Episode 98: Spinal Cord Injury BC, Peer Support, Info Services Pt.2 | Jocelyn Maffin

Manisha Ramlu 0:07

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Manisha Ramlu 0:35

All right, so I'm going to move on to the next question. You began peer advocacy at such a young age, as you mentioned earlier on. So how did these experience kind of influence your path and the way you approach leadership today? I know you mentioned you wanted to go into like, you know, the medical field, but here we are.

Jocelyn Maffin 0:55

So, wow, I don't think anyone's ever asked me that. It is kind of funny to me that I started in peer advocacy and ended up in something very similar. Peer support is a, advocacy sometimes is a component of peer support, and it's a very similar kind of ultimate goal, I think, is to equip each other with our shared experiences and but I did not set out that way at all. I think, how did it affect leadership? That's such a great question. I think, I think my leadership at SCI BC, and in you know, other contexts I've been a leader, was really informed by the understanding how important it is that the right people's voices are in engaged and welcomed and understanding the barriers in in making that happen, and what happens when you don't consult the people who are most affected. One of the things that I did when I worked at Children's Hospital as the youth advocate was they were very keenly aware at the time of the big, they call it, kind of a chasm, a cliff that people fall off of when they get transitioned out of child and youth focused care at Children's and into adult the adult healthcare system. Because when you have a disability or a chronic condition in childhood, everything about the way the healthcare is delivered is developmentally appropriate. So they really don't like you to miss school, so they save up all your treatments and stuff for the summer, which sucks, but it you know that was what was seen as developmentally appropriate. They really don't like to pull you away from your socialization and school experiences. And you know, having your parents around with you, and like all of the everything, was sort of reinforcing of that family orientedness and not a lot of it was about equipping the individual to make their own decisions, like the advocacy I did was a little bit of part of that, but really it's focused on children as part of their families as it I think it makes a lot of sense too. But as the young person becomes a teenager, you kind of have to shift focus, whereas in adult health care, our whole system is based on you managing your own stuff and staying on top of everything. And if you don't call to like, follow up on a referral, or, you know, if you don't know who the right person is to talk to, or maybe you struggle to speak to like authority figures, like your doctors, which is extremely common among young people with disabilities, you get lost in the system. The referrals go out your last clinic day at Children's when you're like 17, 16, depending on what clinic you're part of, and they were finding that many, many young people were like lost to follow up. They didn't know what happened with the referrals. They never got to see them. I remember seeing a pediatric physiatrist rehab specialist at GF Strong the year that I transitioned out of the spinal cord clinic at Children's at 18, and I saw her once, and I never saw her again, and I don't know I got anything out of it. She is lovely. I have seen her since, but I was pretty stable, and well over my teenage years. I didn't remember what it was like to have six surgeries in three years, because I was young. I was really young at the time, and so I didn't have a resilience based on that experience. I had a resilience based on everything being hunky dory just fine. And so that was the sort of advocacy approach there, and everyone was sort of falling off that cliff, including me. I fell off that cliff, and then I had complications that led to a loss of function, because I couldn't figure out who to talk to. I didn't know what was happening with my body, and I didn't recognize the signs of a worsening in my neurological symptoms and that was a really sobering growing up moment for me, and, and that is, unfortunately too common. And so I was part of this project, a bunch of different projects about transitioning to adult care for basically youth and young adult patients at Children's Hospital, and we created a clinical practice guideline to follow for transitioning young people to adult care. And I remember being a part of those discussions as the lived experience person, and I remembered things like how all of the people in the room were participating as part of their job, but I would drive out there while I was in university during the semester, I didn't get paid, I didn't even get my parking comped, and I would show up and be there for two hours and then go home. And it didn't bother me at first, but then I started to be asked to do it a lot. I just became a bit more aware of the how uneven, unequal it can be when you are the person you were like the only person in the room full of physicians and academics and, you know, other medical staff, and you're trying to grapple with the language they're using, their timing—everything was in the middle of the day while I was supposed to be at school—and I felt that the burden was on me to try and give my voice to the problem as best I could to the project. But it was really difficult to be part of that sometimes. And I think my different kind of experiences related to working at Children's and volunteering and consulting and children's really gave me a sense of how silent a lot of patients or youth voices are, especially those who deal with health conditions in that period of their lives, how quiet and unheard they feel, and what a rough ride that is to transition. And if you're in that vulnerable place, it's really you have lots of barriers to having your needs heard and voices heard and and really the developmental approach that pediatrics take taste takes is very trying to normalize, which is great, but I don't think it sets you up for a few of yourself as you need to be aware of what could happen like I was an adult before I realized that people with my condition die in their 20s of infections. Wow, nobody ever told me that, and I can understand you don't want to tell your like six year old, but you know, knowing this, the seriousness of some of those complications would have been, I think, helpful in some ways, to know to take it seriously. And there's no easy shift or transition. It's like, one day you're a kid, and next you're an adult, and you need to know who your specialists are. Like, it was a really rough go and and I think that experience, first of all, it showed me that I was one experience out of a whole bunch of different medical and disability populations who were going through some similar things like transitioning to adult care, and each had really important social and medical and legal reasons that they needed to have their voice heard, And there needed to be a way that their experiences could inform what was being done around them, for them, to them. And I guess that kind of got ingrained in me, because the trend continued in research too. It's incredibly common in research now that people with with of lived experience, of whatever population you know could be, women with breast cancer, could be anything, are recognized as knowledge users and people with lived experience. And there are guidelines about how to compensate us, and there are recognitions of that we should be able to come to conferences that cost $700 and that there should be conferences that offer special rates, like ways that those voices could be contributed in the overall ecosystem of health, social care, justice, social services, that kind of thing, like and, and that was a trend that was happening aside from me. I was just lucky enough to have been thrown in the pool as that was like moving the water toward that. And it was something I, you know, had some experience with, so I was able to sort of go with the flow. Because when I started working at ICORD, consumer engagement, as we called it, or like patient engagement, is another way it's called, like collaborating and working with people who are the beneficiaries of the clinical or research work that you do, became something of value and made a recognition of the need to translate this academic knowledge into something useful for the people who should be benefiting from your work. That whole thing was a trend that was happening apart from me, and I was fortunate to kind of come up through academia at the time that that was happening with a public health lens of like "Nothing about us, without us" and offering the, I don't know, the support, the just valuing the voices of people and and looking for those upstream factors, not just because it was also very common when I was younger, that if you're an adult with a health condition, and you weren't a non compliant or whatever—that you had type two diabetes, and you weren't taking your meds or eating well—you were non compliant. It was very judgmental. And I think a lot has changed, recognizing that there are upstream factors like poverty, like lack of good work and housing that make, you know, paying for your meds sometimes difficult, that make buying good food and preparing it for yourself. Maybe you look after several kids and you don't have time, your mental health, there's all of these reasons that inform why people do the things that they do, and that's a sort of key component of public health and that, to me, always seemed like so logical like, listen to the people talk about their lives and how all of this affects them, and then look with them for the reasons that, that you know whatever goal it is, like better health or better outcomes are difficult, and then work together to remove them. That just seems like—

Manisha Ramlu 13:34

Common sense.

Jocelyn Maffin 13:35

Kindergarten, logic. Right? Like work with your friends, you know, collaborate, cooperate together, and talk to each other, and good things happen.

Manisha Ramlu 13:46

Absolutely but it just the world doesn't work as black and white as we'd hoped it'd be, but I think we're moving into that way of being, but I feel like there's so much more room to grow and evolved it that way. Just going back to the transition period, I know you mentioned that, you know, like, it's not just children transitioning into adulthood, which can be really jarring and abrupt, but individuals who are, you know, transitioning, let's say, from a long term in the hospital now they're transitioning into, like, everyday life. Do you know of any programs that are available at the moment, or if there's any like resources for individuals that are transitioning at the moment?

Jocelyn Maffin 14:33

You mean out of hospital and into the community?

Manisha Ramlu 14:36

Yeah, exactly.

Jocelyn Maffin 14:37

Um. I can think of a few. So we consider our peer support program part of that, and understand that when people are discharged from rehab, they're like little baby birds, you know? We know that the first two years with injury, spinal cord injury. is the most difficult, and they're the most likely in those first two years to be re hospitalized for like a pressure ulcer, a burn and an infection, and we know that that it's funny, because I was talking about the youth to adult care transition, but in spinal cord injury rehab. We call that discharge period after rehab, the first like two years after discharge, they call it the chasm or the cliff, because that's when people in their early phases, early months of their spinal cord injury have to suddenly leave this like pretty protective, caring, proactive environment of rehab into, you're going home, you're dealing with your family and your friends who knew you as a non-disabled person before you're emotionally grappling with how much your life has changed. Because while you're in the hospital, a lot of people feel like their lives are on pause. So then you get discharged, and you suddenly have to grapple with that this is all permanent for most people, and some of it is like you have to reform your relationships, you have to relearn how to like navigate in your community, you know, if trying to think of like other things. So we see our peer support program, especially from the perspective of our resource centre at GF Strong as the program that is aimed at people transitioning out of rehab and into their home community. And it's all of these things are even harder when you're going to a small community, a rural, small, Indigenous community, even like because the supports that understand what spinal cord injury is all about are not there, because it's not that common in the scheme of things. When you come out of rehab, you need an occupational therapist, a physiotherapist and a physiatrist, a rehab specialist and nursing care to some degree, and you may rely on a caregiver as well, like someone who assists you with like activities of daily living, like showering, eating, dressing, that kind of thing. And in small communities, they just don't have a lot of that, and it can be really difficult. It can feel like you don't have a net to catch you if something's wrong, and it can be hard to get into those folks, and even sometimes local clinicians like physios and stuff, they might not feel confident about dealing with someone with a condition that they aren't experienced with. So we try and be that program that, we don't talk about that transition like in our events, we are, we are all about a social community. So we try and have events in the in all of these regions where you can come, it's free, lots of food and good conversation. Sometimes we do pub nights or we go watch local hockey games together. I think the goal, like the events are the excuse, the goal is that you have a posse of people who get you, who get your experience, and ideally are a little further ahead in the experience than you are. So you have something, you have people you can ask and people ways to support each other and then our info line team are the people who like support everybody and enable our peer coordinator staff to do things like hospital visits and connecting people in their community to services and supports that they need, because we can't, we can't expect every peer coordinator to know all that stuff. So that's why we have our info line. Yeah, so we try and be that. But there are also some some other programs that can help, like sometimes your insurance provider, like, if you come if you were injured in a workplace accident, or injured in a car accident and WorkSafeBC or ICBC might do you have more of a like case management kind of system to engage with you, to give you some funding for recreation and stuff like that. And so those can all be like important for your ability to sort of transition in a strong and thought. Away. And there are other nonprofits out there who do pieces of this as well, like in Kelowna, there's a group called Accessible Okanagan. And are a lot of the same people who are in our community there as well, and they're really into recreation and sport and outdoor activities, and so they that's kind of their approach and their crowd, and they do lots of like live music and stuff like that. So, you know, we, we know that we aren't the only way that people with spinal cord injuries find their find their path and find their their way to sort of reimagine their lives and get back into what they want to do. Adapted sport is also a really common way that people accomplish the same thing. They find people who have similar experiences, who they can learn from, and it's all in the context of, you know, getting great at this new sport, or just social community, quad rugby, or wheelchair rugby, is very much like that, and it was like that for me with wheelchair basketball. So we are by no means the only people who do this kind of work, but I think we're probably the organization with the widest reach, like regionally around the province, and a lot of great different programs. And we really want to be the outlook to make sure the people who didn't get connected have support and try really hard to like, "If we don't have it, we want to help you find it." Um, because a lot of people kind of get lost in the shuffle, and it can feel like when you come out of an extended hospitalization, it can feel very confusing and alienating and and we just want to make sure that you find your people, or find the thing that really like lights your fire and helps you come back to what it, whatever it is that makes you thrive right? And so we're just as happy to help you find a single, individual peer in your area that you know you can build a good friendship with, or a sport that does that for you. So trying to think of other organizations, that's what's off the top of my head.

Manisha Ramlu 21:33

Well, that was very informative. So thank you. And yeah, absolutely, I can imagine how isolating it could be, like you mentioned, just transitioning from this like comfort and care in the hospital setting, and the coming out into the community can be very jarring as well. So yeah, that's amazing that you guys have these supports, and definitely will link everything so people know where to find you if they haven't found you already. So many of our listeners might not realize the systemic barriers people with SCI and similar disability space daily, what's one barrier you believe that goes largely unaddressed?

Jocelyn Maffin 23:10

People might be surprised to realize that how much cost and income affects people's inclusion and engagement in their world after a spinal cord injury, because we think about our country as having socialized or single payer or universal health care. But that does not generally extend to things like wheelchairs and in BC, medical supplies like catheters, which is really unjust. I don't know how else to put it, and it also affects the things that I wouldn't say would be normally covered by a health insurance anyway, like the equipment we need to be active in our communities, or sometimes in our work or school as well.

There's a lot of adaptive equipment that has been invented that is incredibly useful, but it's also extremely expensive, and unless you are on PWD benefits like provincial or federal disability pension, most of that is not covered, and if it is, it will be just the basics. And I get that. I get that this isn't meant to be like a luxury sort of pension but, and a good example is so vehicles adapted, vehicles for someone who uses a wheelchair, especially a power chair, are extraordinarily expensive. But think about how many things that vehicle transportation is essential. For even if you're lucky enough to live in the big city and you have access to Canada Line and the bus system and stuff, you can't transport stuff, like a sport wheelchair. If you don't have a vehicle, you can't get beyond the range of the transit system that's only if you're in Vancouver, if you're in their transit system is like four lines, so you can't get beyond the transit system for like, camping or visiting a loved one who lives like further out if you don't have a vehicle that accommodates your power wheelchair and so that that cost barrier of those vehicles, the vehicles themselves these days are usually minivans, are like $60,000 and then you add the lift or the ramp and all that modification, they roll off the warehouse floor or off the shop floor at like, $100,000 sometimes, and where do you get that money from? That doesn't come from, that doesn't come from your PWD, benefits, but it's such a key thing to like going back to work, looking after your family, like regaining your role in society. It's just, especially with a disability, like there are things that you can't do, public transit. If you had a small child and like an infant and a small child and you were in a power wheelchair, are you going to take transit to go to the park? Maybe not. That might be pretty difficult. You might need a bunch of stuff, like one of those little kick bikes or something. How are you going to bring that with you? So the reason I bring that up is that we do an amazing adaptive recreation camp at Whistler every year with Whistler Adaptive Sports Program and the biggest barrier to people coming on this very low cost trip. It's like two nights, three days, five sessions of adaptive rec with all the equipment included, and transportation is the biggest barrier. Yeah, and it's rough for us because there aren't a lot of bus programs, accessible busses that can take more than two people and that can come up and stay with us and drive people to the different sites, and there aren't a lot of rentals of those types of adapted vehicles, so cost barriers, and then differences in coverage between like WorkSafe and ICBC and PWD, and then everybody else, you don't get much and that creates a real difficult problem, because people who need a particular piece of equipment to like work, you know, look after their family or whatever, they have very little likelihood of ever getting it. And, and it makes me so sad, because they would be, it would enable them to be so much more included in their work or life or family.

Manisha Ramlu 28:08

Sorry, and I can imagine it offer more autonomy, like, for example, taking your children to the park, or, you know, seeing a loved one that kind of lives further away, and there's no public transport and like, to me, it's common sense, like these things should be covered, but then there's also so much funding that's available, and that's, yeah, it's not cool, that's not fair.

Jocelyn Maffin 28:36

It's rough. It's a rough thing to kind of live with in your head, knowing that it, that it's such an important component of being part of our society and, you know, like everyone we know, this comes from tax dollars. I get that, and I don't think anyone's trying to, like, take what is unreasonable, but it's also like the way the affordability crisis has affected the things that people with disabilities need. And, you know, sometimes there's not even coverage for wheelchairs, like basic mobility and it can be really difficult. You know, power wheelchairs are really expensive now. You know, that's why we have our swap and shop website on our marketplace, because hoping we can, like connect people who have equipment to offer and people who need it, because not everyone has coverage, and some people who do have coverage, they order something that doesn't work for them, and they have, like, a perfectly good wheelchair or hand cycle or something. And so we try and help be a community that can, like, share what we have, but it's hard when most of your community is dealing with some kind of material need and there's so many systemic issues. Don't even get me started about health, but that's one I think is a really practical one that I don't think most people know about.

Manisha Ramlu 30:15

Thank you for informing us that. Yeah, I had no idea. Okay, let's move on to our last question. And I'm not going to take too much of your time, but you're an outdoor enthusiast and often hand cycle through the woods. How does time and nature contribute to your well being and outlook as a disability advocate and leader?

Jocelyn Maffin 30:38

This is my favuorite question. I only discovered hand cycling after I started working with SCI BC at our Whistler camp, actually.

Manisha Ramlu 30:52

Before we dive into the question, can you tell our listeners what hand cycling is? Oh,

Jocelyn Maffin 30:57

Oh, yeah. Great point. Hand cycles are essentially a bicycle. They're actually tricycles. They have three wheels in general, and they are like a bicycle flipped upside down. So if you imagine the place you put your pedals, your feet on a regular bicycle, if you flipped the bike upside down, then you would have those pedals where your hands are, and you would use your hands in exactly the same way those pedals work to drive to like power the chain that drives the wheels. Um, hand cycles have been around for probably since the mid 70s, um, but since bike technology has improved so much, and e-bikes are so popular that has really pushed ahead handcycles so they they are leaps and bounds better than they used to be. It used to be that hand cycles were so hard to use because you had to have already a lot of power and strengthen your shoulders to make it go, because you don't get the mechanical advantage of being on top of the pedals when you're cycling like you would on a bicycle. On a handcycle, usually they're heavier because there's one more wheel and there's a seat instead of a saddle, and so the bikes, the handcycles themselves, are bigger, and you are, if you can imagine someone sitting in a sitting position with one wheel in front of them, and the cranks are right in front of you, where your arms would be, and you're cycling right in front of you, like, I don't know how to explain it. It's like you're trying to mix a mixing bowl, but horizontally and it's a lot harder, I guess is what I would say. It requires a lot more strength early on. So adding electric assist onto these hand cycles, opened hand cycling for a huge number of people, including me. And I discovered handcycling at our Whistler camp, and I got a chance to try the an adapted mountain bike with an electric motor on it, and I was pretty snobby about it. I was like, I don't need to go with a motor. And then I realized we're riding on trails, steep trails, trails with a little bank to them, roots and bumps and stuff. And you really do need that extra oomph to get out of weird places, to get around corners. But what was bigger, what really like blew my mind and made me such a big, outspoken person about access to recreation, is that you know, on that ride, we went down into what is the Train Wreck Trail and the Sea to Sky trail in the Cheakamus area of Whistler, and I realized that I was like further in to the forest than I had been since I was a child, small enough to be carried by my dad. And the that reality like hit me like a ton of bricks, but it also kind of hit me like, a fog dissipating and show it suddenly, like revealing this whole new world to me that I had forgotten even existed. Like I've always been, I've always grown up, like on the west coast and in BC. And you know, I see the forest. I see it as I drive by it in my car and but being in the forest with the tree canopy above and that sense of coolness and the smell of the damp earth and the sound of the water and like animals and stuff, it was like a magical experience. I came out like, with my mind blown. I was like that, first of all, I was like, now I realize what I was missing by objecting to using adaptive equipment like an electric assist motor. Handcycles are pretty expensive too. So I had a little one for the urban area that it attached to my chair, but it made me realize, like, how much the bike itself limited where I was able to go with it, because it it was hard. It was not like, it wasn't an easy activity with the way that the equipment is designed, and so adding an electric assist motor takes away all of that weight and difficulty and traction problems, and suddenly I was like, able to see parts of the world that I had forgotten existed. And I was like, "Everybody should have access to this. Everybody should have be able to be a part of the benefits that we get from being in nature." And I know I'm hardly the first person to learn this, but it, I think it really showed me that there are parts of it, being included in our world, in our society, in our lives that we almost universally recognized as a positive thing, like being in nature, being active, like physically active, but we don't view that as important enough to fund it for people who are disabled. And there are a few organizations like BCMOS, which is part of Disability Foundation, and SCI BC had a cycling program for a while too, and trying to remove the financial barriers and the access and knowledge barriers so that people can try cycling and get into them, but it's so hard to do, it's so hard to offer that, there's so many barriers. And I see what people's faces when they come back from our camp, and they're like, "I had the power to do that. I did that. I went down that trail, I went up that side of the hill and came back, and I felt powerful and engaged and part of it in a way that is different to how I am every day." And you know, a lot of us joined with other people who brought their own bikes, and so you see how they do it. And it really made me a believer in peer support, and in the knowledge of other peers and the importance of experiencing outdoor recreation in as a part of rehab. And, you know, sometimes I daydream about coming up with my own foundation where I can like people to get the equipment that they need to have those experiences, but I haven't met a really wealthy person, yet, so. [Laughs]

Manisha Ramlu 38:03

[Laughs] Hopefully soon enough! But that's so powerful. And thank you for sharing that. Like, that's so amazing. And yeah, like, nature is, you know, proven to be healing and to be therapeutic and like you said, we forget that, like, you know, me, as an able-bodied person, forgets that, like, oh, being outside and having, like, that fresh breath of air is just so, you know, relieving, and so it's just so calming and it sucks that, like, you know, we don't have funding for, like you said, basic wheelchairs. So finding funding for that would be, you know, very difficult, like you said. And hopefully, as technology progresses, we can kind of create something more adaptable and more accessible, but hopefully sooner than rather than later.

Jocelyn Maffin 38:56

Right now, the bike that I wish I could get is $30,000.

Manisha Ramlu 39:01

Oh, my goodness.

Jocelyn Maffin 39:03

And you don't need that bike in order to do this. It's just a really amazing piece of machinery. But the average handcycle with an electric assist is going to be $5000-6000 on the low side, and then more from there, again, with the cost and affordability barriers, but it is still, I think, worth trying. And there are lots of people out there buy and sell old bikes and stuff. So I just encourage people to not view things from a like, "Oh, that's just not possible," kind of perspective. Like, reach out, ask questions, see what you can find out. And you know, a lot of times, our community or other organizations can help you find a solution for that thing you want to try. And I think it's worth being curious about that, and not saying no before you really know if it's not possible.

Manisha Ramlu 40:04

Absolutely, thank you. Well, that comes to the end of our session. Thank you so much for coming on here and sharing all the knowledge that you have. That was super informative, and yeah, and I'm sure our viewers will find that the information that you provided very helpful, and they'll know where to find you, so.

Jocelyn Maffin 40:27

Awesome. Um, well, I'm sorry in advance for how hard it is to edit me, because I'm super long winded. [Laughs]

Manisha Ramlu 40:34

[Laughs] No, I love it.

Jocelyn Maffin 40:36

Bye.

Manisha Ramlu 40:36

Okay, bye.

Outro 40:37

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