SCI Moving Forward: Episode 1 – Virtual Care and Assistance

May 12, 2020

Barry Munro:

Well, welcome, everybody. On behalf of the North American SCI Consortium, I wanted to thank you all for joining us here today. This is our inaugural webinar, part of a greater webinar series called SCI Moving Forward, and it was created particularly in response to the COVID-19, Co ranavirus, pandemic, and we thought it is important for us as an organization to use our best tools and the assets that we have to help bring together the community. Go ahead there, Jess.

Barry Munro:

So today we're going to have... I'm going to give you a brief introduction of who the North American SCI Consortium is, talk a little bit more about what this program is and what it will be going forward, and the introduce our two great guests who are helping us out today, Bill Fertig from United Spinal in discussing virtual care in the United States, and of course, Stuart Howe from SCI Ontario in discussing virtual care in Canada.

Barry Munro:

At the end of the presentations, we do have lots of time to field questions and answers, and really, we invite everybody that's participating to join in and create a forum of sorts, because this is a living webinar series. We want to hear from you as a community. Now, when we go forward, this could evolve, so what you say here today may shape what you're going to see produced in a couple weeks, so it's really going to try to work with real time and respond to the demand of the community. That's our plan, and that's what we'd like to do with this going forward. Thank you.

Barry Munro:

So let's talk about the North American SCI Consortium. We were created just over a few years ago, and really, it is what it is. It's representing both Canada and the United States, and hopefully in the near future, Mexico, once we get a stronger sense, and parts of the Caribbean and Central America. We serve all of the individuals living with SCI and their families, the SCI-led organizations in both on a local, regional, national, and international sense. We bring together, in what we hope to be, a consortium of all the groups.

Barry Munro:

We in no way deal directly with people on the ground. I'm saying in terms of services. We're there to provide information if we can and would automatically connect ourselves to those people that are servicing and those organizations that are serving the people directly in their own communities. That is really what we're trying to do is bring together everybody and facilitate communication, share resources, just like this is today.

Barry Munro:

We want to be able to have someone the opportunity in New York City to learn about what might be happening in Regina, Saskatchewan, or someone in Southern California find out what's happening in Northern Ontario, Canada. There are different things that are happening. What we find, as a consortium, we have a great opportunity to see different things and best practices throughout all of North America, and some of these practices could be duplicated and we can learn from each other. In some cases, not, but just learn and hear about what people have gone through. I'm sure in some situations, some of the regions are further along on some topics or some initiatives, and they can share their experiences to those that are just starting.

Barry Munro:

I feel that every time we do get together as a community, we're really great in communicating and helping each other, and really, the job of the North American Spinal Cord Injury Consortium is to help facilitate the conversation. Again, we're not there to compete with any of the organizations. In fact, we are inviting all of the stakeholders, be it individuals or large organizations, to come onboard. But we feel that as a community we can come together as one voice, and we need to do that.

Barry Munro:

Many other patient-led organizations, community-led organizations, people-lived experienced, in terms of different maladies or diseases, different conditions, seem to have their act together a little bit better than the SCI community on an international basis, and in the very short time, we've had an opportunity to really try to galvanize and bring us all together. We have a lot of work to do, but we're excited about giving the opportunity. So far, we've been afforded the credibility in speaking to people like the FDA and the NIH and the Canadian Institutes of Health Research. By speaking to them, we can operate and allow one voice coming forward.

Barry Munro:

We've also created some great surveys and properties that have come out of the work of the North American SCI Consortium, which includes an 1,800 person survey in response of 30 days, in responding to the NIH call for looking at the next decade disruption in funding for SCI research. They were actually quite surprised that we could bring together that many people, that quickly, and have such great perspective on this. So we're only as strong as you as members.

Barry Munro:

Then to be part of the North American SCI Consortium, you really, you have a chance to be a member in three different ways. One is a principle member, where's it's very consumer-based, so people like what Bill, United Spinal, is represented, what Stuart is representing in SCI Ontario. Both strong members within our organization who represent hundreds of thousands of people with spinal cord injuries. We thrive on the support of the consumer-based organizations and what they can do, and bring together, and learn a lot from them, and help share.

Barry Munro:

We also invite patron members. Those are individuals, people that really want to join just for the sake of joining on their own behalf, and are not affiliated with any organization in particular. Some of you are listening today, and that's fine, too. You can join as an individual.

Barry Munro:

Then we're looking at, we have partner memberships, when we try to bring in the industry of sorts and other organizations that really represent the interest and activities related to people with spinal cord injury, but do not meet the criteria of the above two. So we're talking like pharma and biotech, some for-profit organizations, some not-for-profits, but organizations that do have a role in what we do and help us out that way.

Barry Munro:

So I encourage you all today afterwards to join as a member and have the opportunity... It's free. It doesn't cost you anything, and you have a chance to even get more information from us. You can be part of the exchange of information. You can be driving a change with your lived experience. You can be engaging directly with the SCI community in talking to and providing research materials, surveys, and such to the industry, and be participating in projects to move research forward. Above all, you're strengthening your voice for the SCI community. We really look forward to having you on board.

Barry Munro:

The more that are on board with NASCIC and our membership, the stronger we are. We only are strong as our membership base, and we're very fortunate to have all aspects of the community represented in our organization and really look forward to moving forward and building on what we have today.

Barry Munro:

When the pandemic came along, we felt that we were in a very interesting position, that there was a proliferation of information that was starting to evolve from various organizations throughout North American in how to respond to the pandemic. In fact, it got to the point where there was misinformation. We felt, as NASCIC, that we were in a unique position. In some ways, we're on the mountaintop in Switzerland. We're not necessarily grounded in one community. We're grounded in the whole continent. And we have the opportunity to see people and resources coming in from all corners of the continent.

Barry Munro:

We thought what better thing for us to serve our community as to somehow create a repository where we can store all these great resources that have been vetted and then been cleared? Clearly there are some that are particular to region, some particular to municipal regions right through to international, where you have a Canadian and an American side, and some are very generic that really apply to us all around the world.

Barry Munro:

These are all resources that we wanted to share, that we felt we needed to organize them, and we need to, more than just put them on a website, create this webinar series where we create dialog. It's important that we push out to you and let you, the community, know what's here, but more importantly, for you to tell us what you want, and you to share with us your experiences so that we can take that back, refine it, and then package it, and send it back out again.

Barry Munro:

Our whole plan is to be this two way communication stream where we at NASCIC can house this in our SCI Moving Forward series and really help communicate great resources, and hopefully improve the lives of those that are out there, and really alleviate a lot of stress. We couldn't have done this without the great support, the Craig H. Nielsen Foundation. As you may know, they were putting in the COVID awards, and we were one of the lucky recipients of such an award.

Barry Munro:

As a consortium and individuals that make up across North America, we have the opportunity, again, to spread this information out to an audience who are, as you all know, lots with SCI, are vulnerable. But because we are, we are even more defiant and stronger and more understanding of our surroundings, and need to become the self-advocates that we are all great at. But we always need help. So that's what we're trying to do.

Barry Munro:

In this series, we've got a list of different upcoming topics, and you know what? Here's the best part. They're not in stone. You guys can change this today. If you don't like what you see, or suggest something that you'd like to see more, let us know. There's going to be a survey at the end of this webinar, and we can evolve it. But more importantly, too, give us the priority of what you want to do. Next week we are going to talk about attendant care. We're going to talk about all aspects of it when dealing with, obviously, safety, dealing with shortages, and sharing some experiences in different jurisdictions.

Barry Munro:

We have dedicated one webinar especially to the Hispanic community, that we think it's important that a community that is somewhat really underserved and very vulnerable that they have a voice and they have an opportunity to understand different aspects of what's going on right now, and share some experiences together.

Barry Munro:

Then we talk about the SCI-specific health concerns. We're looking at some specific things like respiratory issues, and we've seen some information out there. We want to kind of put that together and share that with you all. Look at emergency and disaster planning and supply shortages. Obviously, something that doesn't have to be mentioned too many times. We know what that's all about.

Barry Munro:

Then the big one, of course, is isolation and mental wellness. We are used to being isolated, potentially, as people with spinal cord injuries, but not this way. I think one of my colleagues... Jen, I'm calling you out... made reference to physical distancing, not social distancing, and that's important that we keep that in mind.

Barry Munro:

Then we'll talk about nutrition. We'll talk about resiliency, and we'll talk about self-advocacy and system change, then potentially moving to the new normal. But like everything we've done in our lives, and many of us that are on this call would know that, that we had to take something bad, like take those lemons and turn it into lemonade. There are some actual opportunities right now that are coming out of this crisis, in terms of how we do business, how we communicate with the people in our community, and some of the services that are now readily available that we hope can become permanent going forward. But I don't want to take away any of the fire of our upcoming speakers, so I think we'll just get at it right now.

Barry Munro:

What we'll start with today, we have virtual care and assistance, and I wanted to introduce our first speaker, Bill Fertig, who's Director of United Spinal Association Spinal Cord Injury Resource Center. Bill has been a director of the Resource Center for years. He lives with his family in Virginia Beach, as you may or may not know. Everybody knows Bill. Bill, he works from Virginia Beach but really deals with the whole country in the great things that he does. He's served 25 years as a police officer and training sergeant. His off-duty motorcycle accident resulted in his T7 injury in '99. Bill brings his past varied experiences and 20 years of living with an SCI to his information specialist team, which helps support consumers who contact the SCI Resource Center after injury and once they have the disease onset.

Barry Munro:

As a returning Executive Council Member of the North American SCI Consortium, Bill plans to continue to expand the growing NASCIC membership throughout SCI community, and assist as needed with existing and future project-based initiatives with NASCIC, and without further ado, I'd like to introduce my friend, Bill. Take it away, Mr. Fertig.

Bill Fertig:

Hey. Thank you so much, Barry, for that terrific setup for all of us about what we're going to do, how we're going to do it over time, and it's great to see the ability to be flexible, because it's us. It's all of us that need to demand the information we want, and we need to be the change-makers, because nobody's going to do it for us.

Bill Fertig:

One other brief comment I would make, especially in light of this COVID craziness... I mean there's no other word for it that I've come up with. Unprecedented. That sort of leaves us flat, right? But I just... We, in working together at United Spinal with our chapter members and support group leaders, have just come to realize that we, and that includes everybody in this call, we are strong, we are resilient. We're the survivors. We're the people who rose to the top and moved on, many of us, after a spinal cord injury, some very significant injuries. I know mine is a lower injury, but on three or four different levels, I shouldn't have survived the initial accident. It's all good. We're here. We're moving forward, and we're making change.

Bill Fertig:

Jessica, if you want to move on to some of the content, so that I don't blather on too long. I wanted to talk a little bit about telehealth, and not as a content expert. We are just beginning to learn what telehealth opportunities there are. Jess, if you can advance a slide or two to some bullets, because I'll mess them up. Thank you. Moving my pictures out of the way here.

Bill Fertig:

In the US, and I can really only speak for what I know about here about the health systems, which are significantly different from the way things are organized in Canada, but we've got the VA. It's an entity in and of itself. It's just like it's a whole separate sub-planet, care in the VA. If you're from the US, you've heard bits and pieces of that all over. Medicare, because of this pandemic, has opted, pretty proactively in the way I see it, to provide something that, if we all concentrated here in the US for 10 years, we might not have been able to successfully advocate for her, and that's the broad expansion of telehealth services with Medicare reimbursement.

Bill Fertig:

Medicare and Medicaid, CMS, Centers for Medicare and Medicaid Services, in the US is probably arguably the very biggest healthcare provider, sort of in parallel with Veterans Administration, and then the private insurers, they follow suit in many respects about CMS rule-making. In my own case, I belong to a healthcare company through work that is part of the UnitedHealthcare Group, the largest single, private healthcare provider in the US, and automatically, when I saw Medicare promulgate rule changes greatly expanding telehealth services broadly across the US, I'll give UnitedHealth one thing, they seamlessly signed on board. Two days later, I had a routine wellness visit, just a six month visit with my own PCP, not even a spinal cord injury specialist, just a howdy-do, vitals, you having any problems, double-check on my lab results, and I found out a day before that, one day after the Medicare announcement that I saw, that my visit was now via Zoom.

Bill Fertig:

I'm one of those people who has a good partner and got me all set up with telehealth vitals, home testing materials, a pulse ox, home automatic BP and heart rate monitors, and combined, I was able to do my own vitals as the nurse would've done in the office had I gone there physically, present them to doc. "Hey, Doc, I'm all good. Here's my numbers this morning." He then shared with me the lab results which, knock on wood, were very routine, and that went very seamlessly.

Bill Fertig:

So all of that took five minutes and would've taken much longer in the office. It has to be cheaper. There has to be a trickle down to a reduction in healthcare costs eventually, if we follow this model, because in five minutes, we were done. We ended up chit-chatting about life and things, and we were complaining about the governor for the next 10 minutes. We realized we may as well conclude. That was my PCP visit. And this is usually a really all-business kind of a doc.

Bill Fertig:

Maybe, and healthcare in the US is vastly overpriced and complex because of how expensive it is, and it is rationed because of how expensive it is. Some people get nothing. Some people get a little bit. But our hope is at United Spinal that eventually, because the genie is now out of the bottle... We're coming to a consensus that people are not going to go back.

Bill Fertig:

Now that you can go visit your PCP for your regular visit by telehealth in five minutes from the comfort of home, why on earth would either side want to... and have it reimbursed... why would either side ever want to go back to going and sitting in the office full of sick people coughing on you, and wait your turn to go in the office and do the same thing? It doesn't make a lot of sense. Not everything, obviously, can be done via telehealth, but those things that can, I think they're going to, and I think they're going to remain long after the emergency put us into the mix.

Bill Fertig:

Where all is there telehealth? Well, I want to ask this group, as an open invitation, to help me learn where there are more telehealth services available, because there's no way that my brief preparation for this call informed me of all of the things that are available. Our larger centers in the US, Shepherd Center comes to mind. Craig Hospital, Denver, Colorado. Shirley Ryan Lab in Chicago. Institute for Rehab and Research in Texas, and many, many other really noted spinal cord injury rehab facilities and TBI rehab facilities. They have their own forms of telehealth that are limited, and it's probably a mishmash, a different kind of healthcare provision, but what I've come to know about is the model centers and some other select places... that would be my... one, two, three four... fourth bullet. I'm jumping around here... will have limited telehealth services.

Bill Fertig:

We need to reach out to our doctors, to the major providers that I want to and I need to and that all of us need to get spinal cord injury care from, and inquire about their telehealth services. They're going to expand. They're probably expanding beyond what we all know. I'm actually separately on the board of the Virginia chapter of United Spinal. We're on another Zoom call at 5:30 today, and we're going to be addressing telehealth in Virginia as well. So there's a mishmash out there. There are probably 25 other places that are doing it right now, but haven't managed to make it onto this sheet.

Bill Fertig:

The one of them that... The two other things I want to mention is... Barry, let me know if I'm okay on time. The other two that I want to mention is a unique opportunity, I believe, for the US residents only right now. From one of our hospital member partners of United Spinal, I just did a monthly report. We have 108 rehabilitation hospitals that are paid members of ours, that we have a back and forth relationship with at United Spinal.

Bill Fertig:

One of them is Quality Living Inc. of Omaha, Nebraska. They have a very nice plan. They have a big campus, and they have step down care. They have opportunity for learning how to live in your apartment care before you go to your own home. They have a lot of great programming. Adaptive sports on campus. So they draw inpatient acute patients from a variety of states beyond Nebraska. What they found then was because they have many other patients for 10 or 15 other states, that when they're acute inpatient people went home, the natural inclination was to want to follow up with the great clinicians at QLI, and so there was born the telehealth provided by QLI to their former acute inpatients. Once they started-

Bill Fertig:

Okay. Anyway, QLI is now offering, through a Nielsen grant, a limited amount of PT, OT, speech language pathology, and psych consults that are spinal cord injury-informed specialists, and they're offering that care through a patchwork, but a large patchwork, of individual licensures. Some of the PTs and OTs at QLI, because of the uniformity from state to state of the licensure requirements for PTs and OTs, a little bit more so than for psych evals, they are able to bel certified in 30-35 of the 50 United States, 51 if you count Washington DC.

Bill Fertig:

So they're able to provide funded, no co-pays, telehealth to people in the United States with an SEI backing. Their goal is not to solve everyone's problem. The goal is to take people who feel stuck in a certain way to move on, move forward, and be more successful, whether it's in a PT, OT, speech language path, or psych field, especially now with us all cooped up. I'm sure the psych evals are going to be particularly beneficial.

Bill Fertig:

If anybody listening has any questions about if there are qualifications, licensure in their particular state, please write to me. Pretty easy to find it, unitedspinal.org, but our emails are first initial, last name, so bfertig@unitedspinal.org. Please write to me and ask about it, and we'll help to see if yourself or others that you know are available for... whether the QLI services are available for you.

Bill Fertig:

The last thing that I wanted to throw out here because of NuMotion being one of the two nationwide, in the US, providers of durable medical equipment provision, repair, service, wait forever, all the things that might go into your DME provider. Wait for nine months to get your chair. Whatever. Or they'll return the phone call today. It could be any of those things, but they have been digging in and doing, I'm told, they have concluded 2,000 remote diagnoses or evals that have led to parts ordering via telehealth, and they have paired the two to three to four visit provision on wheelchair repair down to one face-to-face visit, where the technician actually comes to your home and installs the part.

Bill Fertig:

Especially now, and knowing how long the process is, it'll be weeks, hopefully not months, but maybe months until that technician actually comes, so hopefully we're farther down the road to stability in the COVID crisis, but for now, to be able to get a sense do I need new tires? Well, yes, I can do a televisit, and point my phone at my tires, and show my tires are bald, instead of have to schedule for that.

Bill Fertig:

I don't want to take up too much time. I'm happy to answer any questions. I'm not sure if questions are at the end of everyone or not, but I'll pull away now for the time being. Thank you.

Barry Munro:

Thanks, Bill. Just a reminder, everybody. We have the chat option on the Zoom call here, so that please feel free to send in any questions that you might have, or more particularly, what Bill was kind of casting it out there to see if there's any other resources that you can think of. I know my understanding that some of these centers for independent living offer quite a bit in helping in the crisis situation.

Barry Munro:

Really, I should double back to say that today's topic is really about virtual care, because we really don't have much of a choice, and what we're seeing is much like these Zoom calls, that everything has gone virtual, but really, how are we really taking advantage of that, and how this might be something that isn't just a temporary fix. It might be something to help our community beyond the crisis, and that's what we're excited about today. Bill, I'm going to park your questions and answers now, and at the end of Stuart's presentation, we'll open it up to everybody. How does that sound?

Bill Fertig:

Sounds great.

Barry Munro:

Great. I'd like now to introduce Stuart Howe. As you can see in his bio, Stuart is Chief Executive Officer of the SCI Ontario, a charitable organization that delivers and champions excellence in support service and advocacy for people with spinal cord injuries, their families, and the broader disability community. Stuart has had a great career, and having Stuart join SCI Ontario was a great coup for the organization. He brings a brand new perspective in a time that was needed, and his background in new technology and new technology companies has really bode well to what's happening here.

Barry Munro:

As you can see, Stuart is an advanced chemistry PhD. He's a smart guy. He's done a lot with what he's learned, and he's really applied it back to our community, and we're very thankful to have Stuart on the call today. Stuart, it's all for you. Take care.

Stuart Howe:

Thank you, Barry. Thanks for the opportunity to chat. Frankly, after that introduction, it can only go downhill from here. It's a pleasure to join everybody today. It's my first time with a NASCIC audience, so as Barry said, I'm the CEO of Spinal Cord Injury Ontario. We are part of a national federation which provides supports and services and advocacy for individuals with a spinal cord injury.

Stuart Howe:

I was chatting with Bill earlier, and we have a shared heritage with United Spinal, which is kind of important for this conversation. We were founded by veterans back in 1945, so this is our 75th anniversary. The veterans came back and basically refused to accept the medical model at the time, which was basically to go and live in an institution and, quite likely, die within a year or so of whatever, complications, infection. So they said, "Hell, no. We're not doing that. We are actually going to go support ourselves and live in the community." And really, that's the essence of our organization from the outset and still going strong today. It's the whole thought behind some of the work that we've actually been doing in virtual care.

Stuart Howe:

The virtual care in Canada, so I'm going to give you my perspective in virtual care in Canada. I do not profess to know everything, and I know I've got some Canadian colleagues on the line here, so they can add things that they're aware of and correct me in what I'm saying after the fact. Really, looking at virtual care in Canada, I really thought sort of there's really two pieces to this. One is the pre-prep pandemic. What was happening? And then what's been put into place very quickly since?

Stuart Howe:

From a healthcare perspective, really there was very little access to virtual care. We have that public healthcare system, so every province has its own approach to doing this, but I don't think any of the provinces really had adopted virtual care up to this point. Ontario had something called Ontario Telehealth Network, which was a video link for remote, often specialist, consultations, where it required the healthcare provider to be present with a patient in a designated location. So it wasn't particularly user-friendly, but it was far better than not having any remote support.

Stuart Howe:

It was also the system which was the only way physicians could bill for those remote consultations. They weren't particularly keen to do other types, because they couldn't actually bill for it. That started to actually change over the past sort of 12-18 months, and there had been the expansion to other platforms, and the Ministry of Health was really looking at how do they improve remote access now that technology's moved so fast. So the government was moving in the right direction.

Stuart Howe:

From a community sector perspective, which is where we operate, there really was even less. One of our organizations, Spinal Cord Injury BC, I know they were using... they were doing virtual peer connections events, where most of us were still doing in-person events only. Most organizations that are closest to remote would be telephones, and often one-on-one type meetings. There wasn't a whole lot. There were some virtual care pilot projects underway across the country, and many hospitals had started allowing people to access their personal health information through the hospital portals. So similar to some of the stuff Bill was talking about in the US, it was very much organization by organization, and it depended who you were connected to, what level of access you could actually get to virtual care.

Stuart Howe:

So fast forward to March of this year, and when the pandemic hit, all of a sudden, there was a view that actually we all need remote access. How do we do that? So there was a big surge in the use of virtual platforms. A lot of them were pretty much video-based approaches to meet the healthcare providers, so it was the hospitals, some of the family health teams, and a lot of the big health... the industries, the telehealth organizations that really started to try and push those platforms, which was great. It's a big mark forward. Again, sort of to Bill's point, let's just hope we don't go back from having this remote service. It's so huge for our community.

Stuart Howe:

For a community sector, again, people sort of proved their resilience, are moving on and are using Zoom and Skype type of things. I just want to talk a little bit about what we have been up to, and it actually goes back a couple of years. We'd realized that to support our community, many of whom live in remote areas, we needed a different approach to doing that. The slide in front of you I don't think would be of any great surprise to anybody on this call around thinking about the social networks that our community has compared with the general population, and many of individuals with SCI have a much smaller group, and it's family and friends, but frequently, that really encompasses community organizations, the various supports that people have, and the healthcare providers are always part of that social network.

Stuart Howe:

So we decided that what we were going to do is actually build a platform so that people could provide their own... look after and manage their own virtual healthcare and community supports. It's called VIP4SCI, Virtual Platform for SCI. As I said, really the motivation behind this was, from a client perspective, to improve access to primary care, community support, allow them to reduce travel, accessibility, improve information sharing, and a nice single platform for the individual to manage all of the people that are in their circle of support. I think that's what differentiates what we decided we wanted to do from a lot of the healthcare providers' approach, which is really to support the healthcare provider.

Stuart Howe:

We wanted to build something which gave that control to the individual to decide who to invite into that circle of support, when to invite, and what to share with them. Now, this was not completely altruistic, and there was rationales from our organizational point of view around making it easier for us to contact all our clients, especially those in remote communities, reducing travel, increasing the capacity, so our regional service coordinators could interact with more clients easily, and from an information sharing and coordination perspective. It was... We tried to resolve that.

Stuart Howe:

So what we ended up building was really the platform I kind of talked about, where it put the person in the middle to allow them to connect in from peer support, employment. When we were doing the research behind this, we also had primary care through the Mobility Clinic in Kitchener-Waterloo, who's one of the specialist primary care providers in Ontario. They're just a huge supporter and a huge value to our community.

Stuart Howe:

We basically built this platform to allow individuals to bring people together that they wanted. It was going to be, in theory, coming out as a production platform in July or August of this year, but what we did is we fast-tracked it at the end of March, and so it launched on April 3 this year, so we could get out there. The platform is now readily available to all our clients on computer, tablet, or phone, and it's a basic system, where there's a couple of different sort of clients' views. So having a look, you've got the perspective of what a client can see and the others they can control and what they have access to, including on the bottom left hand corner of the blue slot there, something called Cortree, which is our information and e-learning platform, which is a whole other topic of conversation.

Stuart Howe:

Then our staff have a similar type of interface, where they can skip through their clients, manage them, make the connections, keep journals, share information. It's worked out very well. It is up and running, and if you just want to skip one more slide on this, nothing in life is without its challenges. I think some of this comes back to a lot of the issues that will be very similar and some of the stuff that sort of Bill alluded to.

Stuart Howe:

The client access to technology is a challenge for many people in our community, and the more remote you are, the access to the reliable broadband internet is proving to be a challenge, so we're trying to work out how to resolve that. That's going to be a challenge for all telehealth. This is not just a challenge for our particular platform, but very much is going to be something that's faced by many members of our community, and how do we get easily affordable, good technology and broadband internet access?

Stuart Howe:

The other big challenge is around the recruiting the primary care onto it. It's a platform which is very good for the community living aspect, but it's going to maximize out for everybody if they've got that easy access to the primary care. Now that the physician billing is changed, we are hoping to get more of the physicians on board, but what we're going to need to do, and again with these platforms, is our approach would be to build it around the individual with the spinal cord injury. The challenge is a lot of the physicians are working in practices where they're going to want to use one platform for all their patients, not just their patients with a spinal care injury. Can we overcome one of those big challenges and make something that is of enough value to our clients, the patients, that the physicians see the value in actually working that way through?

Stuart Howe:

So from a next steps perspective, we are going to just keep rolling this out, adding as much primary care into this as we can do, building out extra programming. We really want to do family peer support remotely, employment services as well, group sessions, which are big. But host them on a platform where it is secure. It's HIPAA, FERPA, everything is totally secured from a privacy perspective.

Stuart Howe:

Then expand the profile so that it's easier to connect in with your local occupational therapist, physiotherapist, seating clinic vendor. All we need is just a boatload of money to sort of keep that going, and I don't think that's going to be any different from any other sort of IT provider on this. So that's kind of where we are. As I said, I would love for some of the other Canadians to jump on board and talk a bit more about what's happening in Canada, but just to... I share, again, that wish with Bill that we've made such progress, and because of the pandemic, I think we're far further ahead now than we would've been without it, when it comes to everybody understanding isolation, remote support and service. Let's get it on everybody's agenda to keep it moving forward.

Barry Munro:

Well, thank you very much, Stuart. That was an excellent presentation, and thanks again, Bill. I just wanted to reach out to the audience right now and really ask anybody that's had a virtual care experience that might be different than what you're hearing today, and maybe explain to us, maybe it was a different avenue or different platform, or maybe some of the horror stories that sometimes creep up through these things. It's not all a bed of roses out there. We understand that. But I'd love to hear from any individual, if you'd like to share that with us, or feel free to put it in the chat. Jess is going to put up a survey while we're talking.

Jess:

Yeah. I have our first question, so whenever we're ready, I have a question from the chat.

Barry Munro:

Sure.

Jess:

So it's this app is great. Is there a version to expand this to other agencies like SCI BC or United Spinal? Have you also considered expanding the app to other partners like Teladoc?

Stuart Howe:

I'm assuming that's addressed to me.

Barry Munro:

Yeah.

Stuart Howe:

Yes. We actually built the program. So we worked with an Ontario startup company to develop this. We are not developing it in house. We have the... We know what we want. We're going to let the experts actually develop it, but we specifically developed it so that it can be white-labeled and very easily branded, adapted, and modified by anybody who wants to use this platform. So Barry, we've talked a lot to our partners in Canada around using this, and it's readily available to sort of anybody who would be interested in looking at it. I'm more than happy for anybody just reach out to me afterwards, and we can set up sort of demos of what this looks like, put you in touch with the company, if anybody is interested in pursuing this.

Barry Munro:

One thing we should share with everybody is that after this presentation, you will see the slides will be archived. We will be producing the webinar in a finer format, and we'll also be complementing our microsite, all of the different resources that may have been mentioned today, but of course, you'll have the ability to reach out and contact Stuart or Bill directly via their workplace. So that information will all be available.

Barry Munro:

I'd like to know... So we've heard, really, United Spinal and what they have done, and obviously, the work that they're promoting with the telehealth in the United States, and of course, SCI Ontario representation one of the branches in Canada and how they work with telehealth, but more importantly, how they're now working with virtual support. Are there other... I'll ask the group. I've heard talk of great centers of independent living in different cities throughout North America that do provide something similar to all disabled individuals, not just people with SCI, but people that they know right now are vulnerable. I'm asking maybe if anybody is aware of a particular example where they have had success on the ground in this time of pandemic, and if they've had any help from an alternative source, apart form one of these two major organizations that we're speaking of today?

Barry Munro:

Then I'll also ask, have you had direct experience with some of the Model centers in the US, including the PVA Model centers, where they inform... they also offer resources and, in some cases, peer support, and I wonder if anybody in the audience has heard any success from those models as well? What we will do after this is, obviously, we still have some work to do in finding more resources, but again, this is almost a form of crowd-sourcing everybody. It'll be vetted, obviously, but we are going to try to put up as much great examples so that people in different parts of the continent might have easy access to something that they weren't aware of in their own backyard.

Bill Fertig:

So Barry, a couple of comments. One of them is a followup to Stuart, but before I get to that, the followup with the Model centers in the US, the 14 federally designated Model centers, we have had followup with a few of those through our Medical and Scientific Advisory Board. Some of the advisory board members are principle, pivotal staff there, program directors, and lead SCI physiatrists at some of the Model centers, and when we broached the subject of telehealth with them, they were particularly enthusiastic. Like you don't get typically scientists and program directors to write back to you instantly and enthusiastically when they're all in such a busy time as they're seeing in their own facilities during the COVID, so they're very much behind this, and I think, again, the genie's out of the bottle and it's going to be up to us if we want SCI-informed telehealth to help lead that effort.

Bill Fertig:

I would make a comment and followup to Stuart's direct presentation there about the telehealth kind of sphere, with a bit of a cautionary tale. That's somebody mentioned Teladoc, but it doesn't have to be that particular company. There are many companies. We had done some sampling of what I'll refer to as generic healthcare through a major telehealth provider, only to find that they neither had the expertise in spinal cord injury care, nor frankly, were they particularly interested in gaining it or addressing the spinal cord injury community. They basically flat out refused to do that.

Bill Fertig:

I think that... We did some tests, doctor's visits. I got the opportunity, along with a couple other staff members, to participate in sample doctor's visits, where the physicians were unaware that the patient logging on and visiting with them had a spinal cord injury. In my particular experience, the telehealth company provided an opportunity for you to proactively reveal that you had a spinal cord injury and at what level, and provide all your healthcare background. The opportunity for you to proactively provide that background medical information was there; however, it was not a demand field.

Bill Fertig:

I have to tell you, when I do physically go to my PCP's office, I am not getting in to see the PCP before the gatekeepers make me fill out that daily form of what is your visit for today? What is your interest in this particular visit with a doctor today, and what do you hope to gain? They make me check of yes and no boxes of everything that I have of considerations. Am I diabetic? Am I this? Am I that? None of that was demand fields for my test visits with a commercial company.

Bill Fertig:

I would argue that for someone such as yourself, Barry, living with quadriplegia, for whom autonomic dysreflexia can be a very important factor for your doctor to have in their understanding of you before they address your telehealth visit, that if they neither know about autonomic dysreflexia, know that you have it or not, because, say, you haven't revealed it, and wouldn't know exactly how to address it, or how their regular healthcare offerings might be mitigated or changed due to the fact that you might be a quad with AD, I think we're setting people up... As leaders in the SCI field, I think we're setting people up for dangerous kind of healthcare if you don't have systems in place to know that the company you're dealing with that is providing your healthcare, to know that they have SCI-informed healthcare being provided.

Barry Munro:

Bill, you bring up a good point. I just want to go back to some of the questions and shout out to my friends, Heather and Sasha. Thank you. There's a few themes circulation around. Number one is as we evolve through this webinar series, I think we all know that many that are on the call now and know that we have to be self-advocates whatever we're doing through this healthcare system in whatever healthcare system we are, but what about the people that don't have that, an ability, or no, they have that ability and are somewhat new to the systems?

Barry Munro:

My question is there are people in rural communities who are not used to "getting involved with the system." And both United... I put this question back to United Spinal, and obviously, sir, you can deal with rural Ontario as well, and some of those isolated areas. How do your organizations really try to fill in that gap and help facilitate this kind of service to people? Stuart, you tell me.

Stuart Howe:

Apologies. I got lost in a private chat here, so I do apologize for that. Let me just...

Barry Munro:

That's okay.

Stuart Howe:

So facilitating the-

Barry Munro:

Really, those that are in rural, isolated areas that I know they try to access... they frankly don't know where to start, and they might not even have even that kind of access. I wonder what your organization, as an example, does to help those individuals.

Stuart Howe:

So the way that we're set up in Ontario is I have specialists, regional service coordinators, in 14 locations across the province who cover up and support plans, who live literally anywhere, including the fly-in communities in Northern Ontario. So the ideal model is that we actually connect in with somebody with a spinal cord injury very early on in the acute or the rehab stage, and then they become familiar with us, and then we're with them throughout their life when they need something.

Stuart Howe:

But really, the piece is to... We've got people who know where the specialist primary care providers are, where the best access to the physiatrists are, OT pieces, and by having access to a remote platform, we can actually guide people through the maze. That's one of the pieces we do most often is really that information exchange and knowing where those resources are, and then being able to help people access the technologies they need to connect to the people they need to.

Barry Munro:

That's a good point. That kind of brings us back to the purpose of what we're trying to do here in providing the resources and sharing the resources in these particular areas. But you've also touched on another piece, and we're running out of time today, and we're trying to address it going forward, is access to technology and people understanding technology. Technology isn't for everybody, and those that know me can confirm that sometimes I drop the ball on a few things, and I'm supposed to know what I'm doing. But I can imagine somebody that's fresh to this area and is going through all the things that they're going through is how do we help communicate with them and help guide them through the system? Because it is a system.

Barry Munro:

Unfortunately, this isn't cookie cutter. We're hearing about people with private healthcare, people with government-funded healthcare. We have nationally-funded healthcare, and then we have a lot of things in between, and there's even fee-for-service. You'll be hearing about some of the resources going forward, and we're going to try to provide as many resources that we have, we can find out there that are easy to access, but some will require fee-for-service, and in some cases, people that might be accessing this will be willing to pay for it. That's fine, too. It's going to take all things to get us to where we need to go to.

Barry Munro:

I'm looking at the clock right now. We are now winding up on our hour, and I want to thank everybody for their patience today. This was my first webinar this way. I had a few technical difficulties, but I want to especially thank our two speakers for coming on board and pulling this together in a very short time. You're a wealth of knowledge. We will continue to make sure that you're represented in the archive, so people can find you if they need to, if that's okay, and your great organizations can help those that are in need.

Barry Munro:

We do encourage everybody, even after this call, there's going to be a survey that's going to be sent out to you. We ask you to fill that out if you could, but we'll also encourage you to become members of North American SCI Consortium so that you're really more connected to us as you can possibly can. We look forward to really hearing what you have to say, and we want you to guide us going forward. This is your webinar series, so please, please, inform us, activate us, get involved, challenge us. It's all up to you. But again, thank you very much for everybody today for taking the time and joining us.

Barry Munro:

We're back again next week at 4:00 PM, and the issue will be Attendant Care. Look forward to having everybody here, and remember, if you want to be a member of NASCIC, membership is free. We'd love you to join, and that way we can connect to you on a more individual basis. Take care, everybody. Thanks for joining us today.

Jess:

Thanks, Barry.

Bill Fertig:

Thank you so much, Barry.

Stuart Howe:

Thank you, Barry.