**2018 Online KT Conference:**

**Engaging Ways to Engage Stakeholders**

Disability Rights in Science: Community-Engaged Research with People with Disabilities

Katherine E. McDonald

Originally Recorded on November 5, 2018

YouTube Link: <https://youtu.be/2PiVDwRE2PU>

>> JOANN STARKS: Our next session will be with Katherine McDonald who is the‑ she's‑ also a professor of public health in the college of fort and human dynamic and the faculty with the Burton Black institute with Syracuse university. Disability rights and science, community engaged research with people with disabilities will review theory, evidence and actionable strategies relating to engaging people with disabilities as equal members of research team.

After the presentation, Kathleen Murphy will lead the interactive discussion session. So Katie, if you are ready, please take it away.

>> KATHERINE McDONALD: I think my work is going to mirror much of what we have heard from Sarah and Mark.

>> JOANN STARKS: Sorry. This is Joann. I wanted to also please ask our audience in the chat box to really focus on the topics at hand and try and keep your comments related to the session that we're talking about. Not to be too personal, but to really just focus in on the issues we have in the presentation and we hope we don't have to remove anybody who is not able to follow up with that. We want to remind everybody that the chat box is for topics related to the discussion at hand. Katie, please go ahead.

>> KATHERINE McDONALD: Thank you. My work takes ‑‑ what I am going to present today take its don to a more granular level and thinking about how do we do partnerships with people with disabilities. That's why I titled my presentation disabilities and science. How do we move into the space of thinking about how to do science differently so that it helps and advances disability rights?

I will spend time on three main areas. You will often hear me talk about committee engaged research as a general strategy for thinking about how to partner with committee stakeholders and doing scientific inquiries. What do we mean by committee engaged research, why do we want to use it, but then also begin to look at evidence base. Is it working and turn to some actual concrete strategies and drawing from my own work which is largely people with developmental disabilities, but uniquely thinking about how can you do community engaged research.

But to start, I first have some questions for you. So following up on some polls, I am curious. There are two questions presented at once F. on your screen you do not see all of the response options, simply scroll down because I am curious to know how familiar you are with kind of the theory, the evidence based and a variety of effective strategies that you might use to do committee engaged research for people with disabilities. So on a scale of not at all familiar with extremely familiar, how you would self‑rate yourself, but I am wondering what are you most familiar or comfortable with. So wondering if you ever use any of the following approaches to committee engaged research which include collaborative research, community based participatory and inclusive research, action research or outcomes research or some other form of community engaged research.

I know this second question is select one. So select the one you are most familiar with and we'll give folks a moment to consider and respond. This is great. It seems like we have most folks on the call have at least some familiarity and, um, others or moderately familiar with prize approaches to doing collaborative research. It looks like lots of folks work within the patient center. So we probably have a lot of health researchers and collaborators on the line today. But there are also a lot of people that come from the community-based research CBPR tradition. Thank you for sharing your work and where you come from.

The work I want to share today comes from a variety of projects. So instead of infusing you all with the details as we GI wanted to acknowledge the different projects which include the ADA park, the aspire which is academic autism spectrum partnership and research education, the community for all projects, project ethics, and again people with developmental disabilities and the safety project partnering with people with intellectual disabilities and there are a variety of individuals and groups that have contributed to these projects. I want to acknowledge and thank all of them as well as the funders which include the administration for community living and the association for university centers for excellence and disabilities.

You will see at the end are a variety references. If you want to learn more, you can see that at the end of the slides. You will notice when I talk about my work, sometimes I use for people first language and talk about people with disabilities and other times I use identity first language such as autistic adults. Most of us see on the line, reasonable people can disagree about what appropriate terminology and strategies to use to talk about the group of people with disabilities. What I tend to do in my work is something we talk about with each collaborative project. How do people want to be labeled themselves, but also how do they want their community labeled? My language you will see using today reflects the preferences of my collaborators.

First a little bit of background. You know, why are we thinking about how we infuse disability rights into science and why are we thinking about community engaged research as a way to do research with people with disabilities? A theoretical background, if you will. Of course, as we know, people with disabilities experience a host of disparities and there are many things we need to get to health equity and participation or education and equity and one thing that we need is to produce scientific derived information this can help inform the nature of disparities with driving those disparities and help us figure out solution to those can help us achieve equity. So many of us think that science is a good thing and can help for this struggle of social justice. But against, that we've also aware there are legal, ethical and social dynamics that lead people for being understudied. Dimes this work is underfunded or pursued by scientists. Many times they're implicit lie or explicitly excluded and sometimes without their explicit consent. We tend to see often a mismatch of values and priorities in scientific approaches. As a metastatement, people with disabilities have largely had little influence over the scientific enterprise. We want to move beyond that. We want to get ourselves somewhere else. We want to make sure people with disabilities are able to directly participate in research, to be research participants to be included as equals with everyone else. We know that had a host of benefits from the very individual level that I've been asked to contribute and seen as worthwhile, but also we have better information because we are able to understand the experiences and preferences, et cetera, et cetera, of people with disabilities. We also want to move to a place where others aren't making participation decisions for us. We want to have consent processes and research decisions that are self‑determined and made by the individual. Maybe with support.

We also include more people with disabilities and research, we have to pay attention to interpersonal dynamics. It can lead people to feel more or less phased.

So that's where we want to go, but we don't always know where to get. There one of the tools is to use committee engaged research. In this case, I tend to pull most directly from community-based par participatory based research. It is a direct response to the issues that are faced by marginalized populations and research. Under community-based par participatory research, community representatives, in this case people with disabilities, but become full members of the research team N. that collaborative process, there's an equitable exchange of power and expertise. So each person, each party is having something to contribute and valued. So each person has insight and the capacity to contribute, but also needs to learn. And the goal is to not only generate new knowledge and significantly derived findings, but also disburse action for equity.

One of the wonderful things for a host of other forms of engagement is that it can be used with any research quality. Continue can be anything. Theoretically, we think that we want to use these forms of approaches to research because we think it improves the science. We think that it helps improve the capacitation of the committee members, that it can increase self-determination or control one's life and we think it might help budge knowledge translation.

In the next slide, I just illustrate what that collaborative process looks like a little bit more. This is one of the graphics we use in my aspire collaborative a lot to think about what did it look like when we do community-based par participatory research. In the middle, you have three boxes. We first develop a research study. We have to figure out what we're going to study, what's the problem we're interested in, what's our general design and how are we going to have funding with the resources to do that work.

Once we do that, we go to implementation. We have to recruit people, collect data and analyze data and figure out what we found. We move to dissemination. We draw our conclusions. What does it mean to interpret what we have found? We think about what we need to do to do something in response to what we found, and we try to translate those into practice. When we do community-based research projects, we think about community resource sometimes called co‑researchers making unique and different and valued contributions. So for example, I'm a professional researcher. I have a Ph.D. and I'm on the scientific side of being on the academic researcher. So the things that die as research unfolds is we're going to develop as new study. Let's make sure it has scientific value, it builds from previous findings and theories and let's make sure we're leading funder priors so we can attract those resources to do our work. When we move to implementation, I work to make sure what we're doing is safe and scientifically appropriate in how we recruit and get scientific rigor as a general practice. My contributions to the dissemination phase are publishing findings and academic outlets and making sure our work builds on what we have done previously.

My community collaborators make equally valued, but different contributions. We develop our studies; my community partners make sure when we're doing is a community priority and relevant to the community. As we move to data collection, they make sure we're having accessible instrumentation, but also how we recruit people feels safe and is effective reaching people. When we turn to dissemination of our research findings, they help make sure what we produce helps the community, that we have information that is understandable, relevant, publicized in the right venue. They might be flyers and town halls and they're different thing than our scholarly products.

So there are many different ways of doing community engaged research. First popularized by Kurt Levine in the 1940s and they have shared roots, but many different branches and sometimes they can involve different levels of collaboration and power sharing.

I have my next poll question for you which is in the work you have done to date, what aspects have ‑‑ how have you engaged people with disabilities? Have you worked together with people with disabilities to write grants? To design consent protocols and materials? As researchers on IRB applications? To help design recruitment and research instruments? To design interventions? To help recruit participants? Select data to analyze data and share signings and academic outlets or policy and community-based outlets? Again, if you don't see all the response options, just scroll down. This is a select all. So select as many things as you have done. This is exciting because we have a few folks sharing they have findings. We don't see that as often as we always like. We value a lot of people who work with people with disabilities to help recruit, participants to design interventions and even from some of the early phases in designing grant applications and proposals. Thank you. Great to see a lot of varied experience.

So if that's the theory, how are we doing as a field? Are we able to put this theory into action and actualize, if you will, the benefits that we hope? A few years ago, I looked to see what was happening in terms of meeting engaged research with people with developmental disabilities. It is not all people with disabilities, but we know this is a group that is particularly marginalized, but also as research collaborators. When you look at the literature in terms of people talking about does this get us to better science, does it help capacitate the community, does it lead to more empowerment and knowledge translation, you can see that folks say first, yes. We are doing community engaged research with people with disabilities because of the theoretical reasons. All the things we named are important. The infusion disability rights, the opportunity to do better science. That is why researchers are saying we are doing this. They have also said that we believe it is creating more appropriate research and that it's improving the quality of our science and our ability to translate that science into action. They also say it's not easy. There are a lot of things that help them to do community engaged research with people with developmental disabilities, there are things that get in the way. I will talk about those more in a second. It is exciting there are more and more people doing community engage with people with disabilities. You see a lot of us fall short in terms of true power sharing. But there's also a pretty weak evidence based. It is not really clear what our practices are in the field.

A few years ago, I had a chance to study some of my colleagues. They were engaged in a multi‑year project to design a quantitative survey with people with ‑‑ excuse me. Autistic individuals and people with intellectual disabilities around their history with violence victimization and its consequences for health. Over the years they did their committee engaged research, I was able to study that process and learn with them along the way to see how it went. In resonating with what they found in the literature, they agreed in the artifacts of theory search process suggested there were indeed, many facilitators and many things that help promote committee engaged research with their collaborators of disabilities and this included this residence and the values that are community based and disability rights there. That ‑‑ there is a foundation from which to work from. Community members with disabilities talked about how important it was when they saw the academic researchers take those values and translate them into actions and actually demonstrate their commitment to that. As they saw that develop, their ability to contribute developed and it strengthened and solidified their collaboration. They felt because they had paid a lot of attention to the diversity of their team in terms of lived experience, but also in terms of some people who were bridge spanners and academic researchers and had lived the disability for example, they were the ones who helped them collaborate. They placed a lot of different structures that helped them communicate with one another and I will show examples of those in a minute. They also thought because they engaged in reflective practice, they paused to think about how are we doing, what are we doing, can we do it better and that also helped them have a strong partnership. But with that, there was a lot that got in the way. As a place of innovation, there wasn't a lot of history for them to build from. Others would have done that work and created a toolkit for them to use and guide their work. Because so many people were very new to doing this type of work, they didn't necessarily know what kinds of accommodations they needed to be a co‑researchers and community researchers. So sometimes figuring out what those accommodations were as well is also sticking to them over time was a challenge. Sometimes they felt different members had a different understanding of what it meant to give community-based par participatory research and they didn't always have action they reflected that were 100% hearing to the theoretical framework. Often it was because of the inadequacy of resources and time pressures as we talked a lot about the elder presentations that ‑‑d academic pressures can make it difficult to truly collaborate and the time that is needed to do that. Sometimes they felt it was difficult to share power and have opportunities to collaborate to figure out how to communicate with one another in ways that everyone found accessible and understandable. And then they thought the work was hard. In this particular project, they were adapting several existing surveys to be accessible to people with developmental disabilities and they really struggled. It was a lot of hard, hard work and they were also doing that in the contention of violence victimization. They were looking at things that can be triggering. There were dimensions of that that made it difficult. They fell short on being able to truly represent the full range of people with developmental disabilities. But with that said, they did feel they achieved a certain level of success and saw outcomes on multiple levels. They felt as individual project members they had learned, they had grown as an individual as a professional, as a community advocate, they had acquired new skills, they had met new people with added both to their social capital in many ways and had an opportunity to contribute to something meaningful and some to earn money, which was incredibly important to them. They thought their work had paid off in terms of quality of the project that because of the multi‑year work, they rated valid and accessible survey instruments. They had better recruitment and success in data collection efforts and they felt they had created a partnership to leverage that knowledge to turn it into action better than if they had not done that collaborative process. They also thought their work to say something to say look. Look at we, us people with developmental disabilities to use something so routine and look at what we do. They also felt they had created a model of inclusion. We look at a lot of community agencies and they try to create (inaudible) or governing structures that are truly inclusive, but power is difficult to shift and to equalize. They felt they had done a good job and could be a model to other settings to try to think about how do you fully include everyone. And they were excited they had generated new findings they thought would be important to document the extent of violence victimization and implications for their health.

To quote a few of them, things they shared over the years, so on the challenges side, I find it real hard sometimes when group members are talking, and they don't ‑‑ and they have real hard work. This is really frustrating to me. When you don't understand something, it is pretty hard. You feel like why am I here. So that quote helps us think about when you are not truly inclusive, you are not including everyone, you are marginalizing folks. So one person said often we stopped things and go back. One or more people have addressed confusion. We can address that. Another member of that collaborative said that see my suggestions considered and implemented without giving me the 9th degree was also quite lovely. Another added. I am learning more so I can help orders to advocate for themselves. It is empowering to be in charge of a topic like this rather than being on the receiving end of the application of this topic or the study of this project. And in creating other science, another member said it brings people together. So there is not a big gap between the community and researchers. Things are more accurate. Lastly, in terms of social benefits, our societal benefits, sometimes people don't realize people are capable of doing things like this.

So now I want to get to a bit more granular level. I want to show you product of our collaborations, what we have created and make work along the way. And also a few strategies that you might be able to take moment to your own projects. Few things that show what we have created as a project and what I have out there is a sample segment of one of my consent forms from my study. Many of you may have seen university provided Tim blames for doing your ‑‑ templates for doing your content forms. They have a lot of dents and they don't necessarily make sense. What we forget sometimes is that we are not beholding to using those templates. We have a responsibility to communicate is an amount of information, but we have a responsibility to make sure that information is understandable to our target audience or population. What we do in the content forms, for example, this project is we really add a lot of white space. We bold key information and keep sentences short. We define terms. This is a sample consent form we use in the project.

One of the other things that we have done is help reduce the cognitive load of participating and communicating around even just making a decision about being in a study or deciding to continue on with that decision. We have created these visual communication guides. So on the left outlined in purple, you will see one we use with folks as they're trying to make a decision about whether they want to be in the research or not. And there are ‑‑ so this was a focus group. There was a picture of people coming together to talk and it is outlined in green that had a smiley face and a go-ahead signal. And then there's a red one with a cross out and big no’s and hands stopping to say I don't want to be a part of this. People can understand those choices and be able to point to them or to referenced pictures rather than come up with the words themselves. But not everyone is ready to make a decision. Maybe you don't know right now and maybe you need more information from us. Maybe you need to go talk with somebody else about your decision or maybe you want some more time. We continue those visual communication aids during data collection by making sure people remember where they can stop at any point. They can take a break or it's okay to keep going. So we use that same kind of red for I like to stop maybe for today and maybe for the entire project. I would like to end my participation. Maybe I need to take a break. This has been hard work. Sometimes it's physical or emotion. I need a drink. I need to run to the bathroom. I need to move my body, whatever that is or no. I'm good. This helps reduce the cognitive load around what somebody wants.

The of the thing that we have done is response scales that illustrate for folks how we would like them to respond. So for example, on the top of your screen, you see five cylinders that are empty to full in varying levels and this is a question to rate how important something is. So is it not important at all or is it very important and you can see visually this idea of something getting more full as it is more important. To help people understand the differences and how they might want to respond. We have done that with a mile scale or a frown to smiley scale. It looks familiar to those of with you the pain scales used in held care settings. This is from not at all to very much and we have a frown to more neutral face to smiles. And these help folks respond to our survey questions.

Some of our qualitative projects, we have used this approach on the screen in front of you. We want to give folks a sense of where they are in the data collection process. So how far along are we? We might have six major questions that we're asking in our interview guide. And at the start of that, we keep them up 1 through 6. We haven't gotten there yet, and we flip them over to red and maybe cross them out to show the progress. At the end noting look. Check. We got it all. Let's celebrate. That was a really great effort.

We have also done that with focus groups. So we have projected on to a screen our different questions. And so along the top and green text, it says bad things about and along the bottom, you will see four different pictures which are connected to each of our interview questions. We would cross off each question as we got to it and circle in red. People can see where we have been and how much more there is to go.

When we have done things like online surveys, we make sure to define or explain any terms that folks might not be familiar with. So this is an example where we use the hot box. If you weren't sure what we meant by participating, you can click and find a little bit more of a definition. In our ADA Park project, this is an example of how we are working with committee members to display and give information that may be useful to help understand disparities experienced by people with disabilities and help on a local level. We have as medium within each state with people with and without disabilities. And we also display that in a table so that it is accessible to folks using screen readers. In our aspire project, we have created an online healthcare toolkit. We went from basic needs assessment and looking to see where there were healthcare utilization pattern differences from the general population and figuring out where there were unmet needs and how we might begin to create those to creating a toolkit to help support autistic patients and providers to improve the quality of primary care. You can go to AASPIREcare.

So getting more granular. How might you begin to think about using some of what we have done? There are lots of ways to do this? Lots of great strategies. But from our experience, wanting to share a few more as we think about community engaged support and three‑core dimensions. How do we think about relationships? How do we think about accommodations and power sharing? In our experience, this really fuels whether community partners with disabilities feel respected and whether you're able to build trust among members of the collaborative and how do you receive IRB approval. We have many international attendees. We have IRB which is institutional review board. It looks at the ethics and are you protecting participants adequately? Are you minimizing risks? Are you securing informed consent? In other parts of the world, they're equivalent processes, but some people find the IRBs can be a stumbling block to doing collaborative research. So I thought we would share a little bit of our tools there.

First on the relationship side, right, if you're going to do community engaged research, you have to identify potential partners. How do you develop those relationships? And how do you maintain those relationships? What we have found has helped us have successful and very long‑term relationships. One of my collaborative is over 12 years old at this point. And ongoing and continuous to do work together. From the get go of any partnership, really figuring out how to define the goal and the role people will play. What is it we're going to accomplish? What is outside of that scope? What are we not able to do because of skills or expertise of the team or funding constraints or funding limitations? For example. And what role are each of us going to play and how are we going to work together? I the show you an example of something we used in our project. We pay a lot of attention to thinking about who are we going to invite around the table? It is not just an open call. We need to match people in terms of their skills, their experience or expertise, commitment and ability to be part of as research collaborative. So we're thoughtful. What's the diversity we need around the table? What is the experience we need around the table? And making sure we think about how people come together.

In our work, we have multiple stakeholders, but sometimes people part of the service delivery system. Sometimes family members and we're not always able to figure out collaboration strategies so that we can have a full range representation as possible. We often have people who are a part of that and making sure they share values and commitments with disability rights, for example, brings them to the table to being a really good collaborative and treat everyone to respect and make sure accommodation are in place so that we can be inclusive.

We also found time on personal relationships is important. Opening up with ice breakers or visioning exercises or just getting to know each other in social spaces and caring about each other as individuals has been really important. Along the way, we have always evaluated those relationships. Where would we be falling short is in terms of how we treat one another and who is at the table and what we're missing.

If you do community engaged research with people with developmental disabilities in particular and you want to try to share power, accommodations become a really important aspect of that. How did we think about making sure everyone is included and able to contribute because of the environment that we have set up. One thing that's interesting is in each of our projects, none of the accommodations look the same. It is a very individualized process. We do in the research project is figure out with people, what they need and participate to contribute. We recognize those change over time. Or maybe they need something now they didn't need before because their health condition has changed. For example. We work really hard to eliminate any barrier to reliable presence. Some of my projects who work in person, some of them are online collaborations, remote collaborations. For in person one, we provide haven't. That is transporting folks in private vehicle. Sometimes that means Tara transit with people and we do a lot of ride sharing, you name T. we work with everyone to make sure they're at a meeting. This includes authorship. One thing we do at each meeting is say that somebody is in charge of being our process monitor. So somebody is ‑‑ holding the responsibility for keeping each of us accountable to sharing to our group guidelines. We change on who is that process monitor. Again, I will show you that in just a moment.

We work really hard for decisions and discussions that we will have. I will show you more examples in a moment. We always build in breaks. We know this work is hard. And so we make sure to do the self‑care that we need. We offer inclusive food and beverages. We make sure to take into account dietary needs and preferences and again, we make sure to evaluate this. How are we doing in terms of power sharing and folks accommodations? What more do we need to do or how does it need to change.

When we then move into the space of seeking ethics board or review approval, we phase a lot of attention to strategies there. And I should share that I come at this from a variety of perspectives. Not only am I a researcher who needs approval, but I'm also a member of an institutional review board or been a member for many, many years in many different institutions. I have a lot of different experience, but I'm also a study of how we think about including people with disabilities and research. I come at this from a variety of perspective. Making shire that we help educate the IRB or that board and how our co‑researchers are different from the research participants. They are not the same. Often they're confounded in the eyes of the IRB and they want to apply the same lens to co‑researchers when they are in fact not.

Pay careful attention to what are the roles going to be of our community researchers? Are they going to be involved in recruitment and consent ‑‑ recruitment and consent or not because of the nature of that study or because of their preferences? That differentiates how they might be identified or talked about on an IRB application. Because most boards ‑‑ all boards in the United States require that any research have training on ethics, but that is not accessible to people with disability particularly people with developmental disabilities. We actually create project specific trainings and research ethics 101 that are accessible and really targeted to the roles that those community researchers are going to play. We bring those for approval and we do them within the contention of the collaborative.

I will breeze through the next 3 slides because you have them with you. We created with one project to talk about what community researchers can expect, what they will be asked to do and what they will get out of doing the work with us.

Moving on to slide 29 because I know I moved along quickly. These are group guidelines we created together to figure out how to work and share power and respect everyone and make hour that folks feel they can contribute. We do things like saying we will start and end our meetings on time. We will make sure that any thought that seeks folks to express and folks feel welcomed and encouraged and valued. Sometimes we make sure to say our name before we are speaking because some folks struggle with putting a face to a name. Making sure we stay on topic. Sometimes we do check in. Sometimes we do popcorn discussion and whoever has a comment says it. Other times we do round robins. We make sure we hear from everyone. Especially because some people might take more time to think and some people might be less comfortable to jump in when they feel the conversation is going quickly. Those are just a few examples we did in one project.

In terms of our structured communications with one another, on slide 31 there's an example of an e‑mail that we send out. This is my aspire collaborative. Any time we send out an e‑mail communication, the subject line is very specific, and it has a new date. And the body is very structured to say what is the purpose of that e‑mail communication, what actions might the receiver need to do, and all the background information follows. So every e‑mail communication that we send out follow this instruct tour help folks understand what's there. I also work with a lot of folks who are non‑readers who where we do a lot of in‑person work. We have graphical representations and discussions to figure out how to do our work together. We had a new study and how are we going to recruit people and use representations that we know can go out and use flyers. We can make phone calls and just using these to begin to jog ‑‑ or initiate the conversation about deciding how we will do recruitment with any one content.

Worn of the best things is ‑‑ one of the best things is a fabulous strategy to use in a wide array because it is a process for making decisions to help you figure out whether you need to spend more time on a particular topic or you can move on. So this goes from I quote one finger, yay. Or two not thrilled and. If you say any of those, it ‑‑ excuse me. It ends the decision and we then say okay. Let's explain. Let's discuss. Let's generate new ideas. Skipping over that. The other thing we do each time is making sure to check out. How did today's work go? What went well, what can we improve next time. It ends on that note after each meeting. I want to move to discussion because that's where we can have a rich exchange of ideas and resources. But just a few thoughts for myself and conclusion. I do think we can infuse disability rights into science and I do think that par participatory research is one way to get there. It is possible, and it can, of course, address many of the problems we see with traditional research and hopefully (?) translation. And for collecting safe and valid self‑report data among others.

With that said, it requires certain resources and skills and constant attention to include and power. I think we still have a lot to learn, but there are more and more of us doing this and we are creating a shared toolkit.

With that, I will turn things over to Kathleen. Thank you.

>> JOANN STARKS: Thank you very much, Katie. This is Joann. Before we move to the discussion, I want to remind everyone that the presentation files are available for download in the handout pod on the bottom left of the window. If you select one of the items, the link will appear on the bottom of the pod and you can open a link on the window by selecting browse too. You can download the files from the expo page from the conference website.

Now, I will hand it over to Kathleen Murphy who will guide us in the discussion period.

>> KATHLEEN MURPHY: As a reminder, we will have some of the things raised in the chat and then we'll get some reactions from John Kramer and Sandy Finestone.

One of those questions, Katie, a lot of them had to do with your resources, can audience use the visuals, are they validated.

>> KATHERINE MCDONALD: Yes, yes and yes. Many images you see in black and white that are in very simple graphics, I took from the (inaudible) project which is a website full of great graphics that you can use for a variety of purposes and you can either download them for use with attribution. So you will see at the end of my presentation, I have a whole slide on thanking the artists or you can use them in rights to use. We also ‑‑ I had to alter some of my slides because of copyright issues with journals where I published. So a bit of these are manufactured. But the publications that are cited at the end of the handout, you can see some of the original materials. I think that this is public domain. I thank science is public domain. I think it is very important we share with one another. Absolutely. My e‑mail address should be there somewhere too. If you want to exchange resources or ideas, I am happy to do that. Did I get all parts of that, Kathleen?

>> KATHLEEN MURPHY: You will know whether those references discussed and have visual scales validated?

>> KATHERINE MCDONALD: Yes. Absolutely. The two scales that I showed are from my work looking at how we include adults with intellectual disabilities and research. They performed very well. We don't have a lot of micrometric properties on those because they weren't scales, but they are published, and you saw a good performance. It was clear people understood them and were able to respond. By the partners project or by fire. There have been more scales there. So there's more psycho metric work. They performed very well.

>> KATHLEEN MURPHY: This is a specific question is. There is an online tool to have a hot box feature. What was that software?

>> KATHERINE MCDONALD: That's an interesting question because that's from a project many years ago. I actually believe that we designed ‑‑ we did not use call treks for that. We designed that in house based on a prior project at the same university. We had a university scientist that was part of the team and she was able to pull that off. I think you can do it within surveys and you can figure out ways to have the same functionality.

>> KATHLEEN MURPHY: Okay. And as an aside, Rebecca, if you're a grantee, feel free to get in touch and these can help you without that question. Okay. So some other questions have to do with kind of the composition of the stakeholder group. For example, how do you decide when to invite a self-advocacy organization versus an individual to the table?

>> KATHERINE MCDONALD: That's a really interesting question. We found that generally we want to have both things. Self-advocacy organization can be real power houses and being well connected and being effective and being change agents. So they have a pulse on things. They often have really important relationships or networks that can be pulled on to benefit the work that we're doing. So they typically always been a strong research. I can't think of a time when we haven't made sure to have formal representation from leading self-advocacy representation. There are people who don't identify with disability prior to disability rights or don't know about it yet. Or feels comfortable in those circles. So we also make sure to have individual representation as well that folks who haven't been a part of those networks. We have done both in our projects to date.

>> KATHLEEN MURPHY: Identities as we all know are perplexed and different aspects and come to the fore in a given team and what we're representing. This has come up in the earlier times as well. It also has a disability or not. How have you handled that issue or people ‑‑ members of your team who are researchers with members of disabilities?

>> KATHERINE MCDONALD: That's a deeper question than we have time for. In some experiences, we found that folks who have the lived experiences are the most effective researchers. They speak from both perspectives. They are trained as scientists and have experience and help navigate those dual spaces. We have found over time that one of my collaborators feels that sometimes she's less and less a committee member and spends more time as a scientist and feels more out of touch. So she makes sure to include representation that's more diverse and has less experience than she has because all of that is considered. There's also a lot of concerns around discrimination and micro aggressions as a disabled researcher that we have to help navigate with an academic basis, for example. So I think it's rich and rewarding, but not without its challenges. And critically important. That's what we have to do is change who is doing science.

>> KATHLEEN MURPHY: Exactly. And I'm looking at how you address the challenges and build processes when doing community-based par participatory research versus physical, intellectual, visual and hearing. So when we add teams, some research team members bring that up. Have you found other more structured ways of addressing challenges and built processes?

>> KATHERINE MCDONALD: When we have scientist with lived experience, we stumble less in terms of initial plans. We paid attention to the fact if were chalkboards in the room or buildings were (inaudible) or have a safe place for paratransit to let off or have close parking. We just ‑‑ generally take a flexible approach and try to anticipate and then figure out with people anything that we need to do to create accessibility. People that have boundary spanning and not just been about people with intellectual disabilities. We have to figure out how to bring together accommodations that might seem they don't jive well together. So for example, somebody who doesn't want too many inputs from a sensory environment with somebody who needs their watch to speak the time out loud and figuring out how to navigate those together. We sigh things pop up more in collaborations and then we figure out ways to work together so everyone feels accommodated.

>> KATHLEEN MURPHY: Seems like a good segue to questions we posed in reactors. It is not necessary in order to be able to express disability rights. So do any reactors on the phone have anything to say about how you address self‑determination in your work?

>> JOHN KRAMER: Yeah. I can chime in. Kind of quickly there are three different levels that we incorporate first is just overall on the broad level. Our work focusing in and of itself is informed by as a result of disability rights movement. So for example, they made it clear they don't want to sell the workshop. They only want ‑ they‑ don't only want day programs, but they the work. They are working for strategies to make that happen. I think a lot of what Katie said in partnership and power sharing on the project level, we have taken a long‑term view with self‑advocacy organizations. We have had a few ‑‑ our organizations we maintain consistent partnerships, but not every project is super effective or meaningful. Some of them are clearly more than others. They build a long‑term relationship which improves the quality and relevance of our research. And finally, kind of going on an idea of it being personal. Not every person with intellectual disability has to be a self‑advocate. Practice is personal and not every relationship needs to be an organization or stakeholder. We have focused on how do you hire people with intellectual disabilities to work as researchers. They're not just a member of the different group. They're a part of our staff and how do we support that, how do we mentor those both, how do we set a career path for them. How ‑‑ what is their role like internal staff meetings and culture as well.

>> KATHLEEN MURPHY: Thank you, John. So, um, can anyone describe how their research effort were impacted by disability rights? And one particular aspect might be if a community with disabilities they want to kind of get research moving on to a new question, updating the information where the researcher might want to be more focused on replicability and might want to find out the same findings are comparable over time. I don't know if any of that came up in the time the reactors did how the research factors were impacted, and it is a relevance question.

>> SANDRA FINESTONE: So, this is Sandy. I don't say to Kathleen, thank you so much in sensitivity to the needs of your participants. I was textually struck out over and over again. That was part of the discussion. And also that I do like the five‑finger process. I noticed in one of the chat notes that someone mentioned that for those that have visible disabilities, it may not be a way of accommodating or including them, but I think that it's a really nice process for those. I think you know well enough from my discussion right now, I'm kind of a yes, no, right or wrong. I make decisions very quickly, but not everybody does. I appreciate that very much.

As far as how research if it's impacted by disabilities, I will just say that I am very touched often by the researchers that I participate with who are dealing particularly with those patients that are meta static and don't always have the energy to participate in long‑focus groups or need to be accommodated in some other physical way. I want to send a shout out for the researchers I have participated with who are very sensitive to those issues and how nice and refreshing that is.

>> KATHLEEN MURPHY: Thanks, Sandy. Deb, did you have any final thoughts on successful partnerships with researchers and/or practitioners?

>> DEB ROSE: Real there was one of the things on disability rights and especially about combinations. When in working with individuals across the life span, what we have found is really embracing and supporting development of that self‑determination, kind of a proactive way to address disability rights because it is really empowering the individuals to become their own advocate. And who really become advocates for their rights and to rights in the community. We have had several individuals we have worked with that develop those skills. They have become ambassadors and work for change in their community. I wanted to share what I thought as self‑determination to be a key that really support that.

>> SANDRA FINESTONE: This is Sandy. Do you mind if I mention one more thing? One thing that I ‑‑ perhaps I missed in the presentation and that's the issue of care givers for those with disabilities. They have a tremendous amount to contribute to the conversation. And I think it's important that we not overlook the care giver.

>> KATHLEEN MURPHY: Really good point, Sandy. Joann, I think you have some tips to close out the day.

>> JOANN STARKS: Thank you very much, Kathleen and all the reactors. I do want to thank all of today's presenters, Sarah Bowen, Mark Bayer, and Katie McDonald. And also John Kramer, Deb Rose, and Sandra Finestone, who served as the reactors this afternoon.