

Disability Convening

Director's remarks as prepared for delivery

September 30, 2024

- Good morning, everyone. I'm Robert Santos, director of the U.S. Census Bureau.
- I'm a Latino man wearing [insert visual description], and my pronouns are he/him.
- It's an honor to be here with you today.
- I'm so grateful to all attendees, both in-person and virtual for this important conversation.
- As you can imagine, planning an event like this—with so many attendees from so many different organizations—it's a significant undertaking.
- So, please indulge me while I give a huge thank you to both the Census Bureau planning team and our co-sponsor planning team for putting this meeting together.
- And a special thank you to Meeta for her leadership in this effort.
- OK, if you've been around anyone from the Census Bureau at a public event, I'm sure you've heard us say the following:
 - "At the Census Bureau, we're committed to producing statistical data that reflects an accurate portrait of our nation."
- Naturally, I love this message, especially as context to whatever issue we happen to be addressing at the time.
- But what does it really mean?
- I'm assuming we all know what *statistical data* means, but we can get into that later if you want.
- Instead, I'd like to focus my comments on the last few words, which are:
 - "reflects an accurate portrait of our nation"
- So, what makes a portrait of our nation *accurate*?
- Well, if you're a statistician like me, when we talk about accuracy we naturally navigate to concepts like coverage error, measurement error, sampling error and so forth.
- These technical terms characterize the difference between the thing you're trying to measure and the true value.
- But interestingly, there's an underlying assumption that we almost never talk about.
- It's an issue that's before us today at this wonderful convening.
- We assume that the item we're measuring is in fact what we're intending to measure.
- And we're assuming that even if it is what we're intending to measure, that it means exactly what we think it means.
- We need to ask ourselves: Are the various ways we're capturing the concept, the condition of disability, actually capturing the concept in the way we intend?
- And does the resulting data mean what we think they mean?
- My guess is that if there are a hundred people in this room, I'll bet there are a hundred different answers to these questions.
- And just so you know, differences of intention and meaning have actually occurred in a previous decennial census.

- So, here's a quick example because it has relevance to today's convening:
 - In the 1970 census, we fielded a question on our long form—what's now the ACS.
 - It was on Hispanic identity, and marked the first time it was asked in this way.
 - Unfortunately, it was a late arrival to the questionnaire, and didn't receive much testing.
 - The simple question was: "Is this person's origin or descent: Mexican, Puerto Rican, Cuban, Central or South American, Other Spanish" and there was also "No, none of these."
 - It was deployed, the data were gathered, and tabulated.
 - But the results didn't make sense.
 - It appeared that Hispanics were everywhere, like today!
 - Hispanics popped up in Mississippi, West Virginia, Iowa . . . in places that left folks scratching their heads.
 - Well, it turns out that the question was misunderstood by non-Hispanics.
 - Subsequent research revealed that folks in states like Alabama and Mississippi saw the words "South American" in the question.
 - They figured they were from America . . . they lived in the south . . . and so they marked positively.
 - Same for folks in the Central part of America, like Ohio and Iowa, and so forth.
- It's a great lesson in the necessity of due diligence.
- Just like the disability construct, whatever questions are asked . . . well, they need to be understood equally well by everyone—disabled or not.
- And they need to be vetted, researched, and tested before deploying.
- And vetting involves engagement with a broad range of stakeholders.
- That's why we have a number of disability experts and stakeholders here today . . . to discuss disability from their perspectives.
- Anyway, instances like that of 1970 illustrate why the ACS has a rigorous process for considering, vetting, and testing questions prior to revising content.
- Federal agencies have a crucial role in what goes on the ACS because of the requirement that the content must address statutory purposes or court monitoring.
- And you—stakeholders and the public—also have an important role in helping us think through the value and the utility of proposed changes.
- That's why we're taking a whole-of-government approach, combined with broad outreach to the disability community.
- This is the community-of-the-whole approach we need.
- It helps us understand each other and learn from each other.
- Ultimately, it helps us traverse our path to more-informed decision-making on how to measure and what we intend to measure.
- And that's why we're here today.
- So, please know that we care, and we're listening . . . and we know you are, as well.
- Let's enlighten each other over the course of the day with open, honest dialogue on some very complex, nuanced issues surrounding the meaning of and intention of disability measurement.
- Thank you for your attention.