

COVID-19: A Mini-Series Part 3: Perspectives on living with a disability during the pandemic

SUMMARY KEYWORDS

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SPEAKERS

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John Shepherd: For me, it's been a really interesting experience both being a person who lives with disability, and a student of Health Sciences, and I think one of the takeaways for me is that there's a huge scope for the, you know, disability community to get more involved in research in, you know, producing, consuming, transmitting research, because it impacts us so greatly.

[chime]

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Analyssa Cardenas: More than 6 million Canadians live with a disability, and many are especially vulnerable to the impact of COVID-19. While having a disability alone does not always put someone at a higher risk for getting COVID-19 if they do get it, they're at a higher risk for severe illness. People with disabilities experienced unique challenges compared to people without disabilities. For example, the need to interact with more health care providers, it may not be as easy to wash their hands frequently, and access to everyday activities are disrupted. In this episode of rehabINK's podcast: COVID-19 miniseries, we are interested in the experiences of people with disabilities and the unique challenges that this pandemic has brought.

[chime]

01:28

Analyssa Cardenas: Great. So Hi everyone. Welcome to the rehabINK podcast.. My name is Analyssa Cardenas.

David Houston: And I'm David Houston and we are both alumni of the rehabilitation Sciences Institute at the University of Toronto. Today we are joined by Dr. Susan Jaglal and John

Shepherd to discuss the impact of COVID-19 on people living with disabilities. Dr. Jaglal is the interim chair and professor in the Department of Physical Therapy at the University of Toronto with cross appointments to the Rehabilitation Sciences Institute, and the Institute for Health Policy, Management, and Evaluation. She holds the Toronto Rehabilitation Institute University Health Network chair at the University of Toronto, and is also the academic lead for training in the Age-well Networks of Centers of Excellence. Dr. Jaglal thank you so much for joining us. Can you tell us a little bit more about yourself and some of your research interests?

Dr. Susan Jaglal: Thanks, David. I'm I'm a health services researcher and an epidemiologist by trade Now with COVID-19, everybody knows what an epidemiologist is. One of my main areas of research is actually spinal cord injury, where I've done work both on the epidemiology of spinal cord injury. And also on the main piece of work is on developing an online self management program, which our team has been doing for, I'd say the last, the last few years. And so that's—we're developing and evaluating an intervention, and I think that that project, I always say is sort of near and dear to my heart, there's a lot of moving pieces, there's a lot of community involvement, a lot of involvement from stakeholders. So it's not your traditional research project. And so we think really learned a lot, I'd say through that, through that process.

Analyssa Cardenas: Yes. Well, thank you so much for joining us today, Dr. Jaglal. We're really excited to learn about that amazing program. And we are also joined by John Shepherd. John is a PhD student in the Rehabilitation Sciences Institute at the University of Toronto. John is motivated by a desire to better understand the impact of spinal cord injury and similar disabilities at the level of the health system and health policy. He is also an advocate for issues of concern to people living with disabilities. John has been living with a spinal cord injury for 15 years and appreciates the impact of a well informed and responsive healthcare system. He is an active community volunteer and has served on the boards of Toronto Rehab and spinal cord injury Ontario. So thanks for coming to John. Can you tell us a little bit more about yourself as well?

John Shepherd: Sure, yeah. Thanks guys for the invitation. So I'm a student at RSI, and finishing my master's, starting my PhD. And my work, I guess falls in the area of health services and policy research. And really looking at questions of basic epidemiology and spinal cord injury. So things like you know, how many people have spinal cord injury? And what are they like? You know, it turns out we don't—we know less than we would like to know about things like that. So for my master's thesis, I used a database of a primary care medical records. So electronic medical records taken from family doctors offices across the province to identify cases of spinal cord injury. So we can first of all say "Who are these people?" and, like so many questions in health research, you know, it's much less obvious than you would think at first. Having done that, I'm in my PhD, I'm looking to dig into that more deeply. So assemble a rich picture using data from different sources of the population of people living in Ontario with spinal cord injury, and then looking in detail at their experience of the healthcare system over time, and ultimately how that could be improved. So, you know, obviously, with my lived experience, that work is very close to my heart. I've also been involved in the health coaching project that Susan mentioned. And that's another piece of work that's really dear to me, and I'm excited about how

that's grown and how a group of people really a sort of community of practice has come together over time, and I guess, I'm hoping we'll have a chance to talk more about that.

[chime]

05:54

David Houston: Thank you both for taking part of this conversation with us. Our focus for today's episode is to gain a better understanding of the impact that COVID-19 pandemic has had on the lives of people living with disabilities. Prior to the onset of the pandemic, people living with disabilities may have already faced unique challenges. So our first question is: for those of us who may have been previously unaware, how has this pandemic illuminated and exacerbated some of the preexisting health inequities and what new challenges has it introduced?

Dr. Susan Jaglal: Okay, I'm going to turn that one over, over to John, because he made some really tough decisions in terms of how to deal with the pandemic in, in the early days when infection rates were really high. And I think, I don't know, John, putting you on the spot.

06:52

John Shepherd: No, no, happy to do that. And I guess the I just, you know, preface by saying that I speak from my own experience, which means that it's just my experience. So I don't want to hold myself up as the representative for everyone living with disability. Obviously, everyone's circumstances are different, and their choices are different and their options, you know, the options available to them are very different. So, but for what it's worth, you know, from my experience, I took COVID really seriously, really early. I mean, first of all, it was fascinating as a person who studies, epidemiology and you know in my sort of professional life, I'm trying to cut my teeth on these different methods and approaches and analytical techniques and all of a sudden, boom, it's in the front pages. So it was simultaneously fascinating, but also, you know, quite concerning. People may have seen the Johns Hopkins COVID map that I think has disappeared. But early on, everyone was staring at all the time. And I remember refreshing it one evening, and as the numbers were just skyrocketing everywhere, and having this weird kind of experience of like a head rush, you're just thinking, wow, this is, this is real, this is going to change, you know, everything, all of our lives.

So specific to people with disabilities or certainly with spinal cord injury. There's initially a lot of concern about our degree of vulnerability. It was clear, you know, from experience in China, that people, elderly people and people with health conditions were at risk. And we know certainly that people with spinal cord injury don't do well for instance with pneumonia, particularly people with higher level injuries who have compromised breathing muscles. So there's reason to believe that this was really a, you know, exceptionally dangerous situation. So I decided to do everything possible to limit our risk, which basically meant, you know, like a complete hermetic lockdown. My roommate moved out, we've managed to find an arrangement for him that was good.

And most importantly, I stopped having people come into my house every day to help me which was part of my daily routine. So you know, for my morning routine for two and a half hours for cleaning, you know, vacuuming, laundry, stuff like that. And I just completely cut that off. I also you know, wasn't getting deliveries of any kind. So I was doing all my own meal prep, and all these kind of activities of daily living, which are ordinarily, you know, challenging for people who have different kinds of functional impairments. And so it was really brutal, like the first, you know, month or so of COVID was just insane because I basically had no bandwidth, you know, for, for work or anything else because I was just kind of getting through my day, you know, I mean, I wasn't going to the laundry room, my building, so I was like, every part of my daily routine was like washing my socks and hanging somewhere to dry and stuff. It's kind of ridiculous. But in looking back, you know, it was also kind of like independence boot camp. For me, it was like that, you know, enriched like rehab, you know, kind of skills stuff that I would have done if I'd had more time in rehab, but didn't and so, you know, I certainly got something out of that long term, but it was a massive challenge. Now, what's, you know, changed over time? I mean, some of that remains, and I think, you know, it's probably worth talking at some point about the systemic issues. This raises for all people with disabilities because you know, where existing sort of program serves as accommodations might have been in place, a lot of those things went away, at least temporarily. And so life became a lot more difficult and a lot more complicated. And in some cases, those accommodations were kind of like bolt-ons. And so all of a sudden, you know, when other parts of society need to change in terms of how do you get into the grocery store? Or how do you get access to you know, the pharmacy, when plans are changed on the fly the needs of people with disabilities not always taken into consideration. So, you know, you find your vulnerability only increased in an already vulnerable situation. So that's really important.

But for me personally, what's helped in part over time is precisely the fact that as a, you know, a student of Rehabilitation Science and Health Science more generally, with access to journals with you know, my finger somewhat on the pulse of research. I've been able to track you know, knowledge as it's been emerging. And so that's really helpful. So, you know, first, the very first case study of personal spinal cord injury of COVID came out of Italy in, I think it was probably late April, early May. And since then there's been a case series out of Spain and little bits of information trickling out. And overall, I mean, you know, this is all incredibly preliminary and tiny sample sizes. And, you know, not much better than knowing nothing, but at least the indication is, it's not like a, you know, an immediate death sentence that people with spinal cord injury, get COVID and, you know, have a clinical course that in some cases is more favorable than one might expect. And there's interesting theories about why that might be what having to do with what COVID actually is, you know, to what extent is it respiratory versus inflammatory or something, you know, multi systemic, and how does that affect a specific kind of way that people with spinal cord injuries or kind of set up. But, bottom line, I'm not as terrified any longer and so I've been, you know, slowly reintegrating my normal life. And I guess the other challenge for me has just been again, because of my, what I do for a living that I've had a lot more work on top of my normal work, early on, we realized that there you know, people were talking about hand hygiene. And of course, the issues of hand hygiene are very different for people who use wheelchairs, you know, whether you're moving your power wheelchair around with a joystick, or

if you're propelling your manual wheelchair with your hands. There is a very different set of considerations around hand hygiene. So, our project team, the the project team that has been working on this self management project, Susan, introduced—we kind of banded together and really quickly like in a space of about two weeks, put together an infographic on hand hygiene for people who use wheelchairs, and got it out there, and it turns out it went kind of around the world overnight because there is a real need for that information. So, so yeah, I've been happy to be able to get involved in projects like that. And we're doing another kind of special project right now, to create an online resource for people with spinal cord injury who need to be admitted to hospital to acute care, which is also sort of COVID inspired and funded by a COVID grant. So, you know, there's more work and less time. But as I say, I think I'm personally getting now to something of an equilibrium, as so many of us but it's, it's been it's been a real challenge.

13:12

David Houston: Thank you for sharing that. Well, one of the things that you were mentioning about the hand hygiene—and I actually recall seeing you share that infographic on social media. And so, did you mind maybe just kind of explaining a little bit or elaborate a little bit more about that, that infographic, how you developed it, sort of why it's so important and how maybe, you know, we haven't really thought about, you know, using accessibility devices and having to bring that into your home when you're going out into the community and sort of not able to really separate your outside experiences from your safe space inside. Could you just elaborate a little bit more on that, and maybe some other strategies that now people who use wheelchairs mate employ to kind of help prevent the risk?

John Shepherd: Yeah, by all means. Hand hygiene was seen early on as the absolute baseline for protection. And if you think about it, if you use a manual wheelchair, for example, then it's extremely difficult. Like, you know, people may not know this, but you don't actually push the wheels you push what are called push rims, which are sort of adjacent to the tire of the wheelchair, but it's exceptionally difficult especially if you've got, you know, some degree of impairment as I do, because I've tetraplegia or quadriplegia—to your hands, to really avoid touching the wheels and the wheels are all constantly touching the ground, of course. So what that means is that as soon as you leave your living space, your hands are really coming into contact with a lot of potentially contaminated surfaces. So, you know, the countermeasure for that is a pretty elaborate cleaning procedure that, you know, when you come in the house, you wipe down your push rims, you clean your tires, in addition to your hands and forearms. And if you'd be very careful if you use gloves, as most people do, about what to do with those, and so forth. And similarly, if use a power wheelchair, you need to, be mindful about cleaning the joystick and other control areas and surfaces you might touch. So that's a whole set of techniques that's kind of, you know, unknown to the, to the general public, and then early on made going out, you know, a huge pain because you'd have to go through this cleaning procedure that initially took me like 15 minutes, you know, when I came inside the house.

Now, in the interest of full disclosure, I will admit that I no longer do that and that's in part, you know, because I have a lower kind of sense of the risk profile, just because of where we are in numbers of cases and, and you know, what you can assume about how sort of virulent the

COVID virus is outside, also, because so we seen some research, you know, sort of downplaying the importance of what are called fomites. So spread by contact on services versus, you know, airborne, or other forms of transmission. So, but, you know, early on, I used to tell people I assumed, and this is, you know, in the early days of March and April, I just kind of, you know, assumed that as soon as I opened the door to my apartment, everything outdoors was just covered in COVID, because it seemed like the safe assumption to make. But, but, yeah, I think that's an illustration of how, you know, there's a whole set of, you know, techniques that people may not know about, the general public may not realize and the people you know, who use wheelchairs need to be informed about. So, So to your point about how we created the infographic, it was really kind of crowd sourced, like We all contributed our own information, where there were published or authoritative sources, we share them for the most part, this was just taken from people's own life experience and ingenuity. And, and we, you know, combine that and I worked with a graphic designer, who again, is a person who's living with quadriplegia. And, and then we've got it out through our networks, and it's one of those things that just kind of happened, I think, you know, because then the need was so great. And, and the response was really was helpful.

16:50

Analyssa Cardenas: Yeah, that's really great. Thank you for sharing that. And I really like how you use the medium of infographics to share that information. Because I find that having those pieces of information in a way that's easy to understand is so much more effective than having to go through the literature and compare different papers and see what the best implementation strategy is. So that's amazing work. So John, you spoke a little bit about how some services went away during the lockdown and Dr. Jaglal and John, you're both experts in health services and epidemiology. So how has access to health care change during COVID-19 for people with disabilities?

Dr. Susan Jaglal: I think where we've seen major drops in services is in outpatient services because hospitals basically closed down outpatient services. We also saw with primary care, everything moved to online visits. The only thing kind of open was like emergency departments. But then people were scared to go to hospitals, because the rate of infection was much higher in hospitals. So the sort of the fall out, out of all of this, for anybody with a disability or any chronic condition, there was reduced access to services. So people then didn't get the care that that they needed. And so some of the things that you see now is actually higher rates of heart attacks and patients with a with cancer for example, not being able to access their therapies. So you're seeing much greater progression in the disease. So basically any sort of preventive services and outpatient treatments kind of just disappeared. During, this pandemic and now these health services researchers are asking what happened to all of these people? Where did they all go? So there's a huge body of research on that now in terms of looking at, like sort of balancing the, the measures that we put in, in place to bring the infection rate down with respect to COVID. And so we're now at a point where we're not overwhelming the health care system. So, the fallout from that, is at what point do we start introducing these services that people actually need, and at what point are people going to be comfortable actually going back out into society and you know, going to participating in in health care services that are actually that are

actually needed. So your chances of you know, dying from heart attack is now much higher than contracting COVID if you had a pre-existing condition. And we've seen, like emergency there was a report that came out of CIHI [Canadian Institute for Health Information] on Monday, and emergency department visits dropped like 20%. And it wasn't just the people who had the lower acuity conditions where they saw that 20% drop, it was 20% like across the board. So, again, people being very fearful and then not accessing services when they should. So it'll be interesting to see how that how that plays out now, in in the future. So, again, we're at the point now where we're going to be stuck with COVID. So we have to, we have to actually start learning to live with it and because certainly, it's not going away, anytime soon. Anything to add John?

20:49

John Shepherd: Sure. So the issue of ER visits I think is really interesting. People living with spinal cord injury, as well. You know, for from our research, literally our research we've done in our lab are, you know, notorious frequent fliers, as they say, tend to show up in ER a lot because they have problems that, you know, the healthcare system tends to direct that way. It's interesting, one part of this, perhaps is not so bad, which is that I know a lot of people certainly, I, myself, have been doing everything possible to avoid needing to go to ER. So I've been super vigilant about a lot of my own kind of self-management or self-care practices that I know you know, prevent me from needing to go to the hospital, and that's maybe not a bad thing. But on the other side of the coin, in addition to emergency services, regular surveillance has fallen off it because it you know, it's part of the sort of outpatient services they've been constrained or curtailed. And so I've missed out this year on regular surveillance, you know, for instance, urological surveillance. Now, I'm hoping, of course that I can get away with it and I'll go back next year and everything will be fine. But statistically, we know that that surveillance is important. And if it goes away for a large number of people, some of those people will have problems. There are issues that won't get caught. You know, the urological maintenance may suffer. And so I think there is the danger over time, that in various ways, whether it's from people not going to emerge, to deal with urgent things, or whether it's from people losing out on the ongoing surveillance and management, you know, that it's important to keep them healthy. You know, there will be kind of a, you know, ripple, a ripple effect of consequences into the future from this disruption. And I think, you know, it'll be a challenge to the health system, not only to get through COVID and deal with the immediate effects of COVID. But to deal with these larger systemic issues that, you know, kind of require rethinking healthcare from end to end.

23:03

David Houston: I think you raise a good point there about no rethinking that healthcare. And we kind of maybe sort of saw in the response to COVID-19 and how it considered different groups of people. That may be, you know, this healthcare system doesn't necessarily benefit everyone as equally. And so I guess kind of what a question I want to ask there is, how did the response to COVID-19 consider people with disabilities or did it? Was there maybe some pandemic guidelines that directly or indirectly favored individuals without disabilities?

John Shepherd: I mean, the one thing I can say there is that understanding that everyone was scrambling and doing the best they could the extreme cases are exceptional cases, you know, are the ones that people don't think of immediately. I mean, that's kind of understandable. But it means that when you suddenly impose dramatic limits on, you know, people bringing visitors into hospital or being accompanied, going into hospital in the interest of reducing spread, understandably, then the case of someone who needs assistance, right? Who literally may need a family member or support worker to be there with them, in some cases for their survival, right? If they're on a vent, and you know, they, they may need management of that, or just to get around to building that may not be fully accessible. I think in practice, many of those instances, were able to be resolved by people advocating for themselves, but I'm not certain that they were all. I think there, there were, quite possibly are likely cases where people you know, weren't able to receive the health care they needed because their attendant or support worker or family member wasn't able to be there with them. And I guess the other thing is it shouldn't have to be on people to advocate for themselves, you know, when they're like everyone else trying to survive in the middle of a pandemic, and fight those kind of systemic barriers. So I get to understand how, you know, this is more a matter of oversight than malice. But when you're on the receiving end, it kind of doesn't matter.

Dr. Susan Jaglal: Yeah, I would agree with that, John, I think my sense is, it was almost a forgotten group. Everybody was, it was—you know and I, and I agree with you that it wasn't done out of malice. I think it was more done out of ignorance. And in not understanding sort of the implications of some of those decisions, especially around the caregiving, for example, and putting in those types of restrictions, and again to that sort of this issue comes up with the community around social isolation, and how that's probably with this pandemic has been exacerbated in persons living with a disability because of the nature of some of these decisions or policies that are in place.

26:03

David Houston: That's a great point. Do you do you think that like, this is the result of this prolonged social isolation? Like will that have a negative impact on quality of life or functional independence or even physical kind of conditioning moving forward just based on this prolonged time at home? Kind of the pretty intense restrictions that were laid down, sort of blanket restrictions across all of the population without necessity really considering how it might impact some people more than others?

Dr. Susan Jaglal: That's a really good, that's a really good question. And I haven't, there's a great research project I haven't seen anybody do the follow up on that, on that yet, in terms of what the results would look like. One could hypothesize that there would be a negative, more negative outcomes, lower functional status by sort of some of our traditional measures, but I don't know empirically if that. If that is the case.

John Shepherd: Yeah, I mean, I actually think it's fascinating to think about because on the one hand, you're right. there's every reason to suspect that if people don't have access, for instance, to exercise programs or forms of social participation, or even just, you know, the ability

to go out and move about freely, that would have an impact as it is, I think, across all of society. But as Susan says, we don't really know. Anecdotally, I can say that people we work with have expressed a variety of, you know, emotion, strong emotions, again, similar to all of us. But here's—I think, I want to be careful about this. But I think there's a bit of a counter narrative that's interesting to think about. And when I say want to be careful, I don't want to take away genuine concerns about the negative impacts on the community of COVID. But there's an interesting set of kind of opposing dynamics that are, you know, we're thinking about. So what I mean is that people who live with a disability, certainly with spinal cord injury, if their mobility is impaired, they know what it is to be restricted to home. Right? They have a lot of experience with it, we have a lot of experience with it. And hopefully, in most cases, you know, I've gotten kind of good at it. And to that extent, I feel in some senses, like, maybe in a limited way, some of us have had a bit of a competitive advantage, almost in dealing with COVID. And I think, honestly, that's part of the secret behind how you know, this project, you know, as a little microcosm of the community, you know, this community of practice we've been able to be galvanized and double down on our work together and made a lot of progress. Individually, the coaches working with their participants and as a group, kind of, you know, keeping the trial on track, on course, on time, and hopefully delivering a successful interview. So I think that's kind of neat to think about.

And there's also something I will confess to that I want to make clear is not the same thing is it's not like Schaden Friday, which is like taking joy in the, you know, misfortunes of others. It's not that at all. But what I've noticed is that, you know, a persistent sense of, I don't know, if you're familiar with the term 'FOMO', fear of missing out. It's something that's, you know, very, it's triggered by social media, I think, when you see how awesome people's lives are, at least as they present them on social media. And look, I'll confess to the fact that you know, since living with disability, I do have a sense of missing out on things I would love to be doing. And I'm not, again, as we all do, but that's been different. Like I've kind of had a sense of being in the same place, as you know, a lot of my non-disabled colleagues and friends in a different way. I guess since the pandemic and that's been interesting and I would almost say that for me at the same time that I have been very, you know, physically distant and apart from people, that has lessened some of this sense of isolation that I think I felt previously. So that's why I say there's a bit of a counter narrative. And again, I don't want to say that that discounts the real struggles that many people have had and continue to have. But I think there's, you know, I don't know if it's quite a silver lining, but there's certainly something—some, another part of it to think about.

30:20

Analyssa Cardenas: Yeah, for sure. Thank you for sharing that insight. It always helps, I think, to have a more positive optimistic outlook, especially now when I think months ago, I thought, oh, like this will be over soon, it'll blow over. But, you know, I think we're starting to hit a little bit of that wall where it's like, okay, this is a new reality that we just have to learn how to deal with. So on that note, since you were both involved in creating a virtual support and mindfulness program to help people with spinal cord injuries cope during COVID-19. Can you tell us a little bit more about this project and how it was developed?

Dr. Susan Jaglal: Okay, I guess the, this, this whole idea came about because like I said earlier, we're, one of our main research projects is this online self-management program and our main intervention is actually health coaching. We were basically the, you know, the study team, we were having our weekly zoom meeting and a number of our study staff are actually persons living with spinal cord injury. And at the start of one of our regular meetings, we just started talking about the issues people were facing, pretty much that first week that COVID hit and we were all told we had to be we had to be in lockdown. So we just kind of had like a really very open discussion and some of our study staff were saying how it's been difficult for them, how people were very concerned about you know, personal support workers being in long term care homes and also then taking care of them and then you then have a higher probability of becoming infected, so what cautions you should be taking. So, we realize then, that this is going to be considerable issue for people, and maybe there's something we can do about it. So at the same time, through our project and the one of the funding bodies, the Craig Nielsen foundation, put out a call for proposals for. They called it an emergency relief fund. And they were looking for proposals for initiatives that researchers or could do that would support people living with spinal cord injury. So, so we thought this would be this, this would be a nice opportunity to do something. So I'm going to turn it over to John, because the idea for the mindfulness actually came from one of our other study meetings with our health coaches.

John Shepherd: Right. So at the same time that the study team was talking about the issues people were facing and, and what could be done and this opportunity came to our attention. We had been meeting in the afternoons on Friday with our health coaches. So these are the people actually delivering the intervention online and they've been doing so for a while now, this is a program that's, you know, gone through a couple phases over a number of years. And all the coaches are peers, which is to say people living with spinal cord injury. And as I said, that kind of community practices come together and we become very close to each other in the work that we've done developing this program and supporting each other as people work with their participants. And we were all hit as everyone was, by you know, the sort of the pandemics sudden descent on our society. And so we tried to address that among the coaches by making use of the skills of one of our coaches, a woman named Mary-Jo Fetterly, who, you know, has really a fascinating set of life experiences and skills that she brings to the table, one of which is that she's a yogi. So she has been leading yoga and mindfulness practice for many years well before even her own spinal cord injury. And, and so we asked her if she would just leave the group now we'd been meeting by by zoom. One of the advantages of the work we do is we've been virtual since long before COVID. So in that sense, we didn't miss a beat. And we asked, you know, in, in the COVID era, so I think it was, you know, still in March, probably, or very early in April that we asked her to lead us in sort of mindfulness practice as a part of that meeting, you know, so an ordinary business meeting. And we took, I think the first time five minutes and maybe agreed that we'd like to have a few more so expanded, it's like seven or eight. And, you know, after we kind of went over the agenda and opened up the meeting, and I think the, you know, the reaction from people, most of whom had not really experienced mindfulness practice previously, was really positive. People thought this was great, it was helpful. I mean, I remember a palpable sense of just feeling more relaxed, more chilled out and better able to tackle than the remaining, you know, topics, sort of business topics for that meeting, having done that practice.

So we observed as a group that it was really helping us and thought and talked a little bit about why that might be. And then the idea bubbled up to the other project team meetings that we'd been having that Susan mentioned, and a few people I think individually kind of, or, you know, separately, had the idea and shared it with each other. Hey, why don't we see if we can make this more widely available? But these sessions are led by someone living with spinal cord injury for people with spinal cord injury. And that's really important in the way that Mary-Jo has designed it. So that's, I guess, the second piece of the of the background, you know, Susan saw the opportunity and the need, and then this idea kind of bubbled up from the team. And, you know, and Susan wrote the grant and it was a rapid thing and, and, and it got funded and so we've been doing it now for three months and I think people find it really useful. I've found even mindfulness to be incredibly helpful.

36:23

Dr. Susan Jaglal: And I think one of the things, one of the things too that distinguishes the program when we set it up is that at the end of the session, there's a Q&A. And because again, there are thousands of mindfulness apps that are available to people. And again, we wanted something really specific for people with spinal cord injury. And in fact, the feedback that we've gotten is those Q&A sessions are actually also extremely helpful to people we really valued because they're talking to peers and we've had people from all over the world attend sessions, our target was actually really just Canada in the US, but, but there's participation from all over. So that was also really, really nice to see.

David Houston: That's great that you have like that real time feedback to allow the participants to help tailor the program to fit their needs, and sort of really address, you know, the areas of concerns that they might have. So thank you very much for telling us about that program. It sounds like a really, really useful resource and I hope that you guys do continue to carry that forward. Even as we sort of see restrictions ease up, as it sure is a great coping strategy that people can use outside of a pandemic, obviously, it probably has a bit more necessity but it's definitely something that people can have moving forward in their back pocket to kind of help them cope with different sorts of instances that may appear throughout their lives.

38:01

Analyssa Cardenas: Do you think we will be seeing some positive things emerge from this pandemic that could benefit people with disabilities? So some examples are like online learning or remote access or remote offices for work or virtual healthcare tools. What are your thoughts on that?

Dr. Susan Jaglal: I think one of the things that, and we're already seeing it, is the virtual care and being able to now call your doctor and then they can call the pharmacy and refill your prescription. Before you actually had to go to the doctor make an appointment and get that prescription refilled. So, and a lot of cases where you had to jump through a lot of hoops in the healthcare system just to get some basic services and you can't, you know, can't they do this in a more efficient manner? Seems kind of like ridiculous. Now we're actually seeing some, some changes, I would say in the right direction. So I think how care is going to be delivered in the

next decade is going to change dramatically. And I think that's been one of the silver linings out of out of this whole experience.

David Houston: Anything to add John?

John Shepherd: Yeah, I just agreed. Absolutely. And I think all the things you mentioned, I'm going to say are, are those are checked to all of those. I think the more that interaction is mediated virtually, then, you know, that's right, right away a barrier that's removed for people living with disabilities. And, you know, I'm kind of excited to think that you know, next time I look for a job I will appear, you know, if that's if the interview happens on camera, the same as any other applicant, right? So I won't have to go through that awkward thing of like, going to shake the person's hand and they have to, like, you know, bend over and you know, all of a sudden it's like, oh, yeah, you're a disabled person. And, you know, I have vivid memories. The last time, I went through the gamut of job search of how sort of alienating that experience was and how it, it foregrounded my difference. So there's just a little example, I think, of how we've all as a society gotten comfortable with relating in this different way, that I think, you know, kind of inherently takes away some of the barriers and disadvantages. So I'm really excited about that. And I think, you know, I mean, just the podcast that we're doing right now, I think, you know, different ways of sharing information. I think that's all positive for the community. So, yeah, I am actually kind of excited that as we get through this, you know, new opportunities are going to open up for sure.

40:45

Dr. Susan Jaglal: Yeah, and I think another thing just to build on that John, too, is sort of what we call "e-health literacy". And you know, in terms of people being on, on zoom, for example, in video conferencing with our, with our project, in fact we have some individuals, because ours is actually, it's a video conferencing platform. But you'd have people that, you know, "Oh, I can't manage the technology and you know, it's an iPad. And, you know, it'll be much easier if we do this over, you know, over the phone on health coaching" for example. And now we're finding that when we're enrolling subjects that people are so much more comfortable with, with technology than they were before because this is how we're communicating with everybody on kind of like now a daily on a daily basis. So I think that's another thing where we'll where we're going to see a huge shift.

David Houston: That's great. Yeah, hopefully, we can sort of take some lessons and some of the tools that we've had we've been forced to adopt, but actually really integrate them into society. And by doing so we remove those barriers and create more and accessible world for everyone.

Analyssa Cardenas: Well, thanks so much for all of the thoughts and stories that you've shared with us. I definitely learned a lot about how COVID-19 has impacted those living with disabilities and I'm sure our listeners really appreciate that as well.

[chime]

42:11

Analyssa Cardenas: Thanks, everyone for tuning into part three of the rehabINK podcast: COVID-19 miniseries, we would like to thank the University of Toronto for their generous support in funding this miniseries with the COVID-19 Student Engagement Award.

David Houston: We hope you enjoyed this episode on how the pandemic has impacted the lives of people with disabilities. Stay tuned for future episodes and be sure to check out the rehabINK podcast on pod bean, Spotify, Apple podcasts and Google Play Music.

Analyssa Cardenas: If you'd like to learn more about rehabilitation science research or rehabINK, you can visit our website at www.rehabinkmag.com. Until next time!

[chime]