**2018 Online KT Conference:**

**Engaging Ways to Engage Stakeholders**

Co-creating With Stakeholders: A Case of Engaging Through Concept and Design for Program Development

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>> DONNA MITRANI: Our final presentation this afternoon is from Tracy Boehm Barrett and Tannis Hargrove, both from the NIDILRR University of Montana Rural Institute and Training Center on disability in rural communities, otherwise known as RTC Rural. As the director of knowledge translation at RTC Rural, Ms. Boehm Barrett increased knowledge to increase participation of people with disabilities in rural communities, Ms. Hargrove also supports the center as a project director and research associate, their presentation co-creating with stakeholders, a case of engaging through concept and design for program development, will highlight the stakeholder engagement approaches used over the past three years as part of the healthy community living development project. If you have questions during the presentation, please ask them in the chat pod. After the presentation, Kathleen Murphy will lead an interactive discussion with reactors and conference participants. Tracy and Tannis, are you ready to begin?

>> Yes.

>> Thank you.

>> Okay, great. Well, thank you, Donna, for the introduction, and for inviting Tannis and I to speak today. We're really honored to be among a cadre of esteemed conference ‑‑ KTDRR conference presenters and we're excited to share our experience of co‑creating with stakeholders in our program development project.

The development project about which we will be sharing is funded by the national institute on disability, independent living, and rehabilitation. We have no financial conflicts to disclose.

Excuse me. In this presentation, we will provide a brief introduction to our organization, our project, and the practices, outcomes, and impacts of the stakeholder engagement activities we used. Our intent is to provide an explanation of how we implemented our stakeholder engagement throughout the project, the real life challenges and successes we experienced, then we'll have a question and answer period that provides space for you all to ask more about our engagement process and activities.

If you have been listening to the previous online conference presentations thus far about why KT and stakeholder engagement is important, we hope our presentation is a good followup case study to represent how we put the importance of stakeholder engagement into practice. As part of the University of Montana rural institute for inclusive communities, Tannis and I worked specifically on research in KT projects at the NIDILRR funded research center, and part of what we're excited to say as being part of RTC rural is that we have the privilege of working with our longterm organizational partner, APRIL, which is th e Association of Programs for Rural Independent Living. APRIL is a national grassroots nonprofit membership organization consisting of over 260 members from centers of independent living, their satellite and branch offices, Statewide Independent Living Councils, and other organizations and individuals concerned with the independent living issues of people with disabilities living in rural America.

Throughout the decades of work we have done with our Center for Independent Living partners, we Vietnam the integration, preservation and promotion of the independent living philosophy in our work, thus, APRIL has been and continues to be an integral partner playing a key role in this project to connect us to amazing DLIT members and we must acknowledge APRIL's contribution.

The project we are focusing on today, healthy community living, also referred to as HCL is the name of our five year NIDILRR funded development project, the intent of the project is to develop a multimedia health promotion program for people with disabilities to succeed in reaching their personal development goals. By working with APRIL across the country, we co‑created the program which includes two peer led independent living skills curricula, one is a brand‑new curricula called community living skills and the other is an updated version of our long‑standing evidence‑based living well with a disability curriculum, now being called living well in the community under the new HCL program.

Both community living skills and living well in the community were developed to support opportunities for people with disabilities to live well and participate fully in their communities. They focus on self‑determination and building self‑management skills. We worked with our partners to adapt, write, and create new consent and designs for these curricula with the intent for them to be used by trained facilitators and delivered from a website versus, for example, delivered from a hard copy workbook. Each curriculum happens its own website, and ‑‑ has its own website, and they each include slide shows, videos, discussion topics, and both individual and group exercises and activities. Facilitators use the websites to guide participants through the HCL program content in in‑person, face to face workshops. Although we won't be sharing the detailed content of these two web‑based curricula and because they are not yet publicly available, you can still get an overview of each on our HCL program website by visiting healthycommunityliving.com. Once there, you can review a description of the topics within the community living skills and living well in the community, and I encourage you to do this after the presentation.

So because the intent of this presentation is to really describe how we created the HCL product rather than what the details of the product are, I'm going to start diving into the process of our stakeholder engagements. So what is co‑creation? Before I jump into the concept of co‑creation, I want to first provide a little bit of background to set the stage of why we view and came to know that co‑creation is so important for this project.

From the beginning, what we really wanted to do with this project was use and leverage the knowledge we had gained over many years of working with CIL's from program development specifically with us are promotion program living well with a disability, living well with a disability dates back to the early 1990s, grew from research conducted on secondary conditions by the now retired RTC rural researcher Dr. Tom Seekins. The research and program development of living well was centered on the participation from CIL's and people with disabilities which then led to a curriculum that was written by and for people with disabilities he. Throughout the years, as RTC Rural continued to provide training and technical assistance to living well workshop facilitators to implement the program, our engagement with them allowed us to consistently collect feedback from them about any program barriers, strengths and desires from them for its continued development and scaleup, from this sustained relationship building and maintenance over time, we identified an opportunity for program growth to meet the service provider and consumer needs and to update the program to keep fitting within the CIL service delivery context and consumer base.

That said, in the HCL project, living well in the community is an update to living well with a disability. We knew from our experience working with CIL's throughout the years, working with any new product we pursued should need to be created with the end users to mobilize the knowledge gained through our years of knowledge exchanged, thus we envisioned a co‑creation process.

Co‑creation is as a business influence concept about creating valuable products, services and experiences for consumers and the company. Since our research and training center focuses on both individual and systems level research and intervention, we recognize that this business innovation concept fits well with our intent to listen and respond to the needs of both CIL service providers and consumers, noting they do not act in isolation within the CIL delivery system. Additionally, the act of collective creativity shared across a group of individuals and applied at different stages of a design development process facilitates meaningful outcomes that can address community problems and provide a context for integrating design, inquiry and local knowledge.

Our co‑creation approach was executed using participatory curriculum development framework to involve stakeholder engagement in the development, implementation and evaluation of each HCL curriculum. Participatory curriculum development from Taylor's book on designing training courses is a continuous and flexible process that is responsive to the context in which it will be implemented and is inclusive of the end users who will engage and use the curriculum within their context. Use being PCD or participatory curriculum development allowed us to outline process in clear stages of development to co‑create with our partners.

The image on the slide now shows the stages of the PCD framework. There's a large square in the middle of the image that says development teams. The development teams consist of all members of the curriculum development project who in our project include staff from our research center, APRIL and staff from CIL's from across the U.S. who engage understand in the activities listed within each of the PCD stages shown surrounding the center square. The first stage depicted by the red circle on the far left is called the situation analysis. This stage includes conducting a stakeholder analysis, examining the strengths, weaknesses, opportunities and threats of developing the curriculum and then a curriculum fit analysis that looks at if and how the curriculum would or could fit into the context for implementation.

The second stage depicted by the orange circle at the top of the image is the stage of developing a rough outline of the course and curriculum. The specific activities include determining the type of course that is desired or needed, reviewing any existing curriculum to influence or to be adapted to the new curriculum and then to develop the framework for the course itself. The third stage identified in the image as the yellow circle to the far right consists of developing the detailed curriculum content.

Specifically, this involved working with partners to develop it the learning are outcomes of the curriculum, specific content and lesson plans or how and what methods will be used to share and/or teach the content. The final stage which is what we are currently implementing in our current year four of the grant is to implement and evaluate the curricula. For this stage PIL's implement the HCL program, we assess fidelity and evaluate participant outcomes.

So why a participatory process? What the PCD process allowed us to do in a very well outlined way was to work with our CIL partners to identify what consumers want or need to know, how to meet those needs, identify what type of content actually supports learning and the best ways to deliver the content based in the learning objectives, and then how to really evaluate if the learning takes place by considering the context in which the knowledge is applied. By working with CIL's in the past and having gathered the feedback from their implementation of the living well program, we knew that the process to engage CIL partners and gather input for the HCL project should be clear like a continuous pathway to follow together with goals at set stages.

We also knew, however, that what we did should also be flexible enough to be responsive to and navigate various perspectives, opinions and even changing environments within their CIL context as service providers and the participatory process of PCD allowed us to do both. In reality, working with CIL's over the course of three years now has really taught us what is most relevant for participatory program design and delivery, as CIL partners reviewed and delivered the curricula with us, we were able to tailor them to fit within the real life service delivery scenarios and consider how the end user consumers may experience them. Additionally, having four stages of organized activities outlined within the PCD framework that our partners could participate in really helped facilitate thorough and consistent engagement with them over the course of time, which is often difficult to do and to sustain.

To provide a quick understanding of who all was involved in the participatory process, the image on the slide shows each of the players and how they have been connect in the project. All of the key players who contribute to the HCL project include staff from RTC rural, training and technical assistance professional from APRIL and staff and consumers for independent living. From there, RTC rural staff in APRIL serve on the project leadership team to keep the project on track and moving forward following those PCD stages.

Next we organized two different development teams, one team for the living well in the community curriculum and one for the community living skills curriculum. RTC rural staff, APRIL and staff from four different CIL's across the U.S. served on development teams which followed a weekly meeting schedule to develop each curriculum.

We identified and recruited our CIL partners by really leveraging our established relationships with CIL's in part from our long time technical assistance activities over the years to support the implementation of our programs like living well with a disability, these sites offered input and shared interest in the project both prior to and during the actual proposal development of this project. Additionally, APRIL played a key role in helping to recruit other sites assisting with writing transparent and understandable scopes of work to ensure they were framed and outlined in a way that were both appropriate and realistic for the CIL service delivery context and their capacity.

APRIL served as the point of contacted for CIL's as well, to provide consistency and consistent communication between CIL's and the leadership team. This approach as well as the team design itself worked well to steak a foundation of understanding, trust and communication among project participants. We formed solid relationships from where we could then feel confident to try different tools, processes and activities to engage with one another. When those tools, processes and activities didn't work out as well as we had hoped, the solid relationships we had already built really served us by being able to keep making progress and be willing to try another way and another tool and we definitely tried different ways.

We tried and used many tools for engaging our stakeholders and as you can read from the slide, we used a variety of tools and approaches to facilitate engagement with the development team. For example, we used a more formal and structured online classroom to share information, conducted teleconference calls and webinar meetings, had many one on one calls directly with CIL staff, we held in person face to face meetings and our most novel communication tool, however, was Slack, which is a cloud based collaboration tool similar to but more robust than standard instant messaging tools. It allows us to text chat online in specific team channels, share documents, photos and videos all in real time.

It's been a very successful team collaboration and communication tool, though not without some technological growing pains, but additionally we also set up a Flickr photo database to gather photos of what healthy community living looks like from various perspectives and from various people. This photo bank has had much subpoenas and the photos we've contributed have been use the in the two curricula and another way we tried to engage our partners was via social media.

We encouraged them to share their own photos and videos of what healthy community living means to them and even gave our CIL sites digital cameras to use for creating digital content for the web based curricula. Some of the engagement tools we used worked better than others and Tannis will discuss a few of those in more detail a little later.

Now switching gears, curriculum framework used, Tannis will take you through more of the specifics of various engagement processes and activities that executed this concept of co‑creating with our stakeholders in the PCD stages. Tannis?

>> TANNIS HARGROVE: Thank you, Tracy. I'm excited to be here today and talk to you more about the specifics of our project and working coast to coast, we're here in Montana, but working coast to coast with many of our CIL partners can be a real challenge. So I'm going to talk us through some of the ways with the HCL project that we were more successful than others, but we've tried a lot of different ways for engaging stakeholders, and one of them being our onboarding process. So we recruited people, we actually had center for independent living staff on the ground in four, no, five different states who were really excited to get on board with us, so we thought, well, this will be great, we know that we're going to start the project and we know that we want to work with these people and we have a lot of work to do, but of we also need to get them a lot of information and background both about the project, how we'll work together, we need them to set up a virtual office space so they can have Slack and communicate with us effectively in real time, so we did an onboarding process via Moodle, and it was a four week onboarding process where we had them go through various content we created via PowerPoint and then we would get on a conference call each week with everyone and discuss the content and I think overall Moodle went okay, there were a lot of technical difficulties in using Moodle and sometimes I think the challenge with technology is always making sure that people are able to access that was in. This sort of began our team building process so these calls and the onboarding on Moodle was really, really crucial for building that initial rapport and also starting to build trust with our group.

So then after we onboarded everyone and they had a pretty good sense of what we were going to do, we brought them to Missoula, Montana, which was really fun for people, they were really excited about that, and we did a two‑day in‑person meeting and this is where we really formed our development team. We brought the group together, there was about is 15 people, and let them know you'll be working with one curriculum, you'll be working with the other, and then we really started to dig in over the course of two days for that situation analysis and that's where we really started to establish the foundation, the purpose and the direction for working with each other over the next year.

And I will say that that face‑to‑face meeting was extremely foundational in our work for this entire program and to see how far we've come over the last four years, I'm really glad that we were able to bring people to Missoula and they were able to meet each other and meet us and we were all able to have a really good time and form really strong bonds and that was really crucial for this entire project, getting the buy‑in and getting trust and having our stakeholders know that we're open, that they can talk with us, that energy and enthusiasm have contempt the project moving forward in a ‑‑ have kept the project moving forward in a really positive light and I think we did a great job with that first face‑to‑face meeting in setting the tone and helping everyone know that, you know, we're not researchers off in an office somewhere, but we're here, we're people, and we really work to connect and build those relationships about face‑to‑face meeting.

So we came together for that situational analysis and then we stuck with weekly webinars and teleconferences to help us identify the type of course that was actually needed, the target population that we would be writing, the community living program for, reviewing the living well with a disability program, looking for things that were useful, looking for things that were dated, and that really meant that our partners spent time poring over the manuals and over the content, they spent hours each week going through it on their own and then we would come back together as a group and hash it out on a conference call webinar, and sometimes those were more successful than others, but as we started to develop a system for attending the webinars and getting people involved, we started to really build trust and people started to have a lot to stay.

So we developed a framework for establishing those curriculum outlines based on those webinars and the feedback we received from CIL staff, and I really love how this came together and that CIL staff were attending the conference calls but they were also going backing to their consumers on the ground and really using the information from the calls and testing it out with people. So that helped really shape the curriculum and helped us really get on the ground information about what we should be creating and what the real needs for Centers for Independent Living were.

So I again go back to that ‑‑ and you'll see this on the slide, the two‑day in‑person development team meetings as that real foundational piece for just building rapport and trust with our partners and then really empowering them to feel like they knew enough about the project to then take that to their consumers and start having those conversations. And I feel that's what really helped us develop the curriculums and move it forward.

So we also did a couple of really nice face‑to‑face meetings and one of them was an in person conference reception. So at the APRIL conference, we were able to host a reception for healthy community living to talk to stakeholders and get feedback from people who were not on the development teams he. So these are executive directors and administrative staff at the Centers for Independent Living, they're advocates throughout the nation, they're consumers of independent living, they're people with disabilities.

We had a great turnout at the reception, and we were able to do just some qualitative, I guess in the rural you just call it sitting down with people, but we really got to sit down with people and hear what their needs were and hear their ideas and thoughts for what people needed most in these curriculums. And we were able to infuse that into the weekly webinars and weekly communications, and that really enhanced our collaboration and helped us develop content that was really usable.

So then so we had a lot of different ways that we engaged our development team, and then through that process we were able to create two curriculums, which we now call Community Living Skills and Living Well in the Community. So we have these two curriculums but we don't have consumers, so we decided that we would pilot and part of our proposal was piloting the content, so actually having Centers for Independent Living take the curriculums and go through on the website with their consumers in a group for ten weeks. We had four different pilot sites again across the country and these were, the pilot sites were novel.

So the development teams had worked with us for two years and then we made the choice to find new Centers for Independent Living to pilot the program and we did this intentionally because we really wanted to both try out the content and pilot the contents of the program but we really also wanted feedback from people who were new, with fresh eyes and new enthusiasm to do delivery of the program.

So we met weekly with our pilot sites, so we had two facilitators at each Center for Independent Living, and I met with each group once a week for a year to really go through the feedback and talk to them about how their session went every single week. And they gave us an enormous amount of qualitative data about things that worked, things that didn't work, media that was included in the curriculum that just didn't seem to fit for consumers, and they provided us other recommendations or adjustments for the curriculum. And that content was really, really valuable moving forward, as we were able to make changes and really respond to the pilot teams quickly when they suggested changes, and then they were able to see that change.

So I think overall, it's pretty exciting! So we piloted the program, we got the qualitative data from our pilot sites, and then ‑‑ sorry, I'm flipping my pages here, I apologize. So I just wanted to talk a little bit more about what the program included and sort of some ways that we engaged stakeholders that I think are pretty novel or were really exciting for us at the time in particular around some of the content of the actual curriculum.

So for Community Living Skills, we had a development team of six people, and they met each week with us to talk about the content and go over that, and we would have these larger brainstorming sessions and sort of talk about content and people would share stories from their consumers or from their experiences, and we would all have these large discussions around the topic, and for one of the conference calls, we had taken a list of topics we wanted to include in the curriculum.

So we had all talked about it and sort of agreed that we would have ten sessions and that one of the sessions would include a disability history component, and we got to the conference call and we said, you know, do you think this works? Does this look like something that you would be interested in taking or teaching or facilitating? And we had one of our partners say, you know, this disability history just doesn't seem to fit for me. While I'm interested in it, history can sometimes turn people off. I think it's less about knowing the history if you're brand‑new to independent living, and it's more about if you're identifying as a person with a disability. And that's so important for Centers for Independent Living because it really starts to help people unpack a lot of that for themselves.

So that was a real change for us in terms of it was not something that we had really known, and we were able to use the information from centers for independent living to create a session really focused on disability identity. Similarly we had the same experience with technical skills in that technical skills at an introductory level can be a real challenge, so we worked really hard with our teams who said, well, let's break it up into levels, like we see some people who have never used a computer, we see some people who have smartphones and are really tech savvy, and so we actually had our development team actually worked on writing with the technical skills providing us lots of resources so we were able to create something that would work for lots of different people who came into the center.

Then that also allowed us to create sessions that could kind of standalone, so disability identity, technical skills, transportation, instead of having to go through the program week by week and one through ten, we really wanted the program to be flexible, and that was really important to Centers for Independent Living, they work with people on the ground, a lot of times they're in crisis, and we wanted them to be able to meet the needs of their consumers when their consumers may not be able to commit to ten weeks.

So we were able to create it in a way that they can take the transportation session and go through that with a group and that might be all that that person needs at that time. And this is really important for Centers for Independent Living. So we're excited that we were able to do that. And those were some of the successes and things that we were able to make with Community Living Skills.

Then our other development team, which consisted of six different individuals from staff from Centers for Independent Living, worked on the Living Well in the Community. And this was a different group with a little bit of a different focus because they were not creating something brand‑new. Instead, they were adapting the curriculum, Living Well with a Disability, into this multimedia website‑based program. So what was great about this is they were really able to go through the content and then think about how that applied to their lives and to the lives of their consumers and see if it still fit, as we know, things change over time, we really wanted to review the content of Living Well with a Disability with an eye to that, so we were able to make some shifts.

Originally we had problem‑solving as a session, and that didn't seem to fit for people anymore. That seems hard, it seems challenging, the feedback that we received from the development teams led us to realize that people actually look to their community for support. So we decided to rename that session into building support. We did a similar thing with the session that used to be called beating the blues, which feel did not resonate with, that seemed a little doom and gloom, and we were able to change that to staying on course.

Then because this was a curriculum that was already developed, we were able to make adjustments to the existing content ‑‑ sorry, existing concepts and activities on and really think about how those were linked and I think that the development teams were really, really valuable in reviewing those activities and really helping connect the activity with peer support, which is foundational for independent living.

So the other feedback that we really worked with the Living Well in the Community group was making sure that the program was easy to facilitate, and they provided us a lot of media, and the media was really important because the independent living movement is based on the idea that there's nothing about us without us, and we wanted to dispel the myth that to one is like me. People want to see people like themselves. So we really wanted to infuse the curriculum with real people in real places, and our part in other words allowed us to do that, and that made this curriculum, I think, just so much more engaging, and it really hit the mark for our development team.

So through stakeholder engagement, we did some things that were strengths and we also had some challenges in engaging people. Relationship development is key. Did I skip a slide? No. Okay, sorry. Relationship building is a key and is so important to this project. I know that I'm saying that over and over again, but the co‑creation process just would not have happened if we weren't able to meet our partners in person and get to know them personally. And then the idea of things being flexible and responsive to the different stages of the project, so really being able to take the outlines to our groups and having them look through them, having them be able to see the website and see the changes that they were suggesting actually happening in real time, and then establishing accountability for all team members.

So we stuck with those weekly calls. We're gearing up to start another round with the evaluation team because we think it's so valuable for everyone to have the time and space to work on the content and to work through it. And that accountability helped maintain motivation and also serves as a reminder for our common goal and really helps establish that investment in the work.

Some things that were really successful that we did was a lot of direct phone contact with each team member individually and then also those weekly calls. So on our Community Living Skills development team, we had two members who said I love the weekly calls, but sometimes it's hard for me to keep everything straight, I would really love to have a personal call each week. So myself and the technical director at APRIL got on calls each week with the development team members to make sure that they understood the goals and they were able to give us a lot of really good feedback, and that really helped with relationship development.

As Tracy mentioned, APRIL has been a trusted leader and liaison in the disability community, and we are so fortunate to have them here in Missoula working with us. So because of those relationships, I do think we were able to establish rapport and also provide peer support to each other as people within the development team.

So I just can't say enough how exciting this whole process was, and I know that I'm a little bit all over the board, and I think it's partly because I am so excited about some of these things that worked really well. Engaging people on a national level over two years, over three years, keeping them engaged, keeping them excited about it, can be really challenging, but we were able to use Slack and we were really able to make use of the media and programs to make this a really great program.

So some things that worked really well. We used Slack, as Tracy mentioned, which allows you to communicate in real time and we could file share and share photos and videos, and we did a lot of that. We encouraged our members to share photos of themselves, share photos of their successes, share things about their personal lives, about their success of the work and slowly and surely people got on board. We did a lot of in person ‑‑ we did the in‑person meetings which I think were just so foundational, as I've already talked about, we had direct conversations, I spent a loft time on the phone with people ‑‑ a lot of time on the phone with people, and I think that's a great way to engage people.

We also sent thank you notes and treats once in a while just to make sure that they knew that we were thinking about them and that we appreciated their work, and we've had several different web‑based celebrations, which have been really successful, where we come together as a group on a webinar to celebrate the successes that we've had with the project, and everyone just shares one highlight that they've had, and those calls have turned out to be really meaningful and a great way to stay connected with our partners.

Then we'll turn to the challenges. So change is hard. Like I said, we already had the Living Well with a Disability program, and people quite liked it, and people actually quite liked those binders as well. And while some of the clip art was not as gorgeous as our current media, sometimes program shifts can be a little bit challenging.

Also, because we do work, this is a five‑year grant, staff turnover can be really challenging. We're fortunate to have most of the staff on the HCL team remain consistent, but we had a few, you know, we lost a few staff, normal organizational turnover, which becomes really challenging when you're working on this relationship building over national lines and then also ‑‑ I lost my train of thought there ‑‑ when you're working on large time lines, and then it just becomes difficult for a new person to come in and they're not going to have that same relationship.

So then there is also this issue of reaching a consensus on the development team. So not everyone agrees all the time, and that can be a little challenging. That is a tough thing to find the balance and we would go and ask people and everyone would kind of have a different response and then they would work it out, so that can be a little bit challenging. Then also balancing the project goals, so this is a five‑year grant or development project, but balancing that with the needs of Centers for Independent Living and the need for this content now.

So this has been a real challenge is that they want the program, they want to get started the. So we're working on our end to be able to get this to as many people as we can while also meeting our requirement or our stakeholder goals.

So for next steps, like Tracy mentioned, we're in the fourth year, we're just starting the evaluation, so we will be evaluating the programs with eight Centers for Independent Living and we're really excited to get that data and to look at that. We have just finished the pilot, the pilot officially wrapped up in September, so we'll be looking at all of the pilot data to look for trends and use, look at how the content is being used, we'll also be collecting CIL staff and consumer testimonials and hopefully getting some really good data about their satisfaction with the program and how it's impacting their life.

We'll be training our evaluation sites, and then we'll be adjusting the curriculum based on the feedback that we get from both the evaluation and the pilot. And we'll be continuing to engage the staff at the eight Centers for Independent Living who are working with us, so we have 16 facilitators getting ready to put the workshops into use, so we'll be continuing to engage with them so that we can continue to grow the program and to make it fit best for them.

All right. Well, I think we also have a lot of media associated with this because putting things online means you need a lot of photos and a lot of videos, and as part of that, we made a small video to share with you all. So I think we'll turn to the video now.

(Captioned video).

>> All right. So it looks like the video has concluded. We're really excited. I just want to say thank you so much for taking the time out of your day to listen to our presentation. Again, we're healthy community living, you can check us out online at healthy community living.com, here is our contact information if you would like more information about any of the information that we've shared here today, and with that, I think I will turn it over for questions.

>> DONNA MITRANI: Thank you so much, Tannis and Tracy for that wonderful presentation. Now I'll turn over to Kathleen Murphy who will lead us in an interactive discussion. Kathleen?

>> KATHLEEN MURPHY: Sure. Hi, everyone. So I'm on the line here, obviously with Tracy and Tannis, but in case there's anyone who just joined us after the break, we also have some reactors on the line, Shauna Crane is from the Center for Persons with Disabilities at Utah State University, Susan Magasi is from the University of Illinois and the Chicago, and Rylin Rodgers is with us from the Association of University Centers on Disability much so we'll be talking to the three of them in a minute. I did want to address some of the audience chat and comments first. We have a question, and I don't know, Tracy or Tannis, you can all decide who is best poised to answer, but did you have to traverse an ethics board for any of this project or the included studies?

>> Yes. So we had to run all of this through the Institutional Review Board at the University of Montana and for the pilot everyone had to sign an informed consent, yes, so they're very involved through the IRB.

>> KATHLEEN MURPHY: And it sounds like there were some changes in processes, so how did you manage the changes in processes to keep in compliance with ethics mandates?

>> TANNIS HARGROVE: I'm not sure exactly what change in processes you're referring to. The way that we talked about it pretty ‑‑ yeah, I guess I'm just not sure what you're asking there.

>> KATHLEEN MURPHY: Okay. So Lisa has clarified, she means the variety of communication styles. So I think Lisa, forgive me if I'm putting words in your mouth, but I'm imagining that maybe there were different modes of instrumentation. Wait, she's ‑‑ okay. It seems it changed over time. Modes of maybe instrumentation that you had to include?

>> TANNIS HARGROVE: Well, we did use different technologies, so like we started with the onboarding with Moodle and then tipped it away from Moodle, but we actually ‑‑ with the exception of Moodle, which we did use for onboarding, we started the project with Slack right away and really helped support people in using it until they felt confident on their own, and so we did use a variety of communication styles, so e‑mail, phone, Slack, and we just let people know like from the get‑go that we would be doing that and really supported them in feeling comfortable using the technology.

>> TRACY BOEHM BARRETT: And I would add too, this is Tracy, that part of it was providing accommodations for people who needed different types of communication tools to engage with us. So a good example is somebody who found Slack not as accessible with his screen reader that he would have liked, so we made the accommodation to make sure that he received all of the information either over the phone or by e‑mail, so that is part of the different uses of communication style, I would say, wouldn't you?

>> KATHLEEN MURPHY: I'm thinking back to Katie McDonald's presentation on Monday where she was talking in part about including people with disabilities on the research team and having to clarify to IRB boards that these were co‑researchers, not respondents. So how did that work for your project?

>> TANNIS HARGROVE: This project is a development project, and so it's not a research project. So the development team members who were also Centers for Independent Living staff and many people with disabilities were all able to share with us their opinions and information, and none of that had to go through IRB review, so they were basically just sharing their knowledge of their work.

>> KATHLEEN MURPHY: Okay. So following up ‑‑ so Lisa is asking, so you built this variety of communication tools into your initial ethics submission?

>> TANNIS HARGROVE: Yes.

>> KATHLEEN MURPHY: Okay.

>> RYLIN RODGERS: This is Rylin. Can I add another piece from my experience around IRB and working with consumers?

>> KATHLEEN MURPHY: Sure, please do.

>> RYLIN RODGERS: So in the university setting where I was the IRB for one of our projects required that all of our community partners be city certified, and that proved to be a daunting and somewhat overwhelming barrier for many of our community partners, so we worked with the city system to create actually a class setting where we brought people together with the very important intervention of food and snacks and really talked through all that was in the city curriculum of and the tests that they would take and the process, brought in some of our medical students who had to do this getting city certified themselves and talked about their own anxiety with it and challenges around it and really worked together as a team to make sure that all of our community partners were able to successfully complete that process.

>> KATHLEEN MURPHY: Great, thanks, Rylin, that's really helpful. Jennifer Hanratty has also commented: Thank you for that really useful presentation. It seems like a really intensive process and I'm wondering how much time was devoted to keeping everyone engaged.

>> TANNIS HARGROVE: I don't know how to quantify that. This is Tannis. A lot of time. I mean, I would probably say eight to ten hours a week, talking to people. As the projector, we can't get the work done unless they're engaged.

(audio cutting out)

I would say probably ‑‑ and Slack really allows you to do that so you can online chat.

You can see when people are at their desk and then you're able to reach out to them and ask some questions or just relationship build. But I do think it's a lot of time.

>> KATHLEEN MURPHY: Sorry, when you said eight to ten hours, did you mean a week?

>> TANNIS HARGROVE: Yeah.

>> KATHLEEN MURPHY: Okay, wow. Yeah. So that is intensive. So that's helpful to know. Rebecca Parten is wondering, what was the best way you've found to actually reach out to new or potential Centers for Independent Living or the CILs?

>> TRACY BOEHM BARRETT: This is Tracy. Certainly we rely a lot on the networking capacity of our partner APRIL and despite them being focused on rural independent living, they work with urban centers as well because many of their satellite offices are extending out into rural. But beyond that, honestly sometimes we just pick up the phone and have a conversation based on, you know, the CIL network list that is listed on ILRU. I mean, we do rural research, and in our experience know the value of personal communication and you just have to put in that effort.

>> KATHLEEN MURPHY: Okay. So I think Jennifer Hanratty and referring to this level of intensity of engagement. Did you anticipate and build that into the grant to begin with, or was it something you discovered and somehow had to accommodate with your staffing?

>> TANNIS HARGROVE: Well, I guess we built it in. So the we expected that we would meet weekly, with the proposal, we didn't know about Slacking when we wrote the proposal, so that really changed things and we were able to talk with people much easier and much more, but we anticipated a pretty high level of engagement going into it, having worked with Centers for Independent Living for quite some time, we knew that engagement at the CIL level was extremely important and we knew that for that to happen, we would need to dedicate a lot of time.

>> KATHLEEN MURPHY: So it sounds like you either anticipated or were willing. What about other decision makers? Did you have any issues of decision makers resistant the to or misunderstanding the co‑creation process, and what were the tools and strategies to get them on board, if so?

>> TANNIS HARGROVE: Yes. So we had people helping us write content for a website, but we could not show them the website because we were creating it. So the first few months in particular, none of us really knew exactly what we were working toward, so that was a little bit confusing, and I think that's where the relationship thing was really important. I can't even count the number of times I would say we're just so happy that you're sharing this information with us and you have to trust us that this is really helpful. I do think there was a level of just we really frame this as they're the experts, I mean, they're the Centers for Independent Living staff, and we want to come together and hear from the experts and hear how we can use their expertise and get that into the curriculum. So we were able to do that really by building really strong relationships and spending a lot of time reviewing with people goals and objectives for curriculum creation.

>> KATHLEEN MURPHY: Okay. We did have a document request in the chat that we'll share with you later, but let's move on, because it's a nice segue, have you been able to navigate challenges related to balancing project goals versus stakeholder goals? And this is a question that we had asked Rylin Rodgers to think about.

>> RYLIN RODGERS: It's been such an interesting part of the conversation, really because I think we've articulated some of the things that are successful, and part of it is really understanding when there's a conflict around goals and that speaks to our earlier conversation around getting to consensus and sometimes having shared language, so really figuring that out, and fleshing it out really can be critical.

The other piece is that in my experience it has been really just transformative is having co‑creation in the design of the project as a way to address challenges around goals because we're working together to co‑design and identify those goals, that lessens the challenges around goals. I think what was articulated nicely is that some of the challenge comes from the funders and the process in terms of developing a five‑year grant and what the outcome is supposed to be, and one of the other strengths of partnerships is that it's often our stakeholders that can be empowered as advocates to work with systems around some of those issues. So I had an experience working on a care coordination project that had modeled share plans of care, and individuals and families and care teams that were engaged in it wanted them like instantly in the same way that it sounds like this projects team were really interested in the curriculum.

So the way the project was designed is that we weren't supposed to be able to disseminate any of our findings until the completion, and it was the partners that went back and engaged with the funders about how critical it was to be able to share and disseminate some parts of this work earlier as a functional need. So it was a nice example of where are with our consumer partners really can resolve some of the conflicts that we might not be empowered to.

So I think there's lots of history and chances to think about how to address and create that balance both in design and then in resolving conflicts through communication and then using our individual levers to see what can be done. But I also really echo the conversation about this sort of work on relationships and communication as critical, and when you've done that work and you've developed trusted partnerships, then really that conflict can be overcome because there's the willingness to sort of give you a little bit of leeway.

>> KATHLEEN MURPHY: Thanks, Rylin. So this conference, as you know, is sponsored by the center on KTDRR and our (?) primary is ‑‑ so we did include NIDILRR in our conference, Susan is one of them. Susan as you know we've used the curriculum framework that had aspects on what learners want or need to know, how to meet those needs, what content supports learning, how it's delivered, how do you know if learning is taking place. What about your project? Do you use this framework or some kind of similar framework to help plan your projects?

>> SUSAN MAGASI: You so we have used participatory curriculum design in one of our projects, creating a research readiness training for people with disabilities. And I found myself nodding vigorously as you all were talking because many of the concepts that you mentioned came up. I wanted to also, though to, mention I guess a framework that we in part created for some of our work from a research he were but then also, as a faculty member, and we recognize that a lot of students are not getting training in knowledge translation, so I created an elective in knowledge translation, and because of it, a strong vested interest in community engagement, created it using a very community engaged model that we call knowledge translation collaborative, which actually bring both graduate students together and members of the disability community together to form these knowledge translation collaboratives where they really work together as co‑learners of knowledge translation so that students come out prepared to engage with communities and then communities also build the capacity to work as part in other words.

Then they work together over it is course of the semester to do so ‑‑ to create knowledge product rather than full blown implementation, but through that, you know, really building off some of the principles of transformational learning, and it sounds like across a number of projects discussed today, that there have been these elements of seeing problems or seeing issues differently, and we experience that in both our students and our community partner participants, that equity focus knowledge translation model that I mentioned in the previous session that really seeking to go rebalance power relationships within teams, and I find the more I use that, the more I like that as a tool for planning projects to really think about what voices get heard, what gets left unsaid and what opportunities do we potentially miss as a result of that. So that's what I'm going to stay to answer that question.

>> KATHLEEN MURPHY: Just a quick follow‑up, is that training available online?

>> It is not currently. It's done as a graduate seminar here at the University of Illinois at Chicago, but if anybody is interested in how we've done it, I would be delighted to talk you through some of the elements and how we've created it. Also, you know, immersing it in an active line of research, working closely with our local Centers for Independent Living as mentors throughout the process as well.

>> KATHLEEN MURPHY: Sure thing. We'll get you together with SIL.

Shauna, we only have a couple minutes left, but are you able to give some quick tips on building trust with partners who you don't know very well?

>> SHAUNA CRANE: Yes, and thank you. The best I can do is reiterate what this group from Montana has done in initially having that face‑to‑face meeting and bringing everyone in, and I know it's expensive, but there is just not a better way to initiate that trust, and at those face to face meetings, you can work on the relationships, which is where trust comes from, looking for common concerns, a lot of time for conversation, make sure there's plenty of time on the introduction side of things so that people can connect in some way, and then as you set up smaller groups, if you do that sort of thing in your project or your research, don't let them self‑select and then they have to work with other people that they don't know that well and develop those relationships. If you simply cannot afford are to get the group together or the clients, the stakeholders together, then a platform like we're using now through you Adobe Connect that has a video sharing component, make sure everybody has got a camera, and if you have to get them one, it's worth it. And make it so that you can see each other and have an opportunity for conversation that's as close to face to face as you can get it. But the trust is built through relationships, and initially you have to do that when you're looking at each other.

>> KATHLEEN MURPHY: Thank you so much. With that, I would like to take this opportunity to thank our printers Tracy Boehm Barrett and Tannis Hargrove, as well as our reactors, Shauna Crane, Susan Magasi and Rylin Rodgers for the great discussion today.