

Strategies for Promoting Diversity, Equity and Inclusion in NIDILRR-funded Projects

Presenters:

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KATHLEEN MURPHY: Good afternoon, everyone, and welcome to our webcast, Strategies for Promoting Diversity, Equity, and Inclusion in NIDILRR-funded Projects. My name is Kathleen Murphy. I direct the Center on Knowledge Translation for Disability and Rehabilitation Research, and that's who's producing this webcast for you. We want to thank our funder, the National Institute on Disability, Independent Living, and Rehabilitation Research, or NIDILRR.

And we especially want to thank NIDILRR in its capacity as bringing its director to us today, Dr. Anjali Forber-Pratt, who will be speaking on these strategies. I think a lot of you in the audience probably know Anjali, at least by name or have heard her speak before, perhaps. But if not, here's a little bit of background on her.

Dr. Forber-Pratt was appointed to serve as the Director of the Administration for Community Living's NIDILRR on May 24, 2021. And she comes as a scholar. Her primary area of expertise is disability identity development. She came from Vanderbilt University, where her research also included training of special education teachers and the experience of students with disabilities at every education level. She has authored over 33 peer-reviewed journal articles and a number of textbook chapters.

And also, if you can believe it-- that's enough accomplishment for a lifetime-- but she's also a two-time Paralympian medalist in the sport of wheelchair racing and, in 2013, was named both the American Association of People with Disabilities Paul G. Hearne Leadership Award for her status as an emerging leader within the national disability community, as well as a White House Champion of Change, where she had the opportunity to participate in a roundtable discussion that President Obama attended to share her views on disability policy issues.

So we are thrilled to have Anjali with us, and we appreciate also NIDILRR's emphasis on DEI and look forward to hearing what she has to say about it. Anjali?

ANJALI FORBER-PRATT: Excellent. Well, I'm really excited to get to talk with everyone today about diversity, equity, and inclusion, some of my favorite topics, and our view and perspective on this at and across NIDILRR.

As a brief access note, I wanted to share that I am a brown-skinned woman sitting in a manual wheelchair that's not seen on screen. And my hair is long and black and in a ponytail, and I'm wearing a black and white shirt with a green suit jacket over the top.

For those who don't know NIDILRR, the National Institute on Disability, Independent Living, and Rehabilitation Research, we are housed, as Kathleen said, within the Administration for Community Living. And we are the federal government's primary applied disability research organization. And our main purpose is to fund grants that will help to generate new knowledge to promote its effective use to improve the abilities of individuals with disabilities to perform activities of their choice in the community and to expand society's capacity to provide full opportunities and accommodations for people with disabilities.

So today, we are going to be talking more specifically about DEI and strategies and just really looking forward to the conversation here today. And then there will also be an opportunity for question and answer and dialogue. So I think we can go ahead and move those slides out of the way if that's all right. Thank you.

So one of my absolute favorite quotes is from Maya Angelou. And she once said, "We all should know that diversity makes for a rich tapestry. And we must understand that all the threads of the tapestry are equal in value, no matter what their color." And I think about this quote really often in my role as I'm working hard to transform the research enterprise to be more inclusive of people with disabilities and of those underrepresented in research throughout all of its processes. I think about what colors are missing from our tapestry, what populations, and why, and how can we reach them.

And this is no easy task. But for far too long, the world of research has been dominated by predominantly white, cisgender, nondisabled male voices and researchers. But as you heard it a little bit in the brief opening, that's not me. Many of the identities that I wear proudly include being a Paralympic medalist and adoptee from India, a disabled woman, person of color, a researcher, and an activist. And from my experience, representation matters.

As I shared, I do use a manual wheelchair and was adopted from India when I was two months old and grew up with two white parents. And two months after arriving in the United States, I got sick with transverse myelitis, which is what led to my paralysis from the waist down.

As a young child, I thought everyone in the world had a disability and that this was just a phase that I was one day going to outgrow. And I really thought that in order to go to college, have a job, start a family, live on my own, many of these things that we are pushing our research to fill gaps on-- I thought that I first had to be able to walk, because every adult that I knew could walk. So in my mind, I held on to this assumption that in order to gain access to these opportunities, I had to make my disability disappear. In those moments, I felt invisible, and that lack of representation is what led to that assumption.

And I remember, really, it was the sporting event in April that happens every year, growing up just outside of Boston, Massachusetts, where I saw wheelchair racers in the Boston Marathon go flying by. And they were in racing wheelchairs that I just thought was the coolest thing. And I learned through that power of

example that people with disabilities could thrive-- could thrive in work, could succeed athletically and in life. And I latched on to those role models from that moment on, in fact, dressing up as the winner of the Boston Marathon on Halloween and using that as a motivator to me to be that representation for others.

And I say all of this because, as I fast-forward to my research and academic journey, when I then entered college and university and graduate school and early-career faculty life, I once again found that lack of representation to be dismal and something that really has become one of my priority areas as director of NIDILRR to work on improving.

I was reflecting on that kind of academic journey and trajectory, and I realized that in all of my many, many years of schooling, I never had a teacher or a professor who outwardly identified as being disabled. And that just-- that was a powerful moment for me. And I secondly also realized that I could only identify a very small handful of professors and teachers who were nonwhite. And again, this was just sort of a moment to really think about what this means as we're working to bring more inclusion and equity to the research world.

I believe it's important to talk about this from three different perspectives-- diverse researchers as researchers, or as the generators of the science, diverse individuals as study participants, and diverse representation in the knowledge translation materials that we produce and disseminate about the research.

We need all three of these, and we are stronger for them, and I believe that our science is better with this intentionality. And it makes people feel seen by the research that we are doing, and it signals its relevancy. And it's way easier to design with intentionality by embracing these principles up front. And if we apply these principles to our research design from the start, it also can serve as a catalyst to getting diverse representative samples of participants to participate in our studies.

So as I dig into diversity as generators of research and of members of a research team, when we look at statistics and what we know, really to the general US population-- Blacks, Hispanics, and Native Americans are severely underrepresented in the research workforce. And in spite of advancements in the scientific research workforce, some populations have simply not had access to cutting-edge research and training opportunities and don't participate fully in that research workforce. And, of course, there's a variety of reasons as to why this has occurred and why it continues to be perpetuated, which, again, we're going to talk a little bit more about.

But at the same time, we have to be mindful and cognizant of the layers of those barriers. And that's why I intentionally started off with the story of growing up, because we have to think about the layers and the structure of these imbalances and structural systemic inequities that get compounded for an individual throughout a lifetime.

I'm also struck by how hard it is to find statistics about disabled researchers. So the National Center for College Students with Disabilities estimates that 4% of all faculty members have disabilities. And another study from the University of California at Berkeley-- that study indicated that, of their full-time faculty, only 1.5% identify as being disabled.

In the government, there was a recent report from the advisory committee to the NIH director, and that report looked across NIH-funded projects, and they found that less than 2% of principal investigators funded by the NIH reported having a disability. In NIDILRR's portfolio, across our funded grants in 2022, 65 grants were led by principal investigators who reported having disabilities, and that was out of 418 grants, so that's right at 15.5%.

But in comparison to the population of individuals with disabilities in the country, that is-- there's approximately 67 million Americans who identify as disabled, or 25.7%. So I call on us in part, how can we do better on that aspect of diversity? People with disabilities confront multiple barriers to inclusion and participation in the research workforce.

These barriers, as I was alluding to-- they can be societal, attitudinal, physical, or systemic and are compounded for individuals with disabilities who are from one or more additional underrepresented communities, such as being Black, Latino, Indigenous, Asian American, or other persons of color, members of religious minorities, LGBTQ persons, those who live in rural areas, and those who are also adversely affected by poverty or inequality.

This listing of these underrepresented communities and underserved communities are named in President Biden's executive orders on equity. And what I love about this is that disability is included among those other underrepresented populations. And it allows us to talk about disability as a form of diversity in a big and bold way.

The societal and attitudinal barriers are rooted in systemic ableism and racism. And by having disability named alongside these other populations, we are able to employ an intersectional lens and framework to really start to peel back the onion to better understand what are those barriers and what are the strategies that we can do to combat these inequities.

So NIDILRR, we are dedicated to nurturing this next generation of researchers by actively involving people with disabilities in sponsored projects. And this enriches outcomes with depth and with relevance. And we at NIDILRR are committed to deepening disability inclusion expectations and fostering discussions about disability identity and creating inclusive research spaces.

When we talk about including people with disabilities across the research enterprise, this also means-- this means talking about and encouraging the talking about of disability identity of individuals and building inclusive research spaces, where investigators and staff with disabilities are integral members of the research team.

Going back to the data for a moment, that gross underrepresentation of people with disabilities in the scientific workforce-- it's either reflective of the exclusion of people with disabilities throughout the research pipeline or reflective of the stigma attached to revealing a disability, or realistically, probably a bit of both. But regardless, that low representation of people with disabilities in research careers remains a tremendous barrier.

But we're thrilled that NIDILRR-- that many more of these conversations are happening across the federal government with our NIH counterparts, with our NSF counterparts, and with the National Academies, and many specific universities as well. I'm thrilled that we're more deeply engaged in this conversation about how to actually do better.

As a researcher, I reflected on some of my own encounters with ableism that likely point to some of those numbers, why these numbers are so low of disabled researchers. And some of it was the lack of expectations that others had of me. When I was trying to register for an applied technology class or an astronomy class, I was told, well, why do you want to take that? You're not actually interested in science, are you? Think about how that could derail a person's career.

And I do also want to note that I have a very visible disability. And I can't hide it except for a bit here on Zoom, where I've learned that I have to disclose it verbally. But there's many individuals who have less apparent or hidden disabilities and who grapple with that layer of disclosure every day. Is it safe to disclose my disability? Will I be treated differently? Will I receive the research mentoring that I need to succeed? This layer can't be underestimated because I do believe that the numbers that we have are low estimates and that there's many more who do identify as having a disability but have not disclosed it for various reasons.

We also know that there are structures that are in place that perpetuate this limiting nature of disclosure. During graduate school, I fiercely tried to separate my research from my personal experience of disability, and a challenge that some of you may relate to. But it was mentors who urged me to merge those aspects.

And I did so, and it was by embracing that duality, I found a fulfilling space where my lived experiences strengthened my work. And it was able to add depth and layers to the research work that was being conducted. And so I want to plant that seed for everyone to be brave enough to include positionality statements in your own work about you and your team's disability status to help make the less apparent more apparent and to give confidence to students who might not realize that research could be a career path for them.

So as I think through what does this mean more tangibly for faculty members and research team members who are trying to diversify your own project teams, it takes intentional foresight, commitment, communication, and engagement and openness to change practices and procedures and a little bit of humble self-reflection to also ask, what can I do better here?

This value of inclusive research cannot be underestimated. And when I think about inclusive research, it allows for traditionally silenced voices to be raised and to help to shape the research being conducted. Those with the lived experience of disability navigate the world uniquely and often encounter ableism. Those with the lived experience of being a racial minority navigate the world uniquely and encounter racism. Those with the lived experience of being from the LGBTQ+ community navigate the world uniquely and encounter homophobia. Yet, each of these experiences can be valuable to better

understand overarching context, barriers, and challenges and to be equipped to design interventions and conduct research with intentionality to avoid perpetuating -isms or silencing certain voices.

So in order to grow this field of inclusive research, it's on all of us to do better in our work. And so when I think about this, it's how can we design with intentionality inclusive actions and approaches to serve as a model to others, who may be newer in this space? So let's delve deeper into some more specific strategies.

Where do you find team members for your lab or for your research team or collaborators? If you're at a predominantly white institution, have you explored partnerships with nearby Historically Black Colleges or Universities, or HBCUs, or with community-engaged research centers? As I said before, intentional recruitment diversifies project teams. And so including individuals with diverse backgrounds, including disability as co-investigators and members, helps to do this.

To foster inclusivity, there's also resources, such as University Centers for Excellence on Developmental Disabilities, Centers for Independent Living, community-based disability organizations. That's from the disability lens. But then there's also organizations and community-based organizations that are specific to other subpopulations.

I had a chance to visit some of our NIDILRR grantees in Michigan to see how they've built community relationships with local organizations and community members who actively participate in project meetings alongside the research team. And it was really wonderful to see this relationship, but it was also fundamentally important hearing from both the members from the community and from the research team that the engagement had to be mutually beneficial, not just an add-on. So when we work to diversify project teams, it's important to remember that it is a two-way street. It takes time to build trust and to build those relationships with others. Again, that does involve time and commitment.

As you diversify project teams and collaborations, it's also important to establish inclusive meeting practices with equality within the team to set expectations that all members are valued contributors. This counters notions of hierarchy that can exist either in terms of a disability hierarchy, a racial hierarchy, or what have you, and ensures that everyone is feeling valued and as a valued member of the team.

It's also on us leading projects to be conscious of microaggressions and to address them if and when they occur. We have an expectation when leading projects to set the tone for an inclusive culture, which may include course correcting along the way.

Another example relates to accommodations. So accommodations will vary greatly depending on the individual need. Some accommodations may be provided to help to make the research itself better and stronger. So, for example, if a research team member uses a screen reader, it can help to ensure that all the research materials that are being generated and produced are accessible up front via screen reader. This is, again, another area of designing with intentionality.

Another type of accommodation may be completing a specific task in pairs or in smaller teams in order to chunk the task to meaningful pieces to get input from all individuals on a team. But this is also just-- it can be just good practice for a research project.

Another type of accommodation may be setting up a document in a specific way to allow for greater individualized accessibility or readability or understanding. So, for example, as I was reflecting from a project that I used to work on, instead of using words to qualitatively code, we used emoticons and defined find as a group what those emoticons meant. And that allowed for greater ease in what could have been a text-heavy task for the team.

And while many accommodations are low cost or no cost, we also know that some accommodations do cost money. A NIDILRR grantee at Washington State University included accommodation costs for trainees in their original grant budget. And so language that they used in that particular situation was "fellows with significant disability support needs will also be offered up to 40 hours of workplace personal assistance per week plus supplemental funds for housing assistance, moving expenses, adaptive technologies, and conference travel."

At NIDILRR, our budgeting process of what gets submitted to us-- it does not restrict you in the same way that some agencies do in terms of line items. So many NIDILRR grantees, not just that one that I shared, can and do carve out accommodations within the scope of their existing budget.

This brings me to the point of this being both a combination of ensuring our processes are inclusive and that our protocols allow for accommodations in the same way that we see accommodations existing in the real world in school or workplace. Other strategies include how is it that you're actively seeking out candidates from diverse backgrounds when you are in the position to hire? Inclusive outreach and networking-- so attending and hosting events, conferences, and seminars that focus on underrepresented groups in your niche field can help to build some of those relationships. And, again, it demonstrates in a big and bold way that two-way way street.

Those relationships with organizations and networks that support diversity in your specific research area can be then a source-- a talent pool for future hires that you may have. They may also be able to help to amplify marketing of your study depending on what it is that you're engaged with.

We also have found that many NIDILRR grantees have had tremendous success in collaboration with either their university's diversity offices or diversity subgroups within professional organizations, again, around the same perspective of being able to demonstrate that collaborative relationship and to tap into their areas of expertise and resources. And I know that it's hard, and it's messy, but it's also the right thing to do. And this is just one of the many things that we believe here at NIDILRR that we are helping to chip away at this important issue.

Another example at NIDILRR is that we worked hard this past year to update our peer review criteria and to make sure that-- in our project staff criteria, to disaggregate disability from other underserved populations so that we could more directly evaluate and score the extent to which applicants were

describing outreach practices and encouraging applications for employment from people with disabilities and from other underrepresented groups separately and distinctly.

And at the end of the day, when we think about disability as an aspect of diversity, we don't want the involvement of people with disabilities or those who are underrepresented to just be a checkbox or an afterthought. And far too often, that is the case. And so this is why it's important to have conversations like this today and to share resources with each other. We are all a part of this solution, and we need all of us in order to come together to help to really diversify that research workforce with intentionality and inclusion in mind.

Up to this point, I've been mostly talking about disability inclusivity and representation in the workforce. But we also need to think about these same principles of diversifying and being inclusive across our study populations as well. Yes, having a diverse research team helps with getting diverse research samples because you're demonstrating that authenticity and may be able to leverage community connections and broader spheres of influence.

But equity really means, in this context, meeting communities where they are and allocating resources and opportunities to make up for historical systemic oppression and ableism. We have this obligation to build trust with communities that we want to participate in research. Another example is I look across our NIDILRR grantee community.

The Americans with Disabilities Act National Network, the ADA National Network-- they embarked on a year-long process of outreach to better understand the needs of Spanish language speakers and their awareness of the ADA and what the needs were. What they found initially was that sending a webinar link and hoping that people would show up to share this information was not the approach that was going to work best.

They had to put in the hard work of true community engagement so that they made themselves known as a known individual and a known entity. And then eventually, participation and feedback eventually did come from the Spanish language community. Engaging with the community that you intend to study-- it helps to strengthen those partnerships and build that trust.

So now, our ADA project directors and staff are engaged in ongoing networking opportunities with regional community members, community leaders, and organizations from the Spanish-speaking organizations. And it really is a great example of how this does take time, but it can and does come to fruition in really wonderful and beautiful ways.

Another big piece in terms of diversifying our research samples is making sure that we are using diverse recruitment channels to reach underrepresented groups. Again, I've talked about this. It could include community-based organizations. It could also include attending community events in person. So we oftentimes think of our recruitment as being-- as in silos, and we have to break down those silos in order to get to the populations who aren't currently within our samples.

We also know that incentives help. Incentives are appealing to a diverse range of participants. But we also have to take into consideration cultural and socioeconomic backgrounds. So, for example, you don't want to give out Target gift cards as an incentive if the nearest Target is 100 miles away, for example.

You could also get creative and provide organization-level incentives. So, for example, we would provide \$500 or \$1,000 to the school or community-based organization for their agreement to help us to recruit. And we would work together to figure out what those terms and conditions of how they might be able to help us to access the population that we were most interested in. And so there can be creative ways as you're trying to diversify study samples.

Another example is embracing flexible research methods, so being open to using a variety of methods that are more accessible and comfortable for diverse participants. So this might include in-person interviews, telephone surveys, in addition to online questionnaires or focus groups. It might involve having options of how a person might fill out a survey. So it might be, yes, there's a web-based option, but there's also a paper-and-pencil option. There's also this.

And some of these strategies have to be thought about up front in order to ensure that it's included in your IRB application, or you end up having to submit amendments. So again, this is what I mean by designing with intentionality and designing with diversity in mind up front.

The final strategy on this in terms of diversifying study samples that I would recommend here is to close the feedback loop and go back to those same organizations when you have results and share them with them or with their team. And this really humanizes the work, and it builds relationships.

We would often send materials of a research summary and key findings or offer to give a presentation. And they-- the organizations, they would often use this as bragging rights that they or their members contributed to this research or include it in their own newsletters and things like that, and shared with their own donors.

And this matters, but this especially matters to diverse communities. They want to be and to feel seen. And they want to know that their time commitment was a genuine commitment and that that engagement mattered.

The last piece that I'll talk briefly about is around diverse representation in the knowledge translation materials that we produce and disseminate. So this is true for all study materials, but it's imperative to ensure that the research materials generated reflect diverse participant populations. And if we really seek to increase diversity in our participant populations and in the studies that we do, this means outwardly demonstrating that in the imagery that we select and that we use.

So this means ensuring that the photographs and graphics and so forth that we might use in materials is diverse across racial and ethnic groups and across disability groups. Asking ourselves, are there people who are nonwhite represented in these materials? When we think about it from a disability perspective, are you only using images of people in wheelchairs? There's many more disabilities that exist. And this includes really being able to put our own work that we are doing in into that critical lens of asking.

And so when we think about what these best practices may be, we want to encourage using images of diverse people from our own community, avoiding images that promote inequity with status, so images that might perpetuate hierarchy in some way. We want to avoid that.

We want to encourage being able to ensure that the images, whether that's photographs or graphics that are being used-- that they actually resonate with the community. And this means actively working with members of racial and ethnic groups and disability community and using them at various touch points to ask for them to audit the images or materials that you're using or to weigh in, like, hey, did we hit the mark here?

Many of our grantees do this in a variety of ways. Some have a formal approval process across the project director's teams, where they approve materials and are asking these types of questions to ensure that genders are adequately represented, different races are represented, different types of disabilities or religious backgrounds. Others, they use community advisory boards that are often paid as a portion of what's submitted to the grant or using community-based partners to help with this type of work if you don't have individuals that are on your in-house project team.

And this-- thankfully, there are many more resources now that are available that show inclusive and diverse representation of disability and other forms of diversity. But the caveat to that is that there's also still quite a lot of bad stock images out there that do not reflect accurate portrayals of disability or of various religious backgrounds or ethnic backgrounds.

And from the disability side of things, I'm happy to share a few links here in the chat of some of my favorite resources for this. So Disability:IN has a disability stock photography page that is quite wonderful. So does affecttheverb and disabilityimages.com. And then the Human Development Institute at the University of Kentucky also has a new photo library that was just launched. And all of those ones that I just mentioned are all freely available. There are also some entities that have a paid disability collection. So that's Getty and iStockphoto that have made considerable investments in this space as well.

So as I think back to what does this all mean in terms of achieving greater representation and inclusivity in research, it means that we are not an afterthought and that people from multiply diverse backgrounds can participate in research studies without being perceived as a burden, an inconvenience, and that they see themselves represented in the questions being asked and in the identities of the people conducting this research.

So to make this a reality, we have to support each other and to amplify each other's messages and to dialogue with one another today, which is why I'm so thrilled to be having this conversation with you all today. And so we must hold ourselves accountable and support each other on this journey and to be able to ensure that accurate representation continues in our work. So with that, I will turn things over, I think, to Kathleen to kick off our question and answer.

KATHLEEN MURPHY: Perfect. Well, thanks so much, Dr. Forber-Pratt. And it's really a breadth of strategies that you outlined, so really appreciate it.

ANJALI FORBER-PRATT: I was trying to fit so many in, you know?

KATHLEEN MURPHY: I know. We've got the workforce, got the study samples, the KT, the real engagement, and I loved also that you really were reiterating or underlining, you really just have to show up in person, not just throw out a webinar. Oh, thanks. Some people were asking for those links, so you already dropped them in, perfect, because we have staff busy googling around right now.

ANJALI FORBER-PRATT: Sorry, sorry. I should have given you a heads-up.

KATHLEEN MURPHY: So we do have one question from the audience. It's from Janice Baldon-Gutter. And, Janice, you're welcome, I think, to unmute if you want to voice it yourself, or I can do it for you.

JANICE BALDON-GUTTER: OK, I've unmuted.

KATHLEEN MURPHY: OK.

JANICE BALDON-GUTTER: Good afternoon. I just presented at the Kentucky conference for SHRM, Society of Human Resource Management, and I co-presented with Barry Whaley, my director. And we talked about addictions and questions to answer and things like that.

I came up with the idea since it was sponsored by the Kentucky Chamber-- sometimes it's hard to outreach to different states and regions other than your own. And so I came up with the idea of outreaching by looking at the chambers of commerce of the different states and the cities because each one, I found, has a DEI champion.

So I want to know if you think that's a good idea. I haven't done it yet. I wanted to wait for this webinar-- podcast, webinar. But I want to outreach to others other than where I live, Louisville in Kentucky. And I thought about reaching out to the chambers of commerce, DEI strategists there and also in the cities.

And also, I'm looking for other strategies because it's easy to outreach-- well, it's not easy. Sometimes you get rejected even in your own city. [LAUGHS] I'm looking for strategies for outreach to other regions that the center may be assigned to.

ANJALI FORBER-PRATT: Yes, I love that idea, and it's something that I have often encouraged as well. And it can happen at the local, regional level, or at the national level. So there's a National Black Chamber of Commerce. There's a national-- it's a United States Hispanic Chamber of Commerce as well. And I believe that-- and just using those as examples, that there are parallels of that that exist in specific states and regions. And so I think that's a fantastic way to be able to build those relationships.

Again, I go back to-- a lot of this does have to be that two-way street. So when I think about some relationships where we work to build, some of it involved, hey, we're going to go and show up to events that they're doing as well to really build that trust and so forth, because if it's simply saying, hey, will you share information about this study that I'm doing, they're going to be less likely to do that until they know

that it's a true relationship that's built with trust and that it's a mutual relationship, that they see a value of them getting something out of this relationship as well.

And so I think it's a wonderful strategy. And thinking through how-- if you're approaching it with how can I help you as well, I think that that would be my recommendation.

JANICE BALDON-GUTTER: That'll be great. I'll get started.

ANJALI FORBER-PRATT: Yeah.

JANICE BALDON-GUTTER: I've already made the template letters. I was just waiting for this webinar today to get some ideas about that strategy. Thank you.

ANJALI FORBER-PRATT: Of course.

KATHLEEN MURPHY: And we have a comment from Phil Klebine. Phil, do you want to tell us a little more about your data collector DEI training?

PHIL KLEBINE: Well, many people on here already know. But what we're doing is we're making a conscious effort with the spinal cord and traumatic brain injury model systems to include data collector training to improve participant retention and enrollment in our studies, so just on the entire level of the DEI spectrum.

ANJALI FORBER-PRATT: Yeah, that's wonderful, and I was trying to fit so many things in that I did gloss over that. In addition to what you just described, I also highly recommend diversity training, cultural competence training, ongoing training opportunities for your own teams for that exact reason because in order for all of us to diversify this work with intentionality, we all have blind spots, and we all have the opportunities to continue to grow, myself included. And what I have found is that the opportunity to participate in these types of diversity trainings, or DEIA opportunities to learn-- it helps make us better and more aware of what those potential biases may be that we may have.

And it also signals-- and I go back to if you're leading research teams, we set the tone, and we set the tone for inclusivity. So by encouraging attendance and participation in DEIA trainings like that, it also sets the tone that, hey, this is important to us, and it's a value that we hold.

KATHLEEN MURPHY: And we have been talking a lot this afternoon about research, but we do have Mark Harniss here from the Americans with Disabilities Act Knowledge Translation Center. And he's bringing up the TA side of things. Mark, did you want to come unmute, or do you want me to just pose your question?

MARK HARNISS: Or can come off mute. I'm just curious if you have thoughts, Dr. Forber-Pratt, about data collection, particularly in programs that provide technical assistance. There's been a number of initiatives that are focusing on increasing data collection about race and gender and disability, and sexual orientation.

There's been a bit of back-and-forth about how best to do that. I think ACL has some of these initiatives as well. It can be challenging both getting the questions right but also just building the comfort level of the TA providers to ask those questions. I think it's something we're going to be working on for several years, but I wondered if you had thoughts about that and NIDILRR's engagement in that space.

ANJALI FORBER-PRATT: Yeah, great question. And absolutely, I think that we are not alone and you are not alone in asking these questions. I think that part of it is educating both those who are collecting the data and those who are providing that data that these types of demographic questions-- they're optional, but we're asking the questions because we're trying to do better. And putting a data scientist hat on, we can't get ourselves to do better if we don't know where we're starting from.

And so from my perspective, that's why we're encouraging asking these expanded demographic questions and so forth and being able to explain, hey, the reason why we're asking this is to be able to make sure that we are reaching those that have the greatest need, that we're reaching subsets of our broader population who really should and could benefit from this information.

But we also have to-- it's also this fine line of, we also don't want individuals to misconstrue that, by not providing that information, that they're somehow not going to get access to XYZ service and so forth. And we have to just do a better job of educating that.

Another example that I see that-- for those on the university side of things that resonates more is when you're applying to a job at a university and so forth, you get a set of demographic questions, and it walks you through, hey, this doesn't affect your application in the process and so forth. Like, this is just strictly for our HR administrative optional purposes to be able to track these demographics.

And it feels, to me, similar to that of being able to set the tone of, hey, we're asking this with intentionality because we don't know the answers of who we're serving and/or who we're not. But it's optional, and we encourage you to provide that information.

MARK HARNISS: Yeah, I agree, and thank you for that. And I think that question of confidentiality, of trust, really getting systems in place that people trust, and acknowledging the fear that people have of disclosure and stigma are important. So I appreciate your comments about that.

ANJALI FORBER-PRATT: Yeah, yeah. And I would also say, too, just one last thing on that is that we absolutely see it any times that we ask disability questions too. So it's not just-- it doesn't just come up when we're asking about race or LGBTQ identity. It also comes up with disability as well in terms of that self-disclosure and that demographic information.

KATHLEEN MURPHY: Great. And as an aside, speaking of demographic information, I think I forgot to point out, I'm a white woman with shoulder-length blonde hair, and I'm wearing some reading glasses, just to kind of locate that. And moving on, we see Angela Smith has raised her hand.

ANGELA SMITH: Yeah. Hi, everybody. Hi, Anjali. How are you?

ANJALI FORBER-PRATT: Good, thank you.

ANGELA SMITH: Good. On the topic of training, when we were trying to be much more intentional with our consumer advisory board in terms of the representation on there, I spoke to somebody who was a research participant of ours-- African-American woman with a brain injury. And it broke my heart that she felt like she-- and she knew us. She had been involved in our research. But she felt like she had nothing to add to the conversation. And she also felt a little fearful of getting involved at a deeper level than just being a participant in research.

So I know that the-- I think it's the North American Spinal Cord Injury Consortium has a training module for people with spinal cord injuries so that they can understand better, kind of like CITI training from the very beginning what research is about. And this applies to more than just DEI, but it also, I think, really applies to DEI because somebody who has not really been included and had a voice at the table might feel much more like this one woman did, not willing or fearful to actually engage at a deeper level.

And so I'm just throwing that out there as far as training modules. That one was specifically for spinal cord injury. And I don't know of others that exist for other general disability population or specific disability populations.

But I think it's a really important thing because they don't feel like, what do I have to add, what do I have to add to the conversation, unless they feel that they have some knowledge and some basic training about the-- research can be scary to everybody, right? What's going on here? What are they doing? And I think to bring that knowledge base, even just the knowledge, skill set to people, is really important.

ANJALI FORBER-PRATT: Yeah. Thank you, Angela, for that comment. And I couldn't agree more. I mean, I think that the other systemic piece that we're all up against is just historically how research has often been viewed as sort of elitist in a way and that you needed these formal credentials in order to participate in research.

And I think that some of that is what then gets trickled down and captured in the sentiment of the individual that you are describing of, like, wait what? What I have to say matters and could inform others? Like, that concept can be novel for individuals who just aren't aware that, yes, that experience does matter and is considered a valuable part of research and is research in and of itself. And so I think that we do need to amplify that and to educate in that way as well.

ANGELA SMITH: Wholeheartedly agree.

ANJALI FORBER-PRATT: Yeah.

KATHLEEN MURPHY: Thanks, Angela. Catherine Ipsen is with us but does not have audio, so she asked me to voice her question, if that's all right. She says, "One issue that I struggle with is the balance between having representation across groups, for example, rural, disability, Black, American Indian, LGBTQ+, et cetera, and being able to tell a credible story among one or two underrepresented groups.

I've been involved in initiatives that try to collect data with representation from a very broad group and then lack enough recruitment to look at any one group alone and results in running data on white, non-Hispanic versus all others, et cetera. What do you recommend in a world with limited resources, time, and effort?"

ANJALI FORBER-PRATT: That's a \$1 million question, you know what I mean? And it's an important question, Kathleen. I mean, I think that part of it-- and I think that-- like, we require you to describe your sampling strategy with this diversity and element in mind. But I also think that it's important to justify whatever those decisions are to have it match your study's design and the research questions that you're trying to answer, because we know you can't do it all in one single study. Like, that absolutely is the case.

But part of why we are asking for this intentionality of how you're going to ensure representation across groups is for you to put that thought and care into that thinking up front so that it doesn't-- so that, as I was saying, that these elements don't become the afterthought and the, oh, whoopsie, we didn't do the XYZ intentional outreach and effort.

But I agree. We don't have the time and resources to do that level of relationship building and outreach to every single diverse community that exists in this country. I mean, that's just-- we don't have that ability, and that is for sure.

But with intentionality and with being able to describe, hey, for this particular study, we're really, really, really trying to fill this knowledge gap, and these voices are going to help us to answer that research question. You might then oversample in a few subcategories of underrepresented groups with that intentionality in mind and be able to explain that as your decision process.

KATHLEEN MURPHY: Thanks. We do have another-- it's really a comment on Mark Harniss's earlier question about TA. "Regarding Mark's question, we, the New England ADA Center, have begun to ask the question and found, for the most part, individuals have been very willing to respond. It did take us a bit of time to draft our question and vet it with individuals in a variety of communities. Where we don't get many responses is when we get questions via emails. Individuals often don't respond."

So I am going to turn to one more a person who has an important strategy to share about KT materials. Elena, if you'd like to unmute. And then that may-- depending on how fulsome your explanation is, that may be our last question or comment before we close out the hour at the top of the hour at 4:00 PM Eastern. But, Elena, what's your strategy?

ELENA: Well, one thing that's been helpful for our team is we spend so much time and effort trying to recruit diverse populations. And then once you get those people, we decided to just throw it out there and invite people to participate in a photo shoot in their homes or wherever they're comfortable, just with our photo release form from our university with the perimeter that we need representation in our website, in our materials. We would love to showcase you in this cool AT that you're using in your home and how it's helping you in your life.

And we were really surprised how many people were on board with that and were excited to do a photo shoot in their home or outside, in their community, to help bridge that gap of not just having older white women and men in every single photo. So we were really surprised with the outreach for that.

So I encourage other researchers to tag it on to the end of your study when you realize-- when they know you don't bite, and you've had a good experience with your study. Offer the opportunity to engage in a photo shoot if that's something that your team can support. I think that we've been impressed with how receptive people are.

ANJALI FORBER-PRATT: I love that. That's a great strategy. And it also goes to showing that value added can be across multiple ways, not just sharing the information as a participant in the study, but also, hey, your experience and your representation matters to the overall topic. So that's great.

ELENA: Absolutely. Thank you.

KATHLEEN MURPHY: Janice is pointing out, great strategy. Make sure permissions are signed. And Toby Partch-Davies is noting that the University of Kentucky Human Development Institute-- she thinks they did this as well and shared the digital library online. So I wonder, because you mentioned--

ANJALI FORBER-PRATT: That was one of the links that I shared, yep, yep.

KATHLEEN MURPHY: Exactly, yeah. It's the same thing. And we did have a comment-- follow-up from Janice. She'd like to stress the value to entire family seniors and their caregivers, organizations, et cetera, not just the person. She's working with their senior initiatives. She tries to encourage and make learning about disabilities, accessibilities, inclusion valuable and a good experience for everyone in the family or organization.

So I think-- I mean, we may get one more question sneaking in there, but didn't know if you had any final closing-- if I had anything else to say.

ANJALI FORBER-PRATT: I think just a thank you. As I was preparing for this and gathering my thoughts, there's so many different strategies that do exist and that you are already doing and that we can learn from each other. And none of us as individuals are going to get this magically right the first time around. And it's not a simple recipe like that. It's really-- it's the long game in terms of this building these relationships and trust with intentionality to chip away at this macro-level issue to increase diversity and representation.

KATHLEEN MURPHY: But we appreciate you. So there will be-- we are recording this meeting, so we will post a archive of this event on our website on-- if you go to-- it's webcast number 83. And please do give us feedback in the evaluation. And Shoshana is-- our tech person is going to just drop that in the chat. And we will follow up also with an email in case you have to drop off now and don't have time to do that, running off to another meeting, or whatever. And there's the link to the web page where you can, in maybe about a week, find the archive of this event.

And for those of you who are grantees, we do have a peer-to-peer Knowledge Translation Technical Assistance Network. We typically have a call in around late November or December. So that's an opportunity to follow up with some of these strategies and peer-to-peer learning. So thank you to all the thinkers. We appreciate you, and enjoy the rest of your afternoon.