

## **2021 Online KT Conference: Research Results for Policy Outcomes**

*Engaging Communities that Experience Historical Trauma at the Nexus of Disability, Race, Ethnicity, and Culture*

Tawara Goode

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KATHLEEN MURPHY: OK. Welcome back, everyone. We'll be hearing from Tawara Goode and she'll be presenting on engage in communities that experience historical trauma at the nexus of disability, race, ethnicity, and culture. Tawara is director of the National Center for Cultural Competence at Georgetown University. She's an associate professor in the Department of Pediatrics there at Georgetown University's Medical Center in Washington DC. And she will be presenting her own slides today, so we will go to Tawara.

TAWARA GOODE: All right. So good afternoon, everyone, and so pleased to have this opportunity to share some perspectives around historical trauma. So, with that said, I'll just go ahead and advance my next slide.

This is what we're going to do in this very short amount of time that we have together. We're going to identify and describe historical and present-day trauma. These are ones that are experienced by members of diverse racial, ethnic, cultural, and disability groups and communities. We'll differentiate between community outreach and community engagement. Very important.

And we will describe six culturally and linguistically competent approaches to engage communities that have been affected by historical trauma. And again, looking at those at the nexus of disability, race, ethnicity, and culture.

Wanted to share this with you. I just think it's incredibly powerful. It's a quote from James Baldwin. Many of you may know him as a novelist and author, playwright. James said-- and was back in the day-- "History is not merely something to be read. And it does not refer merely, or even principally, to the past. On the contrary, the great force of history comes from the fact that we carry it within us, are unconsciously controlled by it in many ways, and history is literally

present in all that we do. It could scarcely be otherwise, since it is to history, we are frames of reference, our identities, and our aspirations."

And I chose this because I felt it was really very powerful. And I think it speaks to, not just our theme for today, but for many experiences of persons in the United States, tribal nations, and also our territories. And we'll come back to James.

So, as we think about historically, we know that many communities within this country have been really oppressed. They've been marginalized and they've also experienced discrimination. While I'm talking about this in the past, we also know that is current day.

And so, because of these past experiences, they really do affect how various groups interact in this country, whether together or indeed separately. And so, we know that many of these communities experience intersectionality. And this slide just gives an illustration by these word clouds about the various things that we know continue to plague our country as a whole.

So, I want to offer you a definition of historical trauma. There are many different definitions. This is from Brave Heart and it's from American Indian perspective. I find it, again, powerful and quite clear. So, if we look at historical trauma, it's defined as cumulative, emotional, and psychological wounding across generations.

Want to emphasize emotional and psychological wounding across generations. That would include the lifespan, which emanates from massive group trauma. So that even though things may have happened in the past, that the implications of those past experiences continue on with us today.

So, I'm going to offer our first polling question. I'd like to just read it to you. Given that definition of historical trauma and based on the definition that I just shared with you, how knowledgeable are you about the historical trauma experienced by any community in your state? And you select one choice, please.

OK. So, we have a spread that's here. Very few said not at all knowledgeable. However, I am going to commend the very few that indeed indicated not at all knowledgeable. Sometimes, people don't want to fess up to things and I really do appreciate that.

So, if we look at the bulk of the responses, they really fall between slightly knowledgeable and somewhat knowledgeable. And so again, as we think about this whole notion of historical

trauma, it plays out in very different ways in different states and in different communities. Thanks so much for responding to the poll.

We're going to move this next slide ahead. So, as we think about individuals who reside in the United States, territories and also in tribal communities, we can think about which groups may at all have been affected by or continue to be affected by historical trauma. And then as we look again at the percentages and the numbers of people by racial and ethnic group that live in the United States, if you want to call your attention to a couple of categories.

One says some other race. So basically, according to the US Census, there are individuals who do not select any of the previous categories. They don't describe me. So, what do we know about their experiences? And then, we have the category two or more races, and we know that that's one of the fastest growing categories of individuals who self-identify that way in the United States.

And so, as we think about these groups, and if you again think about these demographic groups in the US Census, which experience historical trauma? You can just start to put those in chat. And so, Shoshana would be able to read some of those out again. But I really would appreciate if you're able to do that to give us what you think that you know regarding historical trauma. And we can see those as we move along.

I don't have my chat screen up, so Shoshana, I just trust that you're doing that and can share some. Maybe just a few before we move on.

SHOSHANA: Absolutely. Right. So, Marta says-- and they're coming in fast, so I might be losing some of them. So, Marta says African-Americans, Latinx, Asian-Americans, people with disabilities. Salima says Black, African-American. Jessica Lukefahr says all of them.

Rebecca Bowen says most non-white groups. Jennifer says all of them. Chris says people who are deaf. Terri says two or more, Black, American Indians. Janet says Indigenous American, African-American, Latino, Asian-American.

TAWARA GOODE: OK. So, they are coming in. Would like to also suggest that when we think about people who are deaf, they also belong to some racial, ethnic, and/or cultural group that may indeed look at the perspective of intersectionality. So again, thank you so much for using chat.

So, if we look at the groups that have experienced historical trauma-- and this is from my research for this presentation-- we know that American Indian and Alaska natives have. Asian. Black and African-Americans have. Latino, Latinx, Hispanic. I include all of those, but I may not have all of them.

Latino, Latinx, Hispanic and Latina. And the native Hawaiian and other Pacific Islander. And if we look through history, there are just significant experiences that people had, including genocide. And I decided to define what does genocide mean.

It's such a very difficult term to be able to hear and to think that yes, indeed that happened in our country. And so, I'm not going to go through all of those. You see them. We see from lynching to enslavement. We see oppression and segregation. So, all of these things that have happened to various groups in this country over time.

And so, if we think about historical trauma and disability-- and this is not to minimize the fact that people with disabilities are from various racial and ethnic groups and communities, that they also have experienced historical and present-day trauma. It's just that sometimes, these data and these descriptions aren't listed in the same place.

So, we know that people with disabilities have been institutionalized. And many, far too many, remain institutionalized today. We know that people with disabilities again across disability who have been marginalized. They've experienced segregation and discrimination across the board from employment, to education, to childcare.

Thinking about many kids were not allowed in childcare because they had a disability. That still continues today. We also know in terms of foster care that kids with disabilities have inappropriate placements. Then, we see issues of disproportionality within juvenile justice and detention centers.

And then unfortunately, we see abuse and neglect in terms of persons with disabilities in the settings in which they live. So again, no shortage of things that will be traumatic for individuals. As we look at our current day realities, many persons within these racial, ethnic, and cultural groups continue to experience the isms.

And again, looking that in terms of intersectionality, that compound historical trauma. So, we're not out of this. We're still in the thick of things. So, when I use the term isms, it's an umbrella term that we've used at the Georgetown University National Center for Cultural Competence.

And it can refer to many different behaviors and attitudes, including perceived identity and expression.

And so, when we think about those kinds of experiences that people have generally which are indeed negative that affect their overall functioning, acceptance in our society. Want to speak a little bit about intersectionality. We hear this term a lot. It's been used a great deal.

And the work that we do it at the National Center is really governed by the conceptualization of intersectionality by Kimberle Crenshaw. Her work was back in 1991. It really focused on the marginalization, the oppression and discrimination against women, and in particular Black women. And she coined this term intersectionality.

I would say that currently, we know that this term is used a lot. It's used in many different settings. And I'm going to suggest to the recent disability community. And my experience has been over the last several years that people are using the term intersectionality, I think, in a wrong way. I think that they're substituting multiple cultural identities for intersectionality because they're talking about intersectionality and using that term, but they're not referencing the harm.

They're not referencing discrimination, marginalization and oppression. And so, this is an example from a colleague, Andy Arias, who worked with us. And this is what he is saying about intersectionality. From childhood through adult life, I experienced stereotyping, marginalization, and discrimination because of who I am, because of my LGBTQ-ness-- and Andy used flowery language at times-- my Hispanic-ness and my disability.

And so, as we think about intersectionality from this framework, it is clearly not-- and I'm going to say not an experience where you're looking at multiple cultural identities in which someone embraces all of these identities and it gives them pride and joy. So, let's take a closer look at these concepts. In particular, the demographic data that I just shared, things around intersectionality.

The experiences of these diverse populations historically in the United States and examine the concepts of community outreach and community engagement. So, in our work at the National Center for Cultural Competence, we do differentiate community outreach and community engagement. And we feel pretty strongly about that in terms of governing and the underpinnings of our work.

And so, if we look at community outreach and we look at community engagement, we often hear people use those terms interchangeably as if they're are the same. I am suggesting to you when we think about outreach, it's unilateral in one way. And so, if we think about working within these communities that have had historical trauma and our approach is one way, it can only get us so far.

And so again, when we think about community engagement, it is bilateral and it looks at a two-way exchange. So just to share of you when we think about community outreach again, it's reaching out by a program or other entity to extend assistance like an act of goodwill. There's nothing wrong with that. However, it may not be anything that a given community may be interested in receiving.

Same thing providing professional services specific to a group of people that may not have access to the services. But then also, a systematic attempt to provide services beyond conventional limit. So, these are all ways in which we think about community outreach. And again, I want us to think about it. It is from a one-way perspective that--

Say for instance, universities and other organizations have resources. May have depth and that those resources will rest within that setting. I'd like to share with you a framework for thinking about community outreach and-- sorry. Community engagement. And the citation is there for you to pursue.

This is a very different way of thinking, a very different way of engaging. And this is a process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people. It's a very, very different framework than those definitions that we heard before in terms of community outreach.

And so, as we think about engaging communities that have experienced historical trauma just in terms of listening and reading this particular framework, it's about the well-being of those individuals. So, we're back to polling questions, and there are quite a few this time.

And so, Shoshana is going to bring them up one at a time. So, want you to respond to does your organization, or agency, or program differentiate between community outreach and community engagement? And does your organization or your program have values or guiding principles for community engagement?

And most importantly, did you just do two at a time? I can't scroll down. So, we'll do these two, and I think the next one will come up later. OK. All right. So, we have some organizations, 39%, that differentiate between the two.

We have folks who are just putting it out there. 18% says no. I think so at 23%. And don't know at 20%. So again, thank you so much for responding in a very authentic manner. And so, this one is looking at does your organization of program values or guiding principles for community engagement? 39% said yes. 8% no. 24% I think so and 28% I don't know.

So, I'm going to close this and ask Shoshana to bring up a number four. Thanks. And this is a-- I made things complicated. This is a three-part question. So, for those who said are these values and guiding principles, we want to know if you have them. Are they incorporated in organizational policy? Are they incorporated in organizational procedures and are they incorporated in organizational practice?

So, if you could respond to those, that would be great. Again, it appears that some organizations absolutely have incorporated values and guiding principles into their organizational policy. All right. And other folks are telling us they're not so sure. I'm scrolling down.

Are they also incorporated in organization procedures? And 33% saying definitely yes and others, not so sure. And lastly, are they incorporated into organizational practice? 56% saying yes and the remaining not so sure. So again, I thank you for sharing those perspectives.

I think oftentimes, we have guiding values and principles. They live on our website. They're in brochures. They're in grant proposals, but they don't materialize in the life of the organization. So, let's look at some contextual realities. So, as we think about dynamics and particularly power dynamics between research institutions, communities, and populations, being able to examine that in terms of past, present and future so that we know that what's happened in the past has an impact on what's going on in the present.

And unless there's some kind of reconciliation for other ways, it's going to continue to have an impact on the future. And so again, to really think about what the power dynamics are and what indeed they may look like in the communities that you are attempting to engage. So, I just want to give some thoughts about community engagement and to really look at that within the disability space.

So many times, I have an opportunity to read proposals, I've done a lot of things across the entire country, especially in the space of cultural and linguistic competence and promoting equity. That we see people really giving lip service to community engagement. Again, I said previously that there's the language of community engagement is sprinkled around.

It's everywhere, but it's not based in what the values are of the organization and/or the practices that we see within that organization. We also see that in this disability space, that there's a failure to recognize and appreciate the knowledge and resilience of diverse communities. And some of that I think is even inherent because when we write grants, the grant that we may be responding to, because of the language that's in the RFP whether that's to private or public sector, always focuses on needs.

And when we're so needs focus, sometimes it may obscure the resilience and the knowledge that communities bring particularly in the research base. They know who they are. They actually may indeed know what they need and prefer, but we don't always get that.

Sometimes in this space, we want members of diverse communities to believe, and think, and act like us because that's the lens in which we are seeing the world. And we don't really even think about it from that perspective. It's just the way things are.

We lack the capacity to learn from and partner with diverse communities. And sometimes, that's because of the previous bullet. We want people to believe like, think like, and act like us. And lastly, we have few staff that are representative of the communities to which they're either providing services, trying to engage or conducting research so that research team, that university and research institution, it's not at all reflective of these communities.

And as a result from past experiences, there may be suspicion. There may be lack of trust. So, I'm going to offer you six key strategies and approaches for engaging diverse communities. So first of all, I can just look at the results of the polling that folks shared with us that we have to learn about communities.

When we don't know about communities and we have even the good intent of working within a community, that can go afoul if we don't have the knowledge necessary to be able to enter that community respectfully. So again, very key and critical. Another thing we see, particularly in the conduct of research, is that there's someone and researcher has a great idea and wants to conduct research.

And that may indeed be that person's interest but may not at all reflect the interests and needs and preferences of the community. And so, that sometimes that community engagement doesn't go well because when we go all in, it's all about us and not about the communities in which we're trying again to partner. So, we have to elicit as in, ask and consider the interests and needs of communities before we declare what it is that we want to be able to do.

And we may even be surprised that they may be accepting or they may not because it's not a priority for them. Another thing to do is to explore areas of mutual interest overall. I remember there's a community that was working with a program at Georgetown and it was focused on cancer prevention. And when the grant was over, the community wanted to continue engagement but they were much more concerned about environmental justice.

And it really wasn't the area of expertise for this particular research team, but that research team didn't leave them hanging. It really went about trying to ensure that community was connected with some other resources to pursue this collaborative research agenda. Really, looking at environmental toxins and other concerns. And so again, that is key and critical.

Another thing that we look at is that these relationships indeed have to be based on trust, reciprocity, and respect. And I really want to emphasize reciprocity that the communities bring a lot to the table. Researchers and research institutions bring a lot to the table, but it has to be of a reciprocal nature overall.

And lastly, looking at a commitment to the long haul, we get grants. They are over two or three years and we're gone. Communities are still there. And so, having the experiences where people helicopter in and helicopter out, not knowing. I never got the result of the last study. No one in my community was really engaged in this particular study in a meaningful way.

And so that if we're looking at building relationships, they do indeed have to be the want for the long haul. And I know that's hard, particularly when this grant funded and it's not something that's ongoing. But you can continue to have a relationship with communities in a variety of ways, whether that's advisory or whether that's just a range of activities in which you can be involved.

It doesn't always have to rest within the context of a grant or research study. So, I want to share with you some lessons learned when engaged in diverse communities. So, if we're going to do this and we're going to do this in a very thoughtful manner, we have to understand our own organizational culture and the culture of the personnel that worked there because it's hard to talk

about going out understanding other folks' culture without really looking at the culture of our own organizations.

I think the other thing that really is very important is that there has to be diverse cultures represented within the communities that you're seeking to partner or support. So that when research teams look one way and the community looks totally a different way, it can be problematic in many ways overall. You have to understand the history, the social, political, and economic climates of communities and to understand that within a cultural context.

So that means that you have to do some homework way before you decide that you want to partner with a particular community and engage that particular community in research. Lastly again, we have to recognize that communities have significant strengths, and they have inherent ability to know what their problems are and to really be able to intervene appropriately on their own behalf.

And they may very well want to do that in partnership with you, but we have to have that respect and that understanding about approaching communities. So, this is my opinion. It may not be embraced by all, but I think it's virtually impossible to engage in communities that have had historical trauma, individuals who have experienced a historical trauma and present-day trauma without some level of having skills and knowledge around cultural and linguistic competence. And then, understanding what the principles of equity mean within the work that we do.

So, I'm going to share with you a cultural competence framework. And it was developed in 1989, so that was way back in the day. We continue to use this particular framework in the work that we do. We've tweaked it just a little bit. And it was actually originally done in children's mental health.

And I won't go into the long story, but it includes Terry Cross, Barbara Bazron, Karl Dennis, Mareasa Isaacs and also, James Mason whose name does not appear on the monograph for-- just-- anyhow, his name got omitted and I always like to be able to acknowledge the work that he did.

And so, as we think about cultural confidence again, it really says that we have to have a clearly and defined set of values and principles. And we've been talking about that a lot, but this also says that those values and principles have to be congruent. So, you can't say I value diversity and equity over here, but yet your policies and practices don't support that.

So, they have to be congruent. They just can't be window dressing. And so, as we think about the capacity again within organizations, this capacity must be demonstrated at the policymaking level within the structures of the organization, research institution with the practices that organization research program engages in, that we would see it in the behaviors in the attitude of the staff that work there.

And that again if we look at this, being able to work effectively cross culturally. And that's not cross-racially. It's not cross ethnically, but it's really looking at culture. And we are all cultural beings. And every institution that we work with, whether it's a school, whether it's a hospital, whether it's a university program, mental health setting, aging, whatever that may be, it has multiple cultural layers to it.

And so again, not just thinking about people as it relates to culture, but also thinking about the culture of organizations and systems. I often use this definition of linguistic competence because again, that's team critical. Our framework for thinking about linguistic competence at Georgetown, we want it to have a framework that we can interact appropriately and engage with anyone that comes through the door, or picks up the phone, or is browsing maybe browsing our website.

So, in this one, we're looking at linguistic competence. And I want you to really think about what this may mean in terms of research, is that we have to be able to convey information in a manner that's easily understood. Again, that's by whoever you may encounter. And this may include a number of different groups.

At least from our framework, it may include individuals who have limited English proficiency. It may include people who may or may not be literate, either in their language of origin or in English. It would include individuals with disabilities and then also people who may be deaf or hard of hearing. And so, there are other categories I think that you can fall in there.

At least for this, we're seeing that being able to engage individuals from these various groups that may even cross over specifically in the conduct of research is key and critical. And I can say that my experience of seeing a lot of researchers who are like I'm not going to be including people who speak languages other than English. It's too hard. It costs too much.

It's too difficult. The grant is too short. It is just too complicated. So, we hear those things on a routine basis. We also look at linguistic competence as being able to address the health literacy

and mental health literacy needs of populations. And again, very key and very critical across the board, given the nature of the research that you may indeed be conducting.

And lastly, organizations that are demonstrating linguistic competence in this capacity will have policies in place, structures and practices. They also have procedures. And I want to emphasize and dedicated resources in order to support this capacity. So, I haven't done it in a while, but sometimes I read grants and I look at the populations that they're describing.

And someone's writing a grant and they work in this community and x number of people that speak languages other than English. I go straight to the budget to see has anything been budgeted, particularly if there is no one identified as having language capacity within the grant application. And I can tell you oftentimes, I see nothing budgeted.

So, if we're looking at linguistic competence, we have to have fiscal resources. We have to have personnel resources in order to support this capacity. And so, if we look at the concept of equity, I would say that in the disability space, we've not really defined equity. I think we used a term. I think it's bantered about, but there's not a lot of places that I've seen where equity is defined.

Last year, I had privilege of being president-elect for the Association of University Center on Disabilities. And I focused that meeting on equity to really bring people to the table to begin to talk about what does equity mean in the disability space. So, I'm offering this. This is specifically intellectual developmental disabilities. It's not the broad range of disabilities and it's based on the work of Paul Braverman and others.

And I would say that when we look at health and we look at mental health, those fields are really far in advance for disability because we've not really spent the time, put into research, come up with conceptual frameworks in order to really define what this equity means. So again, we're defining it here as the absence of systematic disparities and unjust systemic policies and practices that unfairly disadvantaged persons with developmental disabilities and their families while unfairly managing persons and families without disabilities.

And so again, looking at this within the context of what is needed for people to live their best lives in the communities of their choice. So again, these are some ways to think about our framing and what it is that we need to do in the disability space to be able to move ahead. So, I want to revisit James Baldwin's quote.

And that is that again, history is not merely something to be read and it does not refer merely or even principally to the past. On the contrary, the great force of history comes from the fact that we carry it within us, are consciously controlled by it in many, many ways. And that history is literally present in all that we do.

And as I think about that, we as researchers, we within the disability community are indeed challenged to understand what does this mean. What does it mean if we're looking to move toward equity in the work that we do? So, I will stop there. I think my next slide is just merely references that weren't listed here.

And I will stop here and stop share. And turn things back over to Shoshana and to others to take us into our next phase.

KATHLEEN MURPHY: Great. Thank you, Tawara. That obviously has given us all a lot of food for thought and we did want to start articulating and synthesizing and talking through some of those thoughts. So, we want to invite Terri, Dwayne and Hilda to join us again.

For those of you who may just be joining, Terri Daly is with us from the University of Central Florida and Dwayne Van Eerd is from the Institute for Work and Health in Toronto. And Hilda Smith is from York University, which is also in Toronto.

During the previous discussion, we heard first from Terri, and then Dwayne, and then Hilda. So, I went to reverse that order and let Hilda any share any thoughts or comments she may have about your presentation, Tawara, or questions.

TERRI DALY: Thank you, Kathleen. I do want to say it's absolutely wonderful to hear a presentation like this happening within knowledge mobilization or translation spaces. Part of my own PhD work was looking at how we can bring anti oppression and equity into knowledge translation and knowledge mobilization.

So, it's absolutely great to see a presentation getting out to so many people. And I really, really liked the emphasis that you put on knowing the history of the community as that for myself is something that I have found is just absolutely vital when working with different communities.

It's that you just can't assume that they have the same history as yourself and that knowing the barriers and the traumas that community is faced is really important to actually being able to develop and maintain an actual, really effective and trusting relationship with those communities. So, no questions because I really support everything you were saying, but I did just really want

to emphasize that point and really thank you for the presentation and everything that you shared with us today.

TAWARA GOODE: Thank you, Hilda.

KATHLEEN MURPHY: Dwayne, did you want to chime in?

DWAYNE VAN EERD: Sure. Thank you. I mirror Hilda's comments entirely. Thank you for a wonderful presentation. I guess I'll note that at our institute, we recognize that building and maintaining relationships takes time, effort, takes work. Our former KT director likened building relationships to a courtship and maintaining them like a marriage.

And like those relationships, things do require some effort on all people's parts. I wanted to say that I thought your six strategies presented, that highlights all of that to me. We really strive to work towards-- and I was really taken by number 5 and 6 in that seemed to encompass so much of it. And I thank you for your presentation as well.

KATHLEEN MURPHY: Thank you, Dwayne. Terri, did you want to say anything?

TERRI DALY: Yeah. I also enjoyed the presentation. And I was struck by the fact that when considering those histories, a lot of times we don't the various diversity within a group. So, within the Hispanic Latino group, there are Afro Hispanics. There are Latinos and Hispanics. They have all different histories of trauma.

And I have partners in a project where the participants said to us, we're not one people. This grant is about Hispanics and Latinos, but we're not one people. We're Cubanos and all this. So, I think that's important. And then, just that cultures continue to evolve and how we possibly can retraumatize people by not being up to date on the language that people use to describe themselves and their histories.

And thinking about how we address them and listening to how they talk about themselves is really important in that linguistic competence piece. So, I thought those are really good points.

TAWARA GOODE: Thank you, Terri. Appreciate that.

KATHLEEN MURPHY: So Tawara, similar to the general tone of the reactors in the chat, which you mentioned you're not looking at, there's a lot of endorsement of what you're saying and people appreciating what you're-- I'll just give you a sample. Sandra Marquise points out in

British Columbia, the First Nations Health Authority has been leading the way in cultural competency and cultural humility in health care and offers an analogous resource.

Beth Houlihan notes that we can use our role in service to the community and eliciting their inherent ability to address their own problems effectively, saying she loved one of your points that you made on one of your slides. And sort out here comments and questions.

OK. So as far as questions, it was put as a statement but I think Diane Leyva really meant this as a question. So, she said the problem with intersectionality is that often, people are discriminated by other oppressed groups. For example, Black, LGBTQ. So, I would imagine this is a question that you get pretty often. So, I don't know if you have a comment on that or-- I mean, it's not really a question.

TAWARA GOODE: Right. Maybe I should seek clarification on exactly what's meant. I gave an example from the literature with Kimberle Crenshaw just to not specify a group, but to talk about harm, marginalization, and oppression. And I gave an example of a colleague that shared from a personal space his experience with intersectionality.

There's nothing that I've seen that said intersectionality is only practiced by certain groups of people. It's about experience that an individual and/or groups of people have within their respective society. And it doesn't mean that Black people can't marginalize and/or oppress other Black people for their LGBT or other kinds of identities. So, I'm hoping I didn't convey that in the way I've described it.

KATHLEEN MURPHY: OK. And it makes-- that was an early on comment, so it may have been that was put in before you made that clarification. So, Kim really had a clarifying question or a extending. Obviously, your presentation made the distinction between community outreach versus community engagement. So, would you consider engaging the community through outreach? So, can one be a step to the other?

TAWARA GOODE: So, I think it was really clear in how I described it in that there's different ways and a different attitude that comes with engagement versus outreach. And so, I think that there are a lot of different steps to engage the community. I provided some.

Or I think I saw quickly in chat that someone talked about the use of cultural brokers. So, to me, you have to be able to make connections with the communities. Meaning, you have to have

knowledge of the community to know that if you are someone outside of the community, how will you be received?

Cultural brokers have been used a lot. So those are individuals that may know the culture of a particular community and say they know the culture of knowledge translation and/or research and that they can serve as go-betweens. And so, that's still a form of engagement as opposed to outreach. Now again, it depends on it.

If you have a grant and it says, oh, you have to disseminate 1,500 flyers within this community, you can do that and I consider that outreach. However, you can also work with people within that community to see how those flyers would be received. Is receiving flyers the best way to communicate within this community? Would they prefer word of mouth?

KATHLEEN MURPHY: So Salima, I think Dr. Goode was addressing your question there. What is your opinion of the use of cultural brokers when entering a community or culture unlike your own? So, I hope that addressed your question. Allison Taylor had a question which, again, was tied directly about your presentation content, but also thinking about that in relation to the way the polls came out.

So, she said from the survey, is it possible that many of us practice these guiding principles without having them formally instituted in policies or procedures? Because then, she notes 56% said they were practiced, but a lower percentage said they were in policies or procedures. Can we be effective in engaging communities without formalizing the practice as an organizational policy?

TAWARA GOODE: I'm going to say to an extent. Because if there aren't organizational policies, procedures, and practices, everybody could be engaged in those communities in very different ways. OK. So, somebody over here may do one thing. Somebody over here may be doing something totally different and there's not any cohesiveness nor, I'm going to say, guiding values for how community engagement would continue.

And then, say for instance you get someone new who comes in and heads the organization and things aren't in policy. Someone will say, OK, we're doing things this way. Whereas perhaps, some of those engagement activities really did work. So, I'm big on formalizing things and ensuring that folks are on the same page, that they've been trained. That is codified in order to promote that competence with an organization on an ongoing basis.

KATHLEEN MURPHY: And I think that's also a really nice tie back to Tonya's presentation earlier this afternoon where Tonya really illustrated the value of when there are organizational policies, and in this case for user engagement. And that can of course be made more specific to engage marginalized communities.

So, thinking about that link, what needs to be in place and institutionalized in an institution in order for these policies to be implemented and monitored? Amy wonders, I wonder if many have not isolated community engagement and policies versus diversity, equity inclusion in their policies.

TAWARA GOODE: OK.

KATHLEEN MURPHY: So, like, there's a DEI goal kind of embedded in that. Might be community engagement, but it isn't really articulated as an autonomous goal or process.

TAWARA GOODE: Right. I will say-- I'm going to say over the last two years-- I could be more specific and say 18 months, we've had three requests from organizations across the country about diversity, equity, and inclusion and what that means and whatever space it may be. So, let's speak to disability space.

And one of the things that I've noticed is that people say diversity, equity, and inclusion like an acronym. You know, it's DEI. So, I like to ask a question which one. Are you talking about diversity? It's related, but it's not the same thing as equity and it's certainly isn't the same thing as inclusion.

So, to me, I would say the work that we've done across the country, and in particular in some university centers for excellence in developmental disabilities and in some other settings in Australia and also in the UK, a worker said that if you're looking at whether it's community engagement, whether it is the conduct of research, whether it's training and technical assistance, how do you thread the lens?

And I would say there's a cultural linguistic competence throughout so that it's not that community engagement lives over here and then DEI or something else lives over here. It's how are all of those things connected and to be able to use that as a lens to guide our work. Sometimes, I've done this training and it's like I'm in that really older age cohort.

So, I have those images of Tina Turner on the slides, and that's because way back in the day-- and my son was way, way, way, way back in the day because he likes to make sure I realize that.

But you know, Tina Turner sang the song that says what's love got to do with it. I suggest to people that they really think about asking the question what does equity have to do with it.

What does diversity have to do with it? What does culture or cultural and linguistic competence have to do with it? What does language have to do with it? And just simply by asking that question, you would be surprised at the differences when you're thinking about knowledge translation, when you're thinking about what does this knowledge mean within different cultural context.

So, I see it as a continuum and fully integrated across the board. I see it as fully integrated across the board. OK. My husband just walked in and I was giving him the you need to be a little bit quiet sign. So those are my thoughts.

KATHLEEN MURPHY: OK. So, you are starting to move the conversation into-- well, and the whole presentation has been to look critically at what are people trying to do with respect to any of these goals which raises the question of evaluation. And Nevada Kennedy has already brought that to our attention, saying Dr. Goode, could you speak on evaluating the effectiveness of organizational policies and procedures on cultural competence.

TAWARA GOODE: So, thank you for the question. And we've had opportunities to do this through various funding sources. A lot of it focused on children with disabilities and special health care needs through Title V programs and that was really to help organizations engage in a self-assessment process so that they could look at what are their policies, what are their practices, how do they allocate resources, what do their staffing patterns look like.

And so, we've done that within that context to-- I'm going to say help organizations take a look of where they are at any given point in time and then to plan meaningfully, including what policies do they need to change to align with their goals. How might they redo budgets to ensure that what they say they want to do, they have resources to be able to do?

And so, I think that this is a wide-open space. It certainly is a space where there could be a lot more research, particularly in the disability space in terms of the effectiveness of cultural and linguistic competence. I would also say that since diversity, equity, inclusion are now the terms of choice and I hear that, I think is very important, again, to define what that means.

So, our framework has been how does cultural and linguistic competence help you and your goals toward inclusion, toward equity and toward diversity? Because we think that there is solid

concrete and evidence-based practices, and you would see them a lot more in mental health than you're going to find them in disability because we haven't done the work.

KATHLEEN MURPHY: And frankly, a lot of the knowledge translation work does come from the health community. So, we do appreciate all you health practitioners who are with us today. And some people are putting in the chat and noting that yes, this is becoming discussed a lot and different definitions come up or memes.

So Salima noted she saw an online meme that read diversity is being invited to the dance and inclusion is being asked to dance. And Jessica Lukfar had seen a difference between equity and equality is equality is the button next to the door and equity is everybody has a sliding glass door. So, there's a lot of directions we can take this in.

I did want, though-- I don't know if Dwayne or Hilda or Terri had any other sort of thoughts that they wanted to bring in. I mean, you don't have to.

TERRI DALY: I just-- one of the things with the disability community is that, again, it's a very-- there are pockets within the community of people with different kinds of disabling conditions. And some of them have very different identity structures. And so, that is another thing that I don't know about how to navigate as a professional in some ways because we were brought up-- probably you also being a person of a certain age-- to talk about people with disabilities and use people first language.

And that narrative is changing. And it's hard sometimes not to offend by just showing your age in a way that we were taught to be respectful of people with disabilities. And now, the language has changed. Do you have any advice for those of us who are navigating those waters on how to-- I mean, other than just I guess asking how do you like to be addressed. Is that the simple answer?

TAWARA GOODE: So, I want to answer that in terms of cultural context. So, I think you need to look at who's saying my identity first. Language disability first language. I would say that it doesn't permeate the entire group of people who experience disabilities.

I would even dare say that there are-- I have a colleague who I'm thinking about. Disability justice advocates. And I am also going to say, a younger generation of people. So that-- I can't assume what individual people want to be called without asking. So being able to ask.

And if I'm writing a paper or something of that notion, I may acknowledge that there are many different ways in which people choose to be referred and I'm respectful of that. In this paper, this is the term I'm going to use. And I can say that I think it gave Latino, Latina, Latinx and Hispanic that.

But those-- and feminist Chicano. There's many different terms. People choose how they want to be referred to. And if you could look at the generational differences in Latinx, and there are communities in which we work where people wholeheartedly reject it. So that's part of the cultural conference framework in terms of acquiring knowledge and knowing who you're working with.

And we have to have enough humility to say I don't know. I'm going to ask. And I may get it wrong, but then I can then get it right.

TERRI DALY: Yeah. I think that's a great policy. I think that it gets difficult when you're trying to communicate with a group and some people want one reference and others want another. But I think in written print, that is a great way of addressing it.

It's a little bit harder sometimes when you're in a group, or doing a focus group, or doing a presentation. But the great policy overall, I think. Thank you.

HILDA SMITH: So, I might just chime in here, as well, related to that conversation. I have found being part of the LGBTQ+ community that there is a lot of tension around the language that is used, particularly in relation to reclaiming the term queer. That is something that myself as a community member has taking me a very long time just to get used to it being used and like just lay situations.

And what I find I do is I contextualize myself. So, I contextualize my history with the language and my usage. And that allows people to see my context and where I'm coming from in that knowing that there is a conversation ongoing and that there isn't a clear definition of what's going on can be really helpful just to like smooth that process in that way so that people are just kind of like yes. This is the context of where we are in the discussion and just grounding this is the language I am using here within this space.

DWAYNE VAN EERD: What if I could jump in as well? But if you have a comment, please don't let me stop you Tawara.

TAWARA GOODE: No. I'm listening.

DWAYNE VAN EERD: Within this part of the conversation, I want to ask you a question, but I don't know how to pose it, I think. So, I'm going to tell the story, maybe. When we engage with research with stakeholders in a research project, by nature we're looking for representatives of the community and probably can't represent the entire community because we don't have the resources, time to do that within a research project.

And particularly because we like to start from the beginning of the project. So, we want to ask opinions about is our research question valid. And then moving through the research, also ask if we can get some help in translating the messages from the research. Heaven forbid we use research speak.

I don't ever want to share a P value with anybody in a community. I want to know what's meaningful or practical about this research. And I'd like that to be in language that's useful practical understandable. But we do face that possibility that we're narrow or we may not have all the representatives.

So, we try to encourage the terms of reference of our engagement to help us to identify others in the community if we need to expand upon the messages or translate the language that we use. I just wondered what your strategy-- there is a question, finally. What is your strategy on how to do that, I guess?

TAWARA GOODE: So, I guess it depends. It depends on the nature of the research and the nature of the community. So, I don't know any study where you're going to have representation from every single person within a given community.

But I will say that-- so it sounds like what you're doing is having representation going back to the community to see is this reflective of who you are is about the best steps that you can take. I will say this is what I've seen a lot in research. I've seen that researchers describe a community, say by disability and/or by race or ethnicity.

And that's all they say about them, as by simply saying your race or simply saying disability describes a population or who individuals are. I think that we need to be much more nuanced in how we describe people. And I don't see that. So, like if someone says this was the evidence-based practice, and I'll ask the question evidence base for whom.

So, who are they? So, someone would say oh, it's evidence-based practice for African American community. It's like, what's socioeconomic status? What state did they live in? I asked all those

questions because that tells me more about who they're describing and who the group may be than simply a racial title or disability title.

KATHLEEN MURPHY: So, I did just want to bring in a question related to that from the chat. It's an earlier chat from Alison Taylor. And so given-- this is context for her question, tying it in. There's heterogeneity within any given community, right?

And we know your presentation emphasized the importance of developing long haul relationships and really listening and getting to communities. So, Alison is wondering, do you have any recommendations for building and sustaining relationships with communities? So, she's agreeing with the importance of that, but what do you do with shifting projects and grant cycles? How do you handle that?

TAWARA GOODE: Yeah, how do you handle that? I think that's hard if you're solely research funded. I did give an example of one example through Georgetown and our Cancer Institute in which the researchers were really poised to help and hand things off to another group of researchers to be able to help with a particular area of interest and need within a given community.

So, I think that it's about the kinds of relationships that you want to be able to create and maintain so that even though perhaps a particular research project is over, do you routinely have a community advisory group? And so, that may be a connection to a community. Can that community advisory group routinely review things that may be in plain language or the appropriateness for a particular community?

And I'm going to say do you hang out with them when you don't have resources. And that's something that we have worked very hard to do. We may establish relationships within a particular community and maintain those over time because you never know when an opportunity may come up. It could be that you have students who can come from high school to the university.

There can be programs that happen. There's just a whole range of things where you don't look like you're a helicopter coming in because you have money and then leaving. It just depends on the nature of the relationship you want to sustain over time with a given community.

Oh, one other thing. I've heard communities clearly say that they may be advocating at a legislative or other kind of level for something that they clearly need within their community, but where are the researchers? They're not there. They were only there for the research activity.

KATHLEEN MURPHY: Yeah. So, it's a relationship. It can be a friendship. So that does tie back at the very end of the discussion period from the first presentation, Janet Rodriguez. We had a chat question. How do individuals with lived experience of disability initiate or join a research team?

Many times, the disablement process and lack of support prevents us from pursuing formal post-secondary education. Will experience and empirical knowledge be considered as valid? So, Janet, I knew that Tawara would cover some of your questions so she just gave a couple of examples of being on advisory boards and how your experience and empirical knowledge are considered as valid.

And there was a presentation in 2018 about disability rights and science community engaged research with people with disabilities that Katie MacDonald gave. So, I did put the link in there that gives at least people some ideas about how to engage.

TAWARA GOODE: So, Kathleen, I'd like to say something really quickly. I know that we don't have a lot of time left.

KATHLEEN MURPHY: No, but it's important so go ahead.

TAWARA GOODE: Yeah. We're just coming on finishing up a project that was funded by PCORI, Patient Centered Outcome Research Institute. And it was a two-year project that's based on a model that we had at Georgetown.

That was truth and reconciliation. And it was ways in which researchers and persons with intellectual and developmental disabilities who have mental health needs can partner in the conduct of research. So, one of the huge things that I look at within the context of equity is that there are, quote the researchers and then there are-- I say participants. But sometimes, the participants are treated like subjects.

Our project looked at having a research team that included two persons with intellectual developmental disabilities and mental health needs as part of our team. So, everything we did, we did with them. And I think the other thing is really very important when we look at this is that

there are-- I wanted to emphasize there are many ways to be engaged in research as co facilitators, folks who help collect data.

There are many different ways to be involved for people with disabilities across racial and ethnic groups, but it's not limited to being a participant in the study itself. We have to define other roles for them and I think that that's key and critical. And those roles don't have to be rooted in whether or not someone has a PhD.

KATHLEEN MURPHY: Exactly. So, I did just quickly put a few links in the chat from PCORI. PCORI is the patient-- Remind me what the C is.

TAWARA GOODE: Patient Centered Outcomes Research Institute. Yeah.

KATHLEEN MURPHY: Yeah. So, we are getting near the top of the hour. And just to close it out, there are a couple of things that I did want to let people know about day two. But before we do that, just really thanks everyone through the presenters and the reactors. It's been a really great kickoff and a lot of rich discussion and food for thought about really--