

## 2024 KT Online Conference

### Lived Expertise Matters

*Presenter:*

Heather McCain

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Transcript for audio/video file on YouTube:  
<https://youtu.be/7rOJdbxFtDc>

Heather McCain: Hi everyone. I am Heather McCain. Our organization is called Live Educate Transform Society (LET'S) because everyone who works for us has lived experience with disability and or neurodivergence and the majority of us are also 2SLGBTQI plus. I'm a white non-binary person who has freckles, wears silver glasses and has a shaved head. And this slide has a logo of our organization, which is a light bulb with speech bubbles. Some of our members think it looks like a hot air balloon, and we're happy with either interpretation. So next slide. This slide has a photo of sunlight filtering through trees at Seymour Provincial Park in North Vancouver. I come to you today from the stolen land of the Squamish, Musqueam, and Tsleil-Waututh people in what is colonially known as Vancouver. This acknowledgement is a tiny piece in the larger context of the ongoing work that must be done to create disruptive change and true reconciliation and challenge the legacies of colonialism. Next slide.

Connie Walker is a Pulitzer Prize winning Cree journalist from the Okanese First Nation in Saskatchewan and has witnessed how indigenous stories have been grossly underrepresented, sometimes misrepresented, and generally misunderstood. Speaking about representation Walker says, I think that you can't underestimate how important and vital it is to see yourself as stories, to see yourself in media, to see yourself respected because that's what it is. It's a sign of respect when you're given the space to share your story and you're given your space to talk about what you care about. Next slide. Walker continues, that I think in doing the work that I've done I've realized just how important it is how informed my work is by my lived experiences, by my perspectives, how that shapes every part of the process in terms of how we approach interviews. And so for our organization, prioritizing lived expertise, all leadership positions at LET'S including boards, staff, and content creators, researchers and workshop facilitators are of the identity that they're advocating for, educating about and or representing. Next slide. And I have a guest on my shoulder, which is my four month old cat who has just jumped up. They're a Calico cat named Talula. So yes, I am proudest to be called a Crip doula. This is a community given disability justice term for someone who has helped disabled people navigate our complex systems, providing resources, support, and building community. And this title was gifted by community members who have felt the positive effects of my work. We can transform our

communities by applying disability justice principles like leadership by those most impacted. Next slide.

Personally, the fifth principle of disability justice, Recognizing wholeness, really speaks to me because each of my identities and experiences form a puzzle piece that when connected to the larger hole form who I am. This slide has an illustration of a tree with orange, red, yellow, and green leaves, and the background is white. All of the experience I have had along the way give me a unique perspective and lived experience and disability justice recognizes and celebrates this. Disability justice recognizes the value of what I bring to this movement. It validates that my lived experience as a person with multiple intersecting identities facing adversities has given me an incredible wealth of knowledge and affirms that knowledge is important and valuable. Next, learning from lived experience is also vital to disability awareness. I've learned from a lot of other disabled people. As a sighted person, I did not think about pee patches until talking with members who are blind and partially sighted.

And this slide has a closeup photo of dewy grass. Guide service and emotional support dogs are trained to pee on grass. All too often, especially in cities like Vancouver, there are no available pee patches near meeting locations. Additionally, many housing developments have discriminatory policies that don't allow dogs to pee on landscaping. And this is consequences for members who rely on working dogs, particularly those who have mobility issues and are not able to walk for long. And this we responded to learning about this from other people's lived experience by making sure that our breaks are long enough for people to be able to go out to their pee patches and come back and also marking them on maps in advance. Next slide. Disabled people can use their lived expertise to find ways to create systems that work for themselves. For example, a student who was affected by post-traumatic stress disorder came up with a system with their professor using a pink post-it and a photo of a pink post-it is shown on this slide.

If the student is experiencing symptoms of PTS, disassociation, panic attacks, flashbacks, et cetera, they put their post-it note on their desk. The professor then takes that as a cue to not call on the student or expect them to participate. And when they're able to engage again, they remove the post-it. Finding creative solutions takes trial and error and requires lived expertise to know how best to meet needs. Next slide. Sharing stories with community members help them think of perspectives they haven't considered. For example, in a chronic pain support group I ran in Maple Ridge, we had several members who worried about being parents with chronic pain. They wondered if they were holding their children back. One member shared a story that had altered her perception. She had run into a neighbor one day and the neighbor said that the day before they'd really been struggling with bad pain and trying to get their groceries.

Our member's son then 17 saw the neighbor struggling, left his friends and came over to help. He loaded the groceries and noticed that she was exhausted and offered to drive the neighbor home. She said she didn't want to take him away from his friends, but he was adamant. He drove her home and put away the groceries, then took the bus back to his friends. This slide has a photo of a young man pulling groceries out of a paper bag. The son didn't expect anything in return. He hadn't told his mom about it for credit. He had told the neighbor he knew how hard life was for his mom, and if there was any way

that he could help someone like her, he'd do it. So yes, they both had struggles because of the mom's chronic pain, but he had also developed an amazing ability to see when people were struggling and compassionately offer assistance.

This really made a difference to how our member viewed her relationship with her son and how others viewed their relationship with their children. Next. Lived expertise also explains experiences that one couldn't possibly imagine unless they lived it. For example, one day I was waiting for a friend outside of a Blends coffee shop. I was holding a hot chocolate, and this slide has a photo of a hot chocolate with a foam heart. A woman walked by and dropped change in my cup. She saw a person in a wheelchair in front of a store with a cup, and immediately assumed that I was asking for change. She saw my wheelchair and made an assumption about me. This is ableism and often unless experienced it is not truly understood. Next slide.

An example of lived expertise and action can be found with one of LET'S newly launched services, which is low sensory spaces. As a person with sensory issues, meaning that I get overwhelmed by crowds, noises, strong smells, tastes, and emotions. Low sensory spaces recognize that there are people who want to participate in events that need a space where they can go to regroup, regulate their emotions, be supported, and be able to step out of the commotion. And this slide has two photographs. The first is from Victoria Pride. It shows a selection of neurodivergent stim toys that we give out, including acupressure rings, slinkies, spinning balls, and textured stickers. And the second photograph shows four people at a Camp Normie musical festival, and they're all playing with the sensory items that we provide. Two of them have their eyes closed, and that's because they were laughing so hard. We could not get a photo with all four of them open, but they really enjoyed having that space. We also had somebody who came into the low sensory space and knit and their friends would come and visit with them for about 10 minutes of the hour and then go off and dance again. And by the night's end, they had knit themselves a crop top. They were able to be able to participate with their friends without having to engage in the overwhelming dance party. Next.

And this photograph shows a picture from Victoria Pride as well of a neurodivergent person coloring. They have soundproof headphones on and a trans possum that they knit in the blue, white, and pink colors. And their parent is next to them also coloring. And the next two photos show the person that I had just mentioned who knit while their friends were dancing. And the second photo shows their knit top. Next. Lived expertise matters also because within our network of community care we know that we can ask for what we need while still preserving our independence, integrity, and autonomy. We engage with each other and create and explore new ways of doing things that lessen our collective dependency on a system that has and continues to harm and disregard our collective needs. Pictured here are nine members of chronically queer. The photo was taken during the 2019 Vancouver Pride Parade. We're carrying signs that say I am a lesbian, I have an invisible illness, I am proud. Spoiler alert, disabled people can be queer too. One member is pointing to their mutant and proud shirt, and my favorite sign is Queer here and a Pain in the Ass for medical and gender systems everywhere. And based on the work that our organization has done with Vancouver Pride since 2019 last

year, based on our recommendations, they changed Vancouver Pride Parade Route and Festival location to make it more accessible. Next slide.

We care about each other in a way that fights against a society that continues to fail us. This is community care and action lived expertise shows that it's beautiful to see the ways that we show up for one another. We need this type of collective access inside and outside the disability community. Next. So thank you very much for listening about Lived expertise. If you have any questions, then please do let us know. Our contact information is included on this slide as well. Our new website is [ConnectwithLETS.org](http://ConnectwithLETS.org).