

Disability Health Equity Research Network Conference

“Moving Disability Measurement Forward”

Director’s remarks as prepared for delivery

September 17, 2024

INTRODUCTION

- Good morning, everyone.
- It’s an honor to be here with you today, and I thank the Disability Health Equity Research Network (DHERN) for the opportunity to engage with you.
- I’m Robert Santos, your director of the U.S. Census Bureau.
- I am a Latino male, and I’m wearing a brown sportscoat and tie, contrasted with a salmon shirt.
- I also sport brown hair that includes a rather long ponytail, which is unconventional among senate confirmed political appointees, much less for an old fogie like me approaching 70.
- But you know what?
- I’ve been spending a lot of my time in office preaching the value of bringing one’s “whole self” to the table.
- Often, as the sole Latino in a room full of decision-makers, I found that my different perspective of the issue at hand—one based on my culture, my values, my life experiences—well, it enriched the conversation and led to better decisions . . . decisions that could never have been reached without diverse perspectives being put on the table.
- In fact, I’ve traveled the country for over 2½ years offering this message of insight and of hope.
- We want and need to be actively inclusive, reaching out into the community to get the insights that facilitate informed decisions making.
- Actively including diverse perspective leads to better science, better methods, more accurate, and more relevant data.
- So, that’s part of the reason I’m here today.
- I’ll circle back on this context at the end of my remarks.

BACKGROUND: WHY WE’RE HERE

- One of the reasons I’m so pleased to be here is to give you an update on the process to revise questions on the American Community Survey (ACS), particularly as it relates to the disability content. I know many members of the public and stakeholders, including DHERN, care deeply about this topic.
- As you know, in October 2023, the Census Bureau posted a Federal Register notice—or FRN—seeking public feedback on revisions to the American Community Survey content for several topics, including disability.
- The revisions were to be put in place beginning calendar year 2025.
- Now, that FRN notice detailed a number of changes to the ACS.

- And the reason we're here today, of course, was the specific proposal to replace the current disability set of questions with an alternative . . . one based on the 2006 Washington Group Short Set, or WGSS.
- This revision would have aligned our ACS disability measures with United Nations international standards.
- And truth be told, the interagency ACS content committee considered a scaled response option set in the early 2000s.
- Now, at the time, paper-pencil was the predominant interview mode.
- Unfortunately, the ACS had very limited space for questions, especially those featuring multiple scaled response codes . . .
- There was simply too little space on the paper questionnaire to support a scaled response option.
- So that didn't happen . . . Instead, the current, abbreviated dichotomous response approach was tested in 2006 and deployed in the 2008 ACS.
- And the rest—as we say—is history.
- But that was then, and this is now.
- For more than 15 years, the disability community, our government, and the public embraced the current question set.
- Over the years, responses to these questions have informed much policy to the benefit people with disabilities.
- Now, let's get back to that FRN.
- Its purpose was to solicit public feedback on the proposed changes to the ACS.
- And indeed, the disability stakeholder community and the public provided a robust response.
- We received more than 12,000 comments.
- The overwhelming majority expressed concerns with the proposed changes to the disability questions.
- Here's a sampling of some of the themes that emerged:
 - A desire for more comprehensive public engagement.
 - Concerns that the existing and proposed questions don't measure more or all types of disabilities.
 - Concern about a break in the data series if the questions changed.
 - Requests for as well as concerns about multiple estimates that can result from graded response categories.
 - Concerns that the proposed cutoff for disability would fail to include those who report experiencing "some difficulty," and, thus, decrease the estimate of people living with disabilities.
 - And, concerns that any alteration could potentially impact insights, program funding, and services.
- We took all of this feedback to heart.
- The Census Bureau and the National Center for Health Statistics (NCHS) carefully reviewed all of the feedback.
- And as you now know, based on that feedback we suspended the implementation of the proposed changes.
- Yes, our 2025 ACS will continue to feature the legacy set of disability questions.
- So, on behalf of the Census Bureau, on behalf of the Interagency Council on Statistical Policy's Subcommittee on the ACS, and on behalf of the federal statistical system—we express our deepest gratitude to all organizations and individuals who offered their valuable feedback.

PURPOSE OF TODAY'S REMARKS

- And so . . . here we are, folks.
- Y'know, I've seen this situation a number of times before in public policy research.
- I'll briefly tell you about one instance.
- It involved my work with Feeding America as a member of their technical advisory group to their research department.
- We'd sometimes go into the field, visiting foodbanks, pantries, and soup kitchens.
- There was this one pantry in California we visited that served a really diverse constituency—Asian and Latin American immigrants, homeless, and others.
- I was consulting on a data collection of pantry clients to improve service using quick feedback forms as fodder for evidence-based improvements.
- But what I witnessed at my visit just astonished me.
- Indeed, there was a rather diverse service population.
- I watched as a group of recent Asian immigrant arrivals were served bags of a healthy mix of fresh fruits, vegetables, canned goods, and so forth.
- The recipients were very grateful despite not speaking English.
- They received their bags and exited into the parking lot.
- But then something astonishing happened pretty routinely.
- They would walk to the back of the parking lot, set down the bags of groceries, and rummage through them.
- Items they did not recognize would be lifted out of the bag and placed on the curb.
- They kept only the food they were familiar with, and leave the rest for anyone who wanted to retrieve it for themselves.
- What did that tell us?
- Well, to me it indicated that the interactions and feedback from the immigrant community had been insufficient to fully understand the importance of culturally relevant foods.
- And, in fact, we conducted a number of convenings with the Asian community during that visit to more fully understand the perspectives of recent immigrants.
- That in turn could lead to more effective gathering of relevant foods for the communities being served.
- This ends up being a big deal in the hunger service community, and in fact a lot has been done in the decade since I had this experience.
- Returning to the topic of disability, so too is it clear that both the methods and the outreach we deployed in the ACS revision process proved insufficient to capture the necessary feedback to make fully informed decisions.
- After all, it wasn't until almost the final FRN that the disability community realized the magnitude of changes being proposed.
- And fortunately for all, there was sufficient time to submit feedback.
- There was also receptivity to hearing all your voices . . . and incorporating all your feedback.
- Yes, we recognize that more could have and should have been done earlier in the ACS revision process.
- We recognize that the issues that have emerged actually transcend the ACS, because the ACS has fairly limited bandwidth with which to gather disability measures.
- But please know that we listened . . . We care . . . We're considering your feedback.
- I wouldn't be here with you today if we weren't.

- Moreover, because the issues are so much larger than just the ACS, we're committed to working with you using a whole-of-government approach.
- That includes the many other federal departments, agencies, and offices that are internal disability stakeholders.
- By collectively working together, we'll produce a better, shared understanding of our diverse data needs.
- This way both the needs of the federal government and the vast disability community can be considered.
- We'll all have a spot at the discussion table.
- Y'know, in the bigger picture . . . we're doing our best to live a continuous improvement model for gathering input.
- Like every organization—federal or otherwise—we are a work in progress.
- The FRN experience represents a real learning experience about soliciting feedback that we can—and will—continue to improve on.
- So, let me tell you about the changes we'll be making to some of our processes as a result.
- I'll also discuss how we collect data on disability, not only through the ACS but through our other surveys, as well.
- I'll talk about how the Census Bureau and the federal government as a whole can work together with each other and with you to better meet your data needs in the future.

IMPORTANCE OF A COMMUNITY-OF-THE-WHOLE APPROACH

- OK, so, let's start with the Census Bureau's mission, which is to serve as America's leading provider of quality data about its people, places, and economy.
- We're committed to producing data that reflects an accurate portrait of our nation.
- We seek to provide high-quality, relevant data that you need and that your communities can benefit from.
- As I travel and speak to people and communities across America, one thing I hear frequently is the importance of data about how we live.
- We need data that better reflect our nation's demographic characteristics such as age, sex, relationship and racial and ethnic groups and geographic levels—data that captures local experience and reflects the rich diversity of their communities and neighbors.
- Combining these data with information about housing can create greater potential for understanding economic development possibilities, addressing community needs, and mitigating inequities.
- We are constantly assessing how we can improve our statistical programs to better serve and represent underserved groups.
- In all our work, an important part of our efforts includes seeking out and listening to diverse voices . . . diverse perspectives.
- I publicly speak often about how doing this actually creates better science, better methods, more accurate data, and even more relevant data.
- Our efforts certainly include listening to our partners and stakeholders, which of course includes you.
- We're taking a community-of-the-whole approach to ensure that we know what your data needs are, and how we can meet them.
- That's why I'm so pleased to be here today.

SOURCES OF CENSUS BUREAU DATA ON DISABILITY

- In the spirit of helping to develop a common, shared understanding of disability data available to the public, let's review what we have at the Census Bureau.
- Now, I'm restricting attention to Census Bureau surveys, and not including data collections we do on behalf of our sister agencies, like the National Health Interview Survey we conduct on behalf of the National Center for Health Statistics.
- Got it?
- Ok, disability data come from three key Census Bureau data sources:
 - The American Community Survey,
 - The Survey of Income and Program Participation's Social Security Administration Supplement, and
 - The Current Population Survey's Annual Social and Economic Supplement.
- Each survey has unique advantages, and all three ask about six disability types—namely, difficulty with hearing, vision, cognition, ambulation, self-care, and independent living.
- People who respond and report any one of the six disability types are considered to have a disability.

AMERICAN COMMUNITY SURVEY OVERVIEW

- But let's dig more into the ACS.
- The American Community Survey is the premier source for detailed population and housing information about our nation and the only source of local estimates for most of the 40-plus topics it covers.
- As such, the ACS is the place to go to understand how disability intersects with other characteristics such as race and income.
- Please note—the primary purpose of the ACS is to fulfill federal data needs that are required legislatively or programmatically.
- Now, in order to propose question revisions to the ACS, federal agencies must meet rigorous justification criteria.
- They have to show how their proposed changes are rooted in statute or regulation.
- But as we know, the ACS fulfills many other needs, too.
- Hey, ACS is a national treasure of socioeconomic and demographic data on our nation's people and places.
- It just so happens that ACS data are enormously helpful to states, cities, counties, and other jurisdictions, as well as to public policy researchers and academic scholars.
- The data are used for policymaking, community planning, economic development, local governance, and infrastructure planning, to name just a few.
- Unfortunately, we're necessarily limited in the depth with which we can capture data on any specific topic because of the breadth of the ACS that's required to meet federal needs . . . the primary purpose of the survey.

PROCESS FOR ALTERING THE ACS

- OK, now the process for altering ACS content helps ensure that the revisions improve the data to better fulfill specific federal needs.
- As a result, adding or revising a question involves extensive testing, review, and evaluation.
- Hey, the question revisions for 2025? Well, they were first proposed in 2018!
- Just so you know, over 25 federal agencies participate in the ACS revision process.

- The Interagency Council on Statistical Policy’s Subcommittee on the ACS (which is co-chaired by Chief Statistician of the United States, Dr. Karin Orvis, and yours truly as Census Bureau director) oversees and facilitates the revision process in coordination with the ACS staff.
- An important step in the process is providing opportunities for public feedback.
- We do this through publishing a series of Federal Register notices soliciting public comments on proposed changes and methods.
- As noted earlier, we review and consider all feedback in developing a final content revision recommendation for submission to the U.S. Office of Management and Budget (OMB).

CONSIDERING IMPROVEMENTS AS A RESULT OF RECENT FEEDBACK

- Now—purely from a process perspective—we’re looking to improve the way we implement content changes to future ACSs.
- Moving forward, we at the Census Bureau can commit to ensuring that stakeholders are engaged earlier and more explicitly as part of the revision process.
- Moreover, the subcommittee on the ACS will also review its protocols to facilitate a more open and engaging content change process.
- Along with our federal government colleagues, we—the Census Bureau—will certainly continue our work with stakeholders and the public to better understand their needs for disability data.
- We’ll use that feedback to assess how the federal statistical system can better address those needs.
- Now, earlier I mentioned that the topic of disability was much larger than what measures can be captured by the ACS.
- As such, we also plan to engage further with the public on the disability topic more generally.
- Note that a significant theme in the Federal Register notice comments we received is a desire for more comprehensive engagement on the broader topic of disability.
- In fact, in the spirit of a whole-of-government approach, the Census Bureau, National Council on Disability, NCHS, OMB, and other federal partners are working together to do just that.
- On September 30, we’re convening a meeting of federal agency disability stakeholders, community representatives, data users, researchers, and advocates to discuss data needs and data uses on the topic of disability.
- This event will inform future ACS iterations and other data collection opportunities for the broader federal community.
- I hope you will tune into that meeting, as it will be livestreamed.

FEDERAL GOVERNMENT-WIDE APPROACH

- Now, I spoke earlier about our community-of-the-whole approach to identify and meet data needs.
- A crucial part of our community is our fellow federal agencies.
- Executive Order 13985 on *Advancing Racial Equity and Support for Underserved Communities Through the Federal Government* specifically identifies persons with disabilities as an underserved community.
- As part of the administration’s equitable data efforts, an interagency working group is now leading the way for the federal government on improving federal disability data.
- Established in March 2024, the Disability Data Interagency Working Group’s purpose is to coordinate activities to strengthen the federal government’s use of disability data to advance equity for people with disabilities.
- The work group is tasked with developing a Federal Evidence Agenda on Disability Equity.

- This working group will be key in helping to determine how federal administrative data and surveys, including the American Community Survey, can improve data collection on disability.
- One of their core functions is identifying existing federal disability data resources and supporting in optimizing, improving, and increasing those resources.
- The working group is co-chaired by the Office of Science and Technology Policy, the Office of the Chief Statistician of the United States, and the National Institute on Disability, Independent Living, and Rehabilitation Research.
- The Census Bureau is also participating.

CONCLUSION

- I want to thank you again for your thoughtful and productive engagement on how the federal government measures disability in our surveys, including the ACS.
- In addition to the changes we've proposed to our ACS content process, we will continue to listen and incorporate your feedback in the future.
- We are committed to meeting our nation's data needs, and we are committed to working with you to understand and address your data needs—whether that's through the ACS, our other Census Bureau censuses and surveys, or through other federal statistical vehicles with the help of the Disability Data Interagency Working Group.
- We look forward to meeting, learning, and further exploring the informational and data needs of the disability community.
- Thank you, and I look forward to your questions.