clients and especially my young clients because they don't realize what they're going to be facing in their 40s 50s and 60s with long term living with a disability and that there is a faster acceleration of aging and arthritis and all the things that go with it osteoporosis and fractures. So, yeah, prevention as much as you can possibly practice is absolutely key and if we can get there's a way to get these things funded. Fantastic. So

1:30:40

Thank you Joanne for sharing that. Yeah, I think that seems to be the overall consensus prevention get ahead of it. Sure, man, do it. I'm gonna go back to

**Charmaine (she)-HQBC 1:30:48**

you. For Yeah, I want to start by also thinking Monica and Amelia and Sandra, thank you for sharing your stories. And it's unacceptable. It's unacceptable and I can guarantee that everybody on this call has probably experienced some form of unacceptable health care and I'm not going to sit here and list off a bunch of programs and policies that are being worked on sit here and tell you about all kinds of great work and projects that help that's that's happening to, you know, help things in the future in the system. Because we all want to be experienced healthcare better right now. And myself included. I just had a very negative healthcare interaction yesterday. So I hear you we all want it to be improved and it can be it can mean life and death. I want to because example especially is is is a very clear one around that. And Sandra jealous of the adorable puppy you've just brought into your lap. But I also wanted to identify as well that we are also trying to navigate all of this while being very conscious of you know, doing things with indigenous cultural safety and humility is top of mind that is also a huge focus right now in the province since the in plain sight review came out. If you're not familiar plain sight report. Maybe Emily, you could share that link as well. And that's where work that I need to UBC we're also very much working on pushing the in plain sight recommendations forward as well as the ones that connect to the Truth and Reconciliation Report. It's really important in my opinion, but also in the eyes of where I work. It's really important that stories are shared. Because if we don't know what's going on and what's not working, we can't push this. This this forward and these changes forward. The stories are super important. Doing so in a way that we're willing to work with others, though, is also going to be key which is, you know, again, what we do with the patient voices network, we need to hear from folks receiving care and working alongside the system and just to get that like concrete example like, like Emilia your experience like that, that would be something that would be really phenomenal to be heard, like the folks who do the education around patient engagement in like medical imaging program at Kapowsin or BCIT like having you be like a speaker to speak to these experiences and teach our future healthcare providers about these things at the onset before they even step into STEM. They know about these things, and they understand. They understand all the bias they have before they even actually start to product practice and health care. So that's something that I just want to reiterate how important your stories are and your voices and speaking up. And I also want to identify that it's not just up to you, that families and friends and caregivers are absolutely key components for changing healthcare as we go forward. And for being part of those patient voices. You know, I mentioned I have a parent with disabilities and I am so frequently their advocate and quite literally physically taking them to get their health care. It's very important and I'll add to that as well as chosen family I have a lot of chosen family as well. That those are absolutely key folks to be having them speak up as well and having them be those advocates for change as well are very important. So thank you again, everyone, especially for sharing your your stories. It takes courage and strength to be able to share that because you have to live with it every day and really grateful to hear that. Back to you Emily.

1:35:02

Thank you for that. Sure, man. Yeah, stories. experiences being shared, super important so that you know people are reminded that this is not changing and as some of you have expressed, so you again for being brave and sharing. I would like to talk a bit about provincial and government support because it did come up a lot in our survey. So from our survey, a little 58% of respondents have made a claim to the Government of Canada or provincial government or an employer and receive disability benefits 32% had not and 5% don't know how to. So I know Heather, this is sort of your area of expertise, if someone was to call you and ask how to apply for disability benefits. I know that it's probably circumstantial to everybody. But I would love to hear a little bit about what you think some of the barriers are for people to apply for Disney disability benefits and some areas that can be approved there

**Heather Lamb** 1:36:01

as well. Sure, I'm happy to answer this one. So the answer is it depends. Because there are such strict eligibility rules for each program. So one of the first questions I ask people is okay, what income if you need do you have per month and what income does your household have? Because unfortunately, some of our programs like provincial disability, are based on family or household income. So if you're partnered with somebody who is making an income then that absolutely affects the disabled person's eligibility. It's not right, but that is the current rule. I will also ask about people's work history. So how much they've worked to try and suss out whether CPP disability or provincial disability is the better option. The reality is if people have any kind of need for medical equipment or supplies pwd is almost always the better option if they qualify, even though they might get a little bit less per month. They would get at least some coverage for basic medical equipment. It's not gonna be the medical equipment a person really needs or wants, but it is that basic level of equipment. So those are the conversations that we would have. The biggest barrier is that the system is complex. I work in the system. I understand the programs and the rules, and I still have to check the eligibility requirements, because they're complicated, and I don't think we should expect everybody to come into this with a huge amount of knowledge. People are often thrown into disability quite suddenly, and don't have the background in knowing this information. So they have to have a crash course in how to navigate the medical system, how to navigate the social services systems, while also dealing with a new diagnosis. All of that is quite emotionally tiring. And consequently, I think people well, they're, they're too tired, they're too busy dealing with other things. And it can be quite difficult to try and figure out the best programs to apply to. So that's where I would suggest always reach out and find somebody who does know the answers to help navigate through that because it's it's a lot to be dealing with and if somebody has been through it before, they can probably point people in the right direction rather than having to start from scratch every time.

1:38:23

Yes, I think that asking for help is pretty imperative if dealing with a new injury as well. Or at any point I'm just going to repost the SC IBC info line in the chat again, for everybody to have. Thank you, Heather does any but yeah, to just jump

**Heather Lamb** 1:38:41

in quickly and see that we assume, or the public assumes that our system covers people with disabilities for everything that's required. Obviously, the people on this call know that that's not the case. But when people are newly injured or newly into this world, they are often shocked at what isn't covered. So things like housekeeping is a huge one for people's health. And it simply hasn't been covered for many years. So it's a real shock to people and that's part of the learning experience is figuring out just how problematic our system is. Yeah,

1:39:15

very good points. Housekeeping. Is something I've written down and underlined here. Sandra, do you want to add to that? You're just muted there.

1:39:28

Happens sorry.

**Sandra** 1:39:31

You're saying or Heather blab is on medical service only. You know prior to that I was working for nine years. I no longer am able to work due to my chronic pain and all of these other disabilities I have. So you are covered about how some coverages are not well how some medical stuff are not covered. I for one want to say like for osteoporosis whether medication I was on. Prior to I did have medical benefits from my work, but since I'm no longer employed with them, I find that the medication I have to take for every three months is like 30 some odd dollars. So like for people who have mobility issues, due to like scoliosis on arthritis is not walking poles. canes are not covered. And these are just some of the things that are essential for us to have currently I'm trying to ask my physician to see if there's any other medication that is covered for osteoporosis, but otherwise, and I'm not started, so otherwise I have to pay on my own pocket. For my medication every three months worth my work benefit. I only have to pay \$12 prior to not getting any more benefits. That's all I have to say.

1:41:20

Thank you for sharing that Sandra. It's good that you're bringing these up to your practitioners as well.

1:41:28

I don't know Vanessa if you wanted to sort of as an individual health care practitioner from your lens, advocating with the larger insurance companies when things don't go through benefits.

**Vanessa Lim, Tall Tree** 1:41:41

That's a great end. So for context, I folks that I usually work with on my caseload typically have insurance funding from either like a Workers Compensation Board, or it could be ICBC which was our motor insurance. coverage in BC. Other options for insurance can be private insurance or sometimes out of pocket pay or long term disability. So a barrier that we that I often face working in the private sector is a lot of these times the adjusters and insurance companies don't come with the same health care lens. So their understanding of certain diagnoses certain needs that clients have or any things simple things even just like equipment, it's not always we are we as a clinician, we are sitting here having to walk them through why individuals need these pieces of equipment or needs or services. A lot of times I find that the adjusters are quite surprised at how much these things cost and it is an it's part of my role as the clinician to have to provide that education to the adjusters. One thing that my I know that my leadership at my at tall tree health they they do meet with quality assurance. I don't know if their quality assurance departments at different funders to talk about a lot of the issues that we bring up with our that we find in our practice to help so that they so that the insurance companies are able to make policy changes on their end as well as educate their employees on how to better manage these claims. My day to day practice is a lot of times forming really good relationships with these adjusters and making sure that they understand what my clients are going through. Because I find that as a clinician, I am actually seeing these clients in person and actually being able to hear their stories. The adjusters are not always getting that face to face interaction with them. So a lot of their needs are not being translated there may be basing their decisions off assumptions or just reports that are being provided to them. That's not always the best depiction of what's actually going on for this person. So in the private sector, it's it's it's can be a bit tricky sometimes. And I think just going back to something that I think was it, a Steve mentioned like what are what are what are we doing to help kind of advocate for these processes to be a little bit better? Why I think we can do more. I think being part of this conversation has really opened up my eyes that I think there's a lot more that can be done. I think the first thing that can be done is force bringing up these issues to the people that can make the changes at these insurance companies or government levels. But I think a good comfortable question to ask myself is what can be done after that? How can we progress that even more?

1:44:56

Thank you so much, Vanessa for speaking to that and I think yeah, that's all walking away from here asking ourselves, what how can we you know, advocate more and make this. Our voices heard. Bruce, you had a question a while back. Apologies for just getting to now. Can we speak and even speak to how invisible disabilities are being addressed in the healthcare system? I'm maybe we could go to Pascal on this dealing, working in pathways with mental health.

**Pascale (she/her) - Pathways Clubhouse** 1:45:30

Yeah, obviously like members here at the clubhouse bearing disabilities, mental health concerns but also physical as well. For those primarily with a mental health diagnosis or mental illness, it's not always apparent obviously and so a lot of actually what the clubhouse does in our model is try to break down all

those barriers, whether it's the healthcare system, just attaining employment, like just any area of life, essentially making sure that the people that come into our clubhouse, we can reduce or eliminate some of those barriers to whatever they're trying to access. That might even just look like like a staff going alongside someone to a doctor's appointment. Or if we're not the advocate just even being in the room with them to have someone else listening in and be that you know, second person there to be aware of what's taking place and because yeah, even just the some of the people I'm supporting, just landlord issues are a big problem for us, where they don't always comprehend. You know, they see their person that has moved into the apartment, and they just make assumptions like, oh, I don't see anything wrong with you. And you know, like, why do you need support? So why do you need me to be gentle with you around this issue? Or like why do you need this? So then, obviously, stepping in to let them know you know, what the scenario is and how can we make this work so that the person is feeling safe and secure in their in their home and they're having their needs met and just isn't something that comes to mind as people who have experiences with PTSD and then someone is hammering underneath their room, you know, it's something that can definitely affect the person and their overall well-being but at a glance, you wouldn't know that they're really struggling with that. So I have less hands-on experience with the medical side of things in terms of, you know, being at an organization that's non clinical, but we do support the individuals coming here with their medical needs and trying to go with them to appointments and to the hospital when needed and seeing where we can advocate for them. Even just sitting alongside them for a phone call if that's too overwhelming for them and they want someone to be there to because it can be quite daunting, like there's often a number of hurdles you have to go through and people you have to talk to and sometimes it's automated calls or you have to go to a website. So if that's something that I feel I can help them with and eliminate some of those barriers and assist them to get the resources they need, then that's kind of what my role looks like.

1:48:41

Thank you for sharing that. Yeah, pathways is doing some really important work. I have shared that website in the chat as well. Mental health is a big part of I think this community and the community as a whole. Patricia, you have your hand up would you like to say something?

**Patricia G** 1:49:03

Yes, sorry. I was stuck on mute there for a moment. I just want to also mentioned with the invisible disabilities how you know, and I don't mean to say anything about, you know about mental illness like it's important. It's its own issue. Sometimes there's intersectionality I have mild PTSD driving specific from surviving a head on collision in 2015. That's actually how I found out I had I was downloads. And so again, it's considered mild. It is very specific to driving and driving in adverse weather in the dark. So on my chart, it says I have PTSD. And so I just wanted to take this opportunity to talk about diagnostic overshadowing. Because all it says on my chart is PTSD. And so, I find that the conclusions that some physicians will jump to when they see that is quite shocking. But for me, I also have invisible disabilities of Ehlers Danlos dysautonomia. I have long COVID You know, like before I got COVID I was working full time volunteering, white collar professional, all that good stuff. And so I find that I have other biological, invisible disabilities. And there's a bio psychosocial model that is implemented a lot but sometimes the

bio part gets sort of dropped. And then you get into psychosocial world where, no matter what's wrong with you. The attitude is that it must be psychosomatic. I've had doctors who've never met me before, say Oh, you must have anxiety. Oh, you must have hypochondria. You must have somatic symptom disorder. You must have adjustment disorder. Despite the fact that I have like at least five different assessments showing like no I don't you know, the only mental health issue is the driving specific mild PTSD. And then you know, this long COVID Like sometimes neurological muscle twitches and migraines and stuff. So I just wanted to speak to it because if you try to access mental health support, inevitably it is intertwined with addiction. And that is a need in society. There is an addiction issue that's you know, everyone knows about it. I think it is something that care practitioners can get tunnel vision about. And so if you're a person with an invisible disability, that does not involve substance use, or if you have a mental health issue that is mild, but it's in your chart, but again, not intertwined with substance abuse. There's very, very little support available, because as I say, like even all the hospitals, they always say, mental health and addictions. They've combined the programming. And so I just wanted to speak to it because it leaves those of us who do not use substances with really nothing. Nothing at all. And I know in my case, I don't want to be further entrenched in stigma. And I don't personally I don't want anything to do with substance abuse programming because it's not relevant to me, like not a judgment call. Nothing to do with. You know, like, it's important, but it's not something that's relevant for me in my life. So I'm sorry to ramble, but I just wanted to put it out there because people like me fall through the cracks and then we just have to pay for our own mental health and wellness support elsewhere. But for people who can't afford that, they don't really get anything.

1:53:15

Yeah, absolutely. Some really interesting points brought up there, Patricia, that I'm sure a lot of people were unaware of myself included. So thank you for telling us about your experience, because I'm sure you're not alone in it. And there are a lot of gaps. Brian, I see that you have your hand up. Would you like to speak

**Ryan Yellowlees** 1:53:35

for me? Yeah. So so I'm like, I'm a clinical counselor, but I've been like for the last six months and I specialize in physical disability counseling. And I've noticed that like, access for people with disability to mental health is very, it's not good at all. It's like it's very hard to get it and people get this idea that man doesn't physical health is separate, but if we have good mental rosters and people with disabilities, about the health things they have would, could be prevented. Because a lot of mental health stress from like, doctors are not getting support for discrimination really is a big impact with people physical disabilities. And I just like find that getting access even counselors watch the refuse clients with disabilities. So it is shocking, so got all this trauma for me in the ICU, then you can't get mental health treatment then the stress of PTSD whatever mental health issues you have compound on your physical health, which is this like and then there's also the property people can't can't afford a counselor \$150 or some counselor charging it's just it's very frustrating to see the mental health field this was me trying to be non-discriminatory but they're very much are they'll tell you it's always in your head or it's adjustment disorder. It's just Yeah, I was like but there's very few people who specialized in physical

stability in my in in counseling Canada, just probably maybe five people including myself, which is just frustrating. I can't make the changes by myself. I can only have the key for one client at a time to help them fight the medical system but there's not enough people like me in mental health to make changes which is frustrating.

1:55:32

Absolutely, that's a great point. Ryan, Charmaine, I see your hand up.

**Charmaine (she)-HQBC** 1:55:37

Yeah, thank you so much for for sharing about that Ryan and Patricia as well from your experience. It's very poignant you know what you have to say around the these mental health aspects around PTSD and, and Ryan You're also a clinician as well. Have have such a unique lens is also you know, being a counselor the the pieces around mental health are absolutely key to to help period it is they are absolutely connected and intertwined. I know that in each guide each QVC is work. It is a huge body of work that we've been asked from the Ministry of Health to to focus on so are our two big key areas that we're focusing now on going forward are indigenous cultural safety and humility and supporting our indigenous communities across the province in culturally safe ways and then the mental health and substance use but the mental health piece is huge part of the direction that the province is going to be focusing on and is now focusing on AI. I wish I could happen faster. That's for sure. None of it happens fast enough and this question around act or this this point around access to is really poignant. You know that Ryan mentioned around, even being able to access a counselor in general but access one that has knowledge and understanding around disabilities is is very poignant to hear and something I hadn't considered before. So that's great learning for me as well personally, is to be able to be considering these pieces. So I just wanted to iterate that these are aspects that are absolutely at the top of the kind of workload and agenda if you want to put it that way across all of the provinces programs. It's and I'm very glad to see that this is a focus because to me, one of the one of the things that came out of COVID was a recognition and understanding of the absolute significance and importance of our mental health on us being able to function and be you know, be who we are COVID and unfortunately shined a light on that for everyone I always I'll stop there I'm gonna see Patricia has her hand up and if you do hear any background noise I apologize if it sounds like a crying baby. It's just my it's just my very needy cat

**Patricia G** 1:58:26

Yeah, I don't want to like tell you like a little trigger warning, but I just wanted to quickly say like, two quick, well, little, little scenarios. Well, three, I'll make them as quickly as possible. So one, my late husband had glioblastoma. He was placed on steroids for the inflammation in his brain. He developed steroid mania, and he was section seven under the Mental Health Act. And he was palliative cancer patients. And I tried to explain to the doctors at the hospital Look, he has steroid mania. Look at his health care plan. Take him off dexamethasone and he will calm right down. They wouldn't listen to me. They continued administering dexamethasone and then he would have his mania and they would inject



him with Haldol and put him in four point restraints and psych ward it took 10 days for me to successfully get him off of the decks so that he would be calm enough to be discharged so he could go and die in the palliative ward. Like, like with dignity.

**Chloe** 1:59:36

So that's one.

**Patricia G** 1:59:38

Two is a friend of a friend she was having a mental health crisis in Vancouver tried to jump off the BC Ferries. So she was section seven under the Mental Health Act. And while she was in hospital, she lost her home she was evicted because she was not at home to pay her rent. So she was discharged from the hospital homeless and then ended up dying from suicide a few months later in homelessness. And then the third situation was with my late brother in law, who was grieving the loss of my husband his brother, and also his father from cancer and went to voluntarily to the mental health ward at one of the hospitals around here. And he was led off on a day pass where he died by suicide from jumping off the Lions Gate Bridge and when my mother in law, asked the psychiatrist at the hospital, why did you let him out on a day pass? The psychiatrist replied, Oh, I didn't know he was depressed. And she said well, he was brought here by the police after having an episode. And he was supposed to be in your care for a month. Why was he out by himself on a day pass? And the psychiatrist response was, oh, well, I had no idea he was depressed. What do you want me to do about it? So you know, I don't mean to be saying like triggering awful things, but like, this is the reaction. This is what I'm seeing happening. And it's like since the pandemic, it's all since the pandemic. So I just wanted it on record somewhere because nothing happens right like there's no recourse. So I'm sorry to be saying these not very happy topics, but I just wanted to put it out there.

2:01:40

Thank you for sharing Patricia. And I Monica has their hand up about this as well. And have it in the chat earlier there was sort of some links and suggestions on how to file complaints with healthcare. But I'm sure in general that just sounds exhausting. And I'm and I'm very sorry that you had to deal with that. Monica.

**dynamicmg** 2:02:06

Yeah, I was just gonna say that. This is part of the problem too, that doctors don't believe us. And they jump like Oh, who knows the husband or wife better than the spouse? Most of the time. I'm not saying that. That's all the time but genuinely speaking, I will tell you oh well. 90%. And the same goes for me too. And as as a daughter when my mother was in kale, and we were as she was nearing the end of her life. You know, when I said when the doctor one doctor came in and said so what are we doing for her just providing complete because she had a disability as well as she's aging. And I'm like, Well, no, we

wanted to live things. And she has a disability and she had cancer and she was going through cancer treatment. And then this one doctor says oh we just providing comfort. I said no, we want her to win as long as possible. Oh, I see your sisters in a doctor. Oh, wait till she hears back from wherever she is. So they she was completely dismissing me. Ah, what do I know and a person with a disability and so this is very, very frustrating and that I am dismissed. Because I'm a woman. I don't even think it's because I'm a woman. Just because I have a disability. I don't know how I want my mother to be cared for or know that what she wants to be cared for. I want to we have to wait till my sister comes back from a conference because she's a doctor. I'm not valid. So I think this is probably upsetting that we're not even being validated.

2:03:50

Absolutely. Absolutely.

**Joanne Smith** 2:03:54

Yeah, so many so much.

2:03:56

I do want to go back to to mental health for a moment here. Just in case there are any resources I know Joanne you have mentioned and resource list as well. That any of the panelists wanted to mention same with Pascal and pathways, how someone might go about finding mental health support and if there is any funding available for that outside of the regular system that we know about.

**Charmaine (she)-HQBC** 2:04:27

I'll jump in just with some very basic information. So I don't know if this is folks, the stuff that folks already know. But as far as access to a physician, I myself I no longer have a family physician due to a sudden retirement and so I'm part I've registered with what's called the Health Connect registry. So this is the new registration system that the province launched fairly recently. So once you're on the Health Connect registry, it's basically a waitlist for access to a physician. So like I said, I myself am on it on that waitlist. Obviously once you have access to a primary care physician, it it opens up obviously access to potentially other things. So I just wanted to throw that into the chat. Some folks don't know about that registry. And also from a very basic information standpoint 811 is that general nurses line that they are absolutely required to follow up on providing you with resources and information so on any phone you can dial 811 And they are supposed to connect you to resources including for mental health. So I just wanted to say that one out loud as well. Thanks, Emily. I was just gonna I was just going to type in a one. I also tried to look up a more detailed bit of information about exactly what 811 can offer, but it lists really kind of in general referrals of information so and it's one of those things that I've found. I've called a couple different times myself and you get a different usually different nurse practitioner on the phone every time so you might have a different experience depending on who you are. I've personally had

some really great experiences talking to them as well. So from a mental health standpoint, I wanted to put that out as well as there is the UN I'm sorry, Emily, I don't have it handy the crisis, the BC crisis line, same thing they are required to follow up as well with you. If you reach out to the crisis line with mental health support and services, they're required to follow up and there's no charge to reaching out to the banking crisis center bc.ca As far as access accessibility with them, I do know that they offer like a text option as well. So you don't have to call you don't have to be in person I know that offer a text option that might be a bit more accessible. For some folks. But that that's the limit of my own knowledge. It's also you know, very challenging. It's very challenging issue and I think it impacts all of us in some way. And Patricia thank you for sharing as well your stories by as well. This past year I have been impacted by suicide several times. So I absolutely I'm someone who, like I said everyone else on the call too. We've all had those experiences that show us how we don't want it to go. It's not the patient and family centered care. We want to see and have so so yeah, thank you for sharing that. And it's it's unfortunate, unfortunate to say that it's relatable to many I'm sure on the call. Vanessa over over to you I see your hand up as well.

**Vanessa Lim, Tall Tree** 2:07:42

Thank you. I just wanted to just keep my hand up here just because I had a couple of resources that myself and my colleague Cassie put together. So Kathy is located on Vancouver Island, so she had a couple of different thing Coover, Island based mental health services that are referral GP referral based so you just need a family doctor to help you put a referral in so I will send those links. I'll put those links into the chat for everyone as well. On the mainland there, it's not a free service but there is a private clinic out of recovery, military counseling and every year they put out a really wonderful document on reduced cost counseling clinics all over the mainland. And it usually runs on a sliding scale based on your income. So I'll also be including that as well. Some psychologists, Clinical Counselors and other service providers also may offer a sliding scale. I don't know which one those are but usually what we'd recommend for our clients who live in more rural areas where we're not sure are not familiar with what resources we have. We always recommend that we give them a call and see what they're able to offer. We always try to advocate for with our clients to see what types of reduced costs services are out there. So I just wanted to put that out there for everyone. I know it's pretty few and far between.

2:09:12

Now, thanks for that Vanessa. Yeah, Johanna, jump in. Yeah, go ahead, join

**Joanne Smith** 2:09:17

Okay, since we're kind of getting some resources here, I just want to jump in. I've seen in some of the chats a couple of inquiries about workshops that I might be hosting. I actually don't have any coming up taking a bit of an extended period of time off from doing some workshops. I'm going to be away for extended period. But I used to do a lot of workshops with SCI BC and I'm not sure if they're online if those had been recorded and online. So maybe you can go to the SCI BC site and check those out. If not,

I know as CIBC still does a lot of nutritional workshops with other nutritionists and chefs out there like cooking with Cory. So check CIBC they again. You guys do incredible work out they're incredibly progressive. You're the best kind of SDI organization out there in terms of the services you're providing other people. Other Other just podcasts. I learned a lot from on health podcasts. The Ultimate Health podcast has been on for years. They have a wealth of information and people with disabilities because of stress because of medications that we may be on. We tend to have compromised immune function. So even if you go to the Ultimate Health podcast and look at you know, ways to support your immune function, we also tend to deal with a lot of arthritis. So there are specifics. You know, podcasts looking at arthritis and supporting bone health looking at osteoporosis. I would also suggest if you'd like more of a scientific approach to health care, the Huberman Lab is a podcast. They are phenomenal their research this individual does, again on specific health topics scroll through for items that you might be interested in to adjust your own personal health complication or condition. Very sciency great nuggets of information on there. So I also if you're have a spinal cord injury and you happen to be on here, I wrote a book 12 or 13 years ago with another nutritionist specific to health complications for people with spinal cord injuries. And it's available in PDF form. Eat well live well with SCI fi.com. You can get the PDF there. So there's some there's some resources for you there as well. Awesome,

2:11:41

thank you for listing those off. I've been trying to keep up and put them in the chats. And those are actually two of my favorite. So I would say if you're gearing up for Huberman lab, make sure you have to do three hours or listen to them over the course of a couple days. It's a lot of information. But that's great. Yeah, I'm Pascal, do you want to talk at all about helping people find mental health support? Is that something that pathways is about Yes.

**Pascale (she/her) - Pathways Clubhouse** 2:12:10

Yeah. So just in general, people want to reach out. I can provide my email address here. They can contact me directly and I can help them navigate specifically the resource they're looking for. I'll just share in the chat just some of the basic ones we put on our web page. Make sure this is to everybody here. That's our website. So you're welcome to explore that are some resources. But yeah, I'm happy to help tailor specific needs that you're looking for. If you want to reach out to me specifically so we can look at finding you a mental health clinician or a group or peer support program or whatever it is that you're looking for.

2:13:05

That's fantastic. I'm just gonna toss your email in the chat if that's alright, you. Okay. Great. Did anyone else want to touch on mental health? Before we move on? We are crazy, but we are getting sort of down to the last 15 minutes here. Okay, Kim, I just want to let you know Kim posted in the chat is the purpose of this forum to discuss our concerns and share resources. Is there anything available after this? So just to reiterate, there's a transcript of the chat that will be available we send a wrap up email to all

attendees, it actually goes out to our mailing list. resources mentioned here will be uploaded to our website. But and the the link to this video will also be in that email. So you will be receiving an email and then resources will be on the website. Give us about two weeks to do that, which is great. There's a ton of resources popping up in the chat. So thank you to everybody for participating and sharing the wealth of knowledge. Um, just a couple more questions that were sort of generated by the survey here that we can maybe talk about. Well, mental health and disability come hand in hand as we've said, Well, we did sort of talk about a little bit of low cost or sport risk support there. So let's move on from that. Okay, well, something that didn't come up in the chat and comes up all the time. Just Adam was saying many of us do not have family doctors. I know that this is a huge issue in BC and our universal health care system. Does anyone have any advice and going about how to find a family doctor and sort of starting that process we have had website posted in the chat a couple time find Doctor vc.ca Anything outside of that, that anyone wants to mention?

**Heather Lamb** 2:15:11

I can jump in here that I hate getting this question because I don't actually have a good answer beyond the resources that have already been mentioned in the chat and by Charmaine there are virtual options. Obviously, they're not going to replace an in person visit with a regular family doctor. I'm well aware of that. But as an interim measure, they may provide some of the support that people need. Of course there's barriers to get to virtual appointments. So I recognize those but they may work for some people for some issues. You know, walk in clinics are busy, emergency rooms are busy, and I don't necessarily see this one getting better anytime soon. So I just hate getting this question. Because I don't really have a good answer.

2:15:59

That is fair enough. Yeah, I have had someone bring up before going to you know, the same walk-in clinic and seeing the same provider that's there so they get to know you but that's not the same as having somebody that is dedicated to your care.

**dynamicmg** 2:16:15

I think that's a really big issue that the province is trying to address. I think it was not so long ago that we put in new legislation to make it easier for clinicians from other countries. And other medical professionals coming into Canada to reduce some of the red tape that you'll face with Yeah, and I also find walking clinics don't always provide the correct treatments for things because they don't know your your health past health issues. So it's better to find a general practitioner nurse

**Amelia Cooper (she/her)** 2:16:51

practitioner that can know more about your health problem. And then also I've been lucky because I had cancer previously. So I was recommended to a nurse practitioner to my cancer program, but a lot of

people with disabilities don't have that resource. So that can be a problem is finding a general practitioner that knows all about your previous health issues and disability as well.

2:17:19

Good points. Thank you Amelia. Patricia.

**Patricia G** 2:17:22

I just wanted to add, but I found mine. It was back in 2011. So it was a whole other world then. But how I found mine is I was going to a walk in and I noticed that they that walk in was a training facility for UBC students. And so my walking doctor was actually a locum and so I just asked her, I said you know, are you going into family medicine will you be taking patients and she was so I just found by basically like lurking around trying to find logos. And that worked well for me. And then also she's now moved to a clinic in Vancouver and it's called Fraser street medical. I'm not promoting them or anything but they're one of the clinics that takes on complex care patients. So they're they're aware of the billing codes. So I don't think they're taking new patients right now. But even just being aware that there are billing codes for complex care patients, you can tell tell a doctor because then if a GP is considering taking you but they don't want to like waste all their time. You know, with complex care patients, if they know that they can actually get paid more. By seeing you a bit longer and like billing it appropriately. Then it will help them not dismiss patients who have complex care as often.

2:18:56

Great knowledge. Awesome. What whatever the clinic that you mentioned, did you maybe want to put in the chat. That's possible. Awesome, Charmaine.

**Charmaine (she)-HQBC** 2:19:07

Yeah, I just wanted to add, thanks for sharing that. And that way that that you found a position yes, that someone put in the chat as well that that physicians are being asked to pull from the registry and to not kind of do the word of mouth one so that they are kind of funneled through that one system to make it so that it moves more quickly. So that is correct. That's what I've heard. So So registering through that provincial site is supposed to be kind of the new model to move that as quickly as possible. Oh, you beat me to it. I was just gonna hit paste on the 211 dot ca website there. Yes, that's another I'm so glad someone mentioned that. I know I had mentioned 811 Previously, which connects you to a registered nurse but 211 is another new resource and a lot of what's on the two on one, website and phone number. It was actually born out of a lot of what we saw through COVID. Folks needing to be connected to other sources and information. So 211 has come come out of that as being kind of a home base for a ton of information and resources for folks. So So you got to lean into that one. as well. Thank you as well for mentioning that Heather, the virtual healthcare appointments I can't believe I didn't think of that right off the bat too, because it has helped me enormously being without a physician right now. And I

sometimes I've had to kind of look up a few different ones and see where there's availability, but I've had very quick turnarounds like same day within 45 minutes to be able to have sometimes a phone call doesn't have to be over zoom with a physician. So again, not accessible for everyone and it doesn't help with everything and of course with complex health history can be challenging, but I have found in her from others, it's a very helpful way to quickly access virtual care. So I wanted to just give my backing on that as well. Yeah, thank you.

2:21:15

Great. Okay, okay. In closing, we did cover a lot of things today, I just want to say thank you to everybody that shares who do share your story so that, you know, everyone knows what's going on and you're usually not alone in your experience. So thank you for being brave to be the voices for those people that are not here. People that don't feel comfortable speaking up. Do does anyone on the panel want to say anything in closing? We got about seven minutes.

**Amelia Cooper (she/her)** 2:21:45

I think Laura wants to speak

**Chloe** 2:21:48

Okay

2:21:54

Thanks, Amelia. Yeah, I just wanted to mention that a lot of people don't know that you know if you have to do a form or get a form completed like I'm the Senior Advisor at plan Institute on our on the National Disability planning helpline we get a lot of people like you said mentioning they don't have a doctor. So how would they get the disability tax credit form filled out because that is the main criteria to get the registered disability savings plan. And the changes did happen within the last year or two that to allow a nurse practitioner and you know, noting that many people in British Columbia and Canada can't get a regular GP or another kind of specialist anymore. So if you can find that nurse practitioner that might help you to be able to qualify or get some of these really important forms done for tax reductions or other services or programs or funding and to definitely read through an entire form to see if a nurse practitioner is now allowed or asking to see if the law has changed on that.

2:22:55

That is great information to have. Thank you Laura and I also planted students awesome. I posted your link in the chat as well. Thank you. Okay, Joanne, Vanessa, Pascal, Heather, Charmaine, thank you so much for being a part of this discussion. Again, a transcript of the chat also a transcript of the entire

discussion will be sent out in an email as well as included on a resource page on our website connector.org in about two week's time, give us a little bit of time. Also, Chloe is going to post the panelists, email addresses. There you go in the in the chat, Vanessa. We didn't have yours if you'd like to post it, you can. If not, no worries. If anyone has any follow up questions or comments, ideas for other accessible community forums or just things they want to add. You can email me directly, ie chambers@connector.org. It's also in the chat there. And Vanessa just added hers. Thank you for attending. The Disability foundation and connector are both nonprofit charitable organizations. So please check out our ways you can support us so we can keep having these events and also connect dra.org for events that we have coming up. Thanks so much. This was really eye opening. And I think yeah, and I promise to broach the subject of ASL and make sure we have that covered at our next online meeting as well.

**Pascale (she/her) - Pathways Clubhouse** 2:24:42

Thank you. Thank you, Robin.

**Charmaine (she)-HQBC** 2:24:44

Lots of tough conversations Everyone, please take care of yourselves. Take good self-care the rest of the team after tough chats. So appreciate it.

2:24:53

Thanks, everyone. Nice to see you can thank you

2:25:08

Recording stopped. Beautiful. Thanks, Graham. Live stream can stop too.

2:25:15

I'm just getting on that right now.

2:25:17

All right, Chloe copied the chat. Awesome, Pascal, thank you so much for being here. So great to meet you. Yeah, there. Thanks for your contribution. Yeah, thank you, everyone. Goodbye. Awesome. Have a great weekend. Okay, sweet. We go. All right, I'm gonna leave. All right. Awesome. we'll debrief next week.



**Ryan Yellowlees** 2:25:48

Okay, all right. Thanks.