

2023 KT Online Conference: Relationship Building

Presenter:

Scott Donia, Ana Paula Salazar, and Sabrina Tonima

Sponsored by AIR's Center on Knowledge Translation
Disability and Rehabilitation Research (KTDRR)

<https://ktdrr.org/conference2023/index.html>

Transcript for audio/video file on YouTube:

<https://youtu.be/3tSjfHI96oQ>

FELICE TRIROGOFF: We are ready for our final panel for today on relationship building, and it's going to begin with Scott Donia presentation, Reflections on the BC Interior Spinal Cord Injury, or SCI, Health. Scott, could you join me on camera, please?

SCOTT DONIA: Hi, everyone.

FELICE TRIROGOFF: Excellent. And Scott Donia is a knowledge exchange lead at Praxis Spinal Cord Institute. Scott, are you ready? And don't forget to self-describe, please.

SCOTT DONIA: Yes, I am. Thank you. Hi, everyone. I'm Scott Donia, and I'm a white male with short dark brown hair, a bit of stubble, and a disgusting mustache that I'm growing out just for Movember, just in recognition and awareness of men's mental health and cancer research. I'm also wearing a green and white plaid shirt.

Just wanted to start with a land acknowledgment. So Praxis Spinal Cord Institute and where I am in Vancouver, just acknowledging that the land that which we are currently located on is the unceded traditional territory of the Coast Salish peoples, specifically the shared traditional territories of the Squamish, Tsleil-Waututh, and Musqueam First Nations. And just wanted to show gratitude to be able to live and play and learn on these areas, and just ask others to try to learn about it themselves.

So a little bit of what I wanted to speak about today was providing some background information on spinal cord injury and how we got to the lead up to the summit in itself, what the goals and expected outcomes of the event were, and some of the reflections that we have afterwards once we've actually had it. So anyone that was actually at the early morning of the day 3 with the Shirley Ryan AbilityLab did a great job of explaining spinal cord injury in itself.

But just for those that weren't and just to reiterate, is that spinal cord injury is highly specialized. Everyone that's affected by it is affected differently. It's highly complex, and there's many secondary health complications as a result of it, so that can lead to difficult care. And it's also low incidence as well, so it makes it that much more complicated at times.

And so after a spinal cord injury, care following that injury typically happens in urban centers, so those major regions in Canada. For instance, for here, it would be in Vancouver. And there's limited knowledge

and resources for those living with spinal cord injuries within those rural communities or anywhere outside of that.

And typically after their injury and when they are shipped home, then people are forced to travel long distances to go back to Vancouver because that's where all the knowledge is based. Sometimes they have to relocate to have that access to specialized care. It can definitely be very problematic for both time and resources as well.

And so from that, I just wanted to show a map of British Columbia in itself for those that aren't too familiar, and broken up into the different health regions as well. So in the bottom left hand corner with the brighter green is where Vancouver is located, and then so that typically is about 30% of urban population located in that region. And everywhere else is that 70%. And specific that I wanted to talk about today is the purple side of the Interior Health, which is 16% of the population.

And so with that difficulty of all these different things of limited knowledge in rural areas and travel, really we were seeing that there is this need for education for those local areas. And so what we wanted to start with was really asking People with Lived Experience, or PLEX, and clinical clinicians, so like for physiotherapists, occupational therapists, doctors, nurses, et cetera, what their priorities were in terms of what they wanted to learn and what they thought was important to the spinal cord injury population.

So we sent out this survey, and really the big difference that we noticed was that there's a big discrepancy in what people with lived experience thought and what clinical-- what the clinical population thought as well. And so really, the top five that you can see is the bowel management, pain and inflammation, spasticity, bladder management, and sexual health. Three of those five are actually in the very bottom for the clinical perspective, so really that big discrepancy was showing that we need to educate a little bit more to get everyone back on the same page.

And so from this, we created educational workshops that were led by an occupational therapist and person with lived experience, because those needs weren't being met. So what they did was started creating these workshops within the local Okanagan area, so within the interior, and doing these workshops for clinicians. That was partnered with PLEX always having some perspective as well and being able to speak on different topics, such as just the basics of spinal cord injury, bowel and bladder care, a family perspective as well.

And so that was just the start of these education that we were trying to bring towards the interior. And now, we wanted to do that because it's been very successful, is that we wanted to bring everyone together, so not just clinicians, but people with lived experience. We wanted to bring those from the government. We wanted to bring industry together, just so that we could all have a say and just really see what's important to everyone and build those networks as well.

And so like I said, it's really building off the success of the Interior workshops, and we had this one day hybrid meeting, both in person and online, on Monday, September 25 within Kelowna, BC, so part of the Interior. For those that aren't familiar with Kelowna, it is closer to the Alberta border actually. It's a beautiful city, mountains, water, but it is still within that regional side.

And so like I said, we wanted to bring together all those stakeholders. We wanted to be able to learn from everyone. We wanted to share those experiences and really build those connections within everyone just to support SCI health within that interior region. And so the topics that were really discussed by all these different stakeholders that we really wanted to learn about was sexual health, and then healthy aging and how that related to pressure sores, bowel and bladder considerations. And then a larger discussion for the future in terms of what we need to focus on as different organizations in order to improve health care the best that we can do.

And so we had some wonderful speakers from diverse backgrounds, people from clinicians from Vancouver, people with lived experience, and researchers from the northern part of BC, researchers from the Interior itself. And what was really important was that for every single topic that we had, we had someone with lived experience really showcasing what they wanted to discuss and what their experiences were. And then we also had a PLEX panel just to really showcase it that much more.

And so the goals of this was trying to facilitate the development of a network among these SCI clinicians and people's lived experience. So to link both just the Interior itself and to link it with where those resources are located within Vancouver, we wanted to provide education about sexual health and aging of those different topics. And then we wanted to further identify where there's gaps and where there's needs to facilitate that knowledge exchange to implement best practices throughout the area.

And so to start, we used this online thing that you can use, an online program called Slido, which allows for in-time questions, questionnaire asking, and you can create word clouds like this. And so what we wanted to start with was, in one word, what do you hope to take away from today. So just wanted to show that result, and knowledge and connections are really the top ones that showed up. So really showcasing that people wanted to learn, and they wanted to create those networks within it as well to be able to rely on each other for that information.

And so how did it go? I think for the first time of us actually doing this, it went really well. We had actually 75 people in person that signed up, but at the door 20 people also showed up. So at times, we counted 95 people in person, and we had about 70 people online with about an average of 50 for most of the time throughout the day.

And we had everyone. We had about 50% of the people there were clinicians. We had about 30 people with lived experience, people from different health authorities and industry as well. Everyone was really well represented. And what we were really trying to discuss besides all the education is focusing on something that we can do, so actionable outcomes and what learning resources are there, and what needs to be created as a result.

And so kind of what happened? What was the outcomes of this? And we saw that there's going to be improved communication and resource sharing between both Vancouver and within the Interior in itself. What was spoken a lot about within the Interior is that they didn't even realize that these resources were available, so making sure that people were aware and how best we can share this in the future,

enhancing the knowledge so people did learn afterwards a little bit more about these different topics, a lot more comfortable in discussing, especially within sexual health.

We were able to see where there might be some gaps, barriers, and perspective within Interior Care and what can be done. And from this, we're working on creating a report in order to share the results of the summit in itself and what we can do in that action-oriented practices later on and then within the partners.

And yeah, generally, it was a very positive experience. Everyone really enjoyed learning, being able to connect. We had a social event afterwards, and I would say 80% of the people that were at the summit stayed for it. And you were able to have both a bit more informal conversation, and you're continuing these education late into the night, so very positive.

But with everything, there's going to be things that you can improve on for next time. And so I just have some very basic images here but that I can elaborate on, and we needed more of everything, so definitely more space. I think, one, thinking that 75 people are going to show up and then 20 more people show up, things were a little tight, especially with people with wheelchairs that do limit the space available, so definitely hosting it in a larger area.

Secondly, more time. I think we wanted to pack in as much as possible, but that did limit a lot more time for discussion that we really wanted to focus on. So having more time, whether that be over one or two days, or just focusing on a few topics and really having larger discussion points the entire time.

And then with everything, even in this post-COVID world, is the audio visual wasn't always the best for the online component, as well as the microphones that were working for the in-person. It could have been a little inconsistent, so different things to be able to test out maybe a little bit earlier and just to be able to problem solve as we went through. But all in all, it was an excellent time.

And so what does success look like in the future? Really, it's continuing to share that knowledge, advancements within community support from the British Columbia SCI Care Strategy that's being worked on. We want to make it sustainable. We don't want just to go and have the summit and leave, so being able to create those networks and continue that conversation. We want it to be sustainable.

And then we want to evaluate. So like I said, we're going to do that report, so having that publication of the meeting themes and outcomes and really something that we can keep going back to and make sure that we are making that difference, and having that discussion and opinions from everyone that was involved, and all those stakeholders having their opinions shown. And I'm happy to take any questions for later. Thank you.

FELICE TRIROGOFF: Great. Thank you. Thank you, Scott. Next, we will hear from Ana Paula Salazar, who will be presenting "Working with Community Partners and Ensuring Meaningful Results: Lessons Learned from a Two-Year Pan-Canadian Academic Community Partnership Project."

As a quick bio, Ana currently works as a postdoctoral researcher in the Rehabilitation Science Program at the University of Montreal in a Pan-Canadian community-based research project to enhance disaster preparedness of community brain injury associations. Ana, are you ready?

ANA PAULA SALAZAR: Yes, I am.

FELICE TRIROGOFF: Perfect. And please don't forget to describe yourself. Thanks.

ANA PAULA SALAZAR: Sure. Hello, everyone. Here is Ana Paula Salazar. I am a white woman with blonde, shoulder-length hair. I am wearing glasses and a white shirt. I am delighted to be here today talking about this work that is aimed to improve preparedness in brain injury associations across Canada. Sorry, I was trying to find the control here.

To give you a quick overview of what I will talk about today, so I will start talking about community-based participatory research and why is it important. And then I will move on to the Brain Injury Pandemic Preparedness project, and I will show you some of the outcomes of this project, some of the challenges, and successes. And I will finish talking about the lessons learned.

So community-based participatory research uses a collaborative approach, involves community and academic partners equally in the research process, while recognizing the unique strengths that each one brings. It has research topics that are relevant to the community. It combines knowledge with action and achieves social change to improve health outcomes and eliminate health disparities. It also brings a diversity of experiences and perspectives that are needed to create evidence and develop appropriate approaches when addressing the needs and well-being of vulnerable populations.

So to give you a concrete example of what is a community-based participatory research, I will talk about the Brain Injury Pandemic Preparedness project. This is a two-year Pan-Canadian community-based participatory research that arose at the beginning of the COVID pandemic from discussions between stakeholders and researchers about challenges that community brain injury associations were facing with the pandemic.

Our team of researchers and executive directors of brain injury associations across Canada involves three co-principal investigators, including two researchers. One is a professor at the University of Montreal, Carolina Bottari. Lisa Engel is a professor and a researcher at the University of Manitoba, and Michelle McDonald is the executive director of Brain Injury Canada. This team is composed also of nine researchers from different backgrounds, including neuropsychology, occupational therapy, physiotherapy, and others, and six executive directors from brain injury associations across Canada.

This Canadian map is just to illustrate the broad representation of the team. In blue, you can see the researchers. In green, we have the community partners. And we have people from British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, and Newfoundland, and Labrador.

So the idea of this project was to bridge the gap between research and community-based brain injury associations. So all the team was involved in all the steps of the project. Since day zero, we worked

together to design the research questions, to write the grant application. We had a core team meeting that managed the steps of the project, and we decided to divide the team into four different small committees.

So we had two committees that were responsible for data collection and data analysis and interpretation of-- the interpretation of findings were actually, we discussed together all the findings. And we also had one committee that was responsible for knowledge translation and the other committee that was responsible for networking.

So the main aim of this project was to optimize community brain Injury associations' care system in the context of COVID and future health crises. We wanted to understand the effects of the COVID pandemic on brain Injury association services. We also wanted to increase networking among these brain injury associations and to develop resources to help brain injury associations in case of a future health crisis.

So this project was funded by the Canadian Institutes of Health and Research. It was a two-year project, as I mentioned, and it was a unique large-scale multi-step virtual research project based on a co-construction model that included three steps. But before, I think it's important to mention that in Canada we have around 70 brain injury associations, and the participants of this study were key representatives of brain injury associations, who had knowledge about the challenges and adaptations the brain injury associations were doing during the pandemic.

This project had two parts. So the first part was an online survey, where we had 45 participants that responded to 29 questions. We also had a co-creation part that included 31 participants, and we had two focus groups and two town halls. And these town halls helped us to develop an online tool. That was the main outcome of the project, and I will talk about that later.

So unfortunately, I will not have time to talk about all the outcomes, all the results of this study, but I brought some points to mention. So we created useful and impactful resources for brain injury associations, with brain injury associations. Oops. OK. So these are the knowledge and mobilization documents that we developed based on the first phase of the study, the survey part of the study. So here, we have an infographic, a report, and a one pager. These documents were developed in both languages, English and French.

We also developed these other documents that are related to-- that are related to the focus group, so the focus groups results. One focus groups were, we focused on the first year of the pandemic. The second one, the second focus group was related to the second and third year and beyond. So these documents were made for brain injury associations, and I'm sorry if they are not very clear here. And all these material are also available in English and French.

We also published the results of our project in the local newsletter of brain injury associations in Quebec. For the scientific crowd, for the researchers of the team, we also published two scientific papers, one about the survey results and the other one about the first year, the early effects of the pandemic on brain

injury associations across Canada. And we have two more coming up, so it has been a very productive project so far. If you want to have access to all these documents, please reach out to me at the end, and I will be happy to talk with or to share them with you.

So regarding our objective of strengthening networks, as I mentioned, we developed with the participants an online portal that were developed to help them to network. So the name of the portal is Canadian Brain Injury Association Network. And this portal was launched last month and is a platform that works with login and password, where staff and board members can find more about the BIPP project. You can find out more about the BIPP project.

They can have access to tools and resources that will help them in case of a new crisis, a new health crisis. So they have resources related to meeting the needs of clients, resources related to public health safety, and resources related to sustainability of the associations. They also have a place where they can see the events that are happening across the country. They can also ask questions and answer questions in network with other brain injury associations in a forum part of the website. And they can also find all brain injury associations across Canada.

So the lessons learned of this project, I need to talk first about the challenges and the successes. So here you have the bilingual part and the online part. These were both either. They were a challenge but also a success because it was very rich to perform a bilingual project with bilingual focus groups and documents. And we wanted to include everyone. As Canada has this characteristic of having two official languages, we wanted to include all the countries.

So it's a Pan-Canadian project. It's a Pan-Canadian project. So this was a success, but it was also a challenge because we always needed to translate, to have someone translating the documents. And all the focus groups were bilingual, so sometimes it was difficult, but it's also a success.

The online characteristic of the project was also difficult. And we all know that with the beginning of the pandemic, we needed to move to online. At the same time we lost physical contact and all the body language that we miss when we are performing focus groups and town halls, we were able to bring people from across the country to participate. So this was both a challenge and a success.

Another challenge we had was the pandemic itself because it is mixed comments. I think it was a very hard moment for everyone, so sometimes it was very difficult to-- it was the subject of our focus group, so sometimes it was difficult to talk about it. But we did it.

The other challenge was the ethical delays that we are very used to in research. But with the pandemic, it was even worse. As researchers, we sometimes have difficult to communicate in a lay language, so it was a challenge at the beginning to develop all the documents in a lay language to give to brain injury associations.

And also, to match the schedules-- sorry-- of everyone was not easy at all because Canada also has different time zones. So this was not easy, but at the same time, we had full engagement of the researchers and the community partners. Everyone was very engaged. We had frequent meetings with

the core team and the full team as well as with the small committees, as I mentioned. We used to meet at least once a month, and so we learned a lot with each other. And as a result, we were able to empower brain injury associations.

So to finish my presentation, I will just talk briefly about the lessons learned of working with community partners, so of performing a community-based participatory research. So the importance of networking, it's very important to increase our collaboration, either between us researchers, but also with community partners, users. So this was very rich, and I think this is a very important lesson learned.

Also, diversifying ways to partner and participate. Sometimes we cannot attend to a meeting, or we cannot perform that task that was given to us, but we can diversify. We can try to be involved in another way, so trying to be flexible, that's the next point. So flexibility, adaptability, trying to talk about our expectations, and then enter the value of communication. So it's very important to talk about what we expect of each person, what will be the role. And then it's very important also to hear about each other. So I think our team was very successful regarding to that.

So to finish, I have here two quotes. The first one is from Michelle McDonald, who is the executive director of Brain Injury Canada. So, "This project has brought brain injury associations together and served as a catalyst to move toward networking and resource sharing. Building a stronger network means a stronger voice, empowerment of associations, and recognition of their work."

And another quote from a researcher that is also a professor at the University of Toronto, Shlomit. So, "This project was very interesting. It filled me with energy to think that there is more of a chance that the research will have an impact. That it's more tangible than other research work that I do sometimes."

So thank you very much. And I will be glad to talk more about this project and to answer any questions you may have.

FELICE TRIROGOFF: Thank you, Ana. And I loved your part about valuing communications. As a communications specialist, I wholeheartedly agree. We've come to our final presentation of the day from Sabrina Tonima on "Accommodating and Communicating about Episodic Disabilities." Sabrina, are you-- there you are.

Sabrina is a knowledge transfer and exchange associate at the Institute for Work and Health, an independent, not-for-profit organization based in Toronto, Canada that conducts and shares actionable research to promote, protect, and improve the health and safety of working people. Sabrina, are you ready?

SABRINA TONIMA: Yes, I am.

FELICE TRIROGOFF: Perfect. And please begin by describing yourself. Thank you.

SABRINA TONIMA: Thank you, Felice, and happy to be here, everybody. My name is Sabrina Tonima, and I'm a Brown-presenting woman with short black hair, wearing a black shirt today. And today, I'll be

talking to you about one of our research projects that we're calling "Accommodating and Communicating about Episodic Disabilities," or ACED for short.

Felice has already given you a little bit of an idea of what it is that we do at the Institute for Work and Health, but to sum it up, we conduct and share actionable research to protect and improve the health and safety of working people and promote their full and inclusive work participation. Our research is in two broad areas, how work impacts health and how health impacts work.

Now, due to the nature of our research, we work very closely with both academic and non-academic stakeholders. So our non-academic stakeholders include people that identify as workers, employers, and policymakers. And we involve them to ensure that our research is relevant and it's something that they would actually use.

I think it's important to talk about our approach to Knowledge Transfer and Exchange, or KTE, before I start talking about the ACED project, because that really laid the foundation of the partnership aspects of the project. There is a strong cultural acceptance at the Institute for Work and Health and recognition that KTE is important. It is a core part of the IWH mandate and our strategic plan, and there are dedicated resources for KTE planning activities, such as stakeholder engagement as well as dissemination of research through easy-to-use communication outputs and channels.

So ACED is a five-year project that brought together researchers and community partners to develop evidence-based workplace tools and resources to support the sustained employment of people who have an episodic disability or health condition. Now, for those of you who may not be familiar with an episodic disability, ACED defines it as long-term or chronic health conditions that are characterized by periods of good health interrupted by periods of poor health. Some examples of episodic disabilities or health conditions include arthritis, anxiety disorders, depression, Crohn's and colitis, chronic fatigue syndrome, multiple sclerosis, and others.

So because episodic conditions are often unpredictable and invisible to others, they create unique challenges in managing workplace disabilities. But given how common they are, workplaces are becoming more and more aware of the need to support employees to ensure that they can productively remain in the workforce. On the other hand, workers, too, are seeking guidance on how to manage their episodic health conditions and keep working.

So based on this, the ACED research team sought to address three questions. How do we help workers get support while respecting their privacy and desire to not share a health condition with others? How do we help workplaces implement an approach to assess individualized worker job needs? And where can workers and workplaces get support and accommodation ideas?

So based on these research questions came the idea of developing a tool kit that would help someone who has identified that they have a problem or a support need, and they're looking to primarily answer two questions. Should I say something at work? And what can I do at work? Now, in an attempt to address the question, what can I do at work, the ACED team developed the Job Demands and

Accommodation Planning Tool, or the JDAPT. And in an attempt to answer the question, should I say something at work, we are currently working on a Communications Decision-Support Tool.

Just so you know, the JDAPT has been launched officially in March 2023, and it has become very popular. Since then, we've had over 6,000 downloads of the tool and interest from several countries outside of North America. And if there is some time, I would give you a little bit of a glimpse of the JDAPT and the Communication Decision-Support Tool. But for the bulk of this presentation, I'll focus on the partnership and relationships that benefited the ACED research team.

So ACED was funded as part of a joint initiative by the Social Sciences and Humanities Research Council of Canada and the Canadian Institutes of Health Research. It's called the Healthy and Productive Work Initiative, and these are two federal research funding organizations in Canada. We also received some additional funding from other sources. It has a large interdisciplinary team that focuses on the research methods. That really was the building block of the tools that were developed.

This team also includes communications experts as well as knowledge transfer and exchange associates. On the other hand, we have multiple partner organizations that are involved as well as an advisory committee of people who have lived experiences of episodic health conditions. And I'll tell you a little bit more about them later on in the presentation.

So it's very clear to us now that we're getting to the end of the project that this project would not have been successful without its partnership aspects. But what had actually pushed us to build partnerships in the first place? Now, the initial impetus actually came from the grant requirements. The Healthy and Productive Work Initiative had sought to support the development, implementation, evaluation, and scaling up of evidence-based interventions, and it required grant recipients to work with non-research stakeholders to co-develop these interventions.

This grant was awarded in two phases. So there was an initial two-year phase where we got to develop these strong partnerships, followed by the five years of funding that was really focused on tool development. So at the beginning stages of the grant, one of our KTE associates worked very closely with the project director and coordinator to identify and reach stakeholders by networking with previous contacts and cold calling organizations who were at the forefront of progressive thinking about workplace disability policies and practices.

Then, there were individual meetings set up with these interested organizations to help determine the scope of their support. Some of these partners actually submitted a detailed letter of engagement at the grant stage. So eventually, we ended up with nine partners from health charities and workplace-focused organizations. We had organizations such as the Arthritis Society of Canada, MS Canada, Realize, which is an organization in Canada that focuses on patients who have HIV/AIDS.

We had mental health groups. We had Crohn's and colitis. So there was a wide range of episodic conditions represented by these partner organizations. We also asked for two representatives from each organization to ensure that we would continue to have representation if one of them happened to move on career-wise.

We also created an advisory committee in 2021, which was comprised of five people with lived experiences of episodic health conditions and disabilities. So there was variability in the health conditions that was represented by them, variability in age, gender, and the job tasks that they performed day-to-day. A stipend of \$500 per year was provided to these committee members to compensate them for their time on the committee.

So what were some of the key partner contributions to this project? I would say, first of all, during tool development, these partner organizations really helped us recruit study participants, because they work directly with patients or people who have episodic health conditions. They provided a lot of input on the questions that we had proposed at the beginning stages of tool development. And then once the tools were drafted, they provided detailed line-by-line review of the draft. And we actually ended up making several changes to the tools based on their input.

They also provided us with very important advice regarding privacy and how privacy is perceived by people who have these episodic health conditions, what some of their concerns might be. And they gave us practical advice, such as where to put the tool on the ACED website, which is something that we had struggled with for a little bit.

Our partners also took part in the ACED knowledge transfer and exchange committee. They provided input during website creation, logo and tagline development of ACED. They also made us aware of opportunities to promote ACED activities and tools.

One of our partner members, partner representatives actually advised us to include people with lived experience throughout the development of the tool instead of just at the end stages where we would test the tool. So that's how we came to create the expert advisory committee. And they had also provided us with the advice that we should offer a stipend to compensate these folks for their work. It's probably not something that we would have thought of otherwise.

Some of our partner organizations provided cash contributions. And one point that I forgot to put on this slide is that they're now helping us disseminate the JDAPT tool. They have it hosted on their websites. They are talking to their patient groups about the tool, so they have been instrumental in the tool dissemination as well.

So while ACED has benefited greatly from these partnerships, there were some challenges and lessons learned. Firstly, communication with partners was crucial. Because this was public funding, we had to clarify at the very early stages that these tools would be free. If we hadn't had that conversation, this could have resulted in a conflict with some of our partners who have a fundraising agenda, and they tend to package tools like this and sell to employer groups. But because we ended up having these communications very early on, everybody was on the same page.

Some of our partners actually went ahead and developed their own resources to address needs within their patient communities. And we had frank conversations where we acknowledge that, yes, research is very slow, so feel free to go ahead and develop whatever you need to do as long as you also promote the final ACED tools. And again, everybody was on the same page about this as well.

There were some external factors that we hadn't really taken into account or we couldn't really predict. For example, one of our partner organizations had a large mandate change that led to less engagement over time. And staff turnover is something that required ongoing outreach from our end to sustain engagement from certain organizations. But because initially we had asked for two representatives from each organization, we could mitigate some of these challenges.

So I've already talked a little bit about the benefits, but I would really like to highlight that there is no doubt that we could not have developed relevant research and these tools without significant input from our partners. And we also had a wider reach, owing to our partners. For example, we had the opportunity to present at large events hosted by our partner organizations. For example, the National Summit on Episodic Disabilities and Employment and a conference for young people with MS.

Our project director also provided expert testimony to the House of Commons Standing Committee on HR, Skills, and Social Development and the Status of Persons with Disabilities. This is something that was facilitated by one of our partner representatives. And lastly, we were the grand prize winner of a prestigious inclusive design challenge, and we would not have known about this opportunity if one of our partner representatives hadn't brought it to us.

OK, so I think I have maybe a minute, and I'll take you through the JDAPT very quickly. It is a Job Demands and Accommodations Planning Tool, which guides a user through a series of simple questions about their job tasks and working conditions. It provides a personalized list of support ideas that are relevant to an individual's job demands, and it does not focus on a health or disability diagnosis. Let's skip over this slide.

There are 24 types of job demands and working conditions within the JDAPT that are organized in four demands, the physical demands, cognitive job demands, working with others, and working conditions. For each demand, the user would rate the importance of the job demand within their overall work, the difficulty that they may have performing these job demands due to their health, and the change in their ability to perform these job demands over time because of their health. They would then get a personalized report and support strategies and accommodations that are related to what they have selected in the tool.

If you want, you can have a look at the ACED website as well as the JDAPT. It's linked here. You could also Google "JDAPT", and it would come up. There is a worker version of the tool that can be used for self-assessment and an organizational version that can be completed by a supervisor, an HR manager, or anyone who's supporting workers. It is free and confidential. It's evidence-based, and it's available in both English and French.

Lastly, just a little bit about the Communication Decision-Support Tool. This is the working name that we have. The acronym is DECIDE. It is an easy-to-use tool that will consider issues that are most relevant to somebody with an episodic health condition or disability, including workplace culture and available resources and their personal goals and preference. And it, too, will provide a personalized summary for the person who is filling this out.

So that is the end of my presentation. Feel free to reach out to me if you have any questions. And these are the websites for the Institute for Work and Health and the ACED research study. Thank you very much.

FELICE TRIROGOFF: Thank you so much, Sabrina. I'd like to invite Scott and Ana back on camera-- excellent-- and Kathleen, who will be facilitating the Q&A. Great. Thanks, everyone.

KATHLEEN MURPHY: Thank you, Felice, for your moderation this afternoon. Yeah, so I'll be closing out the conference. We'll have our Q&A and then some kind of housekeeping. So these were an interesting trio of presentations. As you all know, the panel, we grouped-- you submitted separately, but we thought, well, gee, in different ways, they all have to do with relationship building.

And before I continue, just in case you're just joining, I'm Kathleen Murphy. I direct the Center on KTDORR, and I'm a white woman with shoulder-length blonde hair, blue reading glasses, and blue jacket that has a notched collar over a maroon t-shirt. So anyway, back to the panel.

So I loved how practical some of you were, because over the course of this week, we've heard a lot about stakeholder engagement and different ways, advisory boards, bringing in consultants, bringing in people with lived experience. So one thing that it was-- the last presenter, Sabrina, you talked, you said, this is how much we pay people and that you had detailed agreements with the organizations.

So sometimes, I've noticed in bringing in people to the project, an issue arises about internal equity, like how much are you compensating the people with lived experience versus a physician. So I'm wondering if each of you could talk about, what kind of agreements did you have with your partners?

SCOTT DONIA: I can go first for that. So it's something that we are working towards, actually establishing something, because there's nothing officially in Canada yet in terms of how much you're supposed to pay someone with lived experience. And we do have an internal process that's kind of decided by people with lived experience that we work with in terms of how much that is. So right now, it depends on the amount of hours that-- like for the summit itself and everything there.

So it ends up being right now, we pay them I think it's \$30 an hour, so not quite physician level, but still enough to this would be a standard wage for someone. So trying to make sure that just because they have that lived experience, that's something that no one else necessarily has, that a clinician doesn't, so it's something that we're very aware of. We just have to really establish what those guidelines actually are.

SABRINA TONIMA: Yeah, I think I can add to that, Kathleen. In our case for the ACED project, when the partners got involved at the grant submission stage, their contributions were laid out mostly as in-kind. So whatever amount of time that they would spend working on ACED is something that was counted as in-kind as opposed to a cash contribution.

For the committee members who had lived experiences of episodic conditions, we really took our cue from our partner organization reps who had experience getting feedback from their patient communities.

And based on their suggestion, we went with the \$500 for the year. I think there were discussions about the number of hours that they would spend working on the tool, reviewing and providing feedback. And based on that, we-- yeah.

ANA PAULA SALAZAR: We did not include any participants with lived experience, but all our partners-- they did not receive money for their participation, but their association received some money according to the time they contributed to the project. I don't know if this answers.

KATHLEEN MURPHY: It does. Yeah, as I said, it's just something that needs to be thought through for anybody putting together a project. How are you going to handle this issue? So similarly, all of you engaged external people in your project, and the idea is to get input and feedback. What processes did you use when there wasn't consensus? So again, I don't know, we can go in a round table. Maybe again, Scott, Sabrina.

SCOTT DONIA: Sure. Yeah, it's Scott again. I think no matter what, there should be differences of opinions, and sometimes that's with the majority. And I think trying to isolate, is this the opinion of clinicians, and this is only the very typical opinions of PLEX, is there that difference, or is it just people think differently anyways? So it's trying to go with the majority at times, but know that there's going to be different ways to approach it. So maybe that changes things.

It's not a one-size-fits-all approach. It's trying to bring everything together. So yeah, I think you go with the majority, but also just sometimes take a larger lens view to see where those opinions are coming from. And maybe show alternatives as a result if that's the case.

SABRINA TONIMA: Yeah, so I think in our case, because we were covering a range of episodic health conditions, we did have a lot of different opinions on the tool and some of the language. We started off with reaching out to our patient-- sorry, not patient-- partner representatives, and based on what they said, we made initial changes.

But we had also done a pilot test of the tool with a variety of folks who have a lot of different kinds of episodic health conditions. So wherever there was consensus, we went with that. So what Scott had said about going with the majority, we did do some of that. But then we also did a JDAPT evaluation study towards the end with hundreds of people, and that really showed us where changes needed to happen. So that was our process.

ANA PAULA SALAZAR: Ana here again. I think for us, it was also like that. We also went with the majority, but we really used questions that raised from our discussion as a team. We were able to bring to the discussion during the town hall with all the participants from all associations that participated, and we also asked them to validate what we were discussing as a group, as a team. So yeah, I think it was this way that we did.

And sometimes it was good to see that different opinions were good to make us evolve. Sometimes, one person did not agree with the other one, and it made us think about and brought that idea that was not there at the beginning. And it made us evolve with our ideas and planning.

KATHLEEN MURPHY: And did any of your projects have to give onboarding, like almost formal training to people who might be less familiar with research in order to enable particularly people with lived experience, their participation in the project?

SCOTT DONIA: It's Scott again. So I guess, specific to the project, we did have to do an education session for the facilitator for our summit because they weren't very familiar with spinal cord injury in itself. So it's a lot of inclusive languages and different things like that that we provided some onboarding education for them.

In terms of clinicians and everything that were part of it or industry and different government stakeholders, we tried to keep it very basic language throughout. So we told all our presenters that it should be pretty plain language, not to get too scientific. Or if you were going very clinical with your language, have a disclaimer saying, you know, here's the really fine detailed clinician way of saying it, but this is what it means generally. So I think knowing that you have different audiences and trying to speak to everyone and being very aware of that.

SABRINA TONIMA: Yeah. Hi, it's Sabrina. I think in our case, we had small enough groups where we could do individual consultations that were more informal in nature. So any questions that someone may have had about specific research terminology or methodology could be answered during those consultations.

For our lived experiences committee, we actually had a terms of reference, and we had very specific-- we had laid out very specifically what the tasks of this committee would be. And in the process of conducting these consultations with them regarding the tool, we provided information, again, in very plain language about what some of the methodology is, why we're doing what we're doing. But we didn't really go very, very deeply into the actual research process.

ANA PAULA SALAZAR: Ana here. For us, we had some focus groups that were guided by-- that were facilitated by executive directors that were part of the research team. And for them, we had some training and education about how to conduct a focus group and why is it important to follow the same guide and to have the scientific value of the focus group.

But we decided to do that to reduce a little bit of hierarchy, if I can say, because sometimes we use-- as researchers, we don't have the lay language training. We are always talking with each other, so I think we decided to do that to be able to get them talking more with each other. This was the only education or training that we gave.

But I think our team was very collaborative, as I said. And we learned a lot with each other. I learned a lot, a lot, a lot with the community partners because we-- the first time I presented the infographic, for example, they were like, this is not a scientific poster. So it was a lot of back and forth and forth and forward, but it was very nice.

KATHLEEN MURPHY: Thank you. And, Ana, you mentioned that there was a lot of engagement. So how did you know?

ANA PAULA SALAZAR: Because all the meetings that we had, the engagement of the team. So we had the team involved in all the meetings. Not all the meetings, but the meetings that they could not go, as I mentioned, they diversified. They asked, hey, can you make a report? Can you make a summary of the meeting? Can you send me what you discussed so I can be at the same level when I am there again? So this kind of involvement, you know, like the interest of everyone. So everyone was very engaged.

KATHLEEN MURPHY: So attendance and--

SABRINA TONIMA: And then we had the small committees that helped us also to involve everyone, because sometimes it's not-- it's a topic that not interests everyone, but people were trying to choose which one they were more interested to participate, so by attendance and by, yeah, by the way they collaborate.

KATHLEEN MURPHY: Mm-hmm. Because it's hard enough just to measure, are your partners engaged, but then there's also sometimes questions raised about, well, what is-- how do you measure the outcome of the value of that engagement? So I don't know if any of you have been able to do more long term. Scott, you mentioned there's a network being formed. Or what happened after the event or after the initial development and dissemination of the product, in your case, Sabrina. Do you have any ideas to help people think through documenting the value of even doing this kind of partnership and engagement?

SCOTT DONIA: Yeah, so sorry. It's Scott again. So the summit actually just happened September 25, so we're still very early concept for everything. But I think having those plans in place on how to evaluate and how to continually reach out to keep people involved is really important. And timing, time for everyone is at such a premium, and that can be definitely difficult.

So I think any good KTE plan, knowledge translation plan should have what those barriers are and ways that you can approach that differently, so yeah, whether that be how do you connect to people differently or anything like that. So TBD for the long answer in terms of how the outcomes are really coming together, but I'm excited to see how that's going to turn out.

KATHLEEN MURPHY: For sure.

SABRINA TONIMA: Yeah. Hi, it's Sabrina. So what we do at the Institute for Work and Health is-- and we don't do this for every single project, but wherever it's applicable, we would build these impact case studies where we track the reports on the uptake use and effects of the research within our stakeholders. So it really requires us to reach back after something has been disseminated, reach back to our key stakeholders, and ask, is this something that you've been using? Have you shared this with other people? What do you think about its usefulness?

For the JDAPT, it was launched in March 2023, but we have been collecting testimonials and positive feedback from whoever has reached out to us to learn more about it. People, they have actually on their own reached out and said that it's a great tool, and I've used it, and I've shared it with x amount of people. So we are keeping track of all those comments to eventually build an impact case study for the ACED work as well.

KATHLEEN MURPHY: And, Ana, just on this topic of outcomes, you mentioned in your presentation, I don't have-- oh, I wish I had more time to talk about my study outcomes. So are there other things that you just want to add?

ANA PAULA SALAZAR: It's just I have all the results-- this is Ana again. I have all the results that I can share, but I don't think I have time to discuss about the other challenges that brain injury associations faced during the first year and then during the second year of the pandemic. Yeah, unfortunately, I don't have time right now, but I'm happy to discuss. And I think people will have access to the presentation also.

KATHLEEN MURPHY: Mm-hmm. Sure. And do you see any applicability to the work that you did which came out of the pandemic and COVID to disaster management?

ANA PAULA SALAZAR: Yes, for sure, because this was to prepare. It was preparedness. It was performed during the pandemic, and the idea came from the pandemic. But the platform now has been used by the executive directors by all the associations across Canada. It's a platform to help them during a health crisis or during any disruption in services.

So it could be climate disaster. It could be a flood. It could be anything that it will disrupt their services, so they have materials there that they can use. They have a forum where they can ask questions to each other. They can interact to each other.

And now, Brain Injury Canada has got a funding to continue this, to hire someone to be responsible for this website. So this was awesome, and they will be able to sustain the idea that started with a research project. Now, the project will be a community project that will sustain the website and the networking that started with this project.

KATHLEEN MURPHY: Because it can be so challenging when you develop something, and then just the world changes around you. Like, Sabrina, the toolkit that was developed during the pandemic, right? Because that has a big effect on work.

SABRINA TONIMA: It actually was, the pilot testing version of it was developed pre-pandemic. But we got lucky that most of our-- because we were reaching out to pilot test users Canada-wide, we were already doing some of these interviews on the phone and virtually, so it was an easier transition for us.

KATHLEEN MURPHY: Mm-hmm, because I just feel like for some of those conditions, it's so helpful to be able to do remote work, right?

SABRINA TONIMA: Absolutely. Yes, and we did hear a lot of that in our evaluation studies, and we ended up including that as one of our suggested accommodations.

KATHLEEN MURPHY: Yeah, for sure. That's interesting.