West Virginia University - Center for Excellence in Disabilities (WVU-CED)
WVU-CED May Ability Grand Rounds
Tuesday, May 22 , 2018
2:00 – 3:00 p.m.
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>> All right. Everyone, we're going to go ahead and get started. People might join us along the way. I want to review some housekeeping so that you get the most out of our presentation today. Just in case you haven't used WebEx before, what-- you'll see the presentation slides on your screen. You should be able to see them to the left.

If you want to maximize that, there are two arrows going in opposite directions. If you run your cursor over, it will say full screen. You can click that, and that makes it bigger for your viewing. And it doesn't change anything on our end. So that's one thing.

The other thing is don't forget the CHAT function. So on the top right corner, you see participants, that's where you can see would's joining us today. CHAT. That's a function where, if you want to submit a question for the presenter or just general discussion, you can choose everyone and then enter your message.

Or you can also talk to people who are attending privately and, um, talk about something that's presented with questions back and forth.

We are recording today. We do have closed captioning. If for any reason you want to go back or you want to send the recording forward to someone else, let us know. It will be available on the website.

So with that, let me introduce our speaker today. Dr. Sally Gould-Taylor actually was willing to present and with us last month but we had technical difficulties. So I'm very excited that she hung in there and is back in May to present for our grand rounds.

She is the director of research and evaluation at the Institute on Disabilities at temple and within that roam she's responsible for the development, engagement, support, of research protocols, methods and analysis throughout the institute-based programs and initiatives. Sally's worked with both qualitative and quantitative research projects in human services, disability, and education. Additionally she has taught at Temple for nine years. She earned her Ph.D. in urban education with the focus on anthropology of education. She's a co-principle investigator on the transition discoveries project which is a research project on successful secondly transition among youth with disabilities across Pennsylvania.

Of course, that's near and dear to our heart with the focus on transition as well here in our center. Sally is currently leading three research and intervention projects in the field of disability, including the comprehensive statewide need assessment for the office of vocational rehabilitation in Pennsylvania, project PLAAY inclusive, a newly funded PA developmental disabilities council grant that combines a school-based intervention with community driven training, and addressing issues of race and disability in the school to prison pipeline. And a longitudinal ethnographic investigation of the closure of the Hamburg state center.

So today, she's going to present some of that work. And again, please join me in welcoming Dr. Gould-Taylor. And go ahead and again submit any questions you have along the way through the chat function.

But we'll leave time at the end, about ten minutes for any questions you want to ask. With that, Dr. Gould-Taylor, I'll turn it over to you.

>> Great. Can everybody hear me okay? I hope so.

>> Yeah.

>> Okay, good.

>> Sounds good.

>> Good afternoon, everyone. It's a pleasure to be able to speak to you guys and to talk a little bit about the works we're doing here in Pennsylvania and also a little bit about some, share strategies that he use when we're thinking about maintaining participatory, a participatory kind of role in our research whether it be kind of big picture research or small kind of qualitative tests.

So, um, I'm going to start out a little bit. So this is a slide that just looks at our vision and mission of our institute here.

But essentially the session is going to address thinking beyond the advisor board, guidelines for creating authentic inclusive research design, protocol, data collection, and analysis, some examples of participatory action research that we've done as well as approaches for interviewing individuals with disability for research purposes.

So really we're going to look at kind of big picture, research ideologies around authentic inclusion of people with disabilities in research design from beginning to end. Thus kind of beyond the idea of just an advisor board where people with disabilities can sit within a research project or program.

I'm going to give you some guidelines and some practical ideas around interviewing, around the dos and don'ts. And at the end of the session, we're going to go back and look at the big picture of guiding questions that we use and I use in my work as we develop things and move forward.

And I hope this will be helpful. Okay.

So as I go along and talk about examples of ways to be inclusive in research design and carry out, I'm going to reference three of the projects that I work on here at the Institute on Disabilities. One is project PLAAY inclusive which PLAAY stands for Preventing Long-term Anger and Aggression in Youth. So project PLAAY is a psycho educational intervention that happens in a school-based setting. And it's aimed at dismantling the power structure that happened in minute by minute or hour by hour interactions between people with color who also have disabilities and people who maintain power in those interactions that can essentially make decisions about what will happen to them for the rest of their lives.

So it's based on an intervention model that was used primarily for people of color in the Pennsylvania area and it's been changed a little bit to be inclusive of people of color and people with disabilities.

The other projects that I'm going to reference is a project that we did with the National Disability Council entitled Beyond Guardianship toward alternatives that promote greater self determination for people with disabilities. The publication is available in the highlighted text through the PowerPoint. And this was a role that we had in training the people who did the interviews of people with disabilities about their experiences in guardianship and other options, training the, creating the questions that were used in the, with the people with disabilities and also with the analysis of the data.

And the last project that I'm going to use is a project called transition discoveries. That's a project in which spent four years ago qualitative research among youth with disabilities and family members through out the entire of Pennsylvania to kind of recreate a lexicon of what successful transition looks like based on the wants, needs, goals, desires, and dreams of people with disabilities and their family members. Instead of being based on the regulations of the state, local and Federal Government.

And all of the information for that project is available from that highlighted text.

So the next slide, what do we mean by inclusive research? So for us when we're thinking about research, we're not necessarily thinking about protocol and design, quantitative and qualitative. We're thinking about a broader understanding about how research can be more equally shared and democratic. We see our role as a lot of you said, too, in that in a different role than a typical academy or scholarship that in the academy researchers are typically making decisions about what they research. We're making those decisions here based on the need of the community that we hear. Right?

So for hearing about questions about transition and how, understandings of success and realities are not meeting up, that bursts us onto create projects based on the needs of the people who are participating in the, in and experiencing the issues.

We want to research to be more inclusive ever people with intellectual disabilities. We see great projects that start out with wants or needs that they learn from community members or from an environmental scan with people with intellectual disabilities and their families, and that's where the interaction drops off. They might go back with the final report and help them understand where and how it came. But we want to make sure that inclusive means inclusive in all stages.

This is tough. It makes things take longer. It makes us have to deal with IRB more often and they just have to really quantify and qualify why this is important. This makes the research of more transitional and important. For us the research we do is emancipatory or-- it's giving voice. It's supporting people's voice and it's allowing to participate in asking questions about their own systems, their own things that impact them.

Lastly it's research that matters to people involve them and respect them. So .

>> So I'm going to go over a few over participatory action research methods and use those, use the tenants of those methods to talk about the specifics and some of those, in one of those three examples that I gave.

But essentially PAR supports voice both within the project and throughout and there's a growing attention to the use of this research and methodologies of with involvement with 20 of all levels. We see it situated with a variety of populations that have been historically disenfranchised or not be able to get their ideas heard.

Recently it's moved to the disability field in its entirety. Evidence that PAR empowerment research with persons with disabilities may result in increased skill development, self-reliance, empowerment, and social and policy change.

So the first principle PAR is it builds on strengths and resources within the community. We've seen this in my work through advisor board and community planning committee members that include youths with disabilities, parents and family members, community members, and professionals.

We see that building on these strengths, allows us to have focus groups with key stakeholders which will be an alternative to focus groups from people who have left participatory, understanding of the issues, right? And we have feedback from stakeholders allow us to create a new phase a new question. Often times the beginning part of the PAR principle and dealing and starting a research design starts with a focus group and talking to people who are PAR members of this communities. And then taking that feedback from the stakeholders and starting and continuing another phase of the research, kind of erasing and reconceptualizing and rethinking what we need to do and how we need to do it.

For PAR principle 2, facilitating collaborative partnerships in all phases of the research. That's something we pay a important role to in our work. Often times there's not typically a grant or an RFP that we go for that doesn't include both a community provider that has experience in the community, dealing with some other, dealing with some of the reality and community issues that are kind of happening alongside disability as well as an advocate or self-advocate group that wants to be a part of understanding the phenomenon, understanding the research paradigm. For us we often turn to the Pennsylvania leadership network. They were a big partner for us in our transition discovery project. Essentially the members of the PYLN were members of the research team. They facilitated focus groups, they analyzed data and helped us to understand and determine what our outcomes and outputs were.

We also work with George Washington university on the transition project as they have one of the national post-second transition masters transition projects in the state.

We've also worked with Pattan. For us that's the special ed arm, the training arm, special ed arm in the state of Pennsylvania that allowed us access to that. We also worked on the National Council on Disability for the guardianship project we did, working with lost students from George Washington who acted as interviewers and helped us understand how they were being taught around laws around guardianship in their classes as up-and-coming lawyers and the quality trust.

And most recently for our project PLAAY, we turn to the work of the racial empowerment collaborative in Pennsylvania which allows us to bring our knowledge and expertise working with people with intellectual and developmental disability in the community for 40 years. And their knowledge and expertise working on racial literacy programs and in school interventions and combating the school pipeline and push that into a collaboration that will deal the multitude of issues that are addressing inequities.

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So the next slide and PAR principle 3 is integrating knowledge for action and action for mutual benefit of all partners, right? So essentially, knowledge needs to be included in all phases of the research. We started out with the grant proposal and development of project goals. It's not just the idea around the grant but making sure there's a monetary participation for people who are coming from community programs from leadership, from self-advocacy organizations and making sure that they are paid as experts to participate in these projects with us.

And then it's about creating the research protocol and development. It's the questions that we're asking in our focus groups. It's making sure we're asking the questions in ways that connect people who have lived experiences unlike myself. I've been trained as an anthropologist. I've asked a million questions of a million people all over the world. But I don't have a lived experience of being a young person in transition. Right?

So I turn to people in PYLN who have the experience with young people in disabilities in transition and ask them to take my words and reconceptualize them and refacilitate them so that procedures and the questions of the focus group makes sense. And it's not just stuff related to questions and data gathering. It's all about the experience. Where do they want it to be? Where what do they want the food to be like? What do they want the room to be set up like? How are all those things going to be specifically associated with their own experiences and understanding, cultural, all of those types of things.

So for us we did refocus groups for transition in eight parts of our state. Pennsylvania is a big state. And there's lots of differentiation among culture, idea, et cetera, as you go along the state. So we didn't have eight different focus group paradigms and procedures that look exactly the same because it wouldn't have made sense.

The way that people want to interact and talk to each other in Southeast Pennsylvania and Philadelphia are different toon the way people want to interact and talk to each other in the middle of Lancaster county. It was making sure we were connecting with local people who had experience, knew the communities and making sure we're responsive in the way we're developing that protocol. So that means having to give the IRB protocols. It takes longer but I think it's going to allow for more mutual benefit. More interactive knowledge, right?

So ideas about incentives. So as much as we can. As much as our funding partners allow us, we want to be incentivize people in our project because they're experts and they're giving us time and I think that's a value. The same thing of with the experts that are doing data collecting are getting 35EUD. This is going to young people from this part of the state saying, what do people want? I want to target gift card but that might not fit well for someone who is in the middle of Jobs town whoa has never seen a target. Marketing and dissemination. Make sure our project reflects our goals and vision.

Data gathering, as I is he before, the data gathering was con so we have focus groups that were youth to youth, young people facilitating and asking the questions for and with young people and for the family members and professionals, there were family members and professionals facilitating and asking the questions. And with data analysis. We did a big, large analysis in-house. The qualitative analysis in-house. And yes were take to take pieces of what we did and bring it back to the research member. To the professionals, to the advisor board members, to the young people with disabilities, family members. And we were able to breakdown the qualitative stuff before we were able to see stuff, before we come to conclusions and give it to them to get their point of view how they were reading it, how they were understanding, analyzing what they were seeing. It wasn't just coming from our eyes and our analytic software but really from someone who had an experiential understanding.

And then reports. The reports are created in a benefit for partners how will this benefit your local community? Your local department of ed, your local principals or your local school districts? How will this benefit local community groups that you guys have in developing kind of services and supports around transition. It needed to be able to be readable and legible and make sense.

PAR principle #4 which is promote a co-learning and empowering process that attends to social inequalities. We researchers learn from the knowledge and theories of the community involved. Community members acquire further skills only how to conduct research. Not only people are getting experience of conducting research but they're becoming certified for human subjects, research training either through a city program or a program through the National Science Foundation. Finding accessible locations and limitations to those.

And then being able to let people know about the accessible free low cost locations that we found in their locales so that they can use them in creating community programs, et cetera. And learning about how social and equality gets upheld through research. So really talking about how we're not going to take those steps, how we're going to -- dismantle those ideas. One of the examples is our simultaneous translations of focused groups, and highlight how other projects and institutions may not be addressing the same need. So we held simultaneous translation in Spanish in some of our location for our focus groups in the transition discovers project. Also we have a set up ever data that came out in the themes analyzed. And there's a set that's in Spanish, in English, and there's also a set that's text only so it can be readable for people who have a hard time looking at text and color-- I mean picture and color. Excuse me.

PAR principle #5, so it involves a cyclical and iterative process. Project support growth and development of the community. So in the transition project we were supporting growth of PYLN and schools in the communities and project on guardianship, supporting law students as well as the professor who was teaching the different courses that were dealing with guardianship and other options. Often times that support kind of means that thinks change along the line.

So it may have been as we first started in our relationship with PYLN they were ready to participate and had little to say about how the project to be set up. But as we got through year one of the three year project, they were like, wait a minute, we don't like what we're seeing. We want a different understanding or role in our analysis. We want to do more with the recruitment and retention of participants. And it meant often times that we had to reflect on what we had been doing and then replan or rea professor, right?

Which means that things take longer. But we really call this kind of validation. So we call it so the kind of technical theoretical way of validating workshops or member checks. So going back to the people who are part of the process, going back to the people who are dealing with the phenomenon we're trying to understand and making sure that they believe that the works that we're doing is valid.

Sharing some creed, some pre-results, sharing some of what's going wrong and right and making sure that they're buying in or believe in what we're so doing. So that's where we can utilize advisory committees and community members to under and create and recreate the next round to explore more, to understand things more.

So when we thought about kind of having one round or two rounds of things as all of these projects have, it really ends up having three or four rounds because they're in constant relationship with the community that we're working with.

And it's really about having the work maintain and be translational. Working and disseminating information into systems in realtime. We don't want to spend ten years working on a project then be able to make a report to the government or the school system that these things have to change in the way that transition is understood or taken on in a school system.

We're having conversations all along with all the stakeholders who are participating in this. Sharing with them, bits and pieces of what we have learning to have them question some of the ways and some of the supports and services that are happening. Then we tart to see things change. As you're participating in this transition project, we saw WIOA change. We saw employment first stuff change. And we were able to have conversations with the people that were implementing parts of those laws to make sure that the curriculums that were included pre-employment transition services that we're going money from the WIOA grants make sure the curriculums included the voices of people who are transitioning and what they saw as their needs for successful transition not just what the government was saying had to happen for them to meet certain goals.

And principle 6. Almost done with principles. Disseminating findings and knowledge gains to all partners. So how often do you guys work in your own silos, and you have these great outcomes of a project and you write your report and you write your peer review journal article or you do a poster presentation, and it stopped, right? And then you don't really think about how this knowledge can be really translated for partners in all of these different realms of kind of the world in which we work.

We get to work, we get to work in these interdisciplinary places which is fun and gives us a way to talk to people and make sure our work has value. But stripes we forget that we then need to be responsible for disseminating findings in ways that work for people that they can take up what they're finding, take up what's important and use them for their own needs, right? So for us we were talking about DD council reports, developmental council reports. State meeting, AUCD mediating, AAIDD meeting, PA transition conference. Legislative expo. Going and talking to legislators, presenting them with our findings, talking to them about things that are coming down the legislative pipeline and where they should be thinking about it. Give corps works and different transition programs at different post secondary places. And also youth leadership enters. There's a small picture on the side of the screen that you'll be-- if you click on the link you'll be able to see all 55 plus pages of these kind of infographics that we've created. But it was about meeting community, meeting people at their needs. So we met before we developed this, we met with people who we thought were going to use these info graphic information in their work on a daily basis. We want those principle. We met with people with IUs, we met with teachers. We met with parents, all different people and asked them how this is going to best meet your needs.

What happened was people wanted hard copies, people wanted PDF copies, people wanted them in Spanish. People wanted them without the colorful varieties. We tried to make sure we were reaccept tip of all those things.

Okay. So now let's skip over to kind of some of the more practical ideas around. Once you're there, once you're doing this work, and you end up having to do interviews with people with intellectual and developmental disabilities, how do we make sure the interviews allow for us to get the best information, get the most accurate, the most important information we can? And also privilege and support the ideas and experiences of the people that we're talking to? Right?

And so we know that there's been kind of lots of history around people with disabilities and other protected populations being taken advantage of in research settings. And we want to make sure that not only are people not being taken advantage of but people are feeling like they're able to kind of be who they were and give their most informed and most authentic understanding of their responses to the questions.

So here are just some of interview strategies that we use and I use to train and teach people in a have right of settings. So I train people who are NCI interviews for the state and we also have another kind of interview similar to NCI which is interest monitoring for quality which is the quality assurance arm of our office of developmental programs. These are strategies I have used for lawyers and law students. These are training strategies interviewing strategies that I've used for graduate students from a variety of disciplines that have had little or no experience with people with disabilities.

We use this with some of our provider agencies, kind of all along the gamut. But hopefully these, I know a lot of-- those of you who have had a lot of experience working with people with disabilities, some of this might feel second nature to you. But for me it's important for us to maintain this kind of understanding and continue a conversation about this because sometimes it gets lost. Most recently I was invited to train people who do interviews at the, for the united United States Immigration Bureau. So people who are interviewing people, people looking for visas and green cards who may or may not have disabilities, how to use these strategies to make sure they're giving people the best chance to participate in these really important interviews.

First and foremost, call the person by their name. It might not be the name they're given but it's their chosen name. And speaking directly to the individual and not to an interpreter or companion and not making assumptions whether the individual can participate. We're presuming competence, and it's really about trying to understand what behaviors or what clues or what context we need to see in which how their participation can work.

So making sure that we are fulfilling accommodations that are requested and also framing the surveyor interview as a conversation. Calling it a surveyor an interview can be extremely stressful. There's often times when I've had to change a protocol around interviews or focused groups or surveys because it was stressful for the person participating.

So my protocol might have been to have an hourlong interview or hourlong focus group and I realize I have a person there who has a hard time speak to go me in a direct way or participating. And I talk to the person and say, person or sometimes the person who works with that person and talk about what's the best way. So often times they might break it down. I spent six months recently doing an hourlong interview in one line emails or one line text with a participant. He has a lot to share. He wants to be heard. He wants to talk about how his experience and transition has been beneficial, what he wants his future to look like. But this is the way in which he chooses to communicate with me.

That means modifying my protocol. Changing the way we're setting up to do it. That capturing value information from a valuable expert.

And if I wouldn't have made that modification or that change I would have lost that person's experience. So when specifically interviewing people with intellectual and developmental disabilities, you make sure you speak in clear sentences and concrete concepts. And make sure you're not using baby talk. So gauge the pace of your speech, complexity and vocabulary of your speech according to the individuals.

So people with I/DD may be anxious to please and an individual may tell you what they want to think or hear. So make sure you're trying to elicit accurate information. Sometimes it takes a while. It takes a while to warm up, to get information that really comes from their point of view after they spent so much time telling people who they want to hear or whoo telling people what they need. Be patient, changing routine and environment may require a period of adjustment just like it does for everyone.

So often times when intellectual and developmental disability disses may a a speech disability as well, so give your individual and full attention. Listen attentively, don't interrupt or finish sentences be patient.

you want to give people as much time as they need to speak in a way that works for them so you can hear what they're saying instead of inferring what they're going to say.

you want to ask if you can't understand, you want to ask for them to repeat. If you're still having trouble you can ask him or her to write down or use a person who is familiar with the individual's speech pattern to help you understand what's going on.

Really quiet environment makes a communication easier. So here are kind of my list of interviewing tips of dos. Whether we're thinking of people with intellectual and developmental disabilities. And interviewing is the concept. It could be a focus group. It can be a phone call. It can be emailing back and forth. The least beneficial interview when it comes to someone with intellectual or developmental disability I don't think for anyone is something over the phone.

So if I am a part of the developing the protocol of a research project, I would nix the phone interview right away.

So do, allow extra time as needed, introduce yourself in what your job is. If a person is more comfortable and staff and family, decide if it's appropriate for them to stay or be there with them. Follow-up on responses you do not understand or need clarified. Don't feel uncomfortable, to say, I don't understand, will you repeat that for me? So change the format. If the format nice to be changed, if it's needs to believe four, 15 minute meetings, if it needs to be phone calls or text messages, change the format.

And what I do now for all of my IRB stuff is I make sure I allow for that in my IRB. The format may be changed. Make the interview ads conversational as possible. Develop a rapport. And be warm and understanding accepting and neutral, respectful, honest, and appreciative.

So accepting and neutral doesn't mean, yes, yes, to everything they're saying. So understanding and listening but not taking over and advocating, right?

If the attraction of another person's-- if the attraction of another person's attention and trust, you need to make sure they understand you, you understand them. You want them to feel comfortable.

So some more dos. Explain the purpose of the interview. Address terms of confidentiality. Getting informed consent or assent. And every university has different rules and regulations around that as well as every kind of, every place as well.

So right now I'm doing a closure of one of the state institutions. And I'm getting close to having an interviewed with an individual and things around guardianship and family and even the last kind of the director of the institution may get to make some changes on questions that they're comfortable with me asking or places that they're willing or allowing me to be. This is a different thinking of the structure of the state as kind of giving me different terms of confidentiality and different terms about informed consent that go beyond and different than what my university is saying.

And unfortunately it's the culture of the state and the people running the institution. And I have to be able to be flexible with what they believe in. I can talk to them about my ideas and about ways to change it. But it's kind of-- it's there are culture that I need to make sure that I am respectful of.

So explain the format of the interview. Making sure the person knows how to get in touch with you. Allowing for questions and making sure you're asking one question at a time. So the other big thing here is to be careful about the appearance when note taking.

This is kind of, we need to take notes to make sure that we're passing people's information well. We often times use audio recorders but there are pros and cons to both of things especially based on people who have had a lot of experience working with systems, working with institutions that take notes around their behaviors or have audio taped or video taped their behaviors. It's really about developing a rapport and helping them understand why we might be doing one of those two things.

So for my don't interviewing tips, don't rush. I know it's hard because we have a lot going on in our days. But it really, especially for people with intellectual and developmental disabilities, it hinders their ability to be comfortable and have a conversation with you.

Don't be an advocate. This is a hard one because that's probably a hat a lot of us wear in our jobs in a lot of different ways. If we choose to be an advocate, it's almost the same for us as choosing to recall the experiences of participants as clients. Right? So it's both sides. We don't want to advocate for them for a change while doing the interview. It may be after the interview or as we develop the relationship with the personal or family. We may point them in the direction we know of.

When it's happening in the interview, we want to make sure we're eliciting a true and authentic response from them. And on the same side we want to make sure we're responding and recording their responses as their truth and experiences.

I had a graduate students who continuously responds or records things as claimed and assertions. And I have to keep explain to go him that these are not their claims. These are their truths and that's not the way what we can lie light the information we're getting.

Whether or not you feel like you believe it or you feel like it's authentic, it's the person's truth. So don't interview the interview through an interpreter and not look at or speak to the individual. If there's questions that you have, you can speak to the interpreter before or after or say, hey, I have a question for your interpreter and talk to them. But make sure that everything is directed to the person or the individual first. And don't show strong emotional reactions to their responses. Sometimes we're going to hear things that are painful and hard. We want to make sure that our responses are calm and thoughtful and-- yeah.

And so really we want to at that kind of the art or the understanding of active and reflective listening. So hearing and responding back and kind of the listening clarifying and listening again. It's important to remember that this is not about you. This is about the person with whom you're speaking or visiting and you want to make sure that, if there's issues, that you witness to be impartial and be attentive and listen to understand but not listen to respond, not listen to argue or criticize or even interpret or evaluate. Let the person finish what they're saying and even if you don't agree with them. And at this point some of the clarifying questions that you can ask are really about, can you tell me more about that. Can you tell me how you feel about that. Can you help me understand what you mean, right?

Or give me an example. Right? As oppose to listening so that you can argue or understand or identify with. Right? So body language, facial expressions, those are all things that are really important to kind ever maintain in the setting.

Fidgeting or getting tired or board might reflect that way to the participant. They could think, I don't know what to do. I'm not doing something, what I'm saying is not important. Smiling or gleaming may make the person think, tell me those things specifically. So you want to try to be as impartial which I know we can't be as we can.

So just going along with this. Often times the person who are we are going to interview or talk to don't speak traditionally

so we want to make sure that you're going into the setting understanding who you're going to interact with and underring about the different communication recommendations. You're being prepared for the visit by gathering information before the interview about the person's communication style. For example, asking how the person responds when she is happy, sad, angry, likes something, doesn't like something and obtaining information from family and staff about the person's communication history.

Sometimes that includes assessments or speech therapy or device usage or communication profile or goals. And if a communication device is used it should be identified beforehand and set up the appointment at the time the device is with the individual and in working condition.

So really this is about making sure to acknowledge and understand that everybody communicates and has an opinion about his or her life. And we need to figure out how they communicate and it's possible to learn from people who communicate in alternative ways. It's about maintaining and assuming intelligence and high expectations and gathering information and preparing for communication.

So we have some vocabulary aids that we use here at the institute. It's just a board piece of card stock that we've created that sometimes can help if we're entering into a situation where we don't know a lot about the person's communication style to begin with. Often times that's our first meeting with them and from there we can move on. I gave links where we can download them.

There's a Spanish and English and Haitian creole one. This allows for communication kind of barriers to be lifted and to start to change. And from there, rapport can be built and things can go on.

Okay. So we're almost done. So back to kind of big picture. So we started out talking about big picture with the principles of PAR and trying to connect those to some of the actual works we've done on the institute of disabilities. And I talked about the dos and don'ts and the strategies we use. And then I'm coming back to big picture.

For me these are the guiding principles that I think of as we're developing a research protocol as we're kind of even developing questions in our head about there's this phenomenon or hear about it from the community or see it happening in the community. And we want to make sure that we're seeing and what's going on and the experiences people are having really sit well with the way that we're deciding to investigate that.

And so these are four guidelines that I use in, you know, the way, as I'm teaching around methods and I use to understand and interpret any project or anything that we start out on or any time someone asks us to participate in something with them.

So my first guidelines, I don't have answers to these. These are the questions that keep me moving, keep my head moving as I'm maintaining or trying to maintain a high level of equity in inclusivity. The first guideline is who or what are we trying to understand, the question I ask myself are our inclusive research efforts focused on fixing marginalized people or on fixing the inequitable conditions and structures that marginalize people. These are the questions I ask myself ads looking at unit of analysis as looking at quantitative-- we look at whoa's asking the question? Who are we including in understanding? Who are we excluding? All of those types of things.

Guideline two for me is does our work mitigate or transform? The question here for me is, are our inclusive research efforts a threat to the existence of injustice or do they merely lit gate the symptoms of injustice? Are we participating in the system of injustice by investigating this issue in the way that we're investigating it open are we threatening the system?

Guideline three is, are we dancing around or digging in? Are our inclusive research efforts contributing to the permanent redistribution of access and opportunity or leaving the current distribution in place and helping marginalized people be more comfortable as marginalized people?

So are we talking about inclusion or are we talking about justice? Inclusion for me is helping marginalized people be more comfortable as marginalized people in an included space, in a bigger paradigm or a bigger institution or system. Justice is about disrupting the place, disrupting the system.

And my fourth guideline is who are the experts? Are our inclusive research efforts based in collaboration with marginalized people deferring to their expertise? Or are we working on marginalized people or with marginalized people?

So I wonder if we have some time for questions now with people have any feedback or questions or comments. I can't see anything on my screen. Lesley Cottrell if there's any questions that pop-up, if you can read them to me.

>> Sure. And no questions have come through right now or while you were speaking. I'm unmuting people. And, um, so I'm almost finished. And then we'll open it up. okay, does anyone have any questions?

>> [Background Noise]

>> This is Laurie.

>> Hi, Laurie.

>> Can you tell us about how you recruited people for the interviewing process?

>> So people to be interviewed or people who are interviewers?

>> No, people to interview.

>> It depends on the project. So for our transition project, we did a lot of-- so specific kind of recruiting in the specific locations in which we were moving to. We started with the people who have worked on different leadership training projects in the past in Pennsylvania and reached out to them.

And then we reached out to local transition local council or local IUs, local school districts. But we also reached out to kind of noneducation-based community partners as well. So immigration services and supports, places that were supporting people who were immigrants, places that were supporting people with different, with health or education needs. And we used kind of videos. So some Youtube videos.

We had people from Pennsylvania youth leadership networks go to different community events and talk about it. We sent out flyers. So kind of lots of different levels. And in some places it worked really well. We tend to find there's parts of our state where people are responsive to different community chat rooms or through Facebook.

And in other parts of our state we actually have to go to meetings or we have to go to association groups and go to those types of things. It was a broad gamut.

And for the transition discovers project, we had a total of I think it was over 650 people who participated in focus groups and interviews. which gave us countless hours of audio tape, of audio analysis.

>> Not bad.

>> Um Sally I have a question. This is Lesley. You know, you outlined a lot of different steps that were pertinent to you for research. But it seemed to me that these are the same and would parallel a lot of other things we might be doing which you said which would be training. It could be direct services. Do you find that we could apply this across the board and are the same kind of ethical questions only for research or also how we interact?

>> I think-- absolutely. Those four big questions that are-- you have to forgive me because I'm an anthropologist. I tend to think big in those ways. Those four questions could be applied to curriculum design or to project development ore to leadership training. All of those things. So are we making sure, are we making sure that all of those needs are being met, right? You might change the, you might change the noun in those. So I use marginalized people because I'm trying to make it broad and big. But it-- for you if we're thinking about apparent training

program it might be the noun in those things become are we working on parents of people with disabilities ore are we working with parents with people with disabilities in those questions?

I think these can be used in the works that we do in a lot of ways. Absolutely. And I would argue as a researcher and evaluator that there's something in all of the works that we do that can give us benefit for evaluation or understanding ore research.

So even if it is a training or a curriculum or whatever-- a workshop, whatever it may be, I think knowing and making sure that we're gathering information and outcomes and outputs alongside can benefit all the works that we're doing.

>> Great.

>> And quite frankly I think these four guidelines are what makes a UCED or-- so valuable in the world of scholarship and the world of the academy. I don't think necessarily traditional scholars are asking those same questions.

>> Uh-huh.

>> With the same level of importance in their work.

>> Right. Any other questions? I have one more-- I didn't want to monopolize.

In terms of the last statement you just gave, do you find that, or does your center work with other individuals either through providing trainings about increasing their awareness about these issues? If they're doing research or training or anything like that with individuals with disabilities, how to do that appropriately.

>> Yes. We do. We've worked through kind of some of the service provider agencies around some of this stuff. We worked with the people who do the independent monitoring for NCI and for the, what we call IAM for coup. We developed the instrument in the survey but it's done independently in the state and we train the monitoring or interviewing teams. We work on national scale stuff. When it comes to often times one of the new kind of, the new things we see a lot is people having partnerships between a disability organization and a non-disability organization that's dealing with looking at an issue at the same time.

So we want to go in and train and support the people who say are dealing with health inequity to make sure that they're approaching the work and interviewing and people with disabilities appropriately and with enough knowledge and understanding even though they may be talking about health. Even though people might be talking about food security. We want to make sure that they have the knowledge and background expertise about intellectual and developmental disabilities to make sure they're getting the authentic response from those people even though they're talking about food security or issues of immigration or whatever it may be.

It's about developing those relationships and us learning from them and then learning from us.

>> Absolutely.

>> Often times we, although we want to take on that work we might not be the best people situated in that community to understand that. So we hear from our community that food and security is a big issue. Right? But we don't have the touch. We don't have the reach in our community to understand where all of that is happening.

So in partnering with people who are dealing with food and security, and teaching them about their understanding and us teaching them how disability is affected by it, we can create some sort of research that is responsive so both communities at the same time instead of both working on these things on our own that are only responsive to our own communities.

>> Uh-huh. That's great. Thank you. So-- [Speakers Overlapping] it was very helpful. Any other last minute questions or comments? Okay, with that note, it was very help. And thank

you so much for sticking with us and joining us again this month, Sally.
>> Okay, thank you, everyone. Let us know on the screen if there are any questions. Feel free.
>> Great. Will do. Thank you. Bye-bye.
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