

Episode 97: Spinal Cord Injury BC, Peer Support, Info Services Pt.1 | Jocelyn Maffin

Manisha Ramlu 0:07

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Jocelyn Maffin 0:33

Hi, I'm Jocelyn Maffin. I work with Spinal Cord Injury BC, and I live with a congenital form of spinal cord injury, so I use a manual wheelchair full time and live with all kinds of complications related to my condition. My role at Spinal Cord Injury BC is I'm the Associate Director of service delivery, which means that I support our teams that do direct support and information for people with spinal cord injuries and similar disabilities, and sort of helping them to adjust, adopt and thrive living with a disability in our community. So yeah.

Manisha Ramlu 1:19

Awesome. Thank you for sharing and nice to meet, and I'm so happy you're here today.

Jocelyn Maffin 1:23

Thanks for having me.

Manisha Ramlu 1:25

Of course. Yeah, so let's hop into the questions. So Jocelyn, you've worked across research and advocacy, service delivery. How have these different roles has shaped your understanding what meaningful support looks like with individuals with spinal cord injuries?

Jocelyn Maffin 1:45

That's a really interesting question. You really start with the complex ones. Yeah, I think I would say the through line of all of the different types of work that I've done is that there's all of these different sectors or ways to look at the needs of people with disabilities or the needs of people with spinal cord injuries. And my disability is congenital, so from birth, and it's a kind of an unusual form of spina bifida. And so I worked in the research centre at BC Children's Hospital in a variety of different, like unrelated sectors of health research and

sort of population public health research. And there are so many different ways to look at disability or health conditions as a quote, unquote problem, and but across all of those different ways of looking at those challenges or struggles or health issues. At its core, it needs to be about the priorities and needs and concerns of the people who stand to benefit from it, who are people whose lives are impacted by that work. So when I started my career, actually, it was while I was still in university, I had a role doing youth advocacy, teaching youth advocacy for young people with chronic conditions and life limiting conditions at Children's Hospital. And that was inherently and an approach all about trying to pull out the youth voice in their care and equip young people with the skills that they needed, or maybe even the practice that they needed to have a voice in their health care. And it was because of a big change in legislation that allowed younger people to have a say in their health that wasn't previously allowed there had been an age limit where, under which nobody they didn't have to take into account your feeling about like a child or a teenager's feeling about their health, and then they updated it, and that meant that, for example, a young person with cystic fibrosis who was maybe 13, didn't want to have any more interventions and just wanted to live their life. Well, the legislation then said that that needed to be considered by the physician, even if the parents didn't agree, and as long as the physician believed the young person had an understanding of the situation and. And that was a really gnarly intro to the field. But I had been advocating for myself for a long time and I think what I discovered over the time I went to grad school and I started looking at things with a public health lens, I realized that none of this works well, whether it's biomedical research or program planning for people with disabilities, doesn't work well if you aren't engaging the people who it benefits or affects in a systemic way, systematic way, and I didn't go about my career with that. I didn't set out to find those roles. In fact, I was looking to go into medicine, but I think my own personal experiences kept folding back to the importance of a very clear understanding and engagement with the people who are most affected by the work that we do, whether it's like accessible housing or advocacy in your own health care, that kind of thing, like it all, needs to be informed by people with the experience that we're talking about,

Manisha Ramlu 6:25

Absolutely, like and these individuals are impacted, you know, directly, so their voices matter. And I was not unaware of the young children or young individuals that weren't able to, you know, advocate for themselves, or it wasn't taken account. That's insane, because it's their bodies, it's their lives, like they should be able to determine what they need or want for themselves.

Jocelyn Maffin 6:53

Well, when you think about it, you know, at the time, so I was just out of high school, like in my first couple of years of my undergrad, and so this was like the year 2000/2001-ish, if you kind of have to think about this in the scheme of things, of social change around the more paternalistic way of doing medicine. And you know, paternalism is about professionals or people in authority knowing more about what you need than you do. And that can happen across—it's very common in sort of racism contexts as well. And you're talking about children and children with complex diseases and disorders, disabilities and like medical fragility and stuff, and that really compounds to take that young person's perspective on things just off the table. They're just not even thought to be competent, to speak for them their own needs. Along the same time, healthcare and medicine got much, much better, so we were starting to find that there was more reason for the individual to speak to what they wanted, because we could medically prolong people's lives, but we couldn't ensure their quality of life. So doing more medical intervention could even cause more suffering, and that is where I think the voices of the people most affected really became more of a factor, and I only became aware of it as a concept or as like an issue in the 90s when, and I don't think this is just cystic fibrosis related, but that was a really common example, because the lifespan of people with CF jumped by like 20 years in that decade because of interventions. But for a good chunk of that time, young people, many of them too young to make choices about their health care, were being expected to go through more and more difficult interventions for longer periods of time that isolated them in the hospital or at home, and they really didn't have much in the way of, like, a life for some of them, and they would get infections and then have to be under like, careful isolation. And so, I mean, there's been so many ER episodes and, like, TV episodes about this. So it's kind of an interesting moment in time, and I believe that what happened with the Infants Act, as it was called in BC, at the time, kind of was updated with recognition from previous court cases that young people needed to be able to have a say when these big life-altering or life-prolonging decisions were being made, and that similar for transplant and other conditions. And I remember it's funny to me now that they hired me at like 21 years old, thinking I was going to help that somehow with no training. But I think it was one way that recognized that the people who might have a good handle or a good be able to most relate to the young people who have now the power to make some decisions are people who've had to make some of those decisions. And, nothing about my upbringing was ever that serious medically, like none of it was like life or death in the way that kids with cancer or cystic fibrosis might have had to make decisions. So again, I still don't know why. [Laughs] I clearly, I had a handle of on advocacy in some way, and I and I had some practice in it, and so that was kind of what we did, is we sort of tried to figure out how we could help, how a peer, me, could help a young person facing the possibility of those decisions if they wanted them. And I hope, I don't actually know, but I hope that they had some sort of medical,

legal supports for the parents. The whole fear is that the parents would have made this hard decision, and the kids would be, would be there saying, you know, "I don't know. I don't want that chemo round. I'm done." And the parents be like, "No, we know more about this than you do. We've had, we've looked at the research journals." And that's actually one component, I think, is an interesting theme that I've seen since then, is that there's a lot of great research on so many of our health conditions and disabilities. But one thing that's really changed is that the disability justice perspective of "Nothing about us without us," has found a home in medical, like clinical and to some extent, like legal and rights related work around people with disabilities, like It's not just, there is a recognition nowadays that there's biomedical and clinical wisdom about specific sort of medical conditions, and then there's lived experience wisdom, and that is it, I wouldn't say is like mutually accepted to the same degree, but in a sort of balance, or ideally collaboration, there's a more of a recognition that the medical science is not the only input, it's not the only piece of experience that needs to be considered.

Manisha Ramlu 6:53

Absolutely. And, yeah, like you said, you can't have a model where it's just scientific based. And I think with the rise of like technology, and we have Google, like, literally right at our fingertips. You know, a parent, and individuals think they, like, you know, have all the knowledge, and they know everything, and this is going to be the perfect answer, but, like you said, like it's not, it might not be the right answer for the individual that's experiencing the condition or disease.

Jocelyn Maffin 13:40

Yeah, there's a real tension between, for some folks between what is clinically the best option and what the person's own goals or needs for their life are. And yes, there are some situations in which that individual might not be, I don't like this word, but competent, quote, unquote, to make that decision for themselves, but in the vast majority of situations, especially when we're talking about spinal cord injury or something. These are people with the knowledge who can be adequately informed to make those decisions on their own behalf and so there, I think, as you mentioned, the democratization of access to information, I think, also fed into, you know, people recognizing that the decision-making power should not always reside with the powers that be, with the physicians or the even, like government, etc. So, it's a lot of social change, yeah, I think the last 30 years, and I was there for just a little bit of it.

Manisha Ramlu 15:06

Well, I'm sure we are gonna move towards more of this social change and keep growing until, you know, we have full autonomy of kind of what we want to do. But, yeah, fingers crossed. Um, so, I'll move on to the next question. Um, so, at SCI BC, you lead peer support and info services, what are some innovative ways your team is building community and connection among people with sei across the province?

Jocelyn Maffin 15:43

I think we that's a really good question. We, our organization is pretty old. We started in 1957 and it's had many different iterations of service over the years. And our current model is, I would say, started in sort of 2000, 2002-ish, like in there somewhere, is way before I was on the scene. But we really view peer support as, as the sort of secret sauce of adjusting, adapting and thriving, and it's really gratifying that a lot of our clinical partners also recognize that and see our staff and mentors, who are volunteers, who live with Spinal Cord Injury, as information resources and sources of knowledge, as well as part of the team. And so peer support is the esteem and recognition of peer support's importance has just grown like crazy in the last even the almost 10 years I've been at SCI BC, I think it's been increasingly recognized as an important component for population health, and it's particularly commonly seen in mental health and addictions and in some disability populations. And we, I guess we're fortunate enough to get the support to start doing that quite a while ago. And so the peer support alone is something I think that is innovative, and it really recognizes that even though spinal cord injuries are quite different across different people. Even if you have the same injury level or the same level of impairment, it can affect your body in a very different way. But there's something about learning the learning the ropes of how to manage your spinal cord injury and return to your life and set goals and find the things that you really want to do that is just so much more easily shared from someone who's living it, rather than, you know, we love OTs and PTs, like occupational and physical therapists in spinal cord injury circles, but there's just some kind of power that to add to that great rehab work that really helps transform, or like, translate those messages they're hearing from their rehabilitation experts and clinicians, and put it into real life terms, like you've learned how to transfer from your bed to the toilet or your bed to a wheelchair on your own now, so let's talk about what that lets you do. If you can do that, that means you don't need a caregiver overnight. That means you might be able to travel with a caregiver or on your own, and so just showing how to apply those skills in real life and what that enables you to do, it can be incredibly freeing and motivating for a lot of people. So that's just vanilla level peer support, but we are super fortunate to have lots of clinical and research partnerships, and we've been a part of a few different projects that look at how like, what is the magic around peer support, but is, you know, how do we best match people so it's effective and people get the most out of it, and how do we evaluate it? How

do we know that people are getting the peer support that they're seeking if we can't evaluate it? So all of these things, traditionally, didn't have that kind of data and analysis behind it. In fact, a lot of organizations don't even gather sort of programmatic use data in their communities, and I don't blame them, because it can be hard, especially if it's a small crowd that you're serving, but we have really benefited by being parts of these partnerships, because we learn how we can improve our service, and we also learn how important our work is to the outcomes of people with spinal cord injuries, which is really validating, obviously. I think another huge component that I would call sort of innovative is that we were very early adopters in online means of peer support, and so we were super fortunate in that we had already started our, we call it our Reach Out online peer support program. I think we started in 2017, so before, before COVID. And so when COVID happened, we were like, "Okay, let's just shift everything into online," and so we were ready right away, without realizing we needed to be but it also, like adds a lot of complexity, because it's all the stuff you need to transmit information to people by email, and then email, it gets too overwhelming, and it brought its own challenges, but that program made us uniquely able to offer that peer support during a very difficult time. And one of the things that was an outcome of that same program was that we realized in that the terrible month of March 2020, when things started shutting down, and it started hitting home, and we were all told to like shelter in place for several weeks. We were all scared and isolated from each other. We realized in our own work that we didn't have any, like, what we weren't seeing in the public health messaging was any information that answered the problems that people with spinal cord injuries were dealing with. How do we wash our hands effectively, like if we're touching our wheels all the time? How do you what do you do if you rely on a caregiver? And many, many caregivers vanished during COVID, especially the early time is they were sheltering in place. They had family to look after. They were scared. And also, like, does it affect people with spinal cord injury differently? Are we more vulnerable? Like, there was a lot of questions that were deeply important to protecting ourselves that just wasn't available in the public. And so we set about, we're very fortunate that we had this online program already and great formats, and we had pre-existing relationships with clinicians in who were experts in spinal cord injury. And so we start, we did this long series, I think it was eight videos over two months that were asking expert sessions. And they were, you know, we had a nurse, and then we had a physiatrist, like a rehab specialist, and then we had an infectious disease doctor and a pulmonologist. And just like every time people came up with questions that the first one couldn't answer, we, like, sought out someone else, and it became like a massive, like gathering point for people to feel like, okay, this information might help, and we might be able to do something to protect ourselves. And that was like an emotional support for a lot of folks, and it gave us something to offer. And that program, the Ask an Expert sessions, continues to this day,

not about COVID-19, but with the same approach, which is inviting someone with expertise, ideally someone with spinal cord injury, if possible, to share on their area of expertise and answer some questions. It sounds very simple, right? It's a webinar, kind of, but it is more than a webinar, because it is also it's very grassroots, is very sort of self-directed, or peer-directed, and I think that really resonated with people. I think the last thing I would say is innovative, is we are deeply involved in peer coaching as a model. And peer coaching is an interesting one, because the word coaching is very widely used with very poor definition and but the way we look at it is, it's peer support, but with more of a goal, focus and our peer coaches have more training in brief action planning, motivational interviewing and helping, working with a coaching client appear who wants to tackle something that they need a little more support with and the coach doesn't have to have any expertise on that particular topic. They just need to understand what it's like to live with a spinal cord injury so they can mutually troubleshoot and help find the information needed. So you're kind of on a little journey together toward that goal, and your coach is not supposed to solve the problem for you. They're supposed to help you stay motivated and have the resources you need to solve the problem for yourself. And it's been amazing to see what the response is like. And we're one of the sites of a clinical trial of peer coaching, along with a site in the US, and it's been a really interesting opportunity to sort of again, figure out what makes that service tick like, what does it offer, and how is it helping, and how can we make that more available? So.

Manisha Ramlu 26:15

Wow. Well, thank you for sharing that. And it sounds like you know this is such a you know, informative and community that people, individuals with spinal cord injuries can access and access such a great resource. I'm just wondering, in order for you know someone to receive peer support. What are kind of like the steps in order to kind of get that resource?

Jocelyn Maffin 26:50

We try and keep the barriers as low as possible. So there are a lot of ways you can get it, and there's no cost at SCI BC, I don't think any of our partner organizations in the SCI Canada Network charge for their peer support either, essentially, you just need to get in touch with us. We have an info line, and the team is amazing, and that's you can just email info@sci.bc.ca and they can help you connect with your closest peer coordinator or direct you to our membership form. You don't have to be a member of SCI BC to receive peer support. There's lots of ways of participating, and we don't want to keep you from being part of the community. If you don't like filling out membership forms, or you didn't know we needed one, membership is also free. But as a BC nonprofit society, we are required to have members. So that's kind of partly how that works. So a couple of one of the biggest

ways that people sign up or decide to participate is that they go through their rehab process after their injury. At GF Strong Rehab Centre or at Victoria General Hospital has a neuro rehab and some regional hospitals also have them, and they encounter some of our staff who do either in GF Strong, we have a resource centre office staffed by my colleague, Ryan and Marta as well, and that office is the biggest one. It's the only STI specialized rehab center in the province. So it's most likely, we think somewhere between 60 and 75% of people with SCI go through rehab at GF Strong, and it's an it usually an inpatient experience. Could be anywhere from three weeks to three months and it can be an early experience. It's a lot of work, and you have to really be actively a part of your rehab. And so people will come by our resource centre office, or they'll go to one of the education sessions that Ryan participates in, and helps to offer the sort of real world experience to the education, and they can sign up as a member in the office, or Ryan will like invite them to the most recent in person event. Events are a big way that we bring the community together to encourage those networks of support to build among people with spinal cord injuries. And we, you know, it's fun, like we want people to spend that time, to build those friendships. And so we try and do fun, interactive, like events that you would want to do, even if you weren't living with spinal cord injury. And so you can come to an event, and some of them require RSVP, especially the ones in Vancouver. But you know, the RSVPs, all the information is on our website, under sci-bc.ca/events, and Ryan, when you start to be transitioned home, will connect you to your local peer coordinator in your region. So if you're going home to let's say Kelowna, your peer coordinator is Scottie James, and you would be connected by Ryan. If you sign up as a member on our website and you indicate I am a peer, which means someone with spinal cord injury or similar, you'll receive a welcome email from the manager of our peer support program who lives with spinal cord injury, and that will also connect you to whoever your local peer coordinator is. Peer coordinators are people who live with spinal cord injuries, who've been through it themselves, and they have a region in which they plan events and have monthly meetups that build community and connect people to each other. And usually, if you come out to a large event and we notice that you're not a member, we might send you an email and encourage you to sign up, or at least get our newsletter so you know how you can participate. So there's lots of different ways. We also will, like, match people with another peer who has the answer to the question that they have, or shares an experience, and we have mentors all over the province that they're volunteers with spinal cord injury, and they do regular meetups, and sometimes some of them also do events, and they will also, like, try and connect you with peers who can help you. Like, understand certain issues you're having trouble with. Or, for example, there's someone local to me in Nanaimo who was having to have her home renovated for accessibility, and she really needed some feedback on bathroom setup. Like, how can I renovate my bathroom, so it is most functional for me,

believe it or not, that's not a straightforward like, there isn't a sort of recipe for that. It looks different for everybody. And so we reached out to some local folks and connected her with them so she could go see their bathroom, and I had a bunch of our staff send photos of their bathrooms so they could see how that person could see the differences. And so that's kind of what we would call a one-to-one matchup. She just had, like one to four. There's like four people we matched her with. So it's we have lots of different ways to get peer support and participate in peer support. We try not to be too complicated about how you can participate. Being a member helps us out a lot. It shows our funders and the government that regulates nonprofits that we have stakeholders involved. And it also allows us to, you know, we have the biggest database of people with spinal cord injury in the province, so we are able to speak to some of those demographic concerns and needs and sometimes we work with our members to gather feedback or be consulted on different sort of government policies or questions. So we do our best to see our membership as a source of knowledge and experience, and we see our role at SCI BC is, we are, we are representing those needs and preferences of our membership to whoever needs to know about that for the betterment of all of us, right?

Manisha Ramlu 34:05

Wow. Thank you so much. That was so informative. And I will definitely link all of the website and the email so that you know individuals that haven't signed up for a membership know where to go. But yeah, definitely, I think that that's amazing and yeah, thank you.

Outro 34:22

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