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AUCD

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Directors Retreat

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>> John Tschinda: Good afternoon, I'm the executive director of the AUCD. Thank you and welcome. Thank you for joining us today. I'd like to thank the network planning committee who helped shaped today's meeting. That group felt very strongly that there should be a clear goal and desired outcome for our time together, and shortly I'll turn it over to Tawara to define exactly what that is.  I will also note that we have all three cinder types participating in this meeting, especially for this important topic. It's critical that we have AUCD, LENDs and IDDRC's.

As I mentioned I will be turning it over to Tawara Goode, the director for the national center for cultural competence and president of the AUCD board of directors.  She will review considerations for defining and applying equity in the developmental disabilities field. That will be followed by a panel discussion led by Betsy Humphreys, the director of the New Hampshire Maine LEND program on equitable engagement. That will be approximately 30 minutes following Tawara's 25‑minute presentation.

The panel discussion will lead us into our breakout rooms for another 25 minutes. We will provide you with a guiding question to kick off the discussion in those 10 or 11 different groups and instructions to go with that as well.  We will close the last half‑hour of our meeting with an optional breakout room socializing time or continuing the conversations that were had during those breakout sessions and we'll wrap promptly at 5:00 p.m.  Thank you all for being here this afternoon, and Tawara, I will turn it over to you.

>> Tawara Goode: Thank you, John, and good afternoon to everyone. I just need to share my screen. I can't get rid of all these extra things that are showing up like who's in the waiting room, who's joined.  Again, good afternoon, I'm really happy to be with you today. We really are just going to spend some time together defining and applying the concepts and also the practices of equity and intellectual and developmental disabilities, what does it mean for us?

So the planning committee did an amazing job and came up with these two objectives, which, at the end we'll be able to state the differences between the concepts of diversity, equity and inclusion, specifically within the context of intellectual developmental disabilities, and then apply the concept and practices of equity.  We're going to focus on that, to community engagement activities. With that said, I'm just going to move along right here.

So, as we look at diversity, equity and inclusion, oftentimes we get a lot of requests particularly over the last 18 months or so for training, for technical assistance around diversity, equity and inclusion.  What I've noticed is that DEI and EDI has become an acronym, that people use it like a one‑size‑fits‑all. We know that each of these terms means something different, yet people lump them together as if they're all the same. We're just going to spend some time looking at diversity, equity and inclusion and what does it mean within the IDE context.

When we think about diversity, it's the condition or having or being composed of different elements of quality. Again, a very simple definition. If I think about a word within the lens and also within the IDDRCs, I tend to think about in particular cultural diversity. This gives us a way of thinking about cultural diversity in terms of how we describe differences because there are differences.  It's not our similarities that cause us issues. It is clearly our differences. It's including all the things that you see there and even more from gender identity, to spirituality, to physical abilities. All of these things we're looking at in terms of describing cultural diversity as it relates to comparing one individual group to another.

 I want to take just a little ‑‑ like a deeper dive to look at who are persons with intellectual developmental disabilities and I think sometimes we don't take the time to ask that question because we are so focused on the disability.  This is data that we have from 2019. We don't have 2020 data available yet from the U.S. Census. This is just a general makeup of who lives in the United States by race and ethnicity, at least by the racial ethnic categories that the U.S. Census has given us.  I think it's self‑explanatory, although I want us to think about the question who are persons with intellectual developmental disabilities to call your attention to the category, some other race. Clearly 5% of people estimated in the United States don't self‑identify with any of the terms that you see previously.  So as we think about persons with intellectual developmental disabilities and their families, quite frankly in the communities in which they live, who are the folks that self‑identify some other race. How do they self‑identify? I think that's key and critical as we look at data collection and obviously as we look at engaging diverse communities, which we'll hear from our panel a little later.

The other category, two or more races, I know from data in the U.S. Census that is one of the fastest growing identity groups that we have in the U.S., two or more races in how people self‑identify.  We see, lastly, Hispanic or Latino, Latina or Latinx depending on one's choice of language, can be of any race overall. So this gives us an idea of who's living in the U.S.

Then when we think about the languages that are spoken in the U.S., again, we have a significant portion that speaks English but a fairly significant portion of the population that speaks a language other than English. Again, as you see here from these data from the census, it gives us categories.  I included the Indo European language so you could see what it's like, the same for Pacific island languages, again, what the U.S. census puts in that category. I want to call to your attention other languages that include Native American languages. They put a lot of things in one bag, Arabic and Hebrew and African languages which we know there are a truckload.  Who are persons with intellectual disabilities, how many may speak a language other than English at home. This data doesn't include American Sign Language or other sign languages.

Again, as we look at the populations in the U.S., another data source is from the U.S. Census as well, from this all we know it's been very difficult to collect data on persons with intellectual and developmental disabilities.  We have been using the formula for quite some time. This data source gives us at least an idea based upon self‑identified disability by race and ethnicity. Again, I urge you to look at the categories, some other race, almost 8.5% of people who are noninstitutionalized with a disability, and two or more races, 11%.

So what does that mean for our work? What does it mean when we ask the question, what are people with intellectual developmental disabilities. Same thing in terms of data, looking at poverty status. Again, it's key and critical. This is poverty status by age groupings. There's not a poverty status by age and disability and race and ethnicity that are combined.  That's why you're looking at two very different tables. So again, it really is important that we respond to that question, who are persons with intellectual disabilities and right now we're only talking about race, ethnicity and language spoken. We know there are many other variables.

I keep getting a popup for who's coming in. We look at how many children and adults with IDD. Again, this is from a national survey. We know from papers that have been released recently that this is not the greatest estimate that we have. As I think about racial and ethnic makeup and cultural identities within this population, while we don't know the exact numbers of people with IDD across this nation, what we do know is that they will be representative of the racial and ethnic and other groups that we saw in  that census data. So this is still in the idea of looking at who are persons with intellectual developmental disabilities that we see.

I want to bring up this concept of multiple cultural identities. It's defined in the literature in a number of different ways. You see the categories that are here. Some people identify with one particular group over all others.  We also know that many people compartmentalize. We see this in services and support, especially when there's a lack of trust that I'm only going to share with you a little bit about who I am. I'm not sure I can trust you with anything else. I'm going to hold back.

Then there's integration where people have all of their multiple cultural identities, and I have a colleague, Andy, that I use all the time with this that gives us a very powerful way of thinking about multiple cultural identity within developmental disability.  If anyone knows Andy, this is clearly ‑‑ I'm going to call it Andy‑speak. This is Andy's language and how he may express himself. In terms of cultural identities, he says I come to the table with my LGBTQness, my Hispanicness and my disability. Neither overshadows the other. Neither is more important than the other. They're all part of who I am as a person.  Sometimes we forget all those other identities because we're so focused on the disability.

Also again, this is an answer to the question, who are people with intellectual developmental disabilities. This is determined intersectionality. We've been hearing a lot and clearly hearing it within the IDD space. What I want to call to your attention is that the work that Kimberly Crenshaw did on this years ago and for this particular term of intersectionality as opposed to intersection, being very, very very clear  It talks about membership in many social groups, individuals experience discrimination. What I've heard in our field is people using this term but leaving out the harms part, talking about it as if it's multiple cultural identities as opposed to very specific about oppression, discrimination, and marginalization.  Again, as we think about and use terms, we need to think about it. I am clicking here.

We have my friend Andy again. He is looking through this through the lens of intersectionality. So his statement about intersectionality is from childhood through adult life, stereotyping, discrimination and marginalization because of who I am and how I came to be on this planet.  So really understanding the differences between that when we asked the question who are people with intellectual developmental disabilities. We need to be digging deeper. And this is probably only part of the surface.

So what I've done in the slide deck which you will get, it's more than I can cover in detail by the amount of time that I have, but these are some takeaways, some things that we can consider including acknowledge and respond  To the diversity within neurodiversity. I've been hearing that a lot, this person is neurodiverse, as if there aren't other identities that that person may bring to the table.  Let's go to taking a deeper dive in equity and what does it mean in the IDD space. I had the great pleasure of planning the 2020 conference, very much looking forward to our upcoming conference and all the incredible work that the staff and particularly Danny has done in terms of moving us forward.  So we looked at equity during that conference.

All of the presentations were about that. I have to say that I had an observation when I read all of those proposals in my role as conference chair. It was very clear in many of the proposals that just serving a person with an intellectual and developmental disability, somehow people thought that was a thing with equity.  So we have a lot of work that we need to do going forward to think about this. We can't really talk about equity until we talk about disparity. This is just a graphic representation of two little figures. Disparity gets a bad rap. It can be neutral. It doesn't necessarily have to be something negative.  However, when we look at the disparities in intellectual developmental disabilities that actually impact people in a negative way, we know that it happens at a systems level, at an institutional or organizational level, at the community level, and then from the experiences of individuals as these images tell us across the board that we go from systems down to how disparities impact people.

I want to share with you a framework for thinking about disparities in intellectual and developmental disabilities. If we look at the very bottom it looks at what are the resources and policies that we put in place. Then I think that we're asking the question disparities of what? Because we tend to lump them all together.  This framework really looks at all of the areas as you see them in the gray above housing, child care, recreational, employment. But it asks, is it disparity in accessibility or susceptibility? One way you can think about susceptibility in particular, supports are available to me, accessible, I can get there, but they're not acceptable to me and they're not acceptable to me and/or my family because they haven't taken our culture, language and other things into consideration.

So as we look at disparities, it really is helpful for us to go deeper. What the literature is telling us, obviously equality and equity are not the same thing. However, people still tend to use the concepts and language interchangeably. When you look up what's in the literature in terms of definitions of equity, there's not one definition.  This slide is limited only by its size and these are all the ways that I've seen how equity is conceptualized and defined. This is an example from the University of Michigan around how equity is indeed defined. So we've not really done that work within our network. We might be using the language but we have not reached consensus on it.

So very simple definition is treating all people the same, regardless of needs, circumstances or abilities, or equity, providing folks what they need, the levels of support depending on their circumstances, interests, et cetera.  I've used this graphic before. I think it's really great. It's one of the few graphics that really show disability in terms of illustrating equality and equity. We've taken a little step at coming up with a framework and a way of thinking about equity. It's not etched in stone. It's not out there like this is the thing, but it's something that we came up with rather than to continue to say we don't know a definition.  We borrowed heavily from the health equity literature, particularly Paula Brakeman at the University of California San Francisco. We're looking at defining equity in intellectual developmental disabilities as the absence of systemic disparities and unjust systemic policies and practices ‑‑ and this part is important, unfairly disadvantaged persons with developmental disabilities and their families, while unfairly advantaging persons around families without disabilities.  It's a way for us to think about what does equity really mean, what does it really look like in the IDD space. We also know that we can't really effectively address disparities and the inequities without acknowledging the isms. We live in the U.S. and isms are alive and well in our country. I'll just leave it at that.

As we are thinking about equity, we can't just throw the word out there. We really have to think about things that are much different, much more in detail, including things that may help to contribute to the kind of disparities that we see.  This is the elephant in the room on the table and lots of things that we don't always use in our work in intellectual disabilities. We see it much more in health equity and other places but we don't always see it in terms of ‑‑ maybe we see discrimination or oppression and ableism but we don't see power differentials talked about a lot, classism and sexism.  All of these things are impacting the lives of people with intellectual developmental disabilities and people who provide them with a range of services and support. This is just a quick way for us to think about ‑‑ again, for us to think about implications for equity and intellectual developmental disabilities. I'm not going to, as I said, go through all of these.  I think they're pretty self‑explanatory, however I would like to highlight a couple. That is to advance racial, ethnic and cultural diversity as a strength. That's a whole different frame. We've been hearing that they're issued as opposed to opportunities and strengths. So a couple things for us to really think about.

We also look at deficits within communities because we're always in that space. We are sometimes slow to identify strengths and resiliencies a person with intellectual and developmental disabilities across their backgrounds. We also tend to maybe describe and I still see this in grant applications, folks as hard to reach or not engaged.  I dare say that it's not like folks are so much hard to reach as opposed to we've not been successful in being able to reach them in a way that's meaningful for them.

So again, these are just some ways to think about the cultural competence framework and things that we, within LEND programs, within IDDRCs need to really think about if we're moving toward equity.  This is looking at this as a work in progress and we all have our sleeves rolled up to do this work. Quickly, when we think about inclusion, what does inclusion mean? I think it means different things to different people and very different things in the IDD space.  As we think about the notion of inclusion, again, these are just summary statements here that inclusion is neither defined by federal legislation in the ADA nor IDEA. Again, inclusion is an accepted practice for many but not all who are concerned or affected by intellectual developmental disabilities. These are just some things for you to think about.

As we look in the literature, I just pulled out three conceptualizations of diversity. So when we look at I'm going to say the HR and other human resources, management, that sort of thing, literature, it's the employee experience overall, that people are treated fairly, that they have equal access to opportunities, can they really contribute.  So that is a lens of looking at inclusion. When we look at the disability literature, what we see is getting fair treatment, making products accessible, modifying how we do things, and really dealing with stereotypes. Still dealing with inclusion but from a very different framework.  When we look at it from the LGBTQ literature, and again looking at intersectionality and right now I'm channeling Andy, it also has a different meaning.

So as we work together and think about inclusion, these are some things for us to really gnaw on.  I stumbled upon this website and I really like the way that this group is talking about inclusion. Inclusion typically means inviting those who have been historically locked out to come in. Like come on in, y'all. This group was really questioning who has the right to invite others in? How did the inviters get in, and who's doing the excluding? Really important questions for us to think about across race, ethnicity, disability, culture, language and other factors.

Lastly, I'm sure you're all familiar with the concept of othering. This is basically saying that we are needing to deal with othering overall if we are moving forward in our diversity, equity and inclusion journey.

So, in summary, I feel that inclusion is going to require the tenacity to address the isms because they're alive and well.  We have to have that tenacity in any social/political economic environment because that's where we live. We live in the United States. There's territories and tribal nations. So we have to be able to do this across the board. We know inclusion is going to require insight and capacity to view and respond to inclusion through a cultural lens.  We have to have political will. We have to have expertise to be able to confront disparities, disproportionality and inequities. I put in this reflection about inclusion and belonging.

I remember Amy Hewitt had a conference that we looked at when she was president‑elect and it was like we all belong here.  So there's been a lot of talk about inclusion and belonging, that I can be included and that I'm at the table literally, but I'm not really at the table because I'm just there as a decoration or someone says I can check off a box. As we think about inclusion and people having feelings of belonging, that that really is key and critical.

What does this all mean for community engagement? I want to first differentiate community engagement and community outreach. I also see people using those terms interchangeably. We feel that they mean totally different things. When we think about outreach, it's unilateral. It's like sometimes universities, other programs reaching out to communities.  When we say engagement, it has a different connotation. It means more of a bilateral exchange. Just an example of community engagement that I really liked, this is an excellent book that you can get from the website.

If you read between the lines you're able to look at this with any content.  It's the process of working collaboratively with groups of people affiliated by geographic proximity or special interests or similar situations to address issues and affect the well‑being of those people. That's a very, very different framework than community outreach, which is just getting our message out here or information.

So as we go into the panel, I want you to really think about the implications of these values. These are the values that we created at the national center for cultural confidence. The concept must be extended to communities so that we can't sit in our office and think of the grant and go impose it on a community, which is something that often happens.  We know that communities determine their own needs. Communities should economically benefit from collaboration. Lots of times folks get grants and no one in the community has a role in that grant so communities should economically benefit, a basic premise of equity.

Lastly, community engagement should result in the reciprocal transfer of knowledge and skills across all collaborators and partners.  We as academics, researchers and other sometimes come to the table as if we have all a bastion of knowledge and we really have to look at doing things differently in terms of how we learn from communities.  In conclusion, we still have a lot of work to do in the diversity, inclusion and equity across all programs. I'll stop share. I am, I think, on time. Thank you for this. These slides will be available later. We'll make sure that Dawn has them and Jamie. I think I'm supposed to turn things over to Betsy.

>> Betsy Humphreys: Thank you, Tawara. You are right on the nose; it's 3:30. Thank you so much for that wonderful setup for our panel discussion that we're going to have for the next 30 minutes.

My name is Betsy Humphreys and I'm the director of the New Hampshire Mainland Program. We have four panelists this afternoon representing the LEND, UCEDD and IDDRC programs.  We have four panelists representing three projects across the three partner networks.

The planning committee has invited them because each represents a really unique opportunity to talk about the development of equitable partnerships between community partners and either IDDRC, UCEDD or LEND partners.  I'm going to briefly introduce our four panelists and we'll have about 25 minutes for two questions that I will ask the panelists to elaborate on and I'll tell you those in just a minute after a introduced the panelists.

We have Pablo Juarez, senior associate in pediatrics from the Vanderbilt Kennedy Center TRIAD program, which is the treatment and research institute or autism spectrum disorders. He works with Emelyne Bingham, Lynn, who is a senior lecturer at the Blair School of Music at Vanderbilt University.  You should have more detailed bios in our agenda and I believe that Jamie and Dawn are going to put them in the chat for you now if you want to take a look at more details.  Pablo and Lynn have a project that they've worked on together collaboratively called the Access Inclusion Network of Nashville. We'll be excited to hear about your partnership.

Then we have Hibo Omer who is New Hampshire Mainland Faculty Center. The New Mainers public health initiative and the LEND program have a project called the parent advocacy training project in special education. Hibo, we're looking forward to hearing more about that project.

Then finally, Leann DaWalt, who is the UCEDD senior scientist at the Waisman Center at the University of Wisconsin Madison. Leann is co‑core director of the clinical and translational core within the IDDRC and has he lied heavily on community partners for the work that she's doing.

Welcome, panelists. We're very glad to have you here this afternoon. We have, as I mentioned, two questions that we'd like to ask you and each panelist will have about two minutes to respond to each question.  I'm going to let you know, the panelists have the questions in advance but I'm going to put them out there now for the whole group and then we'll start talking to the panelists directly. The first is about trust and relationship building and we're interested in what your university partners did well to cultivate trusting and equitable partnerships with you.  The second question which we'll get to is what did the university program have to change or learn to do differently in order to make the partnership more trusting and more successful? Those are our two questions. Hibo, I had like to start with you with question one. I'm going to repeat it one more time.  What did your university partners ‑‑ so in this case it would be your partnership with the UCEDD in Maine. What did the partners do well to cultivate the successful community engaged partnership that you have had with the UCEDD?

>> Hibo Omar: Hi, everyone. Thank you, Betsy. Mostly I guess the flexibility. At the beginning we had a plan and a checklist going in. I was doing the outreach for the community but at the same time I had a change of plan last minute, and that flexibility ‑‑ at the same time also Marnie who was leading the project also had a change of mind.  We kind of presented ‑‑ once we brought the community together, we asked them what do you need, rather than us coming in and the university coming in saying that we want to solve a problem. So that listening session was the turning point. Rather than having a class, we had a listening session where every parent had a chance to vent out of their problems and any concern that they had.  So we took notes and we didn't present anything. So that was the beginning and the turning point of the project in a sense that no one was the expert. It was a two‑way process. And then out of that notetaking came out of a new agenda where we have to execute each week what we can handle and being open to the community and saying that we are here to teach you about schools so to narrow down.  They had problems with the hospitals. You name it, they had it. So we wanted to specifically be more useful on education part of it and then we kind of narrowed it down to more IEP. To the surface it came out that many parents didn't like going to the IEP so we focused on the IEP and then the agenda became the IEP ‑‑ watering it down so that they can engage and the laws that happen, kind of empowering the parents and the importance of the parents being there.

>> Betsy Humphreys: You mentioned a change of heart that you and Marnie had in your planning. Can you just say a tiny bit more about your change of heart? It sounded like you maybe had a plan and then shifted it.

>> Hibo Omar: Yes. I didn't want to enforce what I thought was the problem because we had a list and all prepared the agenda prior to meeting with the family, with the parents that we wanted to teach. At the same time Marnie also had a change of mind so once I told her that I'd rather hear from the parents what the problem is, I think I know what the problem is but I don't want to enforce that.  By Marnie opening up for the change ‑‑ because we already put a lot of effort on planning and having an agenda, the whole nine yards. So if she would have said, nope, we already had a lot of work put in, then nothing would have worked and that would have created friction. For her saying, okay, well, this is a good idea, I didn't want to do that also.  That kind of opened up and whatever we had prepared we have to push it aside and then come up with a new thing by listening to the parents and taking notes and then coming again together to see what we can provide parents.

>> Betsy Humphreys: Wonderful, Hibo. Thank you so much. We're going to go to the next ‑‑ and I should give the panelists a heads up. Leann, Pablo and Lynn is the order we're going in so you won't be guessing. Leann, you're up next, so you can build on anything that Hibo has shared or any experiences that may be unique or different in your IDDRC.

>> Emelyne Bingham: Not to sound like a broken record but I wanted to chime in and second the point about listening and flexibility and being open. Research, I think that that can be particularly difficult because you may have a study you've designed and you're funded to implement it in a specific way and I think that what I have learned over time is that you have to be open to change your study design after you've built that relationship.  You can't microwave a relationship. It takes time and going and listening, and a lot of the research we've done across the State Of Wisconsin working with schools and communities, it takes going and trying to understand each school, each town, each unique culture and what's important in schools in terms of what's important to parents and teachers and different professionals.  Building that relationship, for it to be two‑way and understand what are they already doing that maybe we could join in with as opposed to coming and saying here's my research, design and inventions that I think are going to be really helpful to you, but instead trying to understand what are the strategies, initiatives that the community already is doing and how as a researcher could I jump in to try to support some of those interactions that are already happening.  I want to second the idea around listening first and adjusting your pace and being flexible because you can't make it happen quickly. I can say very early on in my career I was really in a hurry to get studies and data and get more funding so I could have a research career and I found it much better to slow down and have more authentic ‑‑ you know, because you're going to end up with better data. I'll stop there.

>> Betsy Humphreys: Thank you, Leann. Can you think of one example to share of a partnership that sort of shifted and changed?

>> Leann DaWalt: I can say two examples. One would be in working with schools; we had a research‑based intervention package that we were hoping teachers would be willing to implement. When we went to different places, different communities, they don't all have staff that do things in the way that maybe ‑‑ in terms of their infrastructure.  So we learned that we couldn't give people big packages. We had to say what are the practices you're doing and would you be able to select one of these inventions, not this entire package. Then on our end as researchers, we had to think through, okay, how can we take the burden of the data collection away and study what's really happening as opposed to assigning people.  Another example and this is work that I did with Sandy at UT Austin, we had developed something that was eight weeks and it was weekly sessions and listening to the community, that wasn't feasible so we needed to adapt. It was once a month, all day on Saturdays. This was a big shift for me as a researcher because we hadn't studied it and designed it that way.  But we listened to Sandy and we needed to shift our approach. Those are two examples that as a researcher I had to start holding loosely my ideas so that it would be a fit.

>> Betsy Humphreys: Wonderful. Thank you. Thank you, Leann. In both cases you and Hibo have described the ability to shift your planning in response to what you were hearing from the community. Thank you. Pablo?

>> Pablo Juarez: I'm going to third all of those things I think, from the time and flexibility, the growth mind‑set part of it too. We've really learned that we can't know everything going into a project and to be open to understanding what the needs are and shifting as needs arise.  In our case, this carries over to most of the work we do but in talking specifically about our all inclusion network of Nashville, we started out in a very small way just partnering with a couple of community partners, the National Zoo, the National Opera and our local botanical gardens, because they really wanted to learn how to better support people with disabilities and particularly families of children with autism.  As we started to provide some supports to them, we started to learn very quickly that there's a lot of things that we need to be able to expand on beyond that from a community standpoint. We have family trainings where we support families and various educational and community‑based efforts but that only goes so far if the community isn't willing to meet you where you need to be.

In terms of a grassroots approach to start to work with as many community partners around Nashville as we can and I think right now we have a list of about 30 and many of these folks have been with us for several years. We initially started out thinking about how can we help you get families into the zoo or into the ballet or into the opera or wherever it is, families that want to be a part of that, and how can you help support them so they're included.  I won't go into all the details right now but along came Lynn Bingham who helped us think about our definition of inclusion and shift that in a number of ways. We're at the point now, fast forward a number of years, we're working with a number of these same partners on what does it look like to meaningfully employ autistic individuals and people with disabilities and not only employ but retain in a way that they're enjoying their work and productive and contributing the best they can.  That's been a really important focus for us because it's one thing to expand your customer base by becoming more inclusive for people with disabilities but then when you actually start to hire and go beyond hiring and think about long‑term retention, that can shift cultures quickly.  We've seen that in places like the Nashville Zoo. They're doing incredible things along those links. But that certainly wasn't our intention when we started out. It was how can we get families in the door and help them have a good time. It's expanded quite a bit and I think stakeholder engagement has been a big part of that.

Our community partners also include many of the local disability‑specific organizations, our local autism organization and our local downs syndrome organization and our local employment organization. We have a lot of folks involved there including families and individuals with disabilities.  I think a lot of it goes back to really being open to change and understanding what we need to shift to be better for the people we're serving and for the communities that we're trying to set up. For us it's always an iterative process like where are we now and what do we need to do next. It never feels finished.

>> Betsy Humphreys: Thank you, Pablo. Maybe, Lynn, you could talk a little bit about your ‑‑ because you and Pablo worked closely, maybe you could talk from your perspective how that partnership developed and shifted and has grown and evolved.

>> Emelyne Bingham: Yes, thank you so much. Just to clarify that I'm an autism self‑advocate and a professor at Vanderbilt and I became affiliated with Pablo and TRIAD because someone heard me speak somewhere and pulled me into the fold of the Kennedy Center and have been consulting on a number of research projects and so on and so forth.  The thing that was interesting to me is their engagement and thereafter reaching out gave me a sense of agency myself. Those two things I kind of call it a cycle of engagement now so that it sort of each feeds upon the other in sort of a synergistic way. The whole is greater than the sum of its parts.  It's been great. It's given me some increased visibility which I feel for me has helped give me a better sense of autonomy. So it was a really wonderful synergistic relationship that I've been able to enjoy with them.

>> Betsy Humphreys: Wonderful. Thanks, Lynn. So Lynn, I'm going to actually start the next question with you if you don't mind. What did your university partners have to change or shift or do differently from your perspective to make it more successful for you to partner? Was there anything that you could identify that you ‑‑

>> Emelyne Bingham: I don't know what it was like before I became affiliated so I don't know that I can speak to change. The university itself where I worked is sort of a different organizational structure than the Kennedy Center that's affiliated with the medical school.  So I really don't know. I can say I think it's been really great to become more involved in more and more projects as the time has gone on. Speaking of culture of change, I really don't have a reference point for beginning but during the time I have been affiliated, it's been really a wonderful time of growth for me and for me to witness this really wonderful inclusion network of Nashville and watching it grow and helping with that. It's been really quite gratifying.

>> Betsy Humphreys: I'd like to go off my script a little if I can with Pablo and Lynn for another minute or so. You referenced that your initial project from the zoo has now ‑‑ is now growing and evolving into something much larger in your community. Can you identify for our audience where that shift occurred or when that shift occurred? Was there something that you can identify that allowed that to happen? I know that's a tough question.

>> Pablo Juarez: I think from a growth standpoint it was just being meaningfully engaged with our partners, so when we were able to get in with the zoo, the opera, the ballet and the Country Music Hall of Fame and they started to feel tangible differences in their ability to serve people, they started to see more people with disabilities come in. They had the outreach and were moving towards engagement with various groups and families.  That was a big part of it, for them to start to feel that internal success and to start to make that a part of that culture. That takes time. I think that's just something that we work with those organizations to nurture.

Over time as we started to get an influx of more partners and we started to really understand better what a more holistic approach would look like, the big shift towards employment started to happen for us as well.  That was driven in large part by our partners asking the questions and being interested in that and by Lynn coming to meetings and asking why aren't you employing more people, and here are some biases around that and here are some things that you could do very easily and some things that might be a little bit harder.  We started to work with them on long‑term plans for that. And that takes time in organizations because each of these organizations have different internal challenges and struggles that they have to work with as well, especially in the last year and a half.

 There's sort of this community‑based drive that everybody's in it together and we meet regularly so everybody can hear these things and these success stories, but then we have to spend time individually with these organizations to ensure that we understand what their unique needs are and we're able to help meet those. There's an overarching reach when we start speaking about Spanish and Arabic speaking communities here in Nashville.  Those language resources are made available and how can we work with you to make sure that we have those things in place.

>> Betsy Humphreys: Thank you. It's very exciting to hear about the momentum that's built within your ‑‑ as a result of your partnership, so thank you both. We'll go to Hibo. Hibo, if you could talk a little bit about ‑‑ you began to talk about this earlier, how things shifted and changed to paying the partnership more successful. Can you think of ways that that supported the project overall?

>> Hibo Omar: Yes. Marnie's availability, because once we opened up and we kind of gained the trust, many parents wanted to bring their IEP because they had questions and how parents are ‑‑ the two extremes. Some have no clue and others are extremely into the IEP. She was very flexible for coming either an hour early or staying an hour late and that increased the trust among other parents.  She could have said, no, I don't have time for this, but her openness to kind of look through and take time, that kind of gave other moms ‑‑ increased the trust because before COVID happened, once they see Marnie in the community, they could recognize her and they would go talk to her. I would say, but that person doesn't know English, how did you guys talk? But language wasn't necessary, at least there was acknowledgment and knowing ‑‑ they know her as someone that they can say something.  At least that was one thing that opened up more of the ‑‑ for the families that were there and for the agency because I was the recruiter.

I was the interpreter at the beginning. We have to also kind of divide that up, and I was just running around so my role became a cultural broker. To make a change, we wanted someone from the school system to be an interpreter. Luckily, we used to bring interpreters.  One thing that we ran into was parents saw that person as they were representative of the institution, that they feared that they didn't trust. So it was a big bump but we kind of created a way of kind of talking to each group separately. For the interpreter, she didn't feel comfortable of her being present because she saw how parents were stiff and didn't even say ‑‑ didn't want to say anything.  She represented an institution, but once I talked to the interpreter that she is there and she could change something by learning the law, we are not doing anything wrong, just learning, so to empower her to go to the school and kind of see what she was supposed to interpret. She was interpreting blindfolded, whereas for the parents, we have to make sure that tell them that she's the change‑maker.  Hibo won't go to school. Marnie won't go to school. This person is already in the school. So then we came to a place, a platform where everyone would agree and then things were much smoother going forward.

>> Betsy Humphreys: Thank you, Hibo. It sounds like you were ‑‑ both you and Marnie were important players in helping that relationship build. Thank you. We just have a few minutes left to wrap up our panel. Leann, I'd like to go to you with this last question.

>> Leann DaWalt: One of the things I wanted to just mention about what as a researcher I needed to change to do more engaged work, as I started to bring in more individuals with lived experience onto the are much team and having family members, self‑advocates as co‑researchers and practically, again, the pacing, making sure we were thinking carefully about where, as a research institution are there barriers for people to have their voices heard and to participate.  We were thinking about the agenda, how are we structuring them, building time in to check to make sure we're not pushing over people, not giving people the opportunity to express themselves and make it manageable for everyone and not filling the meeting with too much so that people weren't heard.  There's so much richness that comes from partnering with co‑researchers and having people with lived experience be part of the team to really engage in asking some questions and helping interpret what we're seeing and learning. I think I've learned and I'm still learning very much just how many barriers there are and how we don't always see what those barriers are until you start to engage more with the community.

>> Betsy Humphreys: Thank you, Leann. And thank you to all of our panelists. I'm wishing that I had Tawara's slide for community engagement again because I think you each have shared really poignant examples of how the partnerships have changed and shifted and what you all have done to work together to make them so successful.  Thank you so much for talking with us for this brief period this afternoon, and I'm going to turn it over to Jamie because there will be opportunities for you to speak to panelists further and do some other breakout work. I think I'm turning it over to Jamie. Is that right?

>> Jamie Koenig: That's correct. Thank you so much, Betsy, for facilitating, and thank you again to our wonderful panelists and for your time and your insights. We will be moving to breakout rooms now to provide an opportunity to delve deeper into these conversations.  I'm also putting the survey link in the chat right now in case you have to leave early so you can still let us know how this event went today.

The breakout rooms are centered around various themes including three rooms to follow up with the panelists.  Hibo will be joined by Sue Russell. For each room the guiding question in the agenda is reflecting on today's conversation, what bubbles up that you can apply in your work. I am opening the breakout rooms now. Feel free to self‑select to whichever one you're most interested in.  If it doesn't come on your screen, you should be able to access them at the bottom of your screen and selecting choose breakout room. Feel free to hop around to different rooms. If you're having trouble joining a breakout room, hang out in the main room and I can assign you once people have started moving out of the room.  And, if you want the captioner to go to the same room as you, please send me a message. Enjoy your conversations.

>> Dawn Rudolph: This is Dawn. I will not take more time away from the discussion that those of you who are chomping at the bit want to get back to but I want to share a slide for a moment and share some thanks and some next steps because I know some of you will not be able to continue the additional breakout groups.  Let me run through this and then we can go back to chatting.

I want to thank everyone for joining today's meeting and I especially want to thank the planning committee for today's discussions. Gail Chodron, Tawara Goode, Betsy Humphreys, and Rodney Samaco were very, very beneficial in helping plan the speakers, the flow of today's meeting, the information that was going to be shared and the focus of the objectives on equity in our work.

So Jamie had dropped a link in the chat box earlier for the evaluation for this meeting, and I wanted to just share it again so that it is available and at your fingertips. If you have feedback for this meeting or for something that you would like to do different in a similar meeting in the future or something different on this topic, we would very much like to have that feedback.  That link is in your chat box now and I encourage you to take a couple moments to click on that link and share your feedback. It's not too long at all.

The notes from the breakout sessions will be cleaned up and they will be shared on the web page for this meeting along with Tawara's slides and any other additional information that is relevant that folks wanted to share out from their groups.  That's really all we had from the end of our meeting today. I'm going to stop screen sharing again. For those of you who need to go to another meeting right now, go somewhere else, please feel free to bow out.

Thank you again for joining us today. If you are able to stay and continue the breakout rooms that you were in, breakout groups are again self‑select so you can join what you were in before or select a different one.  For those of you who are heading out, we wish you farewell. Thank you so much.

>> Jamie Koenig: I'm going to re‑open the breakout rooms. It's possible you'll be whisked back off to the one you were in or you can move around.