**2017 KT Conference:**

**Knowledge Translation Outcome Measurement**

Interactive Discussion with Presenters, Wrap up

Kathleen Murphy, presenters, participants, reactors: Mark Harniss,

Margaret Nosek, Arielle Silverman

Originally Recorded on November 1, 2017

YouTube Link: <https://youtu.be/Vj3JsdmBRaA>

\*\*\*

KATHLEEN MURPHY: Hi, everyone. This is Kathleen. I was just talking, but I'm assuming I was muted so I'll repeat what I was saying. Diane, thank you so much for a really, really fascinating presentation. I'm still thinking about it. It's almost hard to formulate questions about it because the material is so sophisticated, so to really like chew through or make explicit the kind of wonderings that I have, and I'm sure other people are, I think is a testament to how great the presentations were.

And it's a nice complement to the earlier ones this afternoon which were much more practical, hands on, looking at applications, and how might one identify tools for tracking implementation whereas you're a nice counterpoint for thinking through what needs tore measured or what are these processes we're trying to get at the tools we might glean from the LIBRE project and rehabilitation measurements database. So, to start a little more formally, in case anyone is joining, I'm Kathleen Murphy. I direct the Center on Knowledge Translation for Disability and Rehabilitation Research. Mark Harniss is clinical associate professor of rehabilitation medicine at the University of Washington. You do you want to say hi, Mark?

MARK HARNISS: Hey there. Can you hear me?

KATHLEEN MURPHY: Yep. You might want to speak a little more loudly, and just while we're talking about volume, my own voice is a little weak today, so I will keep an eye on that be presenter chat in case I need to speak up myself. And I suggest other people on the phone do that as well. Margaret Nosek. Margaret, I'm assuming you want us to call you Peg as we know you. Margaret, Peg is a professor at the department of physical medicine and rehabilitation at Baylor College and director on the Center for Research on Women with Disabilities, which people call crowd. Peg, you were starting to say hi?

MARGARET NOSEK: Yeah, Hidey-ho and go Astros.

KATHLEEN MURPHY: Great. The third respondent is Arielle Silverman, disabilities research and training consultant and owns her own firm, disability wisdom consulting. Are you with us?

ARIELLE SILVERMAN: I am, hello everyone.

KATHLEEN MURPHY: Great. Thanks so much all three of you. I hope you've gotten a lot out of the presentations and we're looking forward to hearing your ideas about them. So to kind of warm up the crowd and get people besides the handful that have been using the chat a little opportunity to use that and get comfortable with it, we're going to do a couple of polls. The first one is, which aspects below relate most to your work? Choose one. Knowledge creation, inquiry, synthesis, product development. The action cycle, designing and tracking KT strategy implementation and impact. Or does your work really include both aspects? Or really, it's just, you know, you do something else. If you'll remember, these two aspects were presented in Diane's presentation. It was the graph that had the knowledge to action model with the triangle in the middle with the inquiry synthesis and tool product development and then the action cycle going around describing how you would promote use of what knowledge has been created. So, while people are working on that poll in case some of you are just joining us, I wanted to introduce the presenters who are still with us on the phone. I know, Diane, you said you were going to stay with us on the line, right? You're with us?

DIANE FINEGOOD: I'm here and I'll stay.

KATHLEEN MURPHY: Okay. Great. Is there anyone still with us from the LIBRE product or who phoned back in?  Yes. Mary Slavin.

KATHLEEN MURPHY: Thanks so much. And Allen Heinemann or Linda Ehrlich-Jones, are you with us?

ALLEN HEINEMANN: We are both here.

KATHLEEN MURPHY: Wonderful. Thanks so much. That's great. Because I'm sure there will be questions for both of y'all as well as Diane. So let's just kind of look at our poll results. Looks like over half of you consider that your work involves both aspects, and then one in five are focused primarily on knowledge translation or other aspects. Other than that, no other comments. Okay. Let's pull that poll down and put up another one which is in which disability domain do you do most of your work? Would it be employment, participation and community living, health and function, technology, or something else? So, NIDILRR grantees who are with us, you will recognize these categories as priority areas that NIDILRR funds so I just thought I would explain that. I know we have a lot of people outside the NIDILRR community today so that's where those categories came from. Okay. So this is not surprising. Okay. So let's move on from the polls, but given that result, I would ask our presenters since we're not all on the call here today from health and function background that we might want to attend to thinking through how the work we're talking about applies to employment and participation of community living or other fields outside of health. Okay. So the questions that we had asked Mark and Peg and Arielle to think about ahead of time are pretty generic, and what we're going to try to do is link back our discussion to the theme for today which Mark Harniss, you just started to do that in your questions to Diane about, what are the implications if we're thinking about complex systems for tools and tracking implementation. So, the first question is, how does tracking implementation relate to NIDILRR grantees and their findings. So given that this is a conference sponsored by the center on knowledge translation specifically for disability and rehabilitation research, are there specific ways that we can connect tracking implementation or raise concerns about it in relation to being a NIDILRR grantee or disability-oriented researcher? Arielle, do you want to start?

ARIELLE SILVERMAN: Well, I don't know how much this relates to tracking implementation, but I've been thinking in general about the three presentations and how they're connected. And some of the common themes that came up between the three presentations, and I think one of the things that struck me the most is the fact that KT needs to be iterative and not just kind of a process, like a linear process where somebody does a study and publishes the results, and then the results get disseminated to the broader community, but instead, it's an iterative process where stakeholders are brought in at the beginning thinking about how the LIBRE project was conducted where -- were brought in at the beginning of the project, identified problem areas, then moved down to developing specific skill items and then a measure was developed by the research team, and then again with collaboration from the community, and then results were disseminate to the community. So, this iterative process, I think is really critical in determining that there's back and forth between the researchers and members of the broader stakeholder community, and then I think that also relates to Diane's concept of complexity and there's not just a linear relationship. It's really important to have those perspectives intertwined in a reciprocal way.

DIANE FINEGOOD: So Diane here. I would say, I completely agree with that notion of the iterative nature and you can't wait until you have some results and as we used to say in my office, throw them over the fence to the people who you think want to pick it up and read it. You have to be working across that fence and with people all along. One cautionary note, though, in terms of unintended consequences could be, if you work with stakeholders and/or people affected by a disability, prior to getting resources for doing a project and that process you're undertaking is, say, for example, figure out what the interventions are going to be and the metrics and then you apply for the grant and you don't get it, you have a potential challenge there with the individuals who aren't used to the grant life of an academic and the fact that we get, if we're lucky, 10 percent of what we apply for. That kind of circumstance. People can be quite disappointed so I think that's one cautionary tale about that and then the other cautionary tale, which is kind of the opposite approach, I sat on a grants panel recently where a number of the applications said, we are going to co-develop and co-produce the metrics and intervention that we undertake in this particular domain, and then the grant will have committee has the challenge of figuring out whether that's a good project when they don't really have the project well defined and they're not used to that kind of project and you might get compared to other projects where things are well-defined. So I think moving to an iterative process will also require some of our cultures and systems to change as well because they're not really set up to manage in that kind of a context.

MARK HARNISS: This is Mark, and Diane, I think that makes so much sense. And it is a big part of the challenge. I realized as we were, as I was listening to the presentations and thinking about some of the questions that have been posed, I've ended up a little confused by what we mean by, what kind of an implementation we're talking about and I think your intervention level framework helps quite a bit because I think a lot of the implementation that I had in my mind was really at that level of structural elements so thinking about tracking implementation being things like, looking at fidelity of implementation or looking at unexpected adaptations to the interventions we develop or taking it beyond that maybe up to the level of goals to looking at outcomes and obviously the first two presentations dealt a lot with measures of outcomes. And so I think that, kind of being able to think at which levels of that intervention level framework we're thinking about as it relates to implementation is important. And I do agree that we have, especially in the grant writing culture and review culture, we really want to see that you very clearly know all the structural elements and all the pieces and you have it all put together. And so allowing for iterative and reflective design to happen in a project, it can be challenging to write those grants and to get them funded.

DIANE FINEGOOD: Let me just add, your initial comment is right on. We've got a couple of publications out there, the one, I think, that's listed under the intervention level framework slide actually used the framework to look at strategies for addressing obesity. And I think it was actually childhood obesity in that particular paper so we took all of the recommendations for implementation or things to implement and sorted them by the framework and what you find almost every time you do this is that the vast majority of the things that we're thinking about doing are at the structural element level, and we rarely think -- we rarely think about feedback loops and delays as a strategy for change. And certainly as we go up the food chain and get to paradigms, we're rarely thinking about that as a strategy. And it's not surprising because of the evidence-based medicine paradigm culture that we're in and the fact that it's pretty tough to get empirical evidence as it relates to what happens at the goals of the system or we make a change in the deeply held beliefs. I think those are incredibly important areas but we don't study them very well.

And I do think, in particular, the really underexploited one is around feedback loops and delays. We don't usually think about strategies that are in those domains, and yet, if we look at systems and we think about the interconnections and we think about interrupting or adding interconnections, we may have more effective approaches to intervention than if we're just circling in on one of those variables.

KATHLEEN MURPHY: Peg, did you want to bring anything up in the conversation now? I know you have a long, long career of trying to get a lot of things done including, I think, reducing obesity, right?

MARGARET NOSEK: Yes, that was very interesting, actually, to hear Dr. Finegood talk about that model. You know, we've looked at that model and we have tried to add elements that are very specific to people with disabilities, including medications, how disability characteristics, which may affect even the engine itself. Some people who have a mobility element to their disability. And also we try to add environmental variables, and it doesn't fit. You know, it doesn't fit. And it's really hard to get anybody interested in this. I mean, just bade on the number of rejections, people don't seem to really care that, you know, disability and the changes that cause obesity. So, that level needs to be changed and I'm not sure how we as researchers from the rehabilitation field can have the power to get them to listen to us. Which model are we referring to?

MARGARET NOSEK: The obesity map that came out of the UK.

DIANE FINEGOOD: Spaghetti and meatball diagram I like to refer to it.

MARGARET NOSEK: Exactly. Maybe that's next question of how can we move from our critique of what's already out there to getting them to change the model and use it in policy as well?

DIANE FINEGOOD: I guess my reaction to that is, don't try to change the model. Build your own model for your own purposes, so what is it you're trying to achieve? And if it's an understanding of how disability intersects with variables that are also in the environment or related to the individual, then what you need to do is go about building your own conceptual model. I think of that as a conceptual model or just a heuristic. I don't really care, honestly, about those interdependencies. You can't really use that map beyond as a, I think the main tool that it presents is a tool for discussion and for engagement. And when we zoomed out of it and saw that nobody really thought food consumption was driven by food production, it initiated a conversation or was fed into a conversation.

So I think I would think carefully about what the goal is and then construct your own heuristic and it may be causal loop diagram is the way to go but there may be other forms of juristic that are actually more important. Like I'm wondering if you're thinking about disability how it affects an individual's paradigm, what levels of framework are important? It might be that a different frame is more valuable to you.

MARGARET NOSEK: That's good advice. Yeah, because disability changes everything. The kinds of things you have access to, the way you digest food. And so I think what we're talking about is creating another layer on top of that particular model where these elements that we have, we as people with disabilities have to live with every day and how it radically changes the balance in that model.

DIANE FINEGOOD: Yeah, it's also really important to remember what one of the originators in this area said, all models are wrong. Some are useful. And as we said here, you know, the model is really just one articulation and it's the people who, in a sense, were in the room. So, I think it sounds like you don't want to think about it as building on, but as creating a novel tool for the purposes you have in mind.

MARGARET NOSEK: And if I could take the whole issue to one more level, your whole presentation made me realize that I think rehabilitation in this broad field of health promotion research, we tend to apply simple solutions to complex problems. That, what's really going on out there is closer to chaos, you know, with different people, researchers, just taking on their own approach and it can be simple, it can be complex, I mean, it can be complicated but what they're really dealing with is a very, very complex situation. You can't just prescribe physical exercise, in other words. And then say, go back to a meeting. You can't just treat them with physical activity because there are so many other elements, the psychological, the social pressure, the logistical issues, the environmental barriers are paramount for us. So it's so complex. I get really irritated at interventions that do nothing but look at physical activity.

DIANE FINEGOOD: So I totally agree with you that we do too many simple things and think they're going to solve a problem and they're one little structural element. But I will just make the comment that I think sometimes when I think about this and I look at the slide on solutions to complex problems, some of those ideas in there, like building trust, albeit not really simple is a simple concept for tackling that problem. It feels distant for some people, but actually, it could be a very effective approach. So, not all of the solutions that are appropriate for complex problems are complex in and of themselves.

MARGARET NOSEK: That's a kind of hopeful observation. I'm noting, Martinna Roes has the comment, looking for heuristics, triggers in my mind the need to understand underlying mechanism of the intervention/translation/implementation than just looking for "Easy" observable components. So there's clearly a tension here between being aware of the spaghetti and meatballs that we're looking at but also wanting to bite off something

that's measurable and how can one researcher or project intervene within that network of phenomena. So I don't know.

MARK HARNISS: This is Mark. It's a question I've been thinking about as we've been talking and maybe Diane, you could respond to it. Are simple and complicated systems sometimes part of the complex systems? Can researchers who are going to have to write grant proposals that are relatively constrained, can they cut off chunks of a complex system to work on or is it really something that has to be done more holistically?

DIANE FINEGOOD: I guess what I would say is that absolutely systems are made up of systems are made up of systems and it all depends on how you want to draw the boundaries for the system and its interactions with its environment. So defining boundaries is actually a fairly important part of thinking about a system. So absolutely, it's feasible to do that and may be necessary for researchers who are working in a system that still believes in reductionist science. But what I would argue is you'll benefit from always thinking about what you're doing in the context of the whole system in a more integrated way. In other words, don't lose sight of the fact, you've defined the boundaries in some way. There are interactions between that system and other systems, and as you think about the results, it's in an integrated way that they become more powerful.

So, I think that's part of the dance that we might need to do as researchers to get things moving in the right direction. I also personally really want to see people start using some of these ideas to develop, you know, the empirical evidence that policy makers would say a systems approach to intervention actually has proven to be better. There's not a lot out there like that. There are a couple of studies which have used the principles of complexity in doing a synthesis of other studies. So one really interesting study looked at interventions for type 2 diabetes, and they rated the group of papers that fit their criteria, I think there were about 30 papers, but I'm not necessarily remembering that correctly, where they just took the papers. One rater, one axis of rating was, how many of these four different aspects of complexity did they consider or were embodied in the intervention that they attempted. And then a different person rated them for their success in kind of a very simple 0.51 scale. But they found actually quite a good correlation between the number of aspects of complexity that were considered, and the success of the intervention. And I think that's a really important learning and it helps us develop the evidence that's necessary to sort of drive us in the direction of using systems thinking in the way we do interventions, and the way we think about them. Now, interestingly enough, I just came from a conference on complexity in healthcare in which I heard a preliminary presentation of using that same methodology to look at traumatic brain injury and they didn't find correlation but it seems likely that the lack of correlation comes from the incredible variability within and between stories as it relates to traumatic brain injury. You guys are the experts in disability, but my understanding is that there's tremendous variability within and between studies which could make a synthesis of that sort quite difficult to do. I'll stop there.

KATHLEEN MURPHY: So, thank you. It's Kathleen. You know, I think of a telescope and your presentation, Diane, I'm looking at all the stars and thinking about the entire universe. And then if you think also, well, there's also a microscope and the LIBRE project, if we're going to measure anything, then there's incredible complexity in, you know, wherever we look if you're going to be careful enough about the measurement you're developing. So Mary, I don't know if you had any thoughts or reactions or comments as you're listening to this?

MARY SLAVIN: From the microscopic level, you know, when we think about the LIBRE project, we are looking at, I wouldn't say microscopic as much as, you know, very specific focus. And within that focus, it's not looking small. It's looking at something that's, you know, when you think about the complex problems, you have to start somewhere. And picking a somewhere to start that is known to be fruitful because the people who are living with burn injuries tell you that's a fruitful place to start. I think we can then begin to direct activities into areas that are going to inform the larger picture even though we are looking at just a smaller issue which would be social participation. And you know, I find, I've been a clinician in rehab many years and also researcher and professor, and the thing we're missing so much is the measurement piece and being able to look at what we do and how we affect lives in a meaningful way. And I would maintain that the LIBRE is really offering us an opportunity to look at what occurs during the recovery process and allows us to figure out how to intervene in meaningful ways that it might not be the whole picture but it's an important piece of the picture.  I guess that's one important detail. We'll look at data points on spaghetti and meatballs. Here is the experience with the individuals and burns and the types of experiences that should be measured, and how it's important to do that.

MARY SLAVIN: It is a data point. So in that way, yes, it is a very specific point but it relates to something that would be very hard to talk about without a data point.

KATHLEEN MURPHY: And even now, think about a multiverse, to use the metaphor again, so that within everything that we're looking at in spaghetti and meatballs, there are their own incredible complexities. Which ironically is how you get at the paradigm, Diane, in your diagram

MARY SLAVIN: Yeah, I think the going back and forth, here's your scale on the LIBRE profile, social participation scale, and how that fits into the larger world you live in which is why social participation is difficult for people with brain injuries. And when we spoke with people with brain injuries, they agreed it was partly their issue as well as the environment they're in. So they definitely had some opinions on how important it is to change the environment they're in, but also, every person that we spoke with talked about this sort of epiphany they had where they made a decision to become more engaged. And then we'll be able to learn a lot more about what happens during that process by having that one data point of, this is where this person is and why are they there and where are other people, similar time post burn injury, where are they? And looking at the continuum, strategies to help people achieve a good outcome.

KATHLEEN MURPHY: Sure. And Allen, or Linda. I'm thinking about, you know, inventory of measures in your database. How much do they vary in scope? You know, as far as what they measure. Do you have a sense of that?

LINDA EHRLICH-JONES: This is Linda. There's a wide variety. I mean, we do have performance measures. We do have patient reported outcomes as well. You know, as we mentioned earlier, there's over 400 instruments right now, but I don't know that I

could give you a catalog.

KATHLEEN MURPHY: Sure. Obviously, we appreciate having the URL so how much, a big of a chunk that Mark was suggesting, how we want to bound what we're looking at through the number of measures potentially in your database that would be of use.

LINDA EHRLICH-JONES: Yes, and I think I neglected to say earlier, I mean, you can do a search looking without knowing what instrument you're looking for and there are several filters you can use that will help you narrow down to the population whether or not the instrument is free, if there are certain body parts or certain areas that, you know, you want to narrow it down to. So, you can come up, then, with a list that will be some things that are somewhat similar

MARGARET NOSEK: This is Peg. I have a comment, please. I would like to bring up the issue of trust again simply because I see a lot of that -- what did you call it? Congenial hypocrisy?

DIANE FINEGOOD: Cordial hypocrisy.

MARGARET NOSEK: That's it. I see a lot of that. A lot of people go into therapy or go into rehab and nod their head, say, oh, yes. I'll do that. Oh, yes, I'll do all these things you're recommending to speed up my recovery and they go home and they don't do it. So, is that -- you can see this in the utilization rates for assistive technology. They have all kinds of data showing uptake, how much they really do use them. So does trust have a role then? If we could improve trust between the consumers and the researchers or clinicians, would that improve compliance? Now, you're saying yes, I think, if I understood in your chart correctly, Dr. Finegood. But, how? How can you -- what are interventions for that trust factor?

DIANE FINEGOOD: So, really good question which I'm not sure I can answer, but let me think it through a little bit, and ask. What do we know about there's so much cordial hypocrisy. They might be polite but they're not planning to do anything about it. I don't know if there's trust there, but that might be a part of finding out if lack of trust contributes to the situation. In terms of interventions to build trust, one of them would be around repeated engagement and opportunities to share and learn from each other. I suspect our indigenous colleagues here in Canada would argue, understanding where a person comes from like their family. So often, engaging a patient, the place to start is talking about your family and where do you come from and who are your grandparents and grandfathers and things like that. So understanding a person's story is a first step to building trust in really disparate communities.

I actually convened a workshop, several workshops a number of years ago that were titled, Building Trust to Treat Obesity. We found really interesting things in that dialogue. One is that within sector trust actually is harder to build than between sector trust. So here we were talking about academics, governments, NGOs, and for-profit industry. And in each of those, actually working with others in your sector is actually more difficult than working across sectors. So across sectors, the challenge is understanding that people are coming from different places. Within sectors, you're actually competitors.

So this is going a little away from your question about the client practitioner relationship, but maybe following up on studies -- would give you some clues about where the patient provider trust factors could be built. And when you build trust, you actually reduce the complexity of operation and what you're doing and you're more likely to get the signed engagement from the individual that you want.

Understanding where they're coming from for me would be a really important component. And we can't make assumptions based on age, demographics, gender, et cetera, et cetera. I'll just give you one other quick story -- I know we're just about out of time --

KATHLEEN MURPHY: I'm sorry, Diane. We only have 30 seconds left so I think we're going to have to hold on that story and wrap things up, and I do just want to give a big thanks to the other presenters that have joined us today, and invite everyone to join us on Friday. We'll be here during the same hours, 1:00 to 5:00, and our theme for the day is Strategies for Measuring Impact. We will have David Gough from the Epicenter, Mark Carrigan digital sociologist, and Melanie Barwick will give a presentation on KT planning. So, in between, if you want to check out our KT expo, feel free and otherwise we will see you on Friday.