**2017 Online KT Conference:**

**Knowledge Translation Outcome Measurement**

Interactive Discussion with Presenters, Wrap up

Kathleen Murphy, KTDRR; presenters, participants, reactors: Claudia Diaz,

June Gothberg, Dahlia Shaewitz

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JOANN STARKS: And now I'll be handing things over to Kathleen Murphy. She is the director of the center on KTDRR and she has carried out this role for us in the past and has done a great job of moderating the discussion session. Kathleen, are you ready to take it over?

KATHLEEN MURPHY: Hey there, this is Kathleen. Joanne and I are actually sitting around the same table so I'm getting close to the phone so everybody can hear me. We’re going to launch into the last session of the afternoon. The point of this time together is, we have a chance to digest what we’re learning and we have a way to think about how there are cross cutting themes in the presentation, how they apply to our own work. So we do have questions we brought up in registration and we'll also try to be addressing those. In addition to myself on the phone, we have Dahlia Shaewitz, who is a managing director at the American Institutes for Research. Dahlia, are you with us?

DAHLIA SHAEWITZ: I'm here. Hi, there.

KATHLEEN MURPHY: Hi, Dahlia. And I know June Gothberg, the principal research associate from National Technical Assistance Center on Transition at Western Michigan University, have you been able to call into the conversation?

JUNE GOTHBERG: Hello.

KATHLEEN MURPHY: Wonderful. Thanks for joining us. Now, Claudia Diaz, are you on the phone? We didn't see you log in earlier. Perhaps something has come up today for Claudia and she hasn't been able to join us but I just thought I'd check to see if she was. Claudia? Okay. So, if she does join in, we'll integrate Claudia into the conversation but we do have throughout the week some other representatives from the ADA Center systems so we look forward to engaging them. To warm us all up, we're going to start with a couple of polls to get a sense of who is in the room with respect to what might inform our conversation today. So, for poll 1, what roll best describes your reason for attending this conference? Are you a researcher or perhaps you're a knowledge translation professional, which some people may not know that actually is an occupation that's emerging in recent years?

Perhaps you're a technical assistance provider or trainer. You may be a clinician, service provider or practitioner. And I know I often design surveys, and people love to be “other” so that's just fine, but tell us about it in the chat box. What distinguishes you from those other roles?

So, we do have some other here. Natalie DiMeo is a research coordinator in a producer group research department with new responsibilities in knowledge transfer. So that will be interesting to hear more about. Okay. But it looks like we've got about four in ten of you are researchers, a quarter of KT professionals. One in five are clinician/service provider/practitioners, and then 7 percent TA providers and trainers. And Melanie is a scientific writer who is also with new responsibilities in KT.

Okay. so while people finish out that poll, I wanted to introduce the presenters that may have been able to join us back. Chris McBride, were you able to call back in?

CHRIS MCBRIDE: Yes.

KATHLEEN MURPHY: And Ron Saunders?

RON SAUNDERS: Yes, I'm here.

KATHLEEN MURPHY: And Jennifer Flagg, were you able to stay on?

JENNIFER FLAGG: Yep, I'm here.

KATHLEEN MURPHY: Great. So we have one other poll and because so much of this afternoon had to do with audiences, we thought it would be good to get a sense of what audience you try to primarily engage in your KT activities. So we recognize for some of you this question may not apply. KTDRR does a survey every year of grantees and we ask this question of them, and the most highly ranked audience as far as numbers is always other researchers, so we have that here, and then second for NIDILRR grantees typically is clinicians or service providers. We thought we could include policymakers, and typically NIDILRR grantees the third audience they try to reach is people with disabilities and/or their families. And this, of course, is when we force a choice. You might want to scroll down so people can see that they should also include other audiences, which could be businesses. Lauren, can we end the poll?

Great. So we definitely have a mixed audience that people are trying to reach so I think we can go ahead and kick off the discussion now that we have a sense of diversity of our participants. The theme today is overcoming barriers to outreach. How do you think these presentations relate to NIDILRR grantees or others who work in the field? Dahlia, I know you've been prepping for this. Do you have any thoughts?

DAHLIA SHAEWITZ: What I found fascinating about all three presentations was this real focus on stakeholders involving people with disabilities or clinicians or whoever that audience S engaging them in meaningful ways, not just in nonmeaningful ways. So, what I found particularly of interest was Ron's slide 14 where he showed the spectrum and I've always thought of it as a research continuum and where can we plug in our stakeholders, but he really talks about it in a three dimensional way. Not only where we can plug in but how deep can we get in that engagement? And Chris also talked about very deep engagement, and then I'm going to mess up the name, Laura Flagg, but also talked about it in how to get that beta testing, efficacy throughout the stages of development. So not quite sure I'm answering your question but I thought this was an interesting theme that carried through all three presentations.

I guess what I'd really like to know at some point from the presenters is where have they seen some really innovative interesting successful engagement strategies in each of their domains.

KATHLEEN MURPHY: Would any of the presenters like to answer, Dahlia?

DAHLIA SHAEWITZ: I don't know about innovative, but maybe just asking research questions is fun times. I just think there's a lot of really good examples of people who have taken the time and cared to approach this in the right way that makes them stand out against, I'll call them competitors because people are competing for resources in community organizations like mine, so the people that stand out are the people that do it well and it's not necessarily innovative, that an innovative response is required, but just more of a human and personal connection that's created.

RON SAUNDERS: Ron here, that was my hesitation, too, was the word innovative. I think there's a lot of people who are committed to doing integrated knowledge transfer and exchange, you know, with building relationships involving people in meaningful ways. And frankly, to some extent, the growth of that depends on funders, right? To the extent that people who are the funders of research grants demand that, then more of it will happen. But they need to demand it not only in grant applications, they need to be following up that people are actually doing it. But if more funders are committed to that, that would create an incentive for people to do it.

JENNIFER FLAGG: Yeah, hi, this is Jennifer. Sort of piggybacking on this and one of the themes we saw throughout the discussions today was that integrated KT is really critical. So that may not be innovative, but certainly in our experience, we've seen a lot of grantees working on development projects sort of in isolation. They may be involving consumers and stakeholders in the development process but perhaps they're not engaging a transfer partner or manufacturing until they have a prototype in hand. And what we've seen in the past is that often leads to failure either because they weren't aware of something that the company was developing or their output just isn't something that can be realistically produced.

So, now, we're seeing a shift where more and more grantees are involving manufacturing partners at the onset of their projects, and as a result of that, we're seeing more success, which, of course, leads to these products getting to the market and into the hands of people with disabilities to improve quality of life.

DAHLIA SHAEWITZ: Excellent. Thank you, Jennifer. This is Dahlia again. I had one other comment and it's always coupled with a question. I think that technology transfer, reaching out, can sometimes be a challenge for researchers who haven't received training to be able to do that. And I've always been on the mind that not everyone on the research team needs to do outreach, not everyone needs to bring the product to market. You just need some people to be able to do that. And we've run into barriers like having enough time and seeing the connections between engaging stakeholders and then seeing the success that comes from that, the impact. So, I wonder if the presenters could also speak a little bit about that.

JENNIFER FLAGG: This is Jen. I just have to jump in that you mentioned that not all stakeholders on the research team need to be involved, and you're right. I think what we've seen, though, is that often there isn't anybody on the team who has business or marketing or that experience with talking with the manufacturers shall and that's where the stumbling block occurs. So in any research project if you had to do some statistical analysis and you didn't have that capability on your team, you would bring that in. Similarly, if you don't have the business expertise on your team, bring that in. Whether that's collaborating with the business department at injure University, leveraging your tech transfer office. We've seen some grantees who are very successful working with their TTO early on in the project to really sort of identify the market, the potential partners. But if you leave that to the end, it's just a recipe for disaster.

KATHLEEN MURPHY: Great, thanks, Jennifer. And in the chat, Heather Gainforth is pointing out, great point. It will be challenging to know which researchers need to engage and what level of skill is required for all researchers to be able to see the value in the integration of knowledge occurring on the team. June, did you want to chime in here? I don't want to leave you out of the conversation. Is there anything you want to add?

JUNE GOTHBERG: Sure. I didn't want to interrupt. So when I thought about today and the goal is around that knowledge transfer and overcoming those barriers for that, I thought that Dr. Saunders had a really good point that one of the outcomes of today is really thinking about planning for measuring your impact. So not just the implementation stage but looking at what kind of impact these funded projects have. And as a funder, NIDILRR is really interested in funding outcomes more than those inputs. So, for potential grantees, I think this is really helpful because it points out that you need to plan for that evaluation component during your logic model process.

And then I just thought Dr. Flagg brought it home, looking at that framework and continuum of how to get from the planning phase all the way to the impact phase. So thinking about that business case and applying it to all the projects could be really helpful, thinking about planning for that, how are you going to know whether or not you made a difference from inception rather than, you know, trying to think of it as an add‑on. So, that's how I thought this really applied to the grantees and looking at that field work.

KATHLEEN MURPHY: Great, thanks, June. Were there any reactions? Okay. Well I do want to integrate. Some of the questions we promised that came up earlier we would try to address those during this time in the day. So Dahlia, to your point about innovation and innovative strategies and Chris, your use of the videos as a way to researchers could try to recruit to their studies, you know, Heather Gainforth and Lisa Engell both implicit in their reaction was that it is innovative because they're imagining that their research board will be unfamiliar with n kind of subject recruitment. So how did those researchers handle getting IRB approval for the use of these videos? Did they submit a script ahead of time, or how did that work? Do you know?

CHRIS MCBRIDE: No, they didn't. Because we did the videos and we weren't actually involved in those research projects. So we were kind of outside of, I guess, the ethics issue. But that said, I'm not sure that the researchers themselves were. So we didn't have any issues or any consequences to doing those videos, but it probably warrants more exploration from the academic side to know how that should be handled properly from there.

KATHLEEN MURPHY: So, has anyone, you know, on the line or in the chat box done innovative recruitments where you had to explain ahead of time? Typically, you do need to get approved ahead of time. Your consent letter, the tweets, the Facebook posts you might be posting, the things, Chris, that you get where people are asking, could you forward this to your email list, has been approved ahead of time.

CHRIS MCBRIDE: Yeah, and everything ‑‑ that kind of stuff that we receive has been approved. But when we're taking information and translating it for our members, I guess it's interesting, because we're not really bound by any of those restrictions unless we're actually involved in the research project itself. So, it's a bit of a gray area.

KATHLEEN MURPHY: Yeah, that's fascinating. I mean, I do think ‑‑ and this is just based on my experience and the IRB, I do think that to address the questions, it's one word to develop a script for the video and submit that and describe and then get kind of preliminary approval because of course you don't want to invest in the video if the IRB isn't going to approve it and then they watch the video, I would imagine that would work out. Although I'm not an IRB member so I welcome anyone who might be listening in. I think others who our researchers are participating today would be helpful. Yeah, so Heather is saying, I think the script or key messages would be approved and it shouldn't be a problem.

CHRIS MCBRIDE: I agree with that.

KATHLEEN MURPHY: So Lisa, the script would it decrease the humanized aspect of the video, the part that was very engaging? I think someone could get familiar with it, and that as long as they didn't adapt it in such a way that it changed the concept, I don't think you would have to voice the script totally verbatim. But again, that would be something to negotiate. So Heather is saying, we get the key messages that are partners used approved and say they can distribute via their own media channels. Okay. So there's obviously different ways to go about this. It's complex, it looks different every time. Right. And Kathryn Sibley is pointing out, I think you couldn't go wrong by trying to engage the ethics research board as you're developing your plan for this. In other words, Chris, you're saying talking about it often. I think IRB appreciates this as well because they consider themselves to be one of these stakeholders.

DAHLIA SHAEWITZ: Kathleen, this is Dahlia. There was one other thing that really jumped out at me and it was Ron's slide 8 where he talked about the four pillars and the third one was, what researchers mine by. And I found it so fascinating because I work with many researchers who like to be very precise in their language. And yet we saw example of the videos and one was really fun to watch a researcher having a hard time explaining something, but in a real human way. That can be a challenge sometimes to translate information in a way that's relatable, palatable for our general audience or particular stakeholder because when we make it more relatable, we lose that precision of language and it feels less exact. And I'm just wondering if the presenters or anyone in the audience has addressed that and how have you addressed that?

RON SAUNDERS: It's Ron speaking. Yeah, I think it is a real art to be able to take research, the language that researchers use, and turn that into language that knowledge users can access and apply while being faithful to the methodology, right? While being accurate and faithful to the methodology. I think it's a real art. I think we are very fortunate at the institute for work and health that we have a communications manager who is superb at that art. It takes ‑‑ but it takes a lot of effort to sort of painstakingly sometimes go through multiple back and forth with scientist about, you know, with you can we use this phrase instead?

So I don't have a formula for it, but I think it is doable in terms of remaining faithful to the precision of the work while expressing it in language that stakeholders can access.

CHRIS MCBRIDE: I would just add that it's not always just the language. Tone is a component of language, and that's a really important piece when you're trying to connect with, like, for us, with our membership, we try to use a certain type of tone in our language. And that's an extra nuance that's really hard. So, it's not always just the words but how you're using the words.

KATHLEEN MURPHY: Could you give an example?

CHRIS MCBRIDE: I guess, and this is where the balance with precision comes in, but we just would articulate a sentence in a way that would be more conversational than it would be technical. Just as an example. So, you know, you can use different kinds of words, but you could also structure it in a way that would be more familiar to our readers or viewers.

KATHLEEN MURPHY: Okay. I think I see what you're saying. Perhaps conveying research findings could be framed by questions and then the answer to the question.

CHRIS MCBRIDE: Yeah, and you might make it friendlier. Like throw in a couple extra bits that make it friendlier. It's kind of hard to describe that. But, that's sort of an important ‑‑

KATHLEEN MURPHY: I think I know what you're going to talk about, and I'm going to plug. Jess Chaiken is a very active participant and she writes a newsletter for the international newspaper merits.com and I think that's a good example of what you're talking about if anybody wants to check out, she's waving to us, the notes that she writes.

So, I had ‑‑ Dahlia, when you were asking about, you know, does a research team have the capacity to engage in some of this outreach? A similar question could be asked, Ron, when you have your arrow that, you know, people like and love the discussion around it, as you can see. Do you think that, you know, that there need to be selection criteria around who could play those different roles or that it's more the job of the project that research capacity might need to be built among volunteers or, you know, partners who are going to get in various aspects of the project all the way to co‑PI? See where I'm going with this?

RON SAUNDERS: I think so. Well, we do, I mean, we do sometimes target individuals within the key stakeholder communities if we're looking for, you know, particular capacity. Right? So, some stakeholders may be asked to play a stronger role than others would. I suppose an example would be, you know, if we're doing a systematic review of the literature on some topic, and we might have a multistakeholder advisory committee, but we might also have some stakeholders that from our experience have demonstrated a sufficient sort of understanding of research methods or have participated in our systematic review workshops to actually be a reviewer, a reviewer in the sense that they are in there with the research team in terms of assessing the relevance and quality of articles that are part of the, you know, systematic review. So, you could have different stakeholders playing a stronger role depending on their capacity, their expertise.

KATHLEEN MURPHY: And do you provide the training, then, to those systematic team members?

RON SAUNDERS: I mean, for all of the team members we would provide a kind of overview of how the process works, and what the methods are at a high level so the stakeholders advisory committee would get that as well but we also do these workshops on how to conduct a systematic review. So, stakeholders who have participated in that, or who have been part of multiple stakeholders advisory committees and we feel that they now understand the methods enough that they could be a reviewer partnered, as we always do, with a research member of the committee. Then we move them into that extra level of engagement. We could make the engagement more intense.

So, we do different types of capacity building in order to try to allow our stakeholders to become more intensely engaged over time.

KATHLEEN MURPHY: And just while we're talking about your project, Charlene asked earlier, how did you decide on supporters, what organization would support?

RON SAUNDERS: Well that predates my time at the institute but I'm going to take a stab at it based on my knowledge of the history here. So, the Institute has had a practice of having regular review ‑‑ like they're a five‑year review cycle where there was an external review committee that looked at the Institute over a five‑year period and prepared and interviewed people in the Institute, stakeholders who were potentially users of the Institute prepared a report sort of assessing the quality and quantity of the Institute over that five‑year period. And my understanding, although he wasn't here, is that 15 or 20 years ago, one of these reports said, you're doing great research, really high quality research, but we don't think that you're doing enough to get that research in the hands of people who can use it and to ensure that it's relevant to the people who can use it.

So, one of those five‑year review committee reports really pointed to the need to do an integrated KT in order to really make a difference. I think it also happened that at the time there was a very strong KT practitioner at the institute, John Labus, some of you may recognize the name because he's done some important work in the KT literature who was at the institute at the time who was able to help the organization respond to that comment. So at the time, there was a communications function and a kind of dissemination focus but not the relationship building or integrated KT part. That part was much weaker at the time.

And between the review panel and Labus's own personal expertise to help drive that forward, there was a commitment to add those two pillars around relationship building and integrated KT, and ultimately a commitment from our core funder to provide core funding from a KT team and then that was further developed by my predecessor, and I came on board that only about six or seven years ago.

KATHLEEN MURPHY: Got it. So, so much rides in all of this on relationship building and Dahlia is wondering how do or can researchers create a mechanism for engaging stakeholders thus maintaining the relationships that Chris underscored when there is no current project or funding? And Jennifer, since your presentation started with the NIDILRR peer reviewers as your listed stakeholders, so clearly if one is going to be presenting a KT approach and documenting that one has the capacity of its network, as part of the grant proposal, do you have any thoughts about that? Because this is, you know, before you're funded.

JENNIFER FLAGG: Right. Yeah. I know. That's a very challenging aspect, isn't it? And especially with the Need to Knowledge model, if you look at all of the steps in there we actually do talk about completing the activities in those first two stages prior to completing your funding. So it sort of becomes a labor of love and in my experience, one of the best ways to maintain collaborations when there's no funding is by volunteering yourself. You become a champion for whatever causes you're trying to serve, right?

So whether it's getting a little release time from whatever duties you're currently doing professionally or after hours, engaging those stakeholders, I think that's how it gets done and I'd love to hear if there are other opportunities like that, but just as an example, I started up a collaboration with a professor at a local University, other than University of Buffalo, and ended up with an inventor coming to me with a product she had designed and wanted to see if there was any market potential.

So, off‑hours, I helped her hook up with this gentleman at the over University whose technology transfer class completed a marketing report for her. Well, in the end, in our next grant proposal, we wrote this in as an actual project, this collaborative project. So it was just because I was willing to put in that sort of sweat equity at the onset and be the champion for this relationship that that was able to continue into an actual funded period so I'm curious to hear what others have to say on this as well.

JUNE GOTHBERG: This is June. I absolutely agree with what you said and I think there is a relevant approach to putting yourself out there, either as a volunteer or board member maybe for your local ARC, that's in the U.S. But I have seen a lot of collaboration come out of that from different community organizations and higher education when they've come together on to a board or into a voluntary role.

JENNIFER FLAGG: That's a great point serving on boards. That's actually how my interaction with this other gentleman began, serving on the local chapter board. So great point. Thanks, June.

CHRIS MCBRIDE: It's Chris. I would totally agree with the volunteering thing. That's a really, really good way to stay in touch but it doesn't always have to be that involved and I would say that my favorite question from Heather when I talked to her was how can I help? I think that question can be asked periodically just with check‑ins. Hey, Chris, how's it going?

Just wondering if there's anything new or if there's anything you're thinking about we could work on together. Just a simple check‑in every once in a while is really helpful.

KATHLEEN MURPHY: Yeah, I'm just looking at the chat box. Jess is pointing out that maybe keeping the involvement through the debrief when a grant is rejected increases their knowledge of the process. She's responding to Heather, I wonder if anyone has advised how to encourage partnership when a partner grant has been rejected. Academics used to rejection while rejections to our partners can be very disappointing. So, obviously, we're talking about KT and talking about relationship building in this specific context, but it does strike me that this is just true in general and that in some ways, applying for a grant is like applying for a job and I want you to have experience before you even can get the job so you do the internship or the volunteering and build your network and talk to lots of people. Which might address Tinja's question earlier saying I'm talking about the administrator or organization person who is usually the point of contact. What do you do if that person leaves?

Chris, you already pointed out, well, try to have relationships with more than one, or perhaps it might be more than one organization. So some of it is just showing up at conferences like this and putting yourself out there. Because Dahlia is agreeing, a good suggestion, Jessica, can help the entire grant team to understand what areas to improve and keep the partners engaged afterwards. So again, sharing the information about what happened to that grant so they understand as well. We do have about five more minutes. I don't see any other questions in the chat. I think we've addressed all that. We do have these other two questions, right? So how might one use the information that was presented? Dahlia or anyone else on the phone, did you prepare an answer to that that we haven't been able to discuss yet? Have you rolled your comments kind of already in?

DAHLIA SHAEWITZ: This is Dahlia. For me, yeah, I think I rolled it into my comments and also yeses about that communication piece and whose job is it to communicate and can that role be shared, so I really appreciate Jennifer's response.

JUNE GOTHBERG: Hi, this is June. I just had a comment after listening to all three presentations, and that is that we need to be very cautious about using proxies. So there were some challenges brought up of engaging throughout the presentations and understanding that one person has difficulty responding to a larger group, it's also really important to have it the actual voice of the individuals we serve to be at the table through that entire planning implementation analyzing process.

I've seen it done really well several times. One of the researchers that comes to my mind is Dr. Gordon Bonham who had a project with the Maryland rehabilitation State Group. I don't remember exactly what their name was, but it was called the Ask Me project, and they used individuals with developmental disabilities to actually conduct some of the research. So if you Googled it, there's information out there, and I just wanted to put that push out there because I heard Dr. McBride make a statement that he said that co‑responsibility and co‑production is the antecedent to tokenism, and I think that statement is also so valuable when we apply it to our clients.

KATHLEEN MURPHY: Absolutely. And it does, that comment helps us to address our third question. How can overcoming barriers to outreach improve the lives of people with disabilities? You know, Chris, did you want to elaborate on June's point about that?

CHRIS MCBRIDE: Well, yeah. I mean, I think the co‑production of knowledge is one of the major facilitators to overcoming barriers, and when you have the voice of people with lived experience involved, then you're going to get a lot of things right in the project. Whereas, if you're just making assumptions on what you think would be the priorities or the way the language or whatever without having them involved, you're opening yourself up to a lot of pitfalls that will create more barriers than will be overcome.

KATHLEEN MURPHY: Yeah, I mean, it definitely seems like it would increase the relevance of what is being produced, whether it be a developed product or findings for, but we hope people will pick up and use. And in that outreach, Heather is pointing out that we can be clear at the risk of grants on the front end, we need to ensure that the whole group knows that not everything is funded. But, of course, back to the point when we were talking about, that you need the relationship before you can apply for the grant. So, nothing is ever lost in developing these relationships. Then you have that, you can turn around and think, well, if that grant didn't come through, what might make sense going forward?

So, I think we do need to wrap things up for the day unless there's something that somebody really needs to correct or clarify. All right, well, thanks so much to Dahlia and June for thinking through these questions ahead of time. We really appreciate your thoughtful comments and discussion. I don't think the NIDILRR director or our project director are on the line anymore, but we obviously appreciate them joining us at the beginning of the afternoon and I want to give a big thanks to our moderator for today, Joann Starks, who is, basically runs this show. We really appreciate the presenters today, Chris and Ron and Jennifer, especially, for staying on until the ‑‑ I wouldn't say bitter end. I'm going to say sweet end of our afternoon.

And really, to everyone on the line, we really hope that today's session and this discussion has been useful to you. That you can take it and apply it to overcoming barriers to outreach associated with NIDILRR‑funded work or whatever pays your paycheck.

And all of you, so please do join us for day 2 of the conference, which is not tomorrow. It's on Wednesday, but it's during the same hours, from 1:00 PM to 5:00 PM eastern using the same link, same log‑on credentials. Our theme for the day on Wednesday is Tools for Tracking Implementation, and we'll be joined by grantees from the LIBRE project at Boston and Harvard Universities, Lewis Kazis, Mary Slavin, Colleen Ryan & Jeffrey Schneider. Then we'll hear from Alan Heinemann and Linda Ehrlich-Jones from the Shirley Ryan Ability lab, they will be talking about their Rehabilitation Measures Database. Then we'll end the afternoon’s presentations with a really great theoretical presentation on knowledge translation. It's really a not‑miss. It goes into all of its complexities from Diane Finegood of Simon Fraser University. And then to wrap up the day, we'll have another interactive discussion like this one but we'll be joined by Mark Harniss of the University of Washington Center for Technology and Disability Studies. He's also co‑director of the Americans with Disabilities Act Knowledge Translation Center. And Peg Nosek who has been active today. Thanks, Peg. She's with the Baylor College of Medicine, and Ariel Silverman has been with us as well so she'll be talking on the phone and she represents Disability Wisdom Consulting. So please join us. Thanks so much.