

Kimberlyn Leary

Welcome, and good afternoon. My name is Kim Leary, and I have the pleasure of serving as the Executive Vice President of the Urban Institute. I am an African American woman. I have dark hair, and am wearing glasses and a dark jacket, and also a dark shirt.

Before we jump into today's wonderful program, I'd like to share a few notes of housekeeping. We have provided ASL translations and CART captioning, and you can adjust the caption settings with the "Hide/Show Captions" button. This event is being recorded and the recording will be posted online afterward. Speaker biographies and related materials can be found online at urban.org, and there's also a link in the chat to speaker bios. All participants today are muted, but you can type your questions or comments into the Q and A box at any time. Engage with us online, too, by using the hashtag #LiveAtUrban. And after today's program, we'll share a link to a post-event survey, and we ask that you please share your feedback with us. It's helpful for us, and panelists want to hear what you're thinking about today, and it will shape what we at Urban do in the future.

So with the logistics behind us, I want to thank you again for taking time to join us today. We'd also like to thank the Ford Foundation for providing core support to Urban's Disability Equity Policy Initiative, the Disability and Philanthropy Forum for partnering with us on the event planning, and for the participation of all of our esteemed speakers. I'd also like to thank in advance, the co-chair of the President's Council of the Forum and the president and CEO of the Robert Wood Johnson Foundation, Dr. Richard Besser, who will be speaking next.

But let me say a few words to orient us to today's conversation. In October, the Census Bureau announced a proposal to change the way it measures disability that would have reduced the official disabled population estimate nearly in half. But after significant feedback from researchers and from the disability community, the Bureau announced earlier this month that it would put the proposal on hold to deliberate further. Now, it has the opportunity to meaningfully engage with the disability community in exploring how to more accurately and inclusively measure disability in the ACS. Both the current measure and the Census Bureau's initial proposal rely on functional definitions of disability, for example, the ability to see, hear, or walk. But they also exclude millions of Americans, including those with chronic illnesses, psychiatric disabilities, or conditions that affect them intermittently. Accurately estimating the number of disabled Americans is critical for informing public funding decisions, for planning resource and program provision, for enforcing regulations, and understanding the lived experiences of different groups.

And with that, let me now introduce our keynote speaker, Dr. Richard Besser, president and CEO of the Robert Wood Johnson Foundation and co-chair of the President's Council of the Disability and Philanthropy— Sorry, let me try that again! And co-chair of the President's Council of the Disability and Philanthropic Forum. Rich, welcome to the Urban Institute.

Richard Besser

Thanks very much, Kimberlyn. It is truly a pleasure to be here. As you heard, my name is Rich Besser. I'm president and CEO of the Robert Wood Johnson Foundation, and I'm seated at my desk in my office here in New York City. Over my shoulder is a bookcase with some photos and a tall green plant. I'm a white

man with olive complexion, gray hair, wearing a light blue shirt. It is truly an honor to be with you virtually to join this important conversation and to make a few brief opening remarks. I wanna thank you, at the Urban Institute and the Disability and Philanthropy Forum, for your hard work and organizing these critically important panels. I also really wanna thank all those who've been working with us at RWJF on disability—I'm not gonna call you out by name, because whenever I do that, I leave someone out—just know how appreciative I am for the work that you do, and for helping me and RWJF do our work better.

I am truly grateful for all that so many of you have done to spread the word about how important it is to accurately measure disability in order to advance health equity in America. As many of you know, proposed revisions to the American Community Survey of the Census Bureau drew more than 12,000 comments, and led the Census Bureau to announce that they would not move forward with changes to the survey without meaningful engagement with the disability community. That's an encouraging direction, and it's an important one, and I like to recognize when we see our government being responsive. Positive reinforcement is a good thing. I know that as a parent, I know that as a pediatrician. Now it's up to all of us to hold the Census Bureau accountable for its promise. Knowing that true health equity for those who make qualify for government support because of a disability is in danger of being undermined. At the Robert Wood Johnson Foundation, we are paving the way together toward a nation where health is not a privilege, but it's a right. As someone who worked at the CDC for 13 years and led the organization for a little bit of that time, I know how much influence government agencies can have on advancing health equity. And unfortunately, how their actions can sometimes have the effect, intentional or not, of hindering our progress towards health equity. I also know from more than 30 years of working as a pediatrician and community clinics across this country, the people in communities closest to problems are in the best position to lift up the necessary solutions.

In the Census Bureau's next actions, and with this agency partner in designing these questions (the National Center for Health Statistics, also known as NCHS, is part— which is part of the CDC), meaningful engagement with the disability community must be non-negotiable. Leaving the questions as they are, with the flaws others here will share more about, would undermine health equity in the long term. Refining the questions, so that they're comprehensive, will require both the Census Bureau and NCHS to genuinely listen and reassess potential solutions.

I point this out while also acknowledging that philanthropy has its own improvements to make and working toward applying a disability lens across our funding and the ways we work. While RWJF, our foundation, is 52 years old, it's only in recent years that we've begun to make changes to our grantmaking and our own operations to promote disability inclusion. I continue to learn a lot in my role as co-chair of the President's Council for the Disability and Philanthropy Forum, along with Ryan Easterly, the executive director of the WITH Foundation. Through that work, we also engage in participatory grantmaking, by way of the Disability Inclusion Fund at Borealis Philanthropy. This fund lifts up what I was just talking about: community informed solutions. As I mentioned, these are connection points and relationships that have only just begun. Just as the Census Bureau has more to do to keep its commitment, philanthropy, including RWJF, has much more work to do. But you have to start somewhere, and the very act of starting is empowering. And these conversations are invaluable for truly understanding the dynamic, nuanced experience of disability today. And the only way for it to be defined in any real, meaningful way is for those definitions of disability to be shaped by people with lived experience and expertise. I'm deeply grateful to you and your networks for continuing to be advocates

for true health equity for the entire disability community. RWJF supports this work, and we're honored to continue to collaborate with you on the work ahead. Thank you for the opportunity to share my thoughts with you this afternoon, and I can't wait for these informative panels.

Kimberlyn Leary

Rich, thank you so much for joining us and for accentuating how critical it is for us to bring philanthropy and government—community expertise—together on this and so many other issues ahead.

Let's move now to our very first panel, where I have the pleasure of introducing Scott Landes, who's an associate professor of sociology at Syracuse University. Welcome, Scott. And also Sue Popkin, who is an Institute fellow here at the Urban Institute and the co-director of the Disability Equity Policy Initiative, also here at the Urban Institute. Let me invite both to say a little more about themselves, and then we'll commence with the panel.

Sue Popkin

I can start. I'm Sue Popkin. I am an older white woman with curly hair—the salt and pepper—and I'm wearing glasses and a green scarf, and I'm sitting in my office at the Urban Institute with a bookcase behind me, with some knick-knacks on it. I'm really delighted that everyone is here today. As Kim said, I am the co-director of our, I guess, now two-year-old Disability Equity Policy Initiative at the Urban Institute, and we are just delighted to be able to be part of this conversation about the Census Bureau.

Scott Landes

My name is Scott Landes. I'm a white male, short brown hair, brown and grey beard. Dark rimmed glasses with an opaque purple lens. Black shirt, blue sweater, brown corduroy blazer. I'm a disabled scholar. Most of my work focuses on disability measurement and health outcomes, and I'm currently at Syracuse University.

Sue Popkin

Yes, and I should have said, I am also a disabled researcher. I have Sjogren's disease, which is a systemic autoimmune disease. And the sort of motto of our disability equity program is the same as the disability rights movement: “Nothing about us without us.”

Kimberlyn Leary

Thank you, Sue. Thank you, Scott. Let's get started, and we really hope that we can have a conversation take place between the two of you—really the three of us, I suppose—but really, mainly the two of you. But let me begin with a couple of questions, and let me start with you, Scott, if I may. You've done a

tremendous amount of work on how to measure disability. Can you talk with us about the Census Bureau's proposal and how it would have changed the estimate of the disabled population?

Scott Landes

Yeah, that's a great question. So the proposed change was for the disability questions in the American Community Survey. The Census has been using a set of questions that we commonly refer to as the ACS-6 questions. These are the questions that the Department of Health and Human Services said is the standard for disability measurement as a demographic characteristic required by Section 4302 of the Affordable Care Act. The proposed change would have switched to using the Washington Group questions. The content testing that the Census Bureau released, their own testing of this change, stated that this would have reduced the size of the disabled population in the US from 13.9 to 8.1 percent. So in other words, it means that 42 percent of people who reported they were disabled with the ACS-6 questions, the standard for reporting in the US, would not be counted as disabled in the new Washington Group questions. Or, in other words, it would artificially reduce the size of the US disabled population by 42 percent.

I mean, I think the big question that many of us wonder is, why do the Washington group questions underperform? Who are they not counting? And I was— There's— there's other data, the National Health Interview Survey, that fortunately, back in 2011 and 12, they fielded both questions, both the ACS-6 questions and the Washington Group questions. And so, along with some colleagues, Bonnelin Swenor at Hopkins and Nastassia Vaitiakhovich at Syracuse, we looked to see if we can find a pattern of what is it that's different about these two question sets. And what we found is that there's gradations in whether the Washington Group question count someone as disabled based upon number of disabilities. So what we found is using the ACS-6 disability questions, that if people reported one disability (meaning they said, "I just have a vision disability" or "I just have a mobility disability") only 29 percent of those people are counted in the Washington Group questions. Meaning it misses 71 percent of that group. And in this data, 60 percent of people who said they were disabled reported only one disability. Now, if you reported two or three disabilities, your chance of being captured in the Washington Group measures increased to 55 percent and 75 percent. And so, what we found is that the Washington Group questions are really good at measuring number of disabilities. Whether you have one, two, or three. But that's really different from measuring disability status. And, as I understand it, our goal in a survey like the American Community Survey, as well as any other federal survey, is to count disabled people defined as people who report having a disability, even if it's just one disability. And so, using questions that primarily count people reporting two or more, and excluding those with just one disability, to me is counterintuitive and possibly the reason why the Washington Group so severely under perform.

Kimberlyn Leary

Well, thank you, Scott, for giving us the background there to help us to appreciate the specifics of the change and the impact it would have had. Sue, in a recently released Urban Institute report, that you and your co-authors took on describing some of the policy implications of making a change that would

reduce the estimate of the disabled population as Scott's described it. Can you tell us more about what you've learned about the potential impact on federal funding, and also on state and local planning?

Sue Popkin

Sure. I think first, I'd just like to respond a little bit to what Scott said, and say that the questions we already have, we know are an underestimate. And a comment I usually like to make is that they don't count me and a lot of other people with chronic illness. In terms of the policy implications, I think the first thing we learn is that it's very hard to find this information, and it took a lot of digging, and my colleagues did a lot of work to find the information. We know that changing the way we count—we estimate—the disabled population could affect funding and planning in a number of ways. We know that incomplete measures of disability mean biased estimates of key indicators, like employment rates and the share of disabled people who receive federal benefits. And we also know that federal agencies use Census data and inform funding formulas for hundreds of programs. But picking those apart, those formulas apart, to figure out which ones use the ACS disability questions now would be a major undertaking. And maybe one worth considering before the questions are changed. I don't know. I mean I think it would— We'd have to find out how difficult it would be, because they're embedded in these huge formulas for things like housing funding.

However, we were able to find a few clear examples where the ACS-6 gets used to determine funding, including a Department of Transportation program for seniors and people with disabilities, the Department of Housing and Urban Development formula funding for the Community Development Block Grants and the HOME program, and the Low-Income [Housing] Energy Assistance Program. We were also able to find examples of localities who use the ACS-6 questions for their own planning efforts. I think one of the ones we thought was most striking was in Davidson County, Tennessee, who use the Census and ACS data to determine that a considerable number of homeowners in their county were not applying for tax relief and tax freeze programs. Having found that information, they used that to design an outreach effort to up the numbers and get more people to participate.

I think one of the big areas of real concern, however, is around emergency planning preparedness and response programs. And that goes across multiple federal, state, and local agencies who all rely on disability data now from the ACS to ensure appropriate assistance for people with disabilities. The CSC uses disability data to estimate the size and nature of populations that may be affected. For example, FEMA uses disability data as one of its indicators of community resilience for resource, planning and distribution. And particularly after Hurricane Katrina, it became very clear that people with disabilities have vastly different experiences and evacuation, shelter, and recovery than people without disabilities. And so, as climate change continues to exacerbate environmental emergencies, preparedness will only continue to be more essential and getting those numbers right will be more important.

Kimberlyn Leary

So thank you for that, Sue. I think what you're saying is so critical that as we think about the impact on people down the line, that if— without attention to the formulas, without attention to the underlying

definitions, communities, families could find themselves at a significant disadvantage and in a period of some impingement later on.

Scott Landes

Kim, I wonder if I can— I wanna, 'cause, Sue and I were talking about this the other day. The one that really surprised me that I did not know about was the CDC and Agency for Toxic Substance Abuse and Disease Registry, their Social Vulnerability Index. And because we know the disabled people are at higher risk during times of emergency, natural or man-made or human made emergencies, and that this index that the CDC uses is used by localities to help plan for emergency situations. I just, I had no idea. And they're using disability, Sue, and that it seems like to factor in which communities are most at risk.

Sue Popkin

Yeah. And I think it makes it even more important that we have accurate numbers, having an estimates that are inaccurate are going to put people at risk.

Scott Landes

Yeah, because bringing the two questions together, I mean— If we cut the size of the disabled population by half, what does it do to those estimates that these communities are using to get ready? Yeah, I think you're exactly right

Kimberlyn Leary

And how does that affect people in those communities? And how does it affect, ultimately, trust in government? People rely on the government to deliver a set of services and benefits equitably.

Scott, let me ask another question of you. The Census Bureau says that the Washington Group questions are stronger. They've suggested that they're an international standard for disability measurement. Can you tell us a little more about your perspective on this ,particularly the implications of moving to a scaled measure?

Scott Landes

Yeah, that's a great question, Kim. And there's two parts to it, and I want to address both. Both the idea of Washington Group questions being an international standard and then the scaled measure.

So regarding the international standard, it's been stated repeatedly over the past few months by folks who are really proponents of the Washington Group questions, that the international community adopted the Washington Group questions. And I think this is probably accurate if we're considering the work of some of the United Nation City Groups or other groups. But it's also important to realize that the

UN is not the only international agency that works in this space. So in contrast, the World Health Organization has recommended using very different tools to gather information on disability within countries like the Disability Assessment Schedule, which is commonly known as the WHODAS 2.0, or the Model Disability Survey. Now the Washington Group questions are included in one section of the Model Disability Survey. But I find this interesting, they're not included as a way to measure disability or functional limitation. They're included as a way to understand and how much difficulty a respondent has due to a health problem. The Model Disability Survey includes many other questions that measure functional disability or social supports: accessibility of the built environment, assisted devices, and specific disability statuses. I think, also regarding an international standards, and it's important to note, that there are other measures. There's things like Trani's DSQ- 34 that's been validated in a couple of countries. And there's also research by international researchers stating that there's some issues with the way that the Washington Group does and does not measure disabled people.

But I think beyond all those technicalities, I think the bigger point and the larger question that I have, is— are international standards really what the benchmark for the American Community Survey? So it's my understanding that the benchmark for measuring demographic characteristics (such as age, gender, race, ethnicity, and disability in the US), is the standard set by the Department of Health and Human Services that I mentioned earlier. And these standards state that the ACS- 6 questions are the ones that are supposed to be used to measure disability. I know for other demographic characteristics, such as race and ethnicity, we're very clear and we do a lot of work—and the Census Bureau has done a lot of good work, to make sure that we're using standards based upon regional ethnic minorities' understanding of themselves within the US. Not within the international community. And I think we really need to do the same for disability.

Now to the second part, to this scaled measure. 'Cause like we've talked about, the ACS-6 uses... Excuse me. A dichotomous yes/no measure. The Washington Group uses a four-scaled measure. And they really advertised that use of this scaled measure is a way to advance the measurement of disability. Now the trick is that even though they have these four responses— The responses are “no problem at all,” “some,” “a lot,” or “cannot do at all.” Even though they use the scale, they dichotomize it. When they decide what— who is and is not disabled, they take those four groups, divide them into two similar to the ACS- 6, so you're still with a dichotomy: yes or no.

What's perplexing to me is that they really advertise that you can use multiple cut points, and hang with me on this for a second. So what they state is that you can use the recommended cut point, or you can use a more expansive cut point that includes more people, or you can use a more restricted cut point that includes less people. And I think we have to ask, does that really advance the measurement of disability? So if we think about like content validity, we really want questions and surveys, especially those about demographic characteristics that are readily recognized by survey respondents with a clear understanding of what each category means. For instance, if you're asked about your race/ethnicity, you should not have to guess, “Which category do I pick to report my actual race ethnicity?” You shouldn't be confused about that. But that's what you're getting when you get a scaled response on disability. And so I, as a person with vision disability, if you ask me and there's four responses, I'm gonna have to think. “Well, I know I've got a visual disability. Which one of these aligns with that?” And that is in no way clear in the Washington Group questions. Where it's really clear: ACS questions aren't perfect, the ACS-6, but at least there's a “yes/no” and I know what I'm reporting when I answer the question. So this ability to use multiple cut points is heralded as an advance. In my opinion, the only thing that's being advanced

here is the power of data owners and data users to determine who's disabled enough to be counted as disabled. And to me, that's a dangerous movement that does nothing more than increase the inequity experienced by the disabled community.

Kimberlyn Leary

Thank you, Scott, for the clarity, particularly of this last point of helping us to appreciate what's at stake. And I also like to welcome all of the those who've recently joined us on this broadcast. We've had a couple hundred people who've joined us in the last few minutes. Sue, you—

Sue Popkin

Yes?

Kimberlyn Leary

You've, you know— throughout your work with DEPI, you have focused on disability equity so prominently, and it's been such an enrichment to our equity portfolio at the Urban Institute. But you've also outlined some important impacts on equity, specifically on enforcement of ADA provisions. Can you tell us more about what might be affected? Say, DOJ, HUD fair housing enforcement, as we think about the equity impacts here.

Sue Popkin

Sure. And I think, you know— I mean, I wanna echo what Scott said. The fact that they're determining with these questions who counts as disabled is itself an equity impact. Right? That's why I made a point of saying I don't count under these. But I think my colleagues will address this more the next panel, but from our analysis, we think changing the disability measures could have major impacts. The Department of Justice Civil Rights Division uses the current ACS disability data to enforce the ADA. They use it to evaluate the effect of new regulatory changes or to look at whether new policies or practices are discriminatory. An even less complete estimate means less effective enforcement. That is going to affect a lot of people. We also found that HUD, the Department of Housing and Urban Development, uses ACS data in its fair housing work to inform compliance reviews for public housing agencies across the country to assess the need for accessible units in their communities. And again, an even less complete estimate would mean agencies had less, had inaccurate information to enforce compliance. That was all we could find when— in our review, we know there has to be more. It's just really challenging to pick apart all the different levels here.

Kimberlyn Leary

So we're at a critical moment right now, and I'd like to ask each of you the same question. What's the way forward? What needs to happen next? Maybe Scott, we might start with you.

Scott Landes

Yeah, I mean, I really— I really applaud the Census for halting the proposed change. For recognizing that the process did not go the way that it should have, and they really needed to engage. And to me that is the basis of any way forward is meaningful engagement with the disability community. Not— engagement not meaning that you just tell us what you're going to do or why you think we should do it, but you actually engage disabled people around the US to say, “How do you all see disability? How do you think it should be measured?” I mean, in my mind, and this is my opinion is a disabled researcher, I see— And I'm going— I'm interested to see if Sue agrees or not. I see three ways.

I mean, one would be stasis. Stick with the ACS-6. I don't think that's a great option. Because, like Sue stated, there are many disabled people who are not counted even with the current measures, be it people with health disabilities, people with mental health disabilities, people with intellectual and developmental disabilities, with communication disabilities. We're already missing a lot of people.

I think that's what surprised me when these new— this proposed change rolled out is, I was expecting more equity, and it was like, “Wait! You're gonna take us backwards.” And so, to me, the second option, and I just— I hope and pray this is not the case, is that the Census decides that they still want to go forward with the Washington Group questions. To me, that just entrenches more inequality and inequity for disabled people.

So to me, the third way (and this is the one I really, really hope for) is that the possibly that there's a federal interagency technical working group that is formed around disability standards similar to like what has been done with race/ethnicity or with sexual orientation— sexual and gender orientation. And that this is a federal interagency committee that is tasked with saying, “Are there new questions that need to be developed? Are there better questions? Are there ways that we increase the equity for the disability community in the way that we ask these questions?” And I think going to what Rich hinted at earlier, I mean to me, we're at a point that if the government's not willing to do this, can the philanthropy community step up and fund some projects that really dig into trying to figure out what are the best ways and the most equitable ways to measure disability? I don't know, Sue, what do you think? Are there other options that we could pursue?

Sue Popkin

I agree with you. I think the argument for sticking with what we have at least is we'd have data that we could show change over time, right? That's the basic argument. And it would not make things worse. I think moving forward with the Washington Group Short Set questions fairly clearly makes things worse for all the reasons you outlined. But reducing makes the underestimate worse. It sets an artificial standard for who was disabled. And it doesn't add anything other than one new question about communication. Which we don't have now, right. The communication disabilities. I think that I also applaud the Census Bureau for pausing because I don't think this is easy, and I think we need to take the

time The idea of a federal interagency task force is a great one. I think it needs to include the agencies that actually use the data. So it needs to include HUD, it needs to include DOT, it needs to include the HHS and SSA, and all—Social Security Administration—all the agencies that are using this to make determinations, and not just the CDC and the Census Bureau. And data experts, there are a lot of data experts who have been part of this so far, but we need to bring in a broader group. And then, I think you'll hear from every single one of the panelists today, there needs to be meaningful engagement with the disability community that does not mean presenting the idea to the disabled community at a— to a group of people at a meeting and saying, “This is our justification for making this change,” and not hearing what people have to say, not hearing other ideas, not hearing why people are unhappy with that, and take into consideration. But having a real conversation and a real discussion. The same way they've done with other issues like race/ethnicity, the gender questions. I know that, I know the Census Bureau has a history of doing this, and they can do it here as well.

Kimberly Leary

So thanks to both of you for some very specific perspectives on where we can go from here. As you've been speaking with one another, a very robust set of questions has come in from our audience. And well, we thank you for all of those who have submitted questions through the Q and A, as well as those of you who sent us some questions in advance. I've picked a couple of questions, 'cause we don't have— I wish we had more time. We have about 10-15 min or so for questions. So I'm gonna pick a few questions to bring to both of you, and then we'll pick a few more as we have time. As time allows.

So Andrew Myers has asked this question. “How do we balance the need to generate an accurate and inclusive measure of people who experience disability with the need to identify meaningful disparities and inequities?” He further notes in his question that “disability is a contextual dynamic in status, identity, experience” that can change depending on time, resources, and interactions with inaccessible environments. So how would you respond to Andrew's question about balancing the need for an accurate, inclusive measure of people who experience disability with the need to identify disparities and inequities?

Sue Popkin

So I can start and, Scott, you pick up. That, I think— Hi, Andrew! I think one of the issues you're picking up there is disability as an identity versus these functional disability questions in the ACS-6 and the Washington Group Short Set. One of the things that has changed in the United States in the last 20 years or so is people owning disability as an identity, as a demographic identity. I said, I'm a disabled researcher, so did Scott, tight? I wouldn't have done that 20 years ago. And that is a cultural change, and it's one that's not being recognized in these questions. At Urban Institute, we have our own Well-Being and Basic Needs Survey. We are starting to try test different ideas about how you might capture self-identified disability along with these functional measures. And see what works. If that gets us more inclusive space? Scott, you have others?

Scott Landes

Yeah, and thanks for the question, Andrew. I've got a couple of thoughts. And to me, that's one of the issues, because the I mean— the Health and Human Services standards state what Sue just was talking about. That disability is to be measured as a demographic characteristic similar to age, sex, race, ethnicity. Which is really different than measuring what I've heard talked about as functional disability, because just the functional aspect of that. I think because the reality is not every disabled person experiences functional limitations or has different levels similar to what Andrew was, I think, was indicating. I mean, you have some people that because of the accessibility of their built environment or their social supports, they have— their limitations are mitigated, or maybe even eliminated. They're still disabled. I was actually reading through the comments posted to the Federal Register about this change, and people saying things like you know. "Well, I mean, I'm an amputee, but once I put my leg on, I don't have limitations. Am I no longer disabled?" Because, according to these Washington Group questions, the person would not be, or maybe even sometimes in the ACS-6 questions.

I mean, I personally think that the way to do it is similar to what the World Health Organization has done. Is where we ask people questions about their disability status as a demographic characteristic. "Are you disabled? Are you impaired?" And maybe the type of disability. And then you follow that up with a question about "Okay, how many or how— what type of limitations do you experience because of your disability?" And that would allow us to get both pieces of information. A very— a more robust count of how many people are disabled, but then also get to... Okay, among those who are disabled, what are the limitations that folks are experiencing?

Kimberlyn Leary

Thank you. So Deborah Stein has asked a question about Social Security and how Social Security uses this data. She notes that for individual disability decisions, they use a complex— in her words, "Five step assessment process that gets highly specific about types of disabilities. But maybe they use it for some kinds of planning purposes?" I think that's Deborah's question.

Sue Popkin

I think we don't know. I— we weren't able to determine exactly how they use it. We know that they do, we know that they have their own definitions of disability, as Deborah said. I know, for example, since I keep using myself as a reference point here, but Social Security Administration counts my disease for criteria for disability but you know, the ACS-6 doesn't count chronic illness unless it is severely impairing people. Their ability to walk or something.

Kimberlyn Leary

Scott, do you have a response?

Scott Landes

I'm not gonna directly address Social Security or any other agency and how they do or don't use it. I know others do. I mean, I know that Veterans Affairs administration has used these questions to give estimates of how many veterans in rural areas are disabled. Although they also have their own measurements of service-connected disability on a 0 to 100 percent rating. And so, I think we see instances where even federal agencies that have their own disability measures will rely on this data at times because it gives them county-level estimates that they don't always have within their own system. But I think it goes to Sue's earlier point, the engagement that needs to occur going forward has got to include all of these federal agencies. They all are the table saying, "Here's how we have used it, how we could use it, and here's how we also think it should go forward," in tandem with engaging the disability community.

Kimberlyn Leary

That's what I'm hearing about engagement with communities and engagement across the federal government as important here.

So Jonathan Auerbach asked a question. It's straightforward one, and it's this: "Why not have respondents simply self-identify?"

Scott Landes

Yeah, that's a great question, and Jean Hall at Kansas University has been doing some research on this where, Jean's got a survey that that she and her group put out for disabled people. And what they've reported in their research, is that you have some people who will self-identify as disabled but not report any functional limitations. Whereas you have other people that will report high levels of functional limitations and even conditions that we identify as disability, but not self-identified as disabled. We see this a lot among military veterans who are disabled, but don't identify as that status. I think some of it could be generational, some of it could be by community, and some of it could just be who the individual person is. And I think what Jean has proposed, and I think is right, is that there are different ways we need to ask this question. Whether it be about identity or impairment or limitation. And that's why we've got to have better discussion going forward is— representatives of folks within the disability community. Some who say, "This is an identity," and some who say, "No, it's not, it's just an impairment." And some who say, "Well, no, it's just a limitation." And having all these people at the table to say, "How can we bring these together in a way that accurately counts as population?"

Kimberlyn Leary

Sue, anything you'd like to add?

Sue Popkin

No, I think Scott's right. I would just add that we're also at Urban Institute testing those kinds of questions with the survey that I mentioned. We know, some of our research— we've done some research on long COVID using that platform, the Well-Being and Basic Needs Survey. And we found that even people who said they were severely affected by long COVID, not all of them identified as having a functional impairment with the ACS-6 questions, too. So we see the same kinds of contradictions of people not seeing themselves in those particular six questions, like that there might be something else that's impairing them (like fatigue) or isn't picked up?

Kimberlyn Leary

Allison Taylor asks, "Are there proposals out there for questions that would better count those of us with chronic illnesses?"

Sue Popkin

I think that's what Scott and I are talking about. There are, we are work— there are groups who are working on some questions. I think if there is this kind of engagement with the disability research community as well, that the Census Bureau might have the opportunity to help support developing some questions. I know the space on the ACS-6 is very limited, so we're going to have to be sure that it's the right one. But I think taking the time to do some of that testing and see what might be a good, worthy addition is worth it.

Kimberlyn Leary

So there's some proposals that can be developed out of the various kinds engagements that you're talking about, but it sounds like not something that is— a third alternative that would be off the shelf.

Sue Popkin

Not off the shelf, no.

Kimberlyn Leary

Right, got it.

Sue Popkin

I think it's the kind of cultural change I was alluding to before, too, or Scott was too. Generational shift. And there used to be a lot of stigma in identifying as disabled, and people would be very reluctant to ask someone if they were disabled, right? They would— and they were very careful not to say someone's a

disabled person, and eventually we got to “a person with a disability.” But now I'd say that the standard is, people are using “person with a disability/disabled person” interchangeably. And, you know, it's the culture is changing. And I think long COVID may have something to do with that, too. There's so many new people with this new disability.

Kimberlyn Leary

True.

Scott Landes

And I think there are, I mean— I know of at least two or three groups. Urban and Kansas and some groups that I'm working with that are trying to look at what are better ways to ask these questions. And so again, I'll put this plug in: it would be a great place for the philanthropy community to step up and say, “Look, how do we have a centralized, you know, effort here?” Because a lot of the reasons we don't is because of funding. You know, these are researchers that have just decided to do this on their own or with small grants within their institutions. And can we bring this knowledge base together as part of this process? To say, “Yeah, there, there's some great ideas out there. We just need to make sure that they're all at the table.”

Kimberlyn Leary

Krista Scott asks a question that—a set of questions, really—that, I think are quite important. Fundamentally, she asked, “Who wins by reducing the official count of the number of disabled people in the United States?” And the next part of her question is this: “What else can be gained by creating a more inclusive measure practically? How would this shift?”—I guess that's a third question—“How would this shift our resource allocations within the government, and also for people's beliefs about disability in the US?” So just to recap first question is, “Who wins by reducing the official count of the number of disabled people in the US?” Question two: “What else can be gained by creating a more inclusive measure practically? And how would the shift of our resources affect allocations, and also people's beliefs about disability in the US?”

Sue Popkin

You wanna go first, Scott, or you want me to try?

Scott Landes

Well, that “Who wins?” question is one that I admit through this process I've struggled with, because if— someone who's been disabled for 53 years... I mean, I've seen firsthand. I'm sure Sue has, and other's, “Who wins when disabled people are excluded or not counted?” It's non disabled people, and I've also

seen “Who wins?” in the government, typically, when disabled people are undercounted. It's budgets and saving money. It's things like that. I don't want to believe that's what's going on here. I want to believe that's not the motivation to purposefully undercount us in order to save money. I worry, though. I mean, there's just enough of a history in this country that I just— I have those concerns. I don't know if we can answer that, I don't— Sue, what do you think? Who wins?

Sue Popkin

Yeah, I'm with you, I don't think it was the motivation at all. I do think it could, as I said when I was talking about the funding consequences, I think it is the potential consequence.

Scott Landes

Yeah, I do too.

Sue Popkin

If there's less money available, it just— there's gonna be less money to support disabled veterans or disabled children, or any, you know, people with long COVID. All those. There just will be less funding. It is about budgets at the end of the day.

Scott Landes

And, Kim, I think it goes to earlier. To me, it's a lose/lose. I mean to me the disabled community would lose because we would be undercounted and more marginalized. But to me the government would lose because they would lose trust. And I think they already did to some degree in not engaging us upfront, but I think they would lose even more trust if they proceeded to undercount what we know is close to a quarter of the US population. I wish I could tell you who wins, though. I don't know.

Kimberlyn Leary

So, we have almost 600 people on today's call. Let me conclude by asking you, Sue, and you, Scott. Is there a question you'd like to ask of listeners? They won't be able to reply directly, but a question they might be able to take forward in the conversations they'll have back home later today or tomorrow. Do either of you have a question you'd like our viewers to think about in the days and weeks ahead?

Scott Landes

I do, and especially, I mean— It'd be for everybody, but especially for those within the disability community is: “What would you like these questions to include?” I mean, “What do you think they

miss?" And what... I mean to me, this is what the Census Bureau should have been doing. But the question I would put on people's mind is, "What do you think they should look like?" I mean, "How should these questions be asked in order to count you individually with your experience and with your life?" I mean, I think if— I mean to me, that'd be a great thing if we could have a database of what disabled people actually think they should be asked. Like I said, we've done this for race/ethnicity. Pew Research did a great survey asking people, racial/ethnic minorities, "How do you think we should ask you about your race/ethnicity?" And so, I think that's the question we should be asking the disabled communities. "How can we ask questions that would best identify you as disabled?"

Kimberlyn Leary

Thank you, Scott.

Sue Popkin

I couldn't say it any better.

Kimberlyn Leary

Okay, well, thank you, Sue. And really, thanks to both of you for joining in conversation today. And I also want to express my appreciation to all of those who participated in the conversation by formulating and teeing up questions. On behalf of the Urban Institute, thank you, Sue and Scott, for participating in this first panel.

Scott Landes

Thank you, Kim.

Sue Popkin

Thank you.

Kimberlyn Leary

And now, it's my great pleasure to introduce the moderator of our next panel. That moderator is my colleague and friend, Celina Barrios-Millner, who is the co-vice president of Urban's Office of Race and Equity Research. Over to you, Celina.

Celina Barrios-Millner

Thank you so much, Kim, and thank you for that great conversation. Hello, everyone. I'm Celina Barrios-Millner. I'm a Latina woman, mid-forties and I have long wavy hair, and I'm wearing a red shirt and a black blazer today. I'd like to invite my panelists to join us, please. While they're coming on camera, I'm gonna give them a chance to introduce themselves, but I wanted to share with you all an experience I had with data and representation as a young child. I am an immigrant from Venezuela and I moved to Cincinnati, Ohio, where every form I had to fill out from second grade on had had me choose a race and the options were "Black," "white," and "other." And as a Latina immigrant, I figured the only place I fit in was as "other," and every time I took a standardized test, every time I registered for sports, I had to be confronted with that big, ugly word "other" and that really impacted me as a child. And later, I realized it actually also prevented me from participating in opportunities that would have been really beneficial, like finding a peer group or being nominated for the Hispanic National Honor Society, because my school only tracked me as "other." There were many national opportunities, regional opportunities, local opportunities that I never found out about. So I'm really glad we're having this conversation today, and I'm really happy to be joined by such an esteemed panel. So I'm gonna ask you each to please introduce yourself. So we'll start with Meeta Anand, the senior director of census and data equity at the Leadership Conference on Civil and Human Rights.

Meeta Anand

Thank you so much, Celina. And thank you to the Urban Institute and the Ford Foundation for today and for the opportunity to speak. I am a middle aged, mixed-race woman—South Asian, Black and white—with tan colored skin. Long, dark brown, wavy hair with gray streak, and a brown bookcase in my background, and I'm wearing a pink turtleneck, no sleeves. So, thank you! I am the senior director of census and data equity at the Leadership Conference on Civil Rights—Civil and Human Rights—and the Leadership Conference Education Fund. And my work and the work of the team that I am honored to lead, we seek to ensure inclusive data sets at federal and state levels, so that we are making informed policy decisions and truly capturing the lived experiences of all communities. And I'm looking forward to the discussion today.

Celina Barrios-Millner

Thank you, Meeta. Dom, welcome. Please introduce yourself, and Dom Kelly is the co-founder, president, and CEO of New Disabled South.

Dom Kelly

Thank you, Celina, and thank you, Urban Institute. My name is Dom Kelly, as Celina said, I'm the co-founder, president, CEO of New Disabled South. We are the first and only regional disability organization in the country, we work in 14 Southern states. And I am a white man with brown curly hair, wearing glasses, an orange sweater with some flowers behind me, sitting in front of a window. Currently in New York, but based in Atlanta, Georgia. And I'm really, really thrilled for this conversation.

Celina Barrios-Millner

Welcome, Dom! And Marlene Sallo, please introduce yourself.

Marlene Sallo

Hi, everyone, and thank you so much to the Urban Institute for inviting me to speak here today and for my colleagues here on the panel. Happy to be here. My name is Marlene Sallo, and I am the executive director of the National Disability Rights Network. I am a disabled Latina. I'm wearing a black blazer with a purple turtleneck, shoulder-length brown and gray hair with black rimmed glasses.

Celina Barrios-Millner

Welcome, Marlene. Thank you so much for joining us today. I want to get us started by talking about: What does it mean to the— I'm sorry. What does it mean that the disability community wasn't consulted? And why did this happen? We can start with you, Dom.

Dom Kelly

Absolutely. So I think the last conversation was really enlightening, and can echo a little bit of what they said there. But, you know, I think historically, disabled people have not been— had seats at the table. Whether that's when we refer to the Census, whether that's in government, that's really in most situations. Oftentimes the disability community is spoken for, and that has kind of been the default in our society in our culture broadly in our country and in our world. So I would say, while I don't know if it was necessarily intentional to not include the disability community in those decisions, I think oftentimes it's intent versus impact. And in this case, I would guess, is that's probably the case. That this is a situation where it didn't seem maybe necessary to have our community at the table.

And that means a broad, diverse mix of people. The disability community, as we heard in the last conversation, the disability community does not look one way. Disability is a wide spectrum. And yeah, I am— I have cerebral palsy. It's a physical disability, it is visible, and there are many, many people with invisible, non-apparent disabilities, who are not included often in conversations about disability. People with long COVID who are newly disabled, who are not included in conversations about disability. So sometimes, when you have one type of disabled person, it leaves out everybody else. That's why we can't have a, you know, one person represent the disability community. We need to have a broad, diverse group of people. And I think that may have been a part of it. This idea of “We can speak for the disability community” and may maybe not enough of the disability community at the table.

Celina Barrios-Millner

Thank you so much for that. Marlene, what do you think? Why did this happen?

Marlene Sallo

I have no idea why it happened, right? It's kind of hard to identify what the intention might have been, or whether it was intentional to begin with. But the greatest loss is for our community, because we were not consulted, we were not given the opportunity to speak our truth. And to speak to how our disability presents itself, and how the undercounting may ultimately have a very negative effect on our ability to access services in the level that we need it. In our ability to ensure that we are not being discriminated against, both in housing and from an employment perspective, because the funding is lacking due to an undercount, which means that enforcement measures may not be as robust as they should be, and must be. So, it's a loss, in my opinion, that the fact that we were not at the table can ultimately result in our voices being cancelled for lack of being present and at the table.

Celina Barrios-Millner

Thank you, Marlene. Meeta, what does it mean that so many people aren't counted? Including people here with us today.

Meeta Anand

Thank you so much for the question. So I'd like to offer two frameworks by which to look at this. One is a data equity framework, which is really what all of us have been talking about here today. And by that, I mean, communities need to be involved in determining what data are collected from them. So if you think about it, that's just a broader extension, is that— of the principle we heard earlier. The principle of participation from the disability community. Nothing about us without us. Think of that as applying to all communities with respect to data collection. And what that means is that data should be used in service of communities, and not just extracted from communities. And what it further means is, if we are not counting people, then their stories are not being told. It is someone else telling the story of who we are, and these are lived experiences—as Marlene said, not captured. But it is also a question of like, what story do we want to tell of ourselves as a nation and who are we empowering to tell that story? So I just wanted to contextualize that. Like everything we're talking about is a violation of that principle of data equity. And we want to center things in data equity.

Now from a civil rights framework, you know, that I think hopefully, a lot of people here know this. But when you're talking about the Census and the American Community Survey—which is what used to be the long form of the Census for those old enough to remember but is now those sort of evergreen Census that gives us more detailed information—What it means is, you are creating a situation where communities are losing out on federal funding and you were creating a situation where people are losing representation. Now normally, when we talk about representation and Census, people are talking at the first order, which is just— they think of apportionment, redistricting. Like how many, you know— Or thinking of it like the recent cases in Alabama, where, you know, one more district representing the Black community had to be created. And that's not how it works with respect to persons with disabilities, but it works differently. If they are not counted in the Census—we're talking about the ACS, but I'm gonna draw the link in a second—if they're not counted in the Census, then their numbers are not showing up to be able to be represented when we are drawing electoral districts. Now, what is the link? Celina, you

made the link if people do not think that these surveys are for them, they are not going to fill it out. So they're— either because of mistrust, which happens due to lack of community consultation or because the types of questions. They don't think it applies to them. Celina, like I'm right there with you. I never knew what to put on forms, right? So, “Is this form for me?” So you create that situation. And we know for a fact—NDRN has beautiful research on this—persons with disabilities are under counted on the Census. And this leads to a situation where we are depriving communities of their voice and of needed resources.

Celina Barrios-Millner

Thank you so much for really so vividly pointing out, one, that the intersectionality, right, of us as individuals and people and the importance of both the grounding and just data equity and having inclusive community processes. And also the civil rights framework. That's so important. I mean, I feel like the Census is, as imperfect a tool as it is, it's the first— When I served as a chief equity officer, like we were pulling data from the ACS to figure out if our programs are getting to the people that needed to get them, right? Like as a city official in Boston, right? We use these tools every day. And it's really significant when they're not as representative as they could be. Marlene, what are some examples that that you can think of the results of undercounting from your point of view?

Marlene Sallo

Yes, I alluded to a little while ago, and that Sue actually brought up. It's, you know, we have these community development grants that use the data, right? To put funding into the communities to allow for the development of accessible housing. So there's a loss right there. If we don't— if we have an undercount, then how are we going to be able to identify which workers, you know, identify as having a disability and then enforce or antidiscrimination laws to ensure that no one is being discriminated against based on disability? We're also looking at emergency planning and preparedness. And so if the fund— if the— if we're under counted, and we are unable to identify accurately where individuals with disabilities reside within a state or a county and there is a need for emergency evacuation or response, how are we going to be able to accurately and comprehensively put resources into that community if the count is off? And so once again, by way of undercounting us, you are making us invisible. And as a result of making us invisible, we are not privy to the supports that we need, the accommodations that we deserve and need, and to the funding that allows us to live and age in our community. And historically, we've been put in institutions. We will not go back to that. And so we need the money in the community to ensure that we have the resources that we need.

Celina Barrios-Millner

Thank you, Marlene. Dom, how have you seen this underrepresentation and undercounting show up in your work, especially in the South? How do you see this in your day to day?

Dom Kelly

Yeah, so we in the South have seven out of the 10 states in this country that have not yet expanded Medicaid. And as a result of undercounting in the 2020 Census, I think five out of six undercounted states that had more than one percent of the population that were undercounted were in the South. Those Southern states lost out on more than \$400 million, federal dollars, for Medicaid. That is money that goes to people who need access to affordable healthcare. These are states in our region who— where people do not have access to a med— a provider. In Georgia alone, we have nine counties without a single provider. These are folks who don't have the transportation, the access to transportation to be able to get to a doctor or a hospital and/or the coverage to get it. And we know that 17 percent of the coverage gap in non-Medicaid expansion states are people with disabilities. So often we hear that Medicaid is for the disabled community, which it is, and there are significant number of people who are not being covered when our states don't expand Medicaid. And so that \$400+ million dollars that Southern states lost out on because of undercounts just exacerbate the problem. Just exacerbate the issue of our community having access to healthcare.

And it— you know, it's not just the disability community. It is the disability community, but also it is— We have a third of disabled people in this country in the South, and the majority of disabled people in the South are Black and Brown. And this this is a disability justice issue as much as it is a racial justice issue. And in the question in the last conversation, “Who wins?” The first thing that came to my mind was, white people win. Always. White people always win. And that is the case, and we can't talk about equity in account— we can't talk about equity and funding and programs when we talk about disability without talking about the fact that the people who lose out the most in the disability community are Black and Brown disabled folks, Native disabled folks, queer disabled folks. The most marginalized people lose out the most, and that is what we're seeing here in the South. So it is not just Medicaid. It is a variety of issues, but that is the one, I think, with the most tangible. And like with the numbers, like \$400 million of Medicaid funding is a lot of money for our region to lose out on because of 1.3 percent undercount. I mean, that's alarming.

Celina Barrios-Millner

Thank you so much for really painting that picture, and pointing out, like the— how all of these inequities overlap and multiply, and how, by place, people are facing so many injustices at once. And I know that, when we look at almost any outcome, you're always gonna find people of color not having the same outcomes as white people. But what people don't talk about, and what they don't document, is that a lot of those people of color also have disabilities. Who's in the justice system, right? Educational outcomes. Like literally any issue. Health outcomes. Like who was most affected by COVID, right? Like it's all of these. We know that there's so much intersectionality that isn't captured. And that's important, not just in understanding impacts, but in actually designing interventions and programs that can help improve those outcomes. So we have to really understand the— what needs people have.

You know, we've talked a lot about the impacts of undercounting, how we've already seen those impacts, how a lot of people have experienced them here firsthand. But we've also talked about, both in the first panel, and we started to touch on that this was this is a problem of the actual questions that are being used, but also the community process that wasn't there. For actually coming up— not just with

these questions, but in more broadly how the disability community is counted. And so, I was wondering if we could take some time, and I know, Meeta, you talked about the data equity framework and how important it is to have people be a part of— have the community be a part of these conversations. So what, in your opinion, would meaningful engagement with the disability community look like on this issue? But it can be more broad than just the Census.

Meeta Anand

Sure, absolutely. I mean, I will say I do think it needs to be more broad than the Census. Because if you harken back to some of what we heard in the first panel, I don't know if people caught the underlying theme that sometimes we don't know if the right data are being used or if the data are there. Or like, how is it all being untangled? And I think a lot of us, as we've delved further and further into this, there's this recognition that we need better, more meaningful, more actionable data on persons with disabilities and how it impacts their lives and how it intersects with federal programs.

So with that as a context, right? What does engagement mean? I don't want to be the one to speak. So you did offer more broadly. So I would say, one, I think it is incumbent on someone, some agency in the federal government, to help us understand exactly how these data are used for fed funding? How these data are used for enforcement? Where they are used? What are the variables that go into it? So you know, it shouldn't be up to Sue spelunking for weeks on end to try to figure out, “How is this actually done?” We should be able to be given that information. The Census Bureau has indicated that there will be a further convening. Disability groups should be consulted with respect to that convening. We heard multiple questions like, “Well, is there a question on the shelf that we can use instead of what we have and what was proposed”, and the answer was no. So you know, obviously, research needs to be done. But then the Census Bureau and other agencies should be connecting with disability service organizations, disability justice advocates, to be like, “What are the things we should be researching?” And not just consulting with the inner circle that already exists as to what those questions should be.

Celina Barrios-Millner

Thank you so much for that, Marlene, what would meaningful engagement look like for you? And what do we have the opportunity to do, now we know that there's a pause, right? So if we're advising, what would meaningful engagement look like?

Marlene Sallo

I mean, Meeta really hit the nail on the head there with how you can bring disability justice organizations to the table really reach out, like purposefully. Actively reach out to disability rights organizations, disability justice organizations, not just in the DMV area. The, you know, DC, Maryland, and Virginia area. But across the United States. Don't reach out to a point person with the hope that that point person can then connect you or invite others to the table. Be that force. Be forward facing and be proactive about it. Truly, I know that—I'm pretty sure—that the comments have been read. But really pull out from the comments that were, the public comments that were submitted, to truly inform your next steps. Like,

digest it, break it down. Let that guide you as to next steps, and how to approach these questions. And even with an interagency committee of any sort, please make sure that those that are on that interagency committee are individuals with lived experience. Not individuals within the federal government that may make semi-educated assumptions about what should or should not apply to the disability community. Make sure. We are everywhere, okay? Individuals with disabilities belong in every demographic. We are working in every office across the US of A. And I am sure that, whether they have self-identified or not, there are enough individuals in the federal government within the different agencies that can be at the table with any interagency discussion.

Celina Barrios-Millner

Excellent point, thank you. Dom, what would you add? What would meaningful engagement look like moving forward?

Dom Kelly

Yeah, I think, what Marlene and Meeta both said is spot on. You know, I think I would add that there are... We need to think about what Get out the Count campaigns look like in the next, you know, few years. And NDRN has a great resource, actually, on how to make a Get out the Count campaign really accessible. I would say that there are lots of grassroots groups, like ours, who have the background and understanding of how to organize and base-build and message. And we would be great partners in making sure that we can get our communities engaged with Census between now and the next Census count. And we can make sure that groups that are doing Get out the Count campaigns are building accessible campaigns. Events, messaging, etc. That we are a part of all of that. I wanna make sure that when— since people are kind of— Census are talking to our community, that they're going to people in congregate settings. I know that there are specific folks who do that, but like I would guess—and I don't know the data, and I'm sure it's really hard to get this data—but I don't know. I would guess that a lot of people in a community who are undercounted are people who are living in congregate settings. People who are in group homes and nursing homes, in institutional settings. So reaching those folks. That's a lot of the work we are doing around Get out the Vote is around reaching those folks in in those “hard to reach places.” Folks in our community without access to internet. Deaf folks who, you know, may not be able to, you know— may need to use a specific technology. Like, there's all sorts of different ways to make sure that these campaigns are accessible. And I think philanthropy can play a role in making sure that grassroots groups can be out there making sure our communities are engaged with the Census. And then, you know, making sure our groups are a part of and partnering with Census counters. And all the work that happens between now and 2030. I think we have to be a part of that as well.

Meeta Anand

If I can just jump in briefly to plus one everything Dom said, but also, remember the American Community Survey is all the time. So we also need to make sure we are educating all communities, including the disability community, on the importance of the American Community Survey, on filling it

out, and making sure that that survey is accessible to people so that we are not having underestimates (the official term for undercounts for the ACS) in those surveys.

Celina Barrios-Millner

Absolutely, that's a great point. We hit the time to act is always now. Especially when we're talking about representation. Well, I wanna take a few minutes while we have this amazing panel of experts to bring in some additional questions from the audience.

So the first question is for Marlene, but everyone else can also jump in. It comes from Madeline Miller of the University of New Mexico. "My focus in my training is on supporting all older adults like me, and I'm interested in impact of such cuts on older workers and support protections for disabilities and employment. Also, as the US population is aging, how disability might help?" So, Marlene, I don't know if you can start us on that question on the impact specifically on older workers.

Marlene Sallo

So first thing that comes to mind is a thought of like equitable workforce, right? And in order for it to be an equitable workforce, it has to be inclusive. It has to be supportive, especially for older workers, and so, as I indicated earlier, when you have an accurate account, then you are really informing whatever services are available to ensure that there is accessibility and accommodations that are provided. But you're also ensuring that that equitable workforce is protected through the enforcement piece. And so, it's important to have those numbers because then—as an employer, as a county, as a state—I can address disability-related challenges that may present themselves, right? And so that's why, for me, it's so important to advocate for accurate Census data. Because that's that is the key to equity, right? We always talk about equality, but it's also equitable and just. And so it's that accurate count that's gonna take us to that level. And so, knowing how— what the needs of our communities as we age. Knowing that we want to age in place--we have the right to age in place. And being able to facilitate remaining employed as long as you want to be employed with the necessary accommodations goes hand in hand with an accurate count as I view it.

Celina Barrios-Millner

Thank you so much for that. We've been focused a lot, obviously, on the Census and federal agencies so far in this conversation. But Cheri Stoffel is joining us from the Wisconsin Department of Health Services and wants to know what can state departments do to help spread the need for inclusive disability measures? How does an inclusive methodology for measuring disability rates change the narrative for public health? I don't know if you wanna start, Meeta, but whoever wants to take that one.

Meeta Anand

I'll start, but I have a feeling Dom is going to bring us home really well on this one. So I mean, I think everything we've said actually just applies equally well at the state-level. So, you know, the numbers bandied about Census data is that they direct \$2.8 trillion worth of federal funds guiding federal funding. But then that happens at the state level too. There are block grants given to the states that the states then direct the funds. Or the state have their own money, and they then direct the funds. So you— there needs to be an examination just like I said, that sort of forensic analysis at the federal government level can occur at the state government level. Like how are the funds being directed? Which measures are being used? Are these inclusive measures? Are they the right measures? And who are you consulting with to determine what these measures are? Now, obviously you get to other issues. I work a lot on race and ethnicity data disaggregation as well, where you want to know how systems talk to each other and if you can have comparable data. But you do need to start with consulting with the community and understanding what the data are used for. That's true no matter what level of government you're at.

Dom Kelly

Yeah, absolutely. I mean, and I think... Can you repeat the second question? 'Cause I have an answer, I wanna make sure that it is like answering the question.

Celina Barrios-Millner

Absolutely. "How does an inclusive methodology for measuring disability rates change the narrative for public health?"

Dom Kelly

Oh, yeah, I mean it is... First of all, the ACS is, as we've talked about, is flawed already before proposed changes. I think this survey is used, you know, not just in the Census, as Meeta already talked about. And it is— There is one way of seeing disability. It is seen often from a medical model of, you know, "What is the range of functionality that you have?" But that is such a limiting question. I, my— You know, there are days where I am more disabled than other days. I'm in New York in freezing cold weather, my muscles are way tighter than they are on a typical day when I am in my home in Atlanta, Georgia. So there are— a day like today, if someone caught me with the ACS, I would probably answer a little bit differently than I might when I'm back home next week. And that that's just one example. I think if we can have a more inclusive methodology that would help broadly in public health and government. Help us better understand that disability is a wide spectrum of experience. Disability— The ADA covers you if you are an addict in recovery, if you have endometriosis. I mean, there's a long list of things that are considered a disability that the ACS does not take into consideration. So if we can have them— if the methodology can be more inclusive, the questioning can be more inclusive, we can have a better understanding of the needs of the disability community broadly, and how funding and programs can better help our community within government and outside.

Celina Barrios-Millner

Thank you so much. Oh, go ahead, Marlene.

Marlene Sallo

May I add? Because I am a zealous child advocate, and we also need to remember that we have a, you know, accurate counting— We're able to provide health care to children with disabilities, right? And provide support for their families. And it also really plays a role in CHIP, right? The Children's Health Insurance Program. Medicaid, right? And so once again, this is an example, and even though we don't know how it's actually used, we know that it will inform how this health— these health services are made available. So it's important to ensure that it's accurate.

Celina Barrios-Millner

Absolutely, absolutely. And I'll just add, Marlene, that you know— You know, Cheri, I know you probably know this from your work in Wisconsin, but that health commissions and health agencies in particular are always collecting their own data and giving a much more granular picture of the people that they're serving, so that's another opportunity to supplement. Like, I feel like anyone in a government position, we're always in the position to collect data and the way that we do that responsibly to ensure we're getting as much— You know, without burdening people with filling out too many forms, but getting as much information to better serve them, I think it's always a good opportunity. And how you're designing your intake and other conversations with your constituents.

Wanted to move on to, you know, I think, a really great question. You know, we're all— everyone here is very savvy in this space, and I know that we have a lot of great engaged folks that have joined us that are also really active in the space or wanna be more active. But we have Alison Stanton that asked, “Why wasn't the notice of this change in the Federal Register caught faster?” And so I think that's always a question when you're when you're thinking about how to improve the community process. Like, how did this happen? We have such great organizations. We have, you know, a government that that tries to be responsive. So why wasn't this caught faster? And just to add a little more to that, “People found out only days before comments were due. It's horrifying thinking about what would have happened if it hadn't got caught at all. Is anyone working on improving the disability community activist infrastructure?”

Meeta Anand

I'm just going to address part of that. I understand where the questions coming from, but I would like to flip it a bit, if I may. Which is, “Why was the outreach not done to the communities to make them aware that this change was coming?” Why— I know that OMB and OIRA, which is the Office of Information and Regulatory Affairs, have been doing a lot of work on how can they improve public engagement, and they have arguably, already in 2024, started putting in some changes. So I think it's, “How can we make the process at the federal government level better to alert people as to when there are items that are of

interest to them that they might want to engage in?” And make sure it's in language that is understandable with effects that are understandable and in an accessible format. So you know, I think there's just a little bit there, too, about like... There's an expectation on the federal government's part that we're all just sitting here every day like scouring through Federal Register Notices. And some of us might have the luxury and bandwidth to do that, but that's just not always possible. And even when you figure it out, it takes a while to gin up the answers and the activity. Especially if you didn't know it was coming beforehand.

Dom Kelly

And I think there was a— This is Dom. I think there was a question about, how do we improve the disability activist infrastructure? You know, that is the base-building challenge of, you know, this year, next year, last year of like of all time. It's like, how do we get people more engaged and involved? And it's hard. I mean, like, I would consider the— what we do as like. I would consider us a base-building organization. We are really trying to get our community in the South mobilized around all of these issues that impact our community. And it's hard because people can't pay their rent. They can't put food on the table. They are having to worry about, you know, being forced to live in a nursing home if they can't get waiver services. Like, they're being incarcerated. Like, these are the list of— long list of issues that our community faces, and it's hard to ask them to do something when they're just trying to survive. And so, I think for those of us who have the resources and the bandwidth, we have to try to fill some of those gaps. We have to try to work on some mutual aid efforts and help our people on the ground. As well as at a policy level. Like that's, you know, we're doing policy work, but we're also— We also need to be in our communities. We also need to be helping people door-to-door. We have to be going to where they are. Getting them the resources they need to live day-to-day. I think once we do that, we can bring people into the fold and get them engaged more. Get them, you know, down at their state capital or their, you know, city hall, or wherever it is. But first people's needs have got to be met, and unfortunately, disability orgs are just very under-resourced. And we don't have the bandwidth and staff capacity and finances to be able to, you know, do that kind of wide-scale community outreach. So the more that we have, the more of that resourcing we can do to others who need it most, and then we can bring them in.

Marlene Sallo

Yes, plus one to everything that's been said. We are under-resourced. You know, NDRN itself. We work with all 57 states and US territories, and we have full— like our full staff is 39 and not everyone is providing direct outreach to the communities at-large. So remain apprised. Look at social media. We put, you know, all of us pushed it out through social media. We used an alert system through our email, and over 7,000 individuals submitted comments using that alert system. And we will continue to use that in the future. But as Meeta said, we're it's not like we have the bandwidth to be on there all— You know, it's— We're all doing the best we can—and we're all joining forces, especially after going through this— and really remaining in contact to address anything that arises. So thank you for that question.

Celina Barrios-Millner

Well, thank you all so much. Thank you, Marlene, Dom, and Meeta, for everything you do every day for the community, for ensuring representation. And I invite all of the participants here to check out their organizations. We'll be sending you some contact information afterwards. So thank you all for your time today. Please, for the participants, if you can. Please fill out the survey. And I really wanna thank Amber and Rhonda, our amazing interpreters. I know we went a little bit over time, thank you for sticking with us. And if you wanna get in touch, we heard some great ideas in the chat, you can reach us DEPI@urban.org. It's been put in the chat but DEPI@urban.org. We really wanna stay in touch so we can continue to work on this together. Thank you, everyone, for being with us today.