

Mathematica's Center for Studying Disability Policy

Insights from Federal Agencies on How to Engage People with Disabilities in Policies, Programs, and Evaluations

Webinar

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[Derek Mitchell] Hello, everyone. Thank you for attending the Center for Studying Disability Policy webinar, "Insights from Federal Agencies on How to Engage People with Disabilities in Policies, Programs, and Evaluations." My name is Derek Mitchell from Mathematica, and my pronouns are he and him. Before we begin, we wanted to cover a few housekeeping reminders. Closed captioning is available by clicking on the "CC" icon in the lower left corner of your screen. You can also access closed captioning by clicking Control + Shift + A on your keyboard. If you would like to submit comments or questions to our presenters, please use the Q&A panel located in the lower right corner of your screen. Select "All Panelists" from the drop-down menu to submit your questions. If you're experiencing technical issues during the webinar, please use the same Q&A panel located in the lower-right corner of your screen and select "Host." Our team will address your technical issues. Now, I'm pleased to turn it over to Denise Hoffman, principal researcher for Mathematica, to officially get us started. Denise, you now have the floor.

[Denise Hoffman] Okay, great. Thank you and welcome, everyone. As Derek said, I'm Denise Hoffman, my pronouns are she/her, and I'm a principal researcher at Mathematica and also part of Mathematica's Center for Studying Disability Policy. Mathematica is committed to shaping an equitable world in which evidence drives policy decisions. Now, despite a growing emphasis on equity across research and policy, disability is often omitted from those discussions. However, equity is a critical consideration for the disability community, when, even today, information, physical spaces, and opportunities are often inaccessible to people with disabilities. The focus of today's discussion will be on an important component of equitable research -- engaging people with lived experience throughout the research and evaluation life cycle. Here, the goal is to center and empower people with lived experience to guide and also to co-create processes and products in a way that's rarely possible without input from the people closest to the topics and issues.

The phrase "nothing about us without us" is often attributed to the disability movement and underscores why it's important to engage people with lived experience. Meaningful community engagement and research can be designed in numerous ways and described by multiple frameworks. For example, you may have heard of community-based participatory research or culturally responsive and equitable evaluation, among others. For today, we don't want to focus

on a specific framework. Rather, our goal is to discuss meaningful participation in evaluation research by those most impacted by the program or policy in consideration. So, displaying on the screen is a slide showing a spectrum of community engagement, and this was adapted from the International Association for Public Participation. It includes five levels of community engagement. The left-hand side of the spectrum has the lowest amount of engagement, and as you continue on to the right, meaningful engagement increases. Each level includes a description of the participation goal, example activities, and the implicit message to the community. The most basic level is to inform the community of your efforts, perhaps by disseminating fact sheets or giving presentations.

Here, the message to the community is, "We will keep you informed." And, of course, sharing information is helpful, but having a one-way flow of information can lead to community feelings of powerlessness or frustration. Moving to the right along the spectrum is community consultation. This can be done by gathering feedback on select topics and questions through activities like listening sessions, focus groups, and surveys. The message to the community can be, "We care what you think," but if this activity is constrained, may feel symbolic and inauthentic. Beyond that is involving the community in planning and design. This can give voice and power through activities like community committees or interactive workshops, where participants investigate a challenge and suggest solutions. The message to the community is, "We can't do this without you." The next column to the right is "Collaboration." This involves centering the community in decision-making and priority-setting through collaborative design. The message to the community is, "Your leadership and expertise are critical."

Finally, the column furthest to the right is "Shared leadership." Here, final decision-making is from the community and involves community-driven planning and budgeting. The message to the community is, "We support community-led efforts." Policymakers, program administrators, and researchers likely span the range of this spectrum. This includes our panelists today, who offered to be here because their agencies are making strides to better engage people with lived experience. Each agency has historically taken a different approach to engagement and may be at a different point in its journey. Regardless of your starting point, we hope that today's conversation can support your journey and commitment to increasing meaningful engagement.

Before we start, I wanted to briefly note that our conversations today are with some of the federal agencies that we're currently working on projects engaging people with lived experience, and I want to acknowledge that there are many federal agencies and offices not on our panel today that are leaders in meaningful community engagement. But let's go ahead and get started with our panel and introductions. So, to our panelists, please introduce yourself, your agency or organization, and provide a brief high-level overview of the areas of purview of your agency or organization. And let's go ahead with Jeff, Savi, Marie, and then Purvi. So, Jeff, to you.

[Jeffrey Hemmeter] Thank you, Denise. So, hi, I'm Jeff Hemmeter. I'm the acting Deputy Associate Commissioner in the Social Security Administration's Office of Research, Demonstration, and Employment Support. In general, I help design, conduct, and oversee research, evaluation, and policies related to disability and return to work, including our work incentives and Ticket to Work program. We run many of SSA's tests and evaluations of potential policies, programs, or services, and much of my personal work revolves around transition-aged youth in the Supplemental Security...

[Denise Hoffman] Okay, Savi. I think you're on mute.

[Savi Swick] Thanks, Jeff. Back to introducing myself, once I unmute. Hello, everyone. My name is Savi Swick. I've been part of the Department of Labor for the past 13 years, and almost 9 of those I spent in the Office of Disability Employment Policy, or ODEP, as the Director of Research and Evaluation. During that time, I've overseen many different research and evaluation projects, including demonstration projects within ODEP, collaborating with a wide variety of public and private partners, including our colleagues at Mathematica. Since March of this year, I took on the Director of Research position, overseeing the employment and training research portfolio within the DOL's Chief Evaluation Office. In that portfolio are projects from Employment and Training Administration, ODEP, Women's Bureau, and Veterans' Employment and Training Research. While disability employment is the primary focus of ODEP, ETA, Women's Bureau, VETS, and also focus on disability employment. So, from the Chief Evaluation Office, I have more of a global perspective, I would say, on how various agencies are working on disability employment issues and also how they incorporate lived experiences. Back to you, Denise.

[Denise Hoffman] Marie, go ahead, please.

[Marie Lawrence] Hi, everyone. My name is Marie Lawrence. I am a senior social science research analyst in the Office of Planning, Research, and Evaluation, which is the research, evaluation, and data office within the Administration for Children & Families within the US Department of Health and Human Services. ACF runs a number of programs to support children and families -- programs you might have heard of, like Temporary Assistance for Needy Families, Head Start, Child Welfare, and Child Support Services. And my office, OPRE, is responsible for building evidence to improve the lives of children and families, with a focus on those programs and the populations that they serve. I work within our Division of Economic Independence, so I primarily focus on employment and training programs. Very happy to be here.

[Denise Hoffman] Purvi.

[Purvi Sevak] Hi, everyone. I'm Purvi Sevak from Mathematica, my pronouns are she and her, and I'm currently the Director of Disability Business Development at Mathematica, which means I oversee the work that me and my colleagues do for clients like Social Security and ODEP and others that are focusing on disability policy and programs. I'll share today some examples of work that Mathematica's done to try and move in the direction that Denise shared earlier, towards greater community involvement.

[Denise Hoffman] Okay, well, thank you for those introductions, and also, Purvi, that's a helpful segue. So, to each of our panelists, could you speak for about two or so minutes each about the evolution of your work or your agency's work in incorporating people with lived experience in research and evaluation? And we'll go with the same order, so let's have Jeff kick us off.

[Jeffrey Hemmeter] So, for as long as I've been working on evaluations at SSA, we've tried to incorporate mixed methods into our work. We've tried to incorporate experiences of individuals with disabilities in all of our projects -- which are primarily about disability and work -- including, probably most often, as representatives on [indistinct] panels. But for a while, I would say, lived experiences were more of an ad-hoc or nice to have aspect of our research, but not central. We've definitely had more of a quantitative economic cost-benefit focus in a lot of our research, but over the last few years, we've been more intentional about how we've tried to incorporate experiences, making sure it's considered in its own right. For example, we have a project on understanding experiences that typically engages with people with disabilities, not as study participants, but as co-collaborators with SSA researchers on just about every aspect of the study, from study [indistinct] design to recruitment, data interpretation to dissemination.

We don't have dozens of major new projects every year, but I think if you look at our recent efforts, you'll definitely see that our main grant programs have explicitly encouraged including lived experiences in focus areas and methods. We've also started a structural barriers forum internally, inviting speakers with various backgrounds to speak about their experiences to help our staff and research partners better understand the importance of these experiences, as well as how to actually conduct the research. So, on that front, we've also invested a lot in our staff who design and oversee the research and evaluations on qualitative and community- and participatory-based research methods, so that we actually know how to craft procurement, which is our main part of how we do our research. But it's still early in this shift in focus. Early days. Savi?

[Savi Swick] Thanks, Jeff.

[Savi Swick] That's really interesting to hear from SSA's standpoint. Thinking about ODEP, you know, this is something interesting to reflect on, because ODEP has always been at the forefront of incorporating lived experience of people with disabilities in research design, participation and

data collection, analysis, and interpretation. So, you know, ODEP also employs a good number of professionals with disabilities, and so, they clearly have a wealth of lived experience to inform the work they do. So, it's not particularly a novel idea in ODEP, I would say. However, what is novel is lived experience of people with disabilities from an equity lens. In the past, we had always considered people with disabilities as a whole as a marginalized group, given their employment outcomes, compared with those without disabilities. So, in fact, like, lack of accessibility is identified as a barrier in the Executive Order 13985. I actually wrote that down.

Also, you know, the other EO of 14035, which calls out people with disabilities to be part of the federal government reflecting the national demographics. So, with that, so it's really important when we talk about equity because without that emphasis, I think we would have always looked at people with disabilities as one big group, and a marginalized group, at that. But with the equity focus, we started looking at intersectionality between race, ethnicity, and disability, which actually revealed that there are issues if we don't look at it from that lens. Even with this larger marginalized group, people of color with disabilities face multiple ways of being marginalized.

So, keeping all this in mind, I'd like to mention a specific research project in ODEP that incorporated specifically lived experience in a systematic way. In fact, our colleagues at Mathematica helped us conduct this study. It's a project on Research Support Services for Employment of Young Adults on the Autism Spectrum. Or we finally called it REYAAS -- or actually, Mathematica gave us that name and the acronym. The purpose of this study is to identify promising practices and policies to support employment of young adults on the autism spectrum. The design of this study was very much attuned to the need to be inclusive, and as such, had a number of listening sessions with various groups, including youth and young adults with autism, their caregivers, policy developers, and service providers. So, this study was very careful to select individuals that brought lived experiences from a wide variety of perspectives. So, that was really a different way. Like, previously, we kind of grouped all the people with disabilities as a whole group, and the equity lens provided another dimension. Back to you, Denise.

[Denise Hoffman] Great. Thanks, Savi, for highlighting that. Marie?

[Marie Lawrence] Yes, thanks. Thanks, Savi, for the intersectional perspective, there. OPRE is very committed to engagement of interested parties in our research and evaluation. So, to take a sort of high-level historical view on that, I would say we've been on this journey at least two decades, with our journey moving us in the direction of doing this kind of lived-experience engagement work more deeply and more consistently across our projects. Initially, we were engaging people from affected communities and practitioners, in particular, in technical working groups. And then, we have really developed a mature engagement approach to working with tribal communities in related evaluations, then moving to project-by-project engagements of

people with lived experience, which continue now, to the development of office-wide and agency-wide infrastructure for engaging people with lived experience more deeply in more phases of the work.

So, recent accomplishments in that vein include developing standard, what we call "active engagement language" in the templates for our procurements, to use across projects, as appropriate. We've also formed work groups to share lessons across projects and across ACF offices in the Administration for Children & Families. And then, also, seeking feedback from people with lived experience on cross-project documents to guide the development and conduct of new work. So, really trying to develop the infrastructure to do this across many projects at the same time. I also wanted to mention that our approach to research and evaluation studies -- which involves working closely with local organizations to study their programs as they're typically run -- is really promising for us or helpful for us, because it allows us to lift up bright spots in communities and serve the program's interest in evidence-building, as well as ensuring that the programs we're evaluating have been developed based on local insights about needs and strengths of those communities. That was just a high-level history for us.

[Denise Hoffman] Great. Thank you for summarizing decades of work into something we can digest. Purvi?

[Purvi Sevak] Sure. So, at Mathematica, we're encouraging our colleagues to engage with people with lived experience throughout the research process, as discussed today. And, ideally, that means beginning early -- so, when identifying priority research topics, developing research designs -- but then continues throughout, as Denise has discussed. And, at Mathematica, I've found -- or we've found -- that our colleagues that work for foundation clients, rather than federal clients, have begun this journey earlier and are further along on this journey. So, I often look to them for ideas or guidance or, for today [Laughs] examples, as well. So, I'll mention a project studying intimate partner violence whose goal it was to develop policy recommendations for Medi-Cal, California's Medicaid program. And for this project, my colleagues have formed an expert advisory council comprised of individuals with lived experience with intimate partner violence, but also direct service providers, leaders of organizations that provide services related to intimate partner violence, and others with more on-the-ground perspectives. And they're using their input to help shape their research priorities related to prevention of intimate partner violence and coverage of services through Medi-Cal for survivors and those at risk. Another example is a project that I direct for NIDILRR at HHS, focused on increasing and improving services for out-of-school youth with disabilities from minority backgrounds through centers for independent living.

So, early on here, we partnered -- and this is a project Mathematica's collaborating with, with Hunter College, but also in partnership with a center for independent living in New York City.

So, they were involved from the proposal stage, as we were brainstorming what kinds of research projects and interventions to develop and propose to NIDILRR. And we're currently in the fourth year of the project, where we have basically gotten to the stage where we're ready to develop and test an intervention. And even at this stage, we're gathering input from members of the community through the involvement of this center for independent living. So, through members of their community that they are currently or not serving, of how they could and other CILs could better do outreach to this population. And the last thing I'll mention -- and I think that Savi mentioned this, as well -- is we're trying to recognize, also, that people with disabilities are not, you know, a uniform population. People bring different identities -- they come from different communities, and being conscious of that as we look to the community for input and involvement in our research activities.

[Denise Hoffman] Great. Thanks, Purvi. So, for this next question, I want to think from the federal perspective, and Jeff, it sounds like your agency efforts are really meaningful but also a bit more recent. So, Savi and Marie, I'm wondering if you could expand a bit more on where you've seen improvements in your agency's understanding of how programs or policies, based on work that centers people with lived experience, performs versus work that does not include the perspective of people with lived experience.

[Savi Swick] Happy to. So, in the last three years or so, you know, ODEP research expanded its focus on people with disabilities as a single group, as I mentioned earlier, to exploring various intersectionalities within that group. For example, we began highlighting the contributions of people with disabilities from the race-ethnicity vantage point, as opposed to as a whole group. It was also an opportunity to highlight the previously undiscovered parts of this community, such as when you think about Black, Hispanic, Asian, Native American, or American Indian people with disabilities, understanding that a number of those individuals are already in the labor force, contributing, despite the barriers that they face, and that they are among us, beside us, is something that people may not really think about. So, it was an opportunity to highlight those during the various months that we celebrate these groups. In addition, while we keenly acknowledge the issues they face, it's also important to point out the fact that, like I mentioned, they work beside us.

So, when we did the research pieces highlighting different races and ethnicities, we also discovered that some cultures -- for example, Native American cultures -- most Native American languages seem to have no basis for the word "disability." There are no equivalent words that signal disability. So, cultural uses of language also differ greatly. The ability to speak and communicate through spoken language is not the measure of competency, like for example, it is in the Western world, right? So, things of that nature that we discovered during our research. For example, in some other cultures, there's also shame attached to being disabled that comes from a belief that one's disability is caused by that person or his or her immediate family having done

something wrong or by some ancestral thing of that sort of thinking. Why this is important -- these have implications how -- these cultural viewpoints are really important when we enumerate the population with disability by race and ethnicity.

These can lead to under-counting, for example. Right? If people don't want to disclose disability, they may not respond the same way. And also, when we conduct focus groups and listening sessions, it's important to have this cultural context, which allows us more nuanced interpretations of responses, for example. Only those with lived experience from those cultures can help us fully unpack the research findings by, you know, revealing the gaps in our understanding. If we don't have that, we may miss a really important piece in how we interpret the results. So, that's something I wanted to bring up today. Back to you, Denise.

[Denise Hoffman] Great. Thanks. That sounds uniformly helpful, in general and also certainly relevant to the points of intersectionality that you made earlier. Marie, anything to share from your perspective?

[Marie Lawrence] Sure. Thanks. I think I'll take this question by talking about a particular project we have -- one of the ones I mentioned that looks across the documents and processes that we use in our research. So, this project is called Advancing Methods of Contextual Analysis and Participant Engagement, affectionately known as CAMPE. And the CAMPE project aims to build our knowledge of and our capacity to use equitable research and evaluation practices for future use across our projects. And one aspect of this project is we've convened a two-year community advisory board made up of people with lived experience participating in or directly providing ACF services. Importantly, since this is a federal group, I'll say that the CAB is not an advisory committee. Its purpose is, rather, to gather a diversity of perspectives, not to provide consensus. And this group is looking at, like I said, those process documents that we use across projects. So, one of the activities that we had them complete, we asked for their feedback on, was our learning agenda, so our welfare and family self-sufficiency learning agenda, which is a document that compiles what we have learned and what we want to learn in those topical areas. And we learned from their feedback.

They looked at this document over the course of four or five months. And one important piece of feedback that is both about the learning agenda, but I think more broadly, perhaps, that employment and training programs, was the implicit prioritization in some of our learning questions about employers' needs. So, some questions ask about how to help people build skills that are in demand right now in the labor market or skills for occupations that are likely to grow in the future. And these community advisory board members pointed out to us that these questions are oriented for the preferences of employers and the needs of the labor market, but not necessarily toward the interest and goals of job seekers, which might not include jobs in "high-growth fields" but might include interests like entrepreneurship, to start or grow their own

businesses. So, insights like that are really important to us, and we're currently reviewing a full report of their recommendations to decide and report back to them how we're going to incorporate their feedback in the research priorities articulated in our learning agenda.

[Denise Hoffman] Great. Thank you. And I especially appreciated the way you framed collecting diversity of perspectives, as opposed to consensus. I feel like that aligns well with what some of the panelists have been saying about people with disabilities as not being a homogenous group. So, thanks for highlighting the positive developments, but now, to all three of our federal panelists, of course, moving to the right on the spectrum of increasing community engagement, we all know is not without its challenges. So, to each of our federal panelists, could you please discuss places where you've seen federal processes as a barrier to including people with lived experience? And let's turn this to Jeff, to start.

[Jeffrey Hemmeter] So, one of the [indistinct] the compensation for participating in research and in development of things can actually count against one of our main programs, the Supplemental Security Income program. There are some rules that allow us to disregard some earnings, but it's generally limited to about \$60 a calendar quarter, which, you know, kind of precludes substantive involvement in research design, interpretation, and the like, where it's not infrequent or irregular. It's supposed to be ongoing and expected. We found some ways around it, but it was a challenge. Another kind of challenge we've faced is just, to be blunt, staff understanding of the topic, of the method. It's new to many people, so many people, you know -- we want to make sure that we're including the right language in contracts. We want to make sure that we're assess a quality proposal from a proposal that's just checking the box, using buzzwords.

We want to make it meaningful, and we can always include it, but we want to make sure that it's really incorporated into the analyses, into the design, into all of that, and not just kind of as a separate or tangential thing. I mean, it's secondary to the purely quantifiable outcomes and measures and things and the standard dissemination procedure. Thanks. And then, just, finally, from more of an information point of view, doing it right can take several Paperwork Reduction Act clearances. You can't really specify everything that you're going to be doing, and you're learning as you go. Not necessarily learning the method, but you're getting new information about what you need to ask, what you need to do, how you need to revise questions, how you need to do things. There are ways around that. There are generic clearances, which are a lot quicker than the full clearance process. Those are some of the main challenges that we've had so far. Denise?

[Denise Hoffman] Yeah, I saw a lot of smiles when you mentioned the PRA clearance process, so I'm assuming that is a common one. Savi, what stands out to you as some challenges in this space?

[Savi Swick] Yeah, let's start with PRA. Well, I was going to say that I think the main barriers to including lived experience come from these kinds of institutionalized practices that we have to go through as federal researchers, and some of it comes from the belief that existed prior to our current enlightened thinking, I would imagine. A lot of our current rules and regulations are written from a more limited perspective, without taking into consideration the perspectives of the affected community. So, they're limited and probably designed purposefully to simplify things. We tend to like simpler solutions that are easier to execute and cleaner and easier to manage. But sometimes, you know, intersectionality of marginalized groups is inherently complicated and difficult to implement. You might require, you know, translation services, things of that nature that, you know, they require patience, tenacity, and even most importantly, resources, which we sometimes run out of. That generally results in all of us kind of reverting back to old ways or more convenient ways, but it's important to, you know, move forward to figure out the emerging orders and make sure that we don't give up and embrace simplicity for the sake of it, but continue to incorporate these practices.

One other thing I'd like to mention is that when we are thinking about lived experience, a bigger barrier in research is generalizability. And so, your findings could be challenged if you don't, you know, design your study appropriately. So, we have to be careful in how we design studies, based on what research questions we are trying to answer, and what lived experiences are informing us and how. This is true particularly of the disability community, whose lived experiences can vary so much, depending on the type of disability, race, ethnicity, so other socioeconomic factors. So, it's a really very diverse community, and when we are incorporating lived experience, we also have to acknowledge that, you know, perhaps some of it is informative but perhaps not generalizable to a larger community. So, I would like to point that out, as well, as a barrier.

[Denise Hoffman] Yeah, I definitely, to that last point, see how that kind of dovetails with the time and resources that you mentioned, that if you want to try to do those differences justice and understand them, that that takes a lot of resources.

[Savi Swick] Absolutely.

[Denise Hoffman] Marie?

[Marie Lawrence] Sure. These are great points, already shared. I would just add one, I think, related challenge to some of what Savi was just mentioning, which is challenges that can come from the federal procurement rules and regulations. You know, many federally funded research studies -- and most of them in my office are carried out by research firms like Mathematica, under contracts with the government. And contracting is a way, it is a really important strategy that we use to undertake complex projects in a way that adheres to our evaluation policy. So, for example, research contracts ensure that we can carry out studies in a manner that's rigorous,

ethical, and independent from the office or the agency that directly funds or oversees the program involved in the study. However, the process of awarding these contracts can be very time- and labor-intensive, and the ability to pursue modifications to the contracts -- things like changes to the timeline or the scope or the budget -- after the contract has been awarded can be limited and often require really strong justification with our contracting officers. And that means it can be challenging to be really responsive, especially quickly responsive and adaptive to the emergent needs that come from feedback from community experts.

[Denise Hoffman] Thank you. You know, one thing, Marie, that struck me was in thinking about long-term contracts, like, you know, I know that Mathematica has been part of contracts that have run for 10 or more years. And if you think about a contract that's in year 8 of 12, for example, that incorporating lived experience A hasn't happened in the brainstorming early sessions, but at that point, to your point of trying to make adjustments, it's much harder. But great to hear about the efforts for new projects, and I think that speaks to what Jeff was saying earlier. So, I want to loop in Purvi a little bit more. Purvi, you, of course, bring a different perspective as a researcher and someone who oversees a portfolio of work related to disability policy, including many that are under contract to federal agencies. So, Purvi, how did the barriers that our federal panelists just shared align or differ from what you and your colleagues have seen in your work?

[Purvi Sevak] Sure. I wanted to start by touching on something Savi mentioned about generalizability, and also Marie was talking about rigor. Many of us have been trained with, like, the primary... When we were trained, we were not talking about incorporating people with lived experience. And so, it's hard to unwire some folks to sort of allow -- not allow, but to really emphasize the importance of this -- why is this important? It's just as important as making sure your sample is representative or, you know, you have a good response rate, etc, to your survey. Even if we're not getting, you know, a sample of people to offer input and engaging, like, a representative sample, even if we can't put quantitative, you know, estimates around the information we're gathering, it's just as important as the impact analyses that we get, you know, t-statistics for.

I haven't really encountered that as a barrier, I think, because I think we've really embraced this -- the importance of incorporating people with lived experience at Mathematica. But I think, as a field overall, like, we're still -- There are still folks that really push -- or minimize the importance of it. And, anyway, so, I just want to acknowledge that. But one thing I did want to mention is schedules and timelines. I know we heard about resources, as well. Really genuinely engaging people with lived experience and gathering their input in a way that it can shape the research takes time. And we can't build schedules that we built for projects 10 years ago and think we can just stick this in there. You really need to build a schedule that ideally incorporates input from the community that you want to engage. Make sure that the schedule you imagine meshes with their

schedules and availability and that you allow enough, you know, response time as you're gathering input, whether it's on written materials or with scheduling or things like that.

So, I would say I faced that as a barrier on the project that I mentioned with Centers for Independent Living or we had project delays, things that meant that when we had intended to get input from folks, we were not quite ready, but we had to stick with our project timeline, and that meant that we were rushed. And that wasn't ideal. So, in subsequent years, we've allowed for more time to gather input and for getting -- giving them enough time. The second thing I wanted to mention is discussion of roles, responsibilities, and expectations. As Denise discussed at the start of our session, there is a continuum of community engagement. In some projects, co-creation and co-ownership might be possible. And in others, it might not be possible. And it's -- You know, that's okay. Like, it's not always going to be possible to be all the way over to the right on that diagram.

But, also, I found that some individuals with lived experience may be interested in more of a role than we might have imagined on a project, in terms of, like, where on that continuum. Or might be available for less of a role than we had imagined. And so, ideally, I think it's important to discuss expectations from the beginning so we can all land at a place that we're happy and that we feel like we -- you know, we own the work that we're doing both as researchers and the members of the community that we're engaging. I'll stop there.

[Denise Hoffman] Great. Thank you. So, definitely appreciate and acknowledge many of the barriers that all of our panelists raised. But before we move on to the question-and-answer portion of the event, I do want to end on a positive note. So, some of the responses did include things that kind of address some of the challenges, which, to me, is a positive note. But if you could each take a minute or two to highlight what you think has been a notable improvement in process to advance equity and inclusion. And let's keep the microphone with Purvi and then go back to Savi, Jeff, and Marie.

[Purvi Sevak] Sure. So, one thing that I will mention is Mathematica is currently running a Lived Experience Expert Panel pilot. It's called LEEP for short. And what this is, is a group, in this pilot, of 10 individuals with very personal and professional lived experiences that Mathematica has engaged and compensates to provide input on a variety of projects, new proposals, internal presentations, external presentations, blog posts, issue briefs that we're writing. And by engaging them in a panel, as opposed to in a one-off situation, our thinking was that we're building a relationship with them, better understanding what their experiences are, what their interests are. And then, when there's an opportunity for them to engage or get involved in a project, we're -- you know, we're more likely to know that, they're more likely to know that, and it's not just a one-off ask that can feel sort of one-sided or opportunistic.

So, as I've said, we've engaged LEEP members on a variety of projects and dissemination products. The panel includes individuals with a range of backgrounds, across demographics, such as disability, race, and sexual orientation, but also in their expertise in health equity, disability programs, autism, domestic violence, maternal health, mental health, tribal health, et cetera. So, we've tried, even with just 10 people, to cover a lot of different backgrounds. But we will, 'cause it's a pilot, gather their input and our client's input on how the LEEP pilot went, how we could improve it, and hopefully continue it into the future.

[Denise Hoffman] Great. Thanks, Purvi. And, yes, just chiming in that as someone who has had the opportunity to interact, that's been a really great support for some of our work. And I think I've even seen some expansion of that group, too, to include some other people as we've been going along. Savi?

[Savi Swick] Yeah, so, at DOL, there's been a lot of notable changes in this space. In grant-making, there have been, like, really concerted efforts to incorporate, starting from grant-making, which is where we begin program development, to conducting research, providing direct services, and, in a number of other areas, an effort to make equity, lived experiences, and voices of the diverse individuals we serve being reflected in a meaningful way. And it's been incorporated into the framework of thinking about, you know, program development, research, and service delivery. So, I think those types of changes are here to stay, because they've been baked into our everyday processes. And it's not just, like, a buzzword or a temporary thing that we would do please a particular group of people, but more about the way we think about things.

So, I think those types of institutional changes would stay. And I can't give enough credit to ODEP. ODEP has always been, as I mentioned at the beginning of this discussion, you know, at the forefront of incorporating that lived experience in all aspects of the work they do. That is not to say there's not areas that they are trying to improve right now, meaning expanding into other communities that they were previously not. And, as I mentioned, resources are a big factor in that. But, you know, reallocating resources and making sure you are expanding the circles that you get the information out to. They are also incorporating additional communities that, you know, previously, we might not have thought about. So, lots of good changes are happening, and I'm hopeful that, you know, all this work would then continue in many different ways. At DOL, anyways.

[Denise Hoffman] Great. Thanks, Savi. Jeff?

[Jeffrey Hemmeter] I already mentioned our understanding-experiences study with kind of, in essence, similar to the LEEP and CAMPE parts that have been mentioned. But I think another kind of major improvement is coming from, you know, just an agency-wide appreciation of the

true range of valuable, meaningful, and rigorous evaluations that exist. Not just quantitative. It can be -- And even then, I mean, there's more of an understanding that -- the understanding of personal lived experiences complement and enhance the quantitative, which is still expected in a lot of circumstances. But it's not an either/or kind of approach in the method. It can be included in all of the areas that we do. But, you know, I think also that lived experiences -- you know, not just focused on the agency experience and allows us to move past assumptions to better get at where -- what the true barriers are that people are experiencing and perceive so that we can better serve them.

So I think there's been this move with -- We mentioned our structural-barriers forum, trying to get it more engrained into our just SSA ethos about, you know, what we're supposed to be doing, what we do, and getting it institutionalized in that way. You know, and to that end, I do think that SSA has moved away from kind of SSA-dictated demonstration projects. We have our Interventional Cooperative Agreement Program, which is open right now, if you want to make some applications. And while it may not be perfect, it does help us to move past the "federal agency knows best" kind of mind-set and to seek out community-based solutions to issues which are preferably also ones that are informed and include people with lived experiences, abilities across the -- So, you know, I think those are some very good, promising kind of things that we're doing and look forward to seeing how those all play out.

[Denise Hoffman] Great. Thanks, Jeff. And, Marie, would you like to close us out of this portion with improvements that you've observed?

[Marie Lawrence] Sure. I think Savi and Jeff really covered some important ground there -- the institutionalization of these practices and the re-education and what rigor means of both really resonate, I think, with me and my experience at OPRE. I think to close us out, I can share an example of one other project that I think encompasses a number of these things all in one. So, this project is called "Gathering and Using Family Input to Improve Child Support and Temporary Assistance for Needy Family, or TANF, Services." This is a contracted research project with the goal of advancing knowledge about how state, tribal, and local TANF and child-support programs can incorporate input, families they serve, they currently serve, might serve in the future to improve program improvements and operations. And it has a number of components. So, first is to simply describe how TANF and child-support programs are currently using input. Also compiling resources to support programs in using family input. And then engaging several programs, both TANF programs and child-support programs, to use formative-learning cycles to pilot and improve on those resources, and then putting out a revised set of materials and a report of the findings. Actually, Mathematica is the prime contractor on that project, and MEF Associates is the subcontractor.

And, so, I think the goal of the project, in general, is very in line with what we're talking about now, but also an important component of the project is convening a project-long expert working group to provide input on the project across its life cycle. So, that group includes both TANF practitioners, as well as staff members and community members who are part of, like, state and local Family Voice groups from several states. I think at least Colorado-, Washington-, and Ohio-based groups are incorporated. So, this full group of experts provides input on many aspects of that project, from the project goals to the products that are going to be produced to draft and review guides, and they'll also be providing input on drafts of research projects. So you have this kind of multi-layer project that, you know, the primary goal is to build the capacity of local agencies to use family input, but itself is modeling this commitment to engaging expertise of people with lived experience throughout the life cycle.

[Denise Hoffman] Great. Thank you. So, we have a little bit less than 10 minutes for a question-and-answer session. Thanks to everyone who submitted questions. Please continue to do so, and we'll get through them to the best of our ability. To our panelists, I will attempt to direct a question to a particular person, but others can feel free to chime in. Please do if you have something to add. I'm just hoping that we can cover a little bit more ground in directing one question to about one or two people. So, this question just came in, and this builds on what Marie was just talking about. And, so, the question was about when organizing or managing a community advisory group, such as the one, Marie, that you were just describing. Do you have any advice for the number or mix or backgrounds of people to include?

[Marie Lawrence] That's such a good question. So, I think, again, just reminding all of us that the goal there -- the goal with our group in the CAMPE project was to get a diversity of perspectives. So we sort of -- We defined -- An important criterion was that someone had lived experience with ACF programs. And because this project is primarily, although not exclusively, focused on employment and training programs, we were looking for people who had experience with employment and training programs, with the TANF program, which provides funding for the project, but other ACF programs, as well. And then we just sort of -- And we came to this iteratively, frankly, with our contractor, Urban Institute. We just defined some dimensions of diversity that wanted represented, but there was absolutely no quota system. It was a really -- It was an organic process where we said, "We'd like these kinds of diversity represented on the group."

And Urban went out, tapped into its own network to clearly explain the project and the kinds of diversity that we wanted represented and have people kind of self-nominate to learn more about the project. And in those conversations -- They were unscripted. We didn't put an OMB package together. But in these, like, very tailored conversations about the project, Urban learned more about the person, their interests, their background, and the parts of their identity that they wanted to bring into the experience, and kind of put together a summary for us, as federal project

officers. And we said, "Great. This looks like a good mix." The idea wasn't to have a representative group or to get, you know, one person from every racial ethnicity group. It was really to just try to maximize diversity with respect to the number of folks. And I'll just say that group has, I believe, 13 members. And we thought it could be effective with fewer, but we wanted to intentionally build it to be large enough to absorb some attrition over the two-year period, since we know that people have really complex lives, and a lot can change in two years.

[Denise Hoffman] Great. Thank you. So, this next question, Jeff, I'll direct to you, and others can chime in, too. So, a lot of this conversation has highlighted that people with disabilities are not one uniform group. And there were some questions about any different strategies or ways to engage different subpopulations of people with disabilities. In particular, there are a number of questions related to people with intellectual and developmental disabilities or people living in rural areas. So, Jeff, any insight to share about some subgroups of people with disabilities, perhaps those that I just mentioned?

[Jeffrey Hemmeter] Oh, that's very broad, but I will say, I mean, this goes back to the conversation that, you know, Savi and Marie said, is that, you know, it is -- Disability is -- while it may mean something, it is not homogenous in terms of what it means and who experiences it. You know, and I think we've learned that on a lot of projects. I know in the Promoting Readiness of Minors in SSI demonstration project that the SSA worked on with the Department of Education, Labor, and Health and Human Services. You know, an example of this might be -- You know, picking up on the rural aspect of the question, you know, there were frontier sites, not just rural. Like, really -- You know, really out-there sites. And we knew that we wanted to include small-population states, but that really wasn't -- You know, that level of outside of the main, you know, communication structure and things wasn't really on our radar.

You know, and I think it's just a good reminder that the assumptions that we make about how to contact, communicate, and serve individuals may not be totally informed. There are different challenges that really only come to light when you're discussing things with the community and the local partners and providers in an area. And to something Marie just kind of said, you know, all of this is going to take time. It's not necessary -- Getting that input is not random sampling. It's not actually meant to be representative, like, nationally representative. You're getting -- You're purposely sampling people, purposely including people. It's not a one-and-done thing, and you just kind of have to -- as she mentioned. And to everybody who's still listening, I do apologize for talking so fast. I am aware I am a fast talker, so I apologize.

[Denise Hoffman] Thanks, Jeff. And I also wanted to put in a plug. So, there are a number of people interested in intellectual and developmental disability. I wanted to refer you to the Institute for Exceptional Care, which does a lot of work with people with intellectual and developmental disabilities around healthcare. So I encourage you to check that out. They --

That's in the core of what they do, so you may be able to glean some best practices there. So, I think this might be close to our last question. We'll see. But, Savi, what advice would you give to a local government agency seeking to increase community-engagement efforts?

[Savi Swick] That's a really good question. I would say, you know, engaging with groups that have experience in doing so already. As you mentioned, you know, even within the federal government, you know, different agencies are at different places in terms of this community-engagement piece. And a local government actually would -- in some ways, are better situated than the federal government in consulting the local community groups. You know, there may be lots of activities. I would say that would be a very good place to start. I was actually thinking of one of the other projects that we do in ODEP -- RETAIN, Retaining Employment and Talent After Injury/Illness Network project that we're doing with SSA.

You know, when the equity lens came about, we actually quickly pivoted to, you know, working with community organizations to engage people and get the word out to folks out there about the program and also measuring, you know, this program penetration in the way that we deliver services. So I think a local government is well-situated to do that even better than us. That would be my advice -- to immediately tap, you know, already-pre-existing community organizations within that community. I don't know if Jeff or Marie has -- have anything else to add to that. And, of course, using groups like Mathematica. They know how to do, so you should always first consult Mathematica.

[Denise Hoffman] Lots of good contractors in the space, hopefully Mathematica included. So, I think we are just about time. So, thank you very much to all four of our panelists and also to the audience. There was a lot of engagement around this topic, which was really exciting to see. So I hope that this helped give everyone some sense of what is going on and some practical, hopefully, tips and motivation to move to the right in terms of the spectrum of engagement. So, thanks, everyone. A recording of today's event will be available -- there's a link posted -- if you want to refer back to it. So, thanks, everyone. Have a good rest of your week.

[Savi Swick] Thank you. You too.