Barry Munro:

Hi everybody, happy Tuesday. I'm Barry Munro from the North American SCI Consortium and I'm your host again today for our second in our series of webinars. Today's webinar in our SCI Moving Forward webinar series is the Attendant Care in the Time of COVID-19. We thought in light of all the pressures of the pandemic and what's happening right now that we are looking at topics as we move forward that are pertinent to our population in our community and we are asking for input throughout the day, and please use the chat box if you could, and we're looking at also prioritizing topics I think you, as a community, want to hear going forward. We've been very lucky to have two great co-hosts today. I'm going to ask everybody that is participating to please put your mute on so that we can hear our speakers properly and if you want to come in at the Q and A time, please by all means, feel free to ask questions either verbally or you can come in by the chat room that's available to you.

Barry Munro:

Without further ado, let's get started. Okay, Jess.

Barry Munro:

Today's agenda is, again, we will reintroduce who we are as an organization and the series. There is going to be an audience poll but we'll do it through the chat room. We're having a technical difficulty trying to get the poll out and then we'll call upon our two speakers, both Teren Clarke talking about providing care for persons who is living with SCI and caregiver advocacy options by Jenn Wolff. These two topics are, again, relating to the context of the times with what we're going through with the COVID-19 pandemic.

Barry Munro:

Once again, I just wanted to reintroduce our organization, North American SCI Consortium. We have the mission to bring about unified achievements in research, care and cure and policy by supporting collaborative efforts across the spinal cord injury community. We are really a bit of a Switzerland for everybody, if that makes any sense. What we do is help bring together all the organizations involved in our community and all these different aspects and try to find common ground and speak as one voice. It is, by our nature, we're not competing on a fundraising level or anything like that. All we are here to do is support our member organizations, and most particularly, individuals who have decided to join our organization. I can't urge you enough to consider joining our North American SCI Consortium and information about that will be found at the end of this webinar series. It's a free membership. This gives you access to information, but it helps us communicate with you.

Barry Munro:

Once again, I just wanted to introduce this webinar series. We decided with a grant from the Nielsen Foundation to put together a 10-part series that will focus on different issues in our community that we're dealing with, but more particularly in light of and in context of the COVID-19 pandemic and how it's affecting our SCI population. Afterwards, and during the webinars will be stored in archive. They will also be translated into Spanish and there will be a lot of collateral materials that you will find either mentioned today or that will be available from other organizations throughout North America that we are always willing to share and let everybody read about. That will be found on the link that you see here at www.nasciconsortium.org/scimovingforward.com.

Barry Munro:

I wanted to let you know our upcoming list of topics are as follows.

Barry Munro:

We have one next week completely devoted to all the issues related to SCI and the community and what's happening with COVID in the SCI Hispanic community. That webinar will be in Spanish, but there will be English subtitles available afterwards when it's archived, if there is a demand for it.

Barry Munro:

The next topic is SCI specific health concerns and risks amid the COVID-19 crisis, particularly dealing with things like respiratory issues as we are a vulnerable population and we are relying upon experts who have had a lot of great resources on this topic and we want to tap into that and share that with the community.

Barry Munro:

The next one is emergency and disaster planning and dealing with supply shortages. Again, many people that are listening today understand what I'm talking about and we'll learn about different tactics and mechanisms, what people are doing around North America in an attempt to deal with this topic.

Barry Munro:

The big one that we've, as a community, have been dealing with for many years, more particularly now, is dealing with isolation and mental wellness during COVID-19. Of course, what's important for our health, things like SCI nutrition 101, there will some great topics and great resources on that. I think we wanted to focus particularly on resiliency, that we, as a population, are pretty good at it, but we have to draw upon our inner self more than we ever did to get through what's going on right now. In fact, many ways we are an example for the able-bodied population that might need to understand how we get though such things.

Barry Munro:

And then of course, which is always important to us as an organization and all organizations is self-advocacy and system change. Believe it or not, this is an opportunity here with all the changes that are happening. The world's been turned upside down, that there might be some opportunities for us to A, get through the crisis, but B, more importantly, to change things as more of a legacy going forward in the future and we should talk about that.

Barry Munro:

And then of course, at the end we're going to talk about what it looks like going forward and getting back to our new normal. That is to be announced in how we're going to deal with that one because it's an evolving conversation and I think we, as a community, would like a little bit more guidance in what is safe going forward pre-vaccine, if that's the way we're looking at it.

Barry Munro:

These are our two poll questions that we wanted to put out today. Our poll system is not working, but we will ask you to put on a chat group. Number one is, if you've experienced issues with attendant care in COVID-19, please say so. Negative or positive. Something's happened to you that's different than what the norm is let us know and our two speakers will chime in and try to answer those questions or try to answer your queries, address those queries going forward. Again, the other question is looking at all the different topics that we suggested earlier, if there is one or two that you think is of the highest priority, please let us know. That will help us reshape the agenda and how, going forward we can put certain webinars in front of the others to make sure that we're addressing the needs of the community.

Jessica Bassett-Spiers:

And Barry, I just want to interject. I can put this put this back up towards the end of the question and answer period so give some people time to think about it and then bring it back towards the end.

Barry Munro:

That's great.

Jessica Bassett-Spiers:

Does that sound good?

Barry Munro:

Okay, thank you.

Barry Munro:

Our first speaker I'd like to introduce to you is Teren Clarke. Teren is a former CEO of Spinal Cord Injury, Alberta from 2005 to 2019. She's a past chair of the SCI Canadian Executive Director Council and she is a current member of the Strategic Clinical Network of Neuro, Rehab and Vision. She's also a current member of our executive committee at the North American SCI Consortium. Teren is a nurse by trade so she brings a lot of great input and a lot of great passion to care and helping people in our community. And without further ado, take it away, Teren.

Teren Clarke:

Thank you, Barry. Good afternoon, everyone. It's my pleasure to have a chance to share a little bit of information, but also to help collect information from you folks, because truly, you are the experts. We're going to focus on the impact that COVID-19 has had related to the care that may be provided to you in your home. We certainly know that persons with spinal cord injury, who have lived successfully in the community face many new challenges as a result of this current pandemic.

Teren Clarke:

Just to capture a few of them, hired care providers may be fearful of contracting COVID-19 or of being a asymptomatic carrier and passing it on to the recipients of their care services. Hired care providers may suddenly require self-isolation and therefore not show up. Hired care providers may not fully understand how to use personal protective equipment effectively or may experience a short fall in equipment. These are some of the concerns that we've heard already in canvassing people both in the US and Canada.

Teren Clarke:

What can you do to be prepared?

Teren Clarke:

I think one of the first things, and I've heard this shared by the Network of Independent Living Centers and other community organizations is that it's really important to assume that a disruption to your care provider routines will happen during this pandemic and that you may need to rely on persons with little to no prior experience. How do you begin to deal with that? And many of you already know this because you are very resilient folk. But just to emphasize, it's really important to create a back up plan. You're still in charge of your routines and care.

Teren Clarke:

Some of the things you can do. Create a list of your network of supports. This could be family, friends, students, unemployed friends, and really important of those assets to your network, to identify and confirm with two to three individuals who would agree to provide back up care if required.

Teren Clarke:

You need to create a list of organizations and individuals with expertise around SCI that you can tap into in an emergency or your inexperienced care providers could.

Teren Clarke:

Familiarize yourself with training resources to help your back up care providers deliver safe services to you. And this takes some of the burden of continuing to train people, takes some of that burden off of you personally. You need to document all of this. Post on your fridge, your care plan, your personal care directives, should you become ill and have difficulty communicating because that's one of the risks, one of the concerns should you become ill with COVID-19. Again, document, post on the fridge the contact list for key members of your family and your health services team.

Teren Clarke:

How do you prepare your back up care providers? If you receive agency care, inquire about their contingency plans related to dealing with the pandemic, but note that many agencies have been overwhelmed by the demand for in-home support/care during this pandemic. Again, we've heard that through some of the folks that have been feeding information to NASCIC.

Teren Clarke:

Important to discus your care routines with your back up care providers and there's lots of resources, tools available to you. You can visit YouTube. There is lots of videos there and other online training resources to assist the inexperienced care provider to visualize their role in taking direction from you and providing personal care and support in activities of daily living. Again, it's important, we all recognize that you truly are the expert in knowing what you need each day so it's important to convey that to the people that will be providing back up.

Teren Clarke:

You also need to familiarize yourself with the COVID-19 resources specific to living with SCI and these are available from many non-government organizations as well as state and provincial governments, somewhat from federal governments, but it is customized a bit to each location so check those resources out as well. It's an emerging science and we're getting new advice all the time in terms of the best ways to protect people who live with spinal cord injury.

Teren Clarke:

Just to give you an example of an online training tool that's available, this was developed by Spinal Cord Injury Alberta. They developed an online care provider training resource that can be a resource to you and your back up care providers. This is something that I was involved with for about three years in terms of the development. Just to give you a bit of background, because I know some of you are from the US, a few of you are from Canada, but in terms of the context to why we developed this program, there's more than 5000 individuals who live with spinal cord injury in the province where I'm from, which is Alberta. We have a population of 4.41 million and we're located just above Montana.

Teren Clarke:

Life satisfaction is reported highest among community dwellers who utilize the self-managed care option of home care, which is a health services program of the provincial government. In our country, each province is responsible, each provincial government, is responsible for the delivery of home care and home care has the option to provide direct service or contract out direct service to some private agencies. It's probably, in our province, about two thirds is provided by Alberta Health Services employees and about 30 to 40% is contracted out to private home care agencies. I just thought that context might be important for you.

Teren Clarke:

Self-managed care option, which has different names in different provinces is available to persons with spinal cord injury who live at home and wish to be more involved in their community through employment, education, or volunteerism, but face a barrier when receiving direct service from home care because they cannot control the scheduling of their care that they require and that was a huge motivator in terms of developing a program.

Teren Clarke:

Home care workers provided through the direct service option work for home care or a private contracted agency and as such take their direction from the agency. This was a frequent concern that was reported to us from people living in the community with spinal cord injury. That's why they always felt that some of their care providers saw their role as working for the agency who is their employer and they wanted more control over the direction that they can give to people. So the self-managed care option, which has been available since the early 80s, allows the person to use home care allocated dollars and hours to hire their own care providers giving them control over timing and tasks. It also leaves the responsibility for recruitment, hiring and firing to the consumer. There is extra work in that regard, but again, the reports of satisfaction are just so much higher with people who are on the self-managed care option.

Teren Clarke:

Another challenge that the self-managed care program is the availability and experience of workers, particularly in smaller communities or rural or remote areas of the province. I've often heard people say they will hire any person with warm hands and they believe they can train them into a good care provider. But again, this training creates another work burden for the individuals with spinal cord injury.

Teren Clarke:

Our members, Spinal Cord Injury Alberta requested that a training curriculum be made available online and which respected the philosophy of the independent living movement. The curriculum was developed and was guided by a community of persons with lift experience including not only spinal cord injury, but other neuromuscular disorders, cerebral palsy and multiple sclerosis. Then we also had a team of healthcare experts who reviewed all of the materials and sorted the priorities for training that were identified by this committee. The curriculum was tested with in-person training sessions led by the committee members and then an IT company with expertise in adult online learning was contracted to convert the materials to an interactive and easy to use online training experience. And we will be taking a quick look at that before I'm done.

Teren Clarke:

We have SCI Alberta, which is my former employer, they have courses that are available on an online campus on their website but it can be accessed by pretty much anyone and we are looking at getting it available through a link on NASCIC's website, so hopefully make it that much easier for people to find. The courses that are currently there on that campus, there is 22 of them. Some target more people who want to work in the not-for-profit or volunteer sector industry and some, the ones highlighted in red, are the ones that were designed by the original committee. These were the priority areas for training that they identified and that curriculum was developed by them.

Teren Clarke:

Of those, we go to the next slide. Of the 22 courses, 12 are specific to that original care provider training priority. Of those, four of the courses are fairly specific to the Alberta context for care provision. Talking about roles and responsibilities of both the consumer, who is the employer, as well as the employee, the care provider. But there is eight of the courses that have generic application to persons who live with a physical disability and want more control over hiring and training of their care providers. It could be of benefit to people living anywhere in North America.

Teren Clarke:

I apologize at this point, none of them have been translated to other languages beyond English, but depending on the uptick in the future, this is something that might be possible.

Teren Clarke:

Again, just to recap the eight that I feel have very generic application to people who live with SCI and who have caregivers that they want to train. There is one skin care pressure ulcer prevention. We originally developed this fully by our committee and then it was viewed by the committee and Association of Ostomy and Wound Nurses and they really like the program. They really wanted to utilize it to provide more education to people, staff, who work in long term care facilities because of the incidence of pressure ulcers so they asked to add a section that dealt a bit more with protection from moisture. That one has been revamped a bit. But there is also one on feeding and swallowing, general safety, mental health, personal care, respiratory care, basic anatomy, and medication assistance. It covers most of the activities that people might be supported with in their home.

Teren Clarke:

We're just going to give you a quick tour and then I'm going to turn it over to my executive committee colleague, Jenn who is going to talk more about the advocacy, but just so you have an idea of what it looks like. Jessica is just going to log on to the site.

Jessica Bassett-Spiers:

Can people see the site?

Teren Clarke:

There it is. There it is. Thanks, Jessica.

Teren Clarke:

This is the home page for the online campus and it's lists all of the courses, both that are specific to care providers but also the other more generic for people who want to work in the care industry or work in the not-for-profit voluntary sector organizations. You can see there is quite a range of them. You can go in and click any course outline and download a PDF of what the learning objectives are, so if you wanted to explore this a bit more. We're going to just take a quick look at the personal care module.

Teren Clarke:

All of these modules have quizzes throughout them. You have the option of reading the information or hearing it audibly. We're going to be listening to the audible just so you have a feel for it.

Jessica Bassett-Spiers:

Sorry about that. I'm just going to quickly log in.

Teren Clarke:

You bet. I'll continue just talking about the generalities of it. You can have the option to listen and hear all the information presented, but it's very visual and interactive or if you have a hearing deficit, you could also choose to just read all of the text. The two options in terms of working through the learning program. At the very beginning, it gives you an overview of how to use the program as well as what the learning objectives are. We just listen to this quick overview, this is the same for all of the modules.

Speaker 4:

This online training course is self-paced. You can spend as much or as little time in each screen as you need and you can leave the course whenever you like. When you return to your training, the system will start you in the section where you left off. As you work through the course, you'll encounter some screens that have interactive practice exercises. These are optional activities that reinforce key concepts and offer an opportunity for you to gauge your understanding of the course content. These practice exercises do not count toward your test score and you can try them as many times as you like.

Speaker 4:

At the end of each section, there is a test. To progress from one module to the next and/or complete your training, you must achieve a passing score. If you do not pass the test, you can review the material and try again. And here's a hint, the test is different every time so please read the material carefully. When you have verified your understanding of the course content by passing the mandatory testing, you will be able to download and print a certificate of completion. This document identifies you by name and incudes the date that you completed your training. Do not worry if you forget to download your certificate, we keep a copy and you can log in anytime to reprint a copy. You may play the audio version of the program. The audio can be set to automatically play on each screen or be turned off at any time. Enjoy your online training experience and please click feedback at any time to share your thoughts about the course with us.

Teren Clarke:

We're just going to show you one module, a couple of pieces from it. We're just going to look at the learning objectives so you get a sense in terms of what we're hoping people will gain from taking this module, whether it be a family member, a friend or somebody you're recruiting and wanting to train. If you want to go to the synopsis.

Speaker 4:

This course focuses on personal care tasks including those related to personal hygiene, grooming and range of motion exercises. At the end of the training, students will be able to:

Speaker 4:

Define personal care and provide examples of personal care tasks related to personal hygiene. Recognize common bladder issues. Describe how to assist with bladder care and identify ways to reduce the risk of urinary tract infections or UTIs. Understand the personal care and hygiene tasks related to catheter use and ways to reduce the health risks associated with catheterization. Describe general guidelines to follow when assisting in personal grooming routines including hair care, nail care and shaving. Know the step-by-step processes related to hand washing, bed baths, peri care, bowel routine, catheterization, dental care, brushing and flossing and ROM exercises, lower and upper body.

Speaker 4:

Now note that this course includes printable checklists describing the steps involved in several personal care and hygiene routines. These can be downloaded at any time from within the course or from the online resource library.

Teren Clarke:

That gives you an overview of what would be contained in a module and let's just go to, let's see ... any of those you can click on. We'll just look at one of them. It goes from high level information [crosstalk 00:27:05]

Speaker 4:

Personal care refers to the things you may do to assist a person with a basic self-care tasks that are part of daily living like dressing, eating, taking required medications, walking and moving, toilet activities and bathing and grooming. Personal care may also include helping with activities that are important for functioning in the community like shopping, housekeeping, preparing meals, getting to appointments, et cetera. This course focuses on personal hygiene, grooming, and range of motion. Other online courses related to personal care include feeding, eating, swallowing and medication assistance.

Teren Clarke:

Those ones are separate modules within the online campus. Jessica, if you want to go to hand washing. We'll just view that and then we will move on.

Speaker 4:

Hand washing is the most effective way to stop the spread of infection. When washing your hands, use warm water and lots of soap and wash for a minimum of 20 seconds. Click the numbers in order to work through the steps for effective hand washing.

Teren Clarke:

If you click on one.

Speaker 4:

One. Remove rings, bracelets and watches. Wet your hands. Three. Scrub your hands, between your fingers, wrists and forearms with soap for at least 20 seconds and don't forget to scrub under your fingernails. Four. Rinse thoroughly. Five. Dry your hands with a piece of paper towel or an air dryer. Turn off the taps and faucets with the paper towel so that your hands remain clean.

Teren Clarke:

That just gives you a sense in terms of some of the interactivity that's built into the training. Many of the slides are very colorful and they try to include as many little interactive exercises as possible to help with the learning process.

Teren Clarke:

I think we can probably click out of that and [inaudible 00:29:23], I think you probably want to leave questions to the very end.

Barry Munro:

Yes. We'll do that.

Teren Clarke:

And I'll turn it over to Jenn.

Barry Munro:

Thank you very much, Teren, for that. That was excellent. Just a reminder to everybody, the reason why we put together this series and why [inaudible 00:29:41] website is mainly to share these great resources so that people in different pockets throughout North America can see some of the great work that's been put together by service providers and stakeholder groups in different parts of the continent. And as you can see, most of these things are somewhat generic. It's not like we wash our hands differently in northern Canada as we do in southern Florida. It just doesn't work that way. Hand washing is hand washing so, again, very important things that we can consider. We invite everybody that's on this webinar, at any time, feel free to email us and send us a resource that you've come across that you think is very helpful to the community that we can share with the rest and that's what we'll do.

Barry Munro:

Our next speaker is Jennifer Wolff. Jenn is a T10 paraplegic. She came about her injury in a secondary complication. She's been very active in the community for years and worked as a systems change advocate for 10 years with the User First United Spinal Program as well as being the United Spinal representative in Iowa and the hashtag Upgrade Medicaid Program. She is involved heavily with the backbones leadership program and is an author, wrote a book called, Natural Abilities. Does that sound right?

Jenn Wolff:

I have not written a book. Do not give me the credit.

Barry Munro:

Oh.

Jenn Wolff:

Naturally Able is a new e-magazine that several of us write for.

Barry Munro:

Okay, I'll take that. You're an author, that's good enough for me. Jenn's been a great advocate and a wealth of knowledge so I look forward to hearing your presentation, Jenn. Thanks.

Jenn Wolff:

Teren, that was great information, great resources and it makes me want to move to Canada. We're dealing with caregiver shortage in the United States. I want to start off with this short clip that we just released on Monday from a few Iowans talking about their problems.

Cindy Ramer:

Direct care doesn't get enough credit, I don't think, in a lot of ways. A lot of people think that it's the doctors and nurses that are handling all this. They don't realize that the direct care staff is the ones that are doing most of the hands-on work and probably taking the biggest risks. Everybody's gotten sick and none of them have been tested. They just say, "Quarantine for 14 days." Well, that leaves me with no help for 14 days.

Tucker Cassidy:

There has been a number of days where my CDAC provider. If she didn't feel good, okay, well, maybe you need to stay away for a few days so my roommate has helped out.

Cindy Ramer:

We were coming to a point where we were going to be short of staff and now with this virus going on, that has only increased the problem with the staff shortage.

Tucker Cassidy:

Those issues have always existed, but this thing has been like a magnifying glass, just focusing more and more heat and more and more intensity to the problems that we already face, the issues that we are already facing.

Cindy Ramer:

This week it's been an hour a couple of days a week with the bath aid that's been helping me and the nurse.

Tucker Cassidy:

It's making it harder for the caregivers to feel like they can keep providing care because they don't want to be exposing themselves, but it weighs on me to have to think of, "gosh, my mom is coming up here again." We disabled individuals then, because we depend on them, then falls onto us as to the ultimate ... we're the ultimate sufferers of what kind of havoc this can wreck.

Jenn Wolff:

That's my little group in Iowa and very proud of them. It's time that we talk more about systems change and advocacy. I'm getting ahead of myself in the whole, but self-care and care giving is a huge deal across the continuum, across ages, across disability, and caregivers aren't getting paid enough. There's not enough respect in the job, there is hardly any incentives. There are several ways to get involved. Easy ways to do it, in the United States is Caring Across Generations, which is a great organization. It includes membership from the National Domestic Alliance Workers and they are doing several campaigns. You can sign up to be a member, encourage anybody to become a member of this, family, friends. It's about getting policy changed so people get increased pay. They get tax cuts for being a caregiver. There are many, many components to it. That's one way.

Jenn Wolff:

Share the hashtags, if you're on social media. That's a great way to bring more attention to those issues too, especially if you're a storyteller and are willing to put yourself and two or three sentences about what you're experiencing and put #careforall, because any time anybody searches that, including politicians, those stories will get brought up.

Jenn Wolff:

Another option, and the best option right now in the time of COVID is the Partnership for Inclusive Disaster Strategies. I put just a clip on there. Systems Advocacy, if want to go back a slide. The clip that says, System Advocacy Tools, they have a whole list of ongoing advocacy items since the beginning of March, so you can find any group, any specific issues that you are dealing with, you can find something there, whether it's being hospitalized and not having a caregiver being able to come visit you, whether it's lack of personal protective equipment, whether it's the caregiver shortage, there is something in there for you to act on. They have an 800 number, if you are experiencing difficulties with getting any of those things including care, they are the people to call. The 800 number that covers as wide of the country as possible.

Jenn Wolff:

And again, other options are United Spinal Association, the Centers for Independent Living, just knowing who to call and when and advocating for yourself so you don't get sick or suffer, there's no reason to. The thing I'm most excited to share with you today is, and we are in partnership with the Partnership for Inclusive Disaster Strategies as well with the project, is ... there are three of us and I'm an OT with a disability, I'm a wheelchair user as well, three of us came together and thought why isn't the American Occupational Therapy Association encouraging all those students that didn't have field work or therapists that are furloughed to help out with this caregiver gap. And hoping to have some long term systems change to come out of it when they see the disparities that are going on, but I'd like to show the video that kind of explains what the program is.

Speaker 8:

The fact that I never thought that something like this would happen to me. Dealing with a pandemic while being an occupational therapy student was not one of the things that I feared being, but here we are worrying about a pandemic, getting sick and dying. Becoming an occupational therapist is always been something that I've wanted to do. I've worked hard to get to where I am, but because of this COVID-19 pandemic, all of us occupational therapy students have either been sent home or we have to participate in Zoom classes. My main concern is my level one fieldwork.

Speaker 8:

Level one fieldwork is about hands-on experience. All the fieldwork experience in the hospitals, schools, longterm care facilities, they've all mostly been canceled for fear of the coronavirus. So it's terrifying to think that we set these goals to accomplish by a certain deadline and now we're getting pushed back because we can't attend school.

Speaker 9:

I'm a quadriplegic and I rely on a personal assistant to help me with transfers and other activities around the house in order to be independent and to work and engage in the community. It terrifies me to think that if my personal care assistant doesn't come that I'll be stuck in bed and unable to do anything. I won't be able to work, I won't be able to go to the grocery store, I won't be able to do any of the things that I need to do. I really need to make sure that the personal care assistants are available. During COVID-19, the crisis is even more fearful because I don't know if they show up, are they going to be safe to show up. Are they going to get called away because they have to take care of their kids? Are they going to have personal protection equipment? I just don't know.

Jenn Wolff:

I have a spinal cord injury and I'm a board member with the Iowa Chapter of United Spinal Association. The personal care attendant and DSP shortage has had devastating effects across the country. One of our members couldn't take a shower for over 13 days because she didn't have enough personal care assistants and another one is trying to heal from a bed sore and has gone without care for two days. When I talk with other leaders in the disability community in other states, they all have similar stories to tell.

Speaker 11:

I am a mom of a child with special needs. During this pandemic, with two of them home, homeschooled my child, take care of the household and tried to give my child the structure that she needs. She needs a lot of my attention and her self-destructive behavior just doesn't allow me to get things done. I wish I had some help for her. She needs the structure that I just can't provide.

Jenn Wolff:

Our project addresses the needs of these community dwelling people with disabilities and older adults and children with disabilities who are all in crisis because the COVID-19 pandemic has left them without the reliable assistance they need. We'll match them with occupational therapy students who are also in crisis with the help of our partners, national, state and local disability advocacy organizations and academic occupational therapy programs from around the country.

Jenn Wolff:

The occupational therapy students, and in some cases, occupational therapy practitioners who have been laid off because of the COVID pandemic will provide services and supports in the personal care assistant direct support professional roles. This will promote independent living and help community dwelling people with disabilities and older adults avoid going to our care facilities with their current high COVID-19 related mortality rates. Further, this will contribute to the culture of health by facilitating the students learning about self-directed care from the perspective of the person for whom they provide community-based services, thus seeing people as people first, not patients, while at the same time meeting their own crisis need for a level one fieldwork placement.

Jenn Wolff:

That is our hopeful plan. We are still working on the logistics and working out things with the Centers for Independent Living and how to connect these different groups, but the first group is the TAP, which is more the occupational therapy volunteers and those that have been furloughed to volunteer their time and interest in filling in for caregiver positions and again, it depends on each state and each region, but there is a Facebook group specifically for that and then there is a TAP partners group which I invite any of you to join, if you'd like. That's the next slide.

Jenn Wolff:

The TAP partners, and again, we're working with the Partnership for Inclusive Disastrous Strategies so as an individual, call that number and they will connect you with the TAP Program and we will try to find OTs in your state or near you that might be able to help. We're just more of a network trying to figure out how to get both parties to work together, but anybody is welcome to join the TAP partners to share this information as well. It's time for the system to change and to ... it's a win/win for both groups, which is really exciting because we get to train some of the OTs on self-directed care and how to see people as people from day one of their education process and in hopes that they will be able to help join in our advocacy efforts to get some of these things changed including care workers getting paid and reimbursed better.

Jenn Wolff:

I just wanted to end on the fact that when we speak up together and share our stories even though it's hard to be vulnerable, it's hard to put yourself on camera, it's never been more important to share your stories of how COVID and the caregiver shortage is impacting you in order to get policy changed because these are policies that are being decided right now, so it's an exciting time. And if anybody has questions and wants to know more about how to go about that, feel free to contact me.

Barry Munro:

Thank you so much, Jenn, that was excellent. And Teren, great presentations. Again, I apologize, Jenn. Jenn is an occupational therapist, I didn't give you your credentials going into this.

Barry Munro:

Is there any questions from the audience?

Barry Munro:

There's a few things in chat that I did see. I just wanted to, from an administrative point of view, all of the links and resources that have been available in this presentation will be found on our NASCIC website and then you'll also all get an invite to see the final version of the produced version of the webinar that you can share with others as well as the resources that will be listed. Again, we encourage you to share that so much that we also have our staff look at sharing this information on the Facebook, for example, that you mentioned too, Jenn, so that we can bring this information both into your group and back out again so that they can see this.

Barry Munro:

There's Jenn's email if you want to directly contact her, just go into the chat and find that.

Barry Munro:

There was a question that I saw come up a few times, it was asked in the past and I'll ask this to both of you. How do people deal with a shortage in PPE? What are you hearing out there?

Jenn Wolff:

We've gotten a grant through United Spinal and it's hard to find, even to buy. Gloves, we've actually ... I have a friend that's a farmer that has an easier way to get gloves and she's sending me some gloves because everything is being sent to the hospitals and facilities.

Barry Munro:

Teren, what are you hearing about PPE supplies? I know that you have a closet, cottage industry yourself right now in helping people.

Teren Clarke:

Initially there was a real concern from people living in the community that their caregivers wouldn't be provided enough PPE nor would they perhaps have access to it if they wanted to be venturing out in the community. A number of volunteer groups quickly got into the business of making cloth masks based on the best patterns that were available on YouTube and they had a combination, but right now in our province, there seems to be enough masks, gloves available for self-care attendants and the cloth masks are sometimes being used because they are starting to sterilize the masks that are provided by the healthcare system. They are encouraging people to wear cloth masks over top of the N95 and the N91 masks that are pretty common and then they can be turned in and sterilized and then apparently reused. And of course, the cloth masks go directly into the laundry.

Teren Clarke:

There is some videos available to help people appreciate the appropriate way to put on their masks, how their caregivers should remove their gloves and dispose of them. I didn't get into those resources that are available, but those certainly can be posted on the NASCIC website. They are available right now through a network in Canada, through SCI Canada as well as a network that involves a lot of the [inaudible 00:50:08] and therapists that are involved in care.

Barry Munro:

Thank you. I guess the challenge out there is getting our attendants and people providing care services to actually properly use the PPE and really it's incumbent upon us as individuals to do so. I assume that there is some challenges out there. I've heard anecdotal stories over the last couple of months of people really having a hard time getting people to abide by the higher standard of cleanliness and keeping clean for these bookings when they come into our place. I do notice and it was mentioned in one of the chats that some people, what they have done, is they've eliminated the potential of more people bringing in the possible infection in that they are limiting their care itself too. They are trying to limit it down to either family members or an individual as opposed to four or five people that might be coming over a week.

Barry Munro:

Have you heard about people talking about aligning their schedules that way, Teren or Jenn?

Teren Clarke:

There has been a lot of strategies put in by the different provincial health care systems in terms of rules for care providers who are employed by agencies or by Alberta Health Services, for example, limiting the number of contacts that they can have. They've become very strict with the longterm care facilities because like many places that's where the greatest outbreaks have been here in Alberta, our longterm care facilities and our meat processing plants have been the biggest sites for illness and spread.

Barry Munro:

I should mention too, everybody, as we're going through this pandemic, one of the things that we will address later on in the webinar series is what the new normal is going to be like as people in the community that, they talk about reopening different states and provinces and getting back to business, but what does that mean for us with spinal cord injury and our risk, especially quadriplegia and what we're going through. This is an issue and I know these [inaudible 00:52:30] figure out. But again, we're going to address that later on.

Barry Munro:

Is there any other questions out there?

Teren Clarke:

Barry, I put a couple of other [inaudible 00:52:44] I wouldn't mind sharing with the group here today. Again, really important. Care may be working well for you today, but it doesn't mean it's not going to be a problem in the future. Create your plan, document your contingency plans for care. Train your backup care providers and be prepared to implement the contingency on very short notice. I think it's really important, I've been following the COVID literature on a daily basis and it really strikes me, it's really important for people with spinal cord injury to pay attention to the emerging science because it's really recognizing that presenting symptoms for people with spinal cord injury look different for what it would for me. I'm in a high risk demographic because of my age so I've been watching that, but of course, people with spinal cord injury are in a high risk demographic because of the many different system compromises that a spinal cord injury creates.

Teren Clarke:

Stay in touch with your healthcare team, especially the ones who are expert in spinal cord injury and make sure that you're availing yourself of the knowledge. And again, take your knowledge from the experts, not the politicians necessarily.

Teren Clarke:

Try to stay healthy and follow those recommendations by those experts in your community, because it does look a little bit different in each community, the challenges are somewhat different. I hope everyone stays well.

Barry Munro:

Thank you. I did want to apologize again for us not making the polling option available. It was a Zoom glitch for us, but we will do so in the future. You'll see that. But by all means, you know how to get ahold of us. What we want to do, again, is encourage people, Jess, if you can go to the next slide, to really reach out and try to become a member of our organization. It's free. The reason we say that is, the more people that we have connected from all walks of life and depending on who they represent, they could be a family member, they could be an executive with a stake holding organization or they could be an individual with an injury that just wants to get more information or even provide some, your all so much important to the movement, so to speak, in our community across North America. We do ask you to really think about joining as a member just so we can have you in the loop and we can contact or you have the information. You don't ever have to open an email from me, if you don't want to, that's fine.

Barry Munro:

The idea is that we can somehow get into all corners of North America and share some of the great stories and, again, some of the real true heroes out there and what they've done and how they've learned and coped to survive and how they've helped others, but it's been very, very important that we share our information and work together. We're not a large group, but we can be mighty if we want to be. So I do, again, urge you to join the NASCIC and NorthAmericanSCIConsortium.org and then membership. Just click on there and it's real easy to do. It takes about 15 seconds, something like that. That's all I'm going to say.

Jessica Bassett-Spiers:

I was just going to let everyone know that once this video is completed and up on the website, that I will be sending out a link to everyone who registered today.

Teren Clarke:

You're welcome, Jessica, to put my email contact information there if people have questions about the online training program.

Jessica Bassett-Spiers:

Yep. Okay, great. We'll do that as well.

Teren Clarke:

I tried to put that in the chat, but I think it only went to one individual, not whole group.

Barry Munro:

We're all learning how to Zoom, aren't we? Thank you, everybody, for coming onboard. Please let everybody know about the upcoming webinars every Tuesday at 4:00 pm eastern time. We'll be on the air and what we'll have also, next week is a special presentation, it's going to be all in Spanish for our Spanish brothers and sisters that really, we want to make sure that they message is communicated to all walks of life and in different corners of this great continent that we live in. And there's even a possibility of continuing this on into French going forward. Everybody, have a great night and I look forward to hearing and seeing you soon.