

2023 KT Online Conference: Information Sharing

Presenters:

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RONESSA DASS: Hello. Thank you all for being here. And I'll get back to this slide in a second. But as Ashley said, I just wanted to introduce myself. So my name is Ronessa and I am a Master's student in the School of Rehab Sciences. And I am a brown-skinned woman with medium, dark black hair. And I'm wearing a black turtleneck. And just as a disclaimer, the rest of this presentation will be from a rehab and Canadian perspective.

SUSAN CLARKE-TIZZARD: Hi. My name is Susan Clark-Tizzard. I'm a light-skinned woman with short brown hair and glasses. And today, I'm wearing a lavender sweater. I have been a consultant for several research projects concerning Veterans, the Chronic Pain Center of Excellence for Canadian Veterans, Wellness Together Canada, and now I'm currently working with Ronessa on a research project about brain fog and chronic pain.

RONESSA DASS: And the study that will sort of be talking about is funded by the Chronic Pain Center of Excellence for Canadian Veterans, so that is just another disclosure, as they do fund the research. So for today, our main goals are to describe the unique characteristics, values, and goals of Veterans. And to describe different strategies and provide examples of knowledge translation specifically catered to the unique needs of Veterans.

So as mentioned, we are from Canada so we define "Veterans" as persons who formerly served in the Canadian Armed Forces and received an honorable discharge. And Veterans and military members often exhibit a military mindset, which broadly refers to a mission-first, self-last ideology. And this mindset can influence their perception of self and their environment, as well as their comfort levels.

So why do we need specific knowledge translation techniques? This is because Veterans have differences in their communication styles, their expression and perceptions, and their goals and values.

SUSAN CLARKE-TIZZARD: Military communication is very brief, very direct. While civilian communication is typically soft and often circumvents the true meaning of a statement, military communication, as I said, is very direct. This is because, during training or during a battle, things are needed immediately. And you can't take the time to dance around what you want to say. As civilians, this can be interpreted as rude, because our speech is very direct. But that's not the intent of a Veteran.

We have differences in humor and expressions. We often have a very dark humor. As Veterans are exposed to many stressors and traumatic situations, dark humor is a common coping mechanism that is not usually understood by the majority of the public. But it allows the Veteran to move through the situation they're in without emotionally shutting down or getting too emotionally involved in that situation.

Because of the need for expedient and concise communication, Veterans have their own lingo, our own jargon at times. So we may say things. An example would be "C-rats." No, it's not little animals on the ocean. These are combat rations. So this would be prepackaged food that we use in the field. So for us, it's very important to minimize our words.

RONESSA DASS: And some concepts that we use in Rehabilitation Research or clinical settings can actually contradict Veteran training. So an example of this is pacing, which is often emphasized in physiotherapy and exercise-based treatments. However, Veterans may struggle with this concept, because throughout their training, they're told to push through no matter what. So this can create some challenges in rapport and can also limit the efficacy of certain treatments.

Also, Veterans have differences in how they experience health conditions and perceive their environment. And Veterans are vulnerable to a lot of different conditions, such as traumatic brain injury, chronic pain, and PTSD. And a lot of the time, all of these conditions are happening at once, which requires simultaneous care. Also, the way the Veterans respond to different assessments may differ than civilians. So for example, in research settings for chronic pain, we like to use a numeric pain rating scale, which is typically usually very simple and effective. But for Veterans, they might not fully agree with this type of assessment because pain is simply a part of their job and their everyday lives.

And they're told to push through it no matter what. So what might be a 2 for a Veteran, could actually be a 10 for a civilian. So this type of measure when working with the Veteran population is not the most culturally sensitive or useful. Instead, you might want to use something that is a bit more comprehensive and multifaceted and that actually gets at how the pain is impacting the everyday lives of Veterans. So this could be something like the Pain Self-Efficacy Questionnaire.

SUSAN CLARKE-TIZZARD: As a veteran who's lived with chronic pain for many years, my training has helped me to live with the pain. It's not as if I like the pain or welcome the pain, but as a Veteran, we usually embrace it as part of our physicality. Once we have accepted it as a quote unquote "normal" part of life, we can learn to live with that pain and minimize the negative mental effect on our psyche. I actually walked on a cracked femur for 4 and 1/2 weeks until the head of the femur bone broke. When it did, I held myself between two walls because I wasn't going to go to the floor. And finally, help came.

Well, the situation was looked at by my doctor and my doctor had thought that I had a groin pull, but actually, the femur was cracked. So we learn to live with this.

RONESSA DASS: Veterans also have differences in their goals and values. So purpose finding and goal setting should be emphasized within research, but also within a clinical setting. Also, group dynamics and social bonding are preferred in Veteran settings because of their training.

SUSAN CLARKE-TIZZARD: As Veterans, we have very unique bonds with one another, as we share common experiences that nobody else can relate to. If I meet a military Veteran that I served with 30 years ago, it's as if we've never been apart. We pick up just where we left off. The bond is that strong. We've been trained to function as one fluid entity, at times, relying upon one another for our lives.

Incorporating group dynamics is quite useful as it helps to combat the emotional distress and the social isolation that many military Veterans have been exposed to. We have been exposed to critical conditions that may have caused severe mental and emotional distress to the Veterans. And this tends to hold many Veterans back from fully participating within the society of civilian lives. We feel as if the civilians do not understand where we're coming from.

Therefore, we tend to gravitate towards one another within our groups. And in group dynamics, Veterans also follow a no-man-left-behind policy. And we work together as a group. We've been trained to help each other succeed. So if you have a team member that's falling behind on a run, we're going to go back, and we're going to bring that person up with us. We're going to encourage them and support them. And it's the same thing as in life. If we have a comrade, a buddy, who's having a hard time, we're going to go back and give them the support they need to pull through their hardships.

RONESSA DASS: And also lastly, efficiency is highly valued and appreciated in all. And not only in the military, but in the daily lives of Veterans.

SUSAN CLARKE-TIZZARD: Most Veterans, when they were in the military, they worked at a very high level of efficiency, peak efficiency at all times. So military members, Veterans, expect this efficiency from other people. So if I would take the health care as an example, within the health care system, Veterans expect an accurate and expeditious diagnosis and a clear and concise plan of action. If we have that, let's get 'er done. Then we'll give our utmost to succeed.

We don't run from a challenge. We usually embrace it, as our training has taught us to. Among other medical issues, I've had back and spinal surgery due to military service. And as I said earlier, a femur replacement due to a sporting injury. So after working diligently, I have been able to succeed. You would not be able to tell that I have these injuries. That's the Veteran mindset. I've had to change and modify some of my daily physical activities. I no longer run. But I walk every morning. Between 5:00 and 6:00 in the morning, I'm on the road. And now, instead of dancing, I go out and I'm out there kayaking almost every day on the river.

So with researchers, if researchers are untrained in the military culture, and if a Veteran does not experience a high level of communication and efficiency from them, this may lead to some major frustration on behalf of the Veteran, Leaving the Veteran to withdraw from the situation, from the research project. Communication and trust are key.

RONESSA DASS: Thank you, Susan.

SUSAN CLARKE-TIZZARD: My pleasure.

RONESSA DASS: OK, so now that we've sort of broadly talked about some subtle differences in Veterans, we'll now talk about how you can use this information to adapt it for research. So it's very important to have a Veteran partner on your team, because as mentioned, Veterans do have several differences that impacts the way they experience things and the approach that you need to take to your work. So having a person with lived experience on your research is very, very helpful. And I can attest to that, because Susan has been a key part of my master's thesis.

So first thing you want to do is, of course, planning. And you want to make sure that you're providing informed consent. This is not just for the participants in your study, but also for your patient or person with lived experience partner. So when providing informed consent, you want to make sure that you're being as transparent as possible and including all information about what the study is about, who are the involved stakeholders, and what your partner will be asked to do. This is very important to promote autonomy.

Next, you want to consider safety. So confidentiality is very important to Veterans, so you want to make sure that you're protecting and keeping all of their information confidential at all times, and also that you're giving them the ability to withdraw from the study at any time without any repercussions. You also want to address your researcher positionality. As researchers, we are in a position of power over the partners in our study. And because Veterans are trained from their service to follow orders, you want to make sure that you're not abusing this position.

Also, a lot of the research we do with Veterans is very emotionally distressing, so having the appropriate resources nearby is vital. You also want to verify your communication methods. As mentioned, Veteran communication is very direct and concise. You don't want to be sending any wishy-washy emails that might be frustrating. You want to be clear and straight to the point. And although Veterans do prefer group dynamics, many Veterans might have PTSD and they might be triggered by speaking with other Veterans. So you just want to verify whether they would prefer a group or a solo setting.

And as always with anyone involved in your research, you want to express gratitude, whether that be through authorship or honorariums. But for Veterans, feedback on how their service was valuable might be the best way to go. And we'll expand on that in a little bit. And so I'm speeding through it because I know we're running out of time.

So when it comes to implementation, the most important things you want to consider are why the research is needed, and the sense, and the value of the purpose of the study. So here's just a quick excerpt of what I used in my study when recruiting a person with lived experience. And I just basically said what the phenomenon is and why it was important. And if you want, I can send this later, but I won't go into it now.

You also want to make sure that you're being strategic about where you're sharing information. So in Canada, we have the Department of Veterans Affairs and our Military and Family Resource Centers that are great ways to share information. But also because Veterans are a very social group, you can do

social media or community groups through The Legion. And engaging with a trusted member might be the best way to share information because trust is very important in Veteran communities.

And for feedback, you want to give specific feedback throughout your different communities. So basically, just show [AUDIO OUT] what you found in the research [AUDIO OUT] be used [AUDIO OUT]. There we go. OK. Sorry about that.

So just to quickly sum up, you want to make sure that you're giving specific inputs to your Veteran partner and basically just let them know how their input was used. So if they were involved in something like qualitative analysis, maybe you can tell them how their opinions helped you devise a code, or a category, or a theme. But most importantly, because Veterans are service-driven, you want to show them how their input actually contributed to the Veteran community because this will help them make sure that they will be engaged in future research studies if they know that their contribution actually helped to make a difference.

And I know that we're out of time, so I'll just quickly say these points. Having a Veteran partner involved in your research improves the rigor and the quality of work by making sure that you are doing work that is actually relevant and culturally appropriate. But it also helps to make sure that you can actually improve Veteran health care outcomes by having rigorous and well-designed studies. And also, disseminating information to Veterans helps to empower them to become active contributors for their own health care and well being.

And here are three takeaways. And I can send the slides. And I'm happy to answer any questions at the end or through email. Thank you.

SUSAN CLARKE-TIZZARD: Thank you.

ASHLEY CLARK-PURNELL: Thank you, Ronessa and Susan for sharing that information on the benefits and considerations for including Veterans in research. I'm sorry you ran out of time, but we'll be answering some questions in regards to your presentation once the last member of the panel concludes. So can't wait to hear your responses to the questions that popped up in the chat.

So next, we're going to have Michelle Meade come on camera. And Michelle Meade is going to be presenting on designing and implementing a national Resource Center. So Dr. Meade is a professor with tenure in the University of Michigan's departments of Physical Medicine and Rehabilitation and Family Medicine. She is the principal investigator and director of two separate interdisciplinary centers from the National Institute of Disability, Independent Living and Rehabilitation Research, so NIDILRR again. And if you want to read more about her bio, I will post a link in the chat. So with that, I'll pass it to you, Dr. Meade.

MICHELLE MEADE: Thank you so much. I am a middle-aged white female currently wearing glasses and a magenta sweater. Today, I'm going to be talking about how we've been thinking about and how we've designed a national Resource Center and our technical assistance activities, for not only our RRTC on promoting healthy aging among adults with long-term physical disabilities, but our other centers.

Want to thank, of course, NIDILRR and their funding through not two, but three centers-- the IDEAL RRTC, the AHEAD-DC RRTC, which promotes equity and health and functioning, and our Michigan Spinal Cord Injury Model Systems. Particularly, thanks to Joanna Jennie who serves as our main contact for technical support, Krista Woodman who's our webmaster, Robyn Rontal and the members of the CHRT Team, and of course, our advisory panel members.

Once again, the objectives of this presentation are really to describe the focus of it and how that of the RRTC on healthy aging and how that led to this conception of knowledge translation, and technical assistance, and the specific types of activities that we do, and then provide an overview of the National Resource Center. First of all, the mission of the IDEAL RRTC is to understand and enhance healthy aging for people with long-term physical disabilities, and especially those from traditionally under-served and marginalized communities.

We recognize that this is not a factor just of the individual or the impairment, but really about the interactions between the individual and their environment, whether that is the health care system, the policies at the state or federal level, or the factors in their direct social environment. This really led to a variety of activities for that center, both to identify the environmental factors that are associated or that support healthy aging for adults with long-term physical disabilities, and then to begin to develop interventions to modify the environmental factors.

As mandated within the grant application, we are also supposed to serve as a national resource center. And what that means and who we serve as a national resource center for, I think is often done on a grant-by-grant basis. For us though, serving as a national resource center really meant considering and engaging with a wide range of stakeholder groups and asking them what types of things are needed, where are they finding information, where do they see the gaps, and how is the University of Michigan with our specific background expertise and such, really able or uniquely suited for filling that gap?

When we think about the idea of improving environmental factors, this is so that it's not always about individuals with disabilities doing more, or trying to twist themselves to navigate the health care system or various processes. We recognize that in the environmental factors, including the built environment attitudes and such, serve as significant barriers that make it harder to interact in the health care community and employment environments. And so our key part of our conceptualization is how to make this as easy as possible. Because of this, we wanted to first identify and ensure or enhance access to those information about those relevant policies or programs, health care systems, and such.

Our advisory panel for the IDEAL RRTC really is there to connect us with individuals with disabilities through national organizations regional organizations. They help make sure that we represent the concerns. They don't just know the concerns of one individual, but are of the perspectives of folks from different backgrounds and different types of impairments. And so we really tasked them with reviewing and providing us feedback about where our research, and what information knowledge translation and other types of outputs, where that fit in for their group.

The individuals on our panel, once again, some of these we knew before we started the grant and had long-term connections with. These included the Ann Arbor Center for Independent Living, now the Disability Network of Washtenaw, Monroe, and Livingston Counties. But others were identified by our project officer and engaged later, such as No Wrong Door Virginia. Once again, we were trying to get folks from diverse backgrounds, different types of communities, and people who were already on the ground doing things so that we're not reinventing the wheel.

The key pieces of information we gathered from our advisory board were who they served, what their stakeholders top priorities/issues are, as associated with aging and disabilities, and what are the preferred formats of information. This then was used to help shape the types of outputs that were developed. We began this particular RRTC in 2018 and had not really started social media use as a center at that point. But because of the recommendations, we did begin to do a Facebook public group for individuals living and aging with physical disability, and a Twitter account. The Twitter account was more aimed at health care providers and younger professionals.

Once again, if we would have had adolescents and that would have been our target group, the types of social media would have been different. So we were really trying to listen to how people are getting information, what they're already interacting with, so that we're not trying to create a new platform or rather, we want to use existing sources of information, existing information gathering processes, and optimize or refine, tailor our products with that in mind.

Towards this end, we created the National Resource Center for Aging with Disabilities. This is part of a really comprehensive methodology, including the outputs of social media, policy briefs, videos, that include the dissemination and technical assistance and training activities. We identify what the methods are and who the primary audience is that it is being created for, to keep that in mind. We're also thinking about the section was, what part of the grant is it discussed under? And what part of the budget do we provide funding for it for under?

The name of the National Resource Center was, once again, identified in collaboration with our advisory board and thinking about how it would be integrated and used as a search function. Most individuals at this point, not all, are going online to try and find information. They're just hunting around. So we wanted to try and get a name that captured the attention that was likely to pop up and that allowed for a comprehensive understanding of what we did, and then for advertising and outreach.

The focus, once again, of the National Center for Aging with Disabilities is to have a searchable database of information about programs and policies to benefit or support individuals living with disabilities. As we were developing what this would be used for, the use case was really thinking about both clinicians and individuals working in primary care, trying to find resources in their community for their patients with disabilities, or individuals or family members searching for the same type of information.

We identified topic areas we felt that it was important to address for this group of individuals. And these include assistive technologies to the policies housing, transportation, and legal services. Beginning in 2020, we also began to add COVID-related resources and services that we could find and that were

available. That very much changed the landscape of who was out there providing information and what type of information or services they had.

Currently, our resource center provides or has information on over 3,000 programs in, I think, all 50 states. This is what the website looks like. What you can see is that resources are searchable at the state level or the national level. It is searchable by topic, or searchable by keyword, or zip code. Individuals can then find a program within their area. I don't know if I'll have access to the keyboard, and I know there's other folks coming on, but we also have similar information about policies. And so we've populated the resource center with information about policies that are relevant to living in aging with disabilities so folks could better advocate for themselves.

Information, once again, is findable. You can print out, bookmark these pages and resources, have them emailed to you, and get back to you later. Do you want to go? I'm going to avoid the live demonstration now so I can finish up. We do have an individual who staffs the National Resource Centers. Ms. Joanna Jennie is online most days, and if she cannot directly answer the phone calls that come in, she will respond within two to three business days. Most of the searches are for information. People are just looking for help with navigating all the information in the space. And that's one of the key pieces we have for our resource center.

This includes both information about the specific programs in your area, or in a specific area, as well as those national centers who may be conducting research. This is an overview of some of the assistance that has been provided in the last year. It goes up and down, but most of it is related to or about resources that is covered by the National Resource Center. I think having someone to talk to, I think, is particularly important for older adults who are not used to navigating the internet, who would much rather work with an individual to say, this is what I'm looking for. Can you help me find it? And that is one of the key pieces our technical assistance provides.

We tried to increase outreach and awareness about the center by sending a postcard to clinical practitioners. We accessed the mailing list of the American Academy of Family Physicians and the American Geriatrics Society as well as AAPMR and sent them out this postcard to let them know that this online database and associated resource was available.

We also send out quarterly newsletters. We have our information involved in the NARIC News and Notes. And then we try and provide tailored information for Advisory Panel Members to include in their existing newsletters, websites, and email blasts. If you have any questions about what we do, why we do it, and how, please let me know. I will be staying on for the question and answer session.

ASHLEY CLARK-PURNELL: Thank you, Dr. Meade, for that presentation. It was great to hear about the National Resource Center and all that you've done to get it all set up. And I see there's quite a few questions in the chat, so we look forward to hearing your answers.

Our next presenter is Erin Near and she will be presenting on "There's No Age Limit for Gambling Harms." So Erin has a Master's degree in public health from the University of Guelph, with combined work in education and the public health field. And she is coming from the Responsible Gambling Council. If you

want to read more about Erin's bio, Elizabeth just dropped it into the chat. But with that, I will pass it on to you, Erin.

ERIN NEAR: Thank you, Ashley. Good afternoon, everyone. My name is Erin Near and I am a research analyst with the Responsible Gambling Council. I am a white woman with long blonde hair wearing a blue sweater. Today, I will discuss a project that the Responsible Gambling Council worked on with gracious funding from the Ministry of Ontario in Canada. Our work focuses on older adults and the risk that gambling has on this specific population.

Firstly, for those of you who are not as familiar with the Responsible Gambling Council or RGC, we are an independent, non-profit organization, operating out of Toronto, Ontario, Canada. We have over 35 years of research, prevention, education, and policy guidance. We provide global insights on responsible gambling as we have in-depth knowledge of leading practices across many jurisdictions. We have done work all across the world, all throughout Europe, North America, Australia, as well as many other locations worldwide.

We work with stakeholders across the field, including regulators, industry, treatment providers, families, as well as players, to prevent problem gambling and reduce its risks. The Responsible Gambling Council is not anti-gambling. We believe gambling exists and so should we, however, it should be done in a safe way.

While gambling can have its risks for many other populations, for this specific project, we focused on older adults ages 65 years and above. Research suggests that older adults are at an increased risk of experiencing gambling-related harms due to a number of things. First, limited financial resources. For example, someone could be living on a fixed income.

The second is loneliness and/or isolation. So for example, coping with the loss or death of a spouse, family member, or friend. As well as limited leisure opportunities. For many living in older adult communities and homes, there may be limited opportunities for this age group to enjoy social opportunities. Gambling can act as a social opportunity in many instances. For many living in those older adult living spaces, trips to the casinos are very common as a social outing. And we often see higher risk of gambling-related harms in those instances.

With the past research in mind, the Responsible Gambling Council wanted to create a product that would help lower the risk of gambling for older adults. With gracious funding from the Ministry of Ontario, RGC was able to conduct a project specifically geared towards older adults. The Older Adult Program Gambling Awareness Project involved the development of a poster campaign as well as an accompanying pamphlet to educate older adults, their families, as well as professionals such as human service providers, community agencies, health care providers, as well as many other professionals about gambling.

The project aims specifically for the poster campaign and pamphlet, aimed to increase awareness of the risks of gambling and relevant sources, to gather more information, seek help, or speak to a professional. Another aim was also to increase knowledge of low-risk gambling strategies and elements of lower-risk

play. So putting into effect things like setting a time limit, or setting budget limits, as well as to prevent the impact of gambling harms on older adults in Ontario, Canada.

From the previous community outreach programs that RCG has done in the past, we have learned that before developing materials to educate and inform certain populations, that it is imperative to get their insights on the things that specific audience would like to see, what types of messaging speaks to them, as well as how to best reach the audience. So for this project in particular, we wanted to get the target audience's perspective to tailor a product that was effective as well as engaging.

We worked in partnership on this project with the Peer Elder Abuse Prevention Network or PEAPN, for short, which is a network that consists of agencies serving older adults, service providers, community advocates, and older adults. They currently represent over 50 members from non-profit organizations, municipal, regional, and provincial government, post-secondary institutions, faith-based communities, businesses, as well as many other groups. We conducted a focus groups with the PEAPN Network during one of their reoccurring meetings. And this was important to get views and opinions based on how these groups worked with older adults.

With this partner, we also conducted a focus group, specifically with their Caribbean seniors group, which is a group that is very active in their community, and very active in conversation together, and they meet on a regular basis. So we thought that, due to their engagement in creating that safe space for older adults, it was imperative to discuss various topics and that they would provide effective feedback for us. These are some of the following questions that we asked within the focus groups. We wanted to get a sense of their level of knowledge on gambling so we asked them what is gambling to them, what types of gambling games they are familiar with. "When gambling is a problem" was a major question we asked, because problems can look different for everyone. So we just wanted to get a gauge.

We also asked what the needs of older adults in relation to problem gambling are, whether there's enough information available about the issue, and if there are any barriers that we should have been aware of when creating these materials about accessing information, services, or support. Some other questions that we asked were, "What types of information should this awareness kit include?" "What languages should things be translated to?" "The best way to reach older adults." As well as "How to share and who to share it with?"

So we learned a lot from these focus groups and what older adults wanted to see. One of the most prominent overarching themes was that there is an overall lack of education about gambling in general that is accessible to this target audience. There's also a lack of information and education about the harms, warning signs, and impact. And another important theme we took away from the focus groups was the stigma surrounding the topic of gambling. Many older adults felt that there is stigma surrounding gambling. And many people do not want to admit or talk to anybody about their gambling habits because they are embarrassed.

Something else that came up within our discussion was the need for educational materials to be reflective of the community. For example, many advertisements about receiving help for gambling harms is

generally geared towards a younger audience, which therefore, we learned that it makes it difficult for this community to connect with the information, as older adults may not always be pictured themselves. And similarly, after speaking to the Caribbean seniors group, it was made apparent that they would like to see some advertisements that are culturally specific within their community. It was mentioned that this would help older adults to feel more comfortable about having conversations of gambling habits and harms.

And lastly, another key theme that came out of these focus groups was the need for information to inform family members. From an educational standpoint, it's important to educate families, especially with older adults who are living on a fixed income, have limited social interactions and outings, to ensure that they are looking for the signs of gambling-related harms, such as avoiding conversations about gambling, borrowing money from family members or friends, and money disappearing from savings accounts, or neglect to sleep or eat, even, in order to keep gambling.

We also learned some key themes from the focus groups that were more delivery specific, which was important. Older adults wanted to see more information about gambling harms, including financial harms, relationship harms, as well as emotional or psychological distress. The original idea for this project was actually a toolkit with multiple pages, key messages, as well as some activities. However, we learned quickly that these focus groups, we needed to shift the scope of the project to poster as well as an educational pamphlet, because it was highlighted time and time again, the importance of key, short messages and attention-grabbing images that relate to the community best.

If we were to create a full toolkit, there would have been multiple messages and more text on the page. So we decided to shift to a poster campaign and create an educational pamphlet with key information that was easy to read for this group. It's really important when creating a product that is in an area that is accessible to the population that you are working with, but also something that will draw their attention in frequently visited areas. During the focus group, we asked how and where we should put this poster as well as the pamphlet. Some frequent responses included, in the news, at doctor's offices, libraries, churches or other places of worship, community centers, older adults' homes, as well as banks, and newspapers.

Just to wrap things up and to summarize what we learned throughout this project, firstly, the most important thing that we learned was the importance of engaging the target audience. While it's very important to look at the research, in this case, it was important to note that older adults can be at risk for experiencing gambling-related harms. In order to target this audience the best and create something that was beneficial for them, it was important to tailor the products to the specific needs of the target. By looking at best ways to reach the target, identify delivery methods, specific content, and identify suitable language, it allowed for the audience to better relate to the product and be more effective as well. Thank you very much.

ASHLEY CLARK-PURNELL: Thank you so much, Erin. It was great hearing that information. [LAUGHS] And I see a lot of claps and applause in the chat. So great job. So now I'm going to ask all of our presenters to come back on camera and we can go ahead and start the QA session, which is going to be facilitated by Kathleen Murphy. Kathleen?

KATHLEEN MURPHY: Hello, everyone. I'm the ghost behind the chat so far. My name is Kathleen Murphy. I'm the director of the Center on Knowledge Translation for Disability and Rehabilitation Research. I'm a white woman with shoulder-length blonde hair, and I'm wearing blue-framed, reading glasses and I'm in front of a plain AIR background, and wearing a houndstooth jacket-- that means checks-- and underneath it is a Navy blue scoop neck dress.

So this was-- I love the way this panel has hung together. So many kind of cross-cutting themes across these three presentations. So thank you so much. We're getting a lot of kudos. Andrew Hamilton said, "Awesome so far. Thank you so much for wonderful presentation, insightful," blah, blah, blah. But I have been pulling out questions along the way throughout this whole past hour. So I do want maybe to start first with those presentation-specific questions. So we're going to go back to Ronessa Dass and Susan Clark-Tizzard.

Someone was like, "Wow, what a good research." And wanted to ask, "Is there any selected body or agency for the knowledge transfer for the Veterans in this study?"

RONESSA DASS: Elected body as in like an organization type thing?

KATHLEEN MURPHY: Yeah, he might, I don't know if it's the pronoun for the person that put in the question, but possibly, because this is a second day of this conference. And I was moderating on Monday. And I explained that our funding agency, NIDILRR, funds five knowledge translation centers. And Center on KTDORR supports all of the grantees and cross-disability audiences. But some of those, like we'll hear later this afternoon, one of them focuses specifically on employment issues. So this would be for Canada, right? Is there a kind of KT organization, perhaps funded by the Canadian Institutes for Health Research, specifically focused on Veterans issues?

RONESSA DASS: Yes, thank you for clarifying. There's no institution that I know of that specifically focuses on KT strategies, but my research is funded by the Chronic Pain Center of Excellence for Canadian Veterans and they have a lot of different knowledge products and also do a lot of work in knowledge translation to create products for Veterans.

KATHLEEN MURPHY: So it's kind of a proxy. That's helpful. Thank you, Ronessa. And I don't know if this question from Selima would be better, I mean, either one of you could address it. But I think this might actually be maybe more for Susan Clark-Tizzard. So Susan, you talked about differences in communications, and experiences with pain, and reactions to adversity. So she's wondering, do you find that the differences you discussed are stable, regardless of time spent in service?

SUSAN CLARKE-TIZZARD: I would say they're stable to an extent. I must say that the longer the Veterans have been in service, the more reinforced and the more ingrained the behaviors and the beliefs are. So the longer we're together, the stronger, as I said, the behaviors and the beliefs are. Yes.

KATHLEEN MURPHY: That makes sense, it's almost an acculturation.

SUSAN CLARKE-TIZZARD: Yes.

KATHLEEN MURPHY: Because I also was pointing out that, regarding a communication style specifically, this is relevant for some ethnic groups. And it did make me think about, across this whole conference, we are trying to have presentations that talk about knowledge translation for specific communities. And that membership in a community isn't necessarily static. So it's kind of an interesting example of that, that you can be more intensively a member or not. Or we heard on Monday about youth. And it occurred to me, well, eventually they're not young anymore, right? So they're going to have to roll off your advisory board. So things like that. It's just kind of an interesting food for thought. So we appreciate those comments and questions.

And I will want to move on to those that came in for Doctor Meade's presentation about designing and implementing a National Resource Center. A lot of people just had kudos for you, Michelle. Mustafa Bukhari well-explained, "And I learned a lot." So you talked about in your presentation the importance of including people with lived experience, which, of course, is, again, kind of a cross-cutting theme across this whole conference. But that person is wondering, "if it does not need to be influenced by their level of education." So could you address intersectionality that has come up?

MICHELLE MEADE: I think that is a very important point, and intersectionality by education, by race, by community, by experience. I think that's one of the reasons why, for us, having organizations which have more familiarity with the cross-cutting issues and the various communities that they interact with, that it, I think, on the organizational level, they're engaged specifically in saying, how do we learn the best? How do we make sure we provide services, resources, supports for this broad based? And what are the best practices that we've already found?

I found sometimes when we engage an individual, they may have less insight both about experiences beyond their own, and they also have less resources to serve as a champion and facilitate to leverage existing resources to continue to get the message out. And so we try to engage organizations with different perspectives. The Paralyzed Veterans of America, the AARP, which was a more general organization, but for older adults. Thinking about the ones, Warriors on Wheels is primarily African-American faith-based organization in Detroit. So thinking about how these organizations reflect different communities with different educational levels, ages, and such, and listening to them and their best practices and strategies, I think was the approach we took with this process.

KATHLEEN MURPHY: Great. I'm just putting a little note here. I don't know, AARP, you mentioned. Is that its name now? Or is it still an acronym for the American Association of Retired People?

MICHELLE MEADE: I know they always refer to themselves as AARP. So we've never spelled out the whole thing. And everyone knows who we're talking about as related to them.

KATHLEEN MURPHY: I think it is just AARP.

[INTERPOSING VOICES]

But again, since we have a lot of people here who might not be familiar with AARP, it's a major advocacy organization for people over the age of 50 in the United States. And they do a lot of advocacy around like Social Security or various kinds of aging issues. So it's a pretty important partner. Good job, Michelle.

Let me go ahead and try to connect this. So there's a question Selima has. So again, it's we can kind of segue, continuing the intersectionality theme. "A lot of the people on your advisory board or the target audience for your center would have people with physical disabilities. So do you or would you include external NIDILRR funded research, recruitment announcements in your newsletter, if the population of interest is people with physical disabilities?" That's the question.

MICHELLE MEADE: We haven't. It becomes hard. How many do we do? Our newsletter only comes out quarterly. We are more likely to allow folks to post those on our social media. Once again, our Facebook group is a great platform for doing that. Once again, Facebook is not for everyone, but older adults, folks my age and older and such, it works really well with. And thinking about that type of strategy or approach. You may have noticed that one of the people on the committee was just checking for Matt and Eric and their both advice and how we interact in touch with them has been very helpful to think about what our existing techniques, and strategies, and other resources.

KATHLEEN MURPHY: Sure. And if one of our tech support could put NRIC.com in the chat. NRIC is also funded by our founder, NIDILRR, and it stands for the National Rehabilitation Information Center. So they house a lot of the products that NIDILRR grantees produce, as well as other rehabilitation research. So people may be interested in perusing their website at some point.

So I think this is the last question for you, Michelle. You talked about-- my parents are still with us. They're 91 and 95, and so are my in-laws who are in the 90s as well. So I'm very, very familiar with how people who are older do not necessarily want to use online resources. So you talked about alternatives to that, which was so helpful. Selestén is wondering, "What do you think about the one-to-one method to identify that issue at the personal level? And what is to be done once you find available supports are not enough to help fully the beneficiaries?" So are there complements to that?

MICHELLE MEADE: No, it is a really hard question, because at least the Online Center is more about finding and identifying resources. And we do take the extra step not just to find out what's online, but all of our online resources were vetted, or most of them. We've called them, we make sure they're still up, who do you talk to that they're still relevant? And then when someone reaches out, that additional follow up is done. But we don't have benefits counselors on staff. We can't do mental health counseling. The limits of what we can involve or what we can provide, I think, are very much evident. And we try and then find and direct people to those resources that can provide additional assistance and support.

KATHLEEN MURPHY: Some information and referral.

MICHELLE MEADE: Mm-hmm.

KATHLEEN MURPHY: That makes sense. And I know you have your toll-free line. So I'm sure the people answering it are very helpful, as or as helpful as they can be. So people liked your presentation. "Thank you for a wonderful presentation. So insightful."

Let's turn now, if we can, to Erin Near. Someone is commenting, "Through benign gaming apps like "Wordle," there are advertisements for apps like "Bingo Cash" or "Solitaire Cash" that include intense pressure to gamble. Does your work address that sort of infiltration into the aging population?"

ERIN NEAR: Yeah, that's a really great question. We're doing a lot of work right now on the benefits and negatives to advertising in the gambling space, specifically on apps like this. So it is something in our research that's ongoing, but there is a lot of research out there right now from major players in the responsible gambling field that does address that sort of infiltration to the aging population. And we are seeing negative effects from that, unfortunately.

KATHLEEN MURPHY: Yeah. It's so unfortunate because it's really, on the one, like from a knowledge translation perspective, it's such a clever way. To think about, where are people going? If they're going to "Wordle," so the advertisers know, go there. And so I often think that as KT scholars or practitioners that copying advertising can be so helpful or what they're doing. But it's unfortunate when it's a little nefarious.

So I like to ask too when we have these panels, you know, we've talked about aging, we've talked about Veterans. So there's a lot of cross-cutting themes. We've got people from Canada, people from the US. And as you were listening to each other's presentations, was there anything that you yourselves wanted to ask to another presenter?

MICHELLE MEADE: I know, I just found it really fascinating, and especially thinking about how to format that message for Veterans, and the short, succinct approach, both for providing or helping to maybe translate the research that we do, as well as for the issues of recruitment. And just maybe communication about problems that come up or such. One of the issues I know we faced here was, how do you share information about security breaches to a Veterans population?

KATHLEEN MURPHY: Yeah. I mean, that's-- there was a comment I kind of skipped over talking about how confidentiality is so important to the people who participate in your studies or your projects, but it's also important to researchers too, because we really want to make sure that our data is secure and keep those promises in our consent letters. And it's increasingly challenging. So thanks for pointing that out, Michelle.

We did also have a little comment or question about funding. And I don't think that anybody here can really explain how to get similar projects funded in Africa. However, at least I can speak. Our funder, NIDILRR, very much is interested in international outreach. And NIDILRR grantees can partner. So if you do see someone who identifies as a grantee, you may want to reach out to that person and explain what you might have as a possible partnership. But as far as our funding, I don't think that anyone outside the US can apply for it directly. But we always, we love our international partners. So I'm going to turn it--

MICHELLE MEADE: And, Kathleen?

KATHLEEN MURPHY: Yes, ma'am?

MICHELLE MEADE: Can follow up and ask that? At one point, I thought you did do like rush grants or grants to small grants provided by your organization to facilitate additional knowledge translation or such in other areas. Would something like that be an opportunity in the future to enhance international outreach?

KATHLEEN MURPHY: So I have raised that question. Dr. Meade is referring to back in 2003 to 2009, it was the first NIDILRR project I worked on. The Research Utilization Support and Help Project had stipends and grantees could apply to promote uptake of their work. So I have asked that question and I know another grantee has used that strategy. So it's something, if you're thinking about, when you're looking at an RFP, ask the project officer. And they probably will say, if it fits with this RFP, yes, it's a possible strategy. But don't think anyone international can be like what we call the prime.

So I'm going to turn the baton back over to our fabulous moderator, Ashley Clark-Purnell, who's going to move us along. Thanks, all.