

The American Community Survey: Changing Content for Changing Needs

Disability Briefing

Tasha Boone

Assistant Director for Decennial Census Programs

Donna Daily

Chief, American Community Survey Office

Julie D. Weeks, Ph.D.

Chief, Measures Research and Evaluation
National Center for Health Statistics



National Council on Disability

February 8, 2024

Agenda Items

1. Why does the ACS include this content?
2. What was proposed for change in content?
3. Where we are in the process?
4. What are the issues and how are they being addressed?
5. What are the next steps related to this content?

Why does the ACS include questions on functioning disability?

- The ACS is collects information on functioning and disability to help governments and communities enforce laws, regulations, and policies.
- The information provides a consistent approach with international standards for disability conceptualization and measurement.
- Based on the 2014 Content Review, the Federal agencies that use the disability data for their programmatic needs are:
 - Department of Health and Human Services
 - Department of Housing and Urban Development
 - Department of the Interior
 - Department of Justice
 - Department of Labor
 - Department of Transportation
 - Department of Veteran's Affairs
 - Environmental Protection Agency
 - Equal Employment Opportunity Commission
 - National Science Foundation
 - National Telecommunications and Information Administration
 - Social Security Administration

How do changes to the ACS occur?

- The ACS is a key data source for numerous Federal statistical agencies and other executive branch agencies
- The Federal statistical system is a steward of the ACS
- The Interagency Council on Statistical Policy (ICSP) Subcommittee on the ACS advises the Chief Statistician of the United States at OMB and the Director of the Census Bureau on how the ACS can best fulfill its role in the portfolio of federal household surveys and provide the most useful information with the least amount of burden.
- Changes to the ACS follow a proscribed process and proposals must meet specific decision criteria
- A Federal government agency justifies a need for new survey measurement on a specific topic and there are no other sources that could reasonably meet the information needs
 - Need is determined by:
 - Regulatory
 - Statutory
 - Programmatic
- All proposed content is subject to normal questionnaire development and pretesting prior to being considered for inclusion on the ACS

Proposal Justification

- Assesses difficulties in functioning consistent with current biopsychosocial model of disability (ICF)
- Provides programmatic requirements for disability data
 - National Health Interview Survey – National Health Survey Act of 1956 provided for a continuing survey and special studies to secure accurate and current statistical information on the amount, distribution, and effects of illness and disability in the United States
 - Greater granularity – level of functional difficulty and severity, not simply the presence of any functional difficulty
- Comparability with other data collections
 - National Health Interview Survey (since 2010), National Health and Nutrition Examination Survey (since 2019), National Survey of Family Growth, Pulse, field testing for inclusion in other federal surveys, over 70 Multiple Indicator Cluster Surveys (UNICEF), all USAID collections including the Demographic and Health Surveys, the World Bank Living Standards Measurement Survey and programs, censuses and surveys collected in over 125 countries (to date)
- Consistent approach with international standards for disability measurement and disaggregation
 - Allows for cross-culturally comparable comparisons of U.S. with other countries
 - Meets UN *Principles and Recommendations for Population and Housing Surveys* (UNSD P&R rev. 3, UNECE)
- Meets international reporting requirements (such as 2030 Sustainable Development Goals)

WG-SS Widely Tested

The WG-SS has been rigorously tested, both cognitively and in the field, in multiple languages and in multiple countries...

- The development of the WG-SS began with a review of existing disability questions, including, questions used in censuses and surveys. Based on the results of cognitive testing, individual questions were either modified or abandoned.
- Multiple rounds of cognitive testing were carried out in 2006 in fifteen countries: Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Philippines, Uganda, Mexico, Tanzania, Vietnam, Argentina, Brazil, and Paraguay.
 - An overview of cognitive testing results can be found here: Miller K, et al. 2011. Results of Cross-National Structured Cognitive Interviewing Protocol to Test Measures of Disability. *Quality & Quantity*. 45(4):801-815. Available here: <https://link.springer.com/article/10.1007/s11135-010-9370-4>
- Additional testing was carried out under the auspices of the Budapest Initiative. In this round of testing, interviews were conducted in English, French and Spanish in seven countries: Bulgaria, Germany, Portugal, Spain, Switzerland, the US and UK.
 - More information on the findings in this round of testing can be found here: https://wwwn.cdc.gov/QBANK/report/Miller_NCHS_2008BudapestReport.pdf#page=16
- Field and cognitive testing of the WG Extended Set on Functioning, which includes the WG-SS, were undertaken by Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka in 2009.
 - An overview of the testing results can be found here: United Nations Economic and Social Commission for Asia and the Pacific. 2006. Results of the Testing of the ESCAP/WG Question Set on Disability. <http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/ResultsoftheTestingoftheESCAP-WGQuestionSetonDisability.pdf>
- Additional resources with information on the methodologies and results of WG question testing may be found here: <http://www.washingtongroup-disability.com/methodology-and-research/testing-methodology/>

NCHS Proposal for Disability Content Change

The revision: 1) eliminates the words “deaf”, “blind” and “serious”; 2) changes the number of response categories from two to four; and 3) adds a question on communication functioning.

ACS Question Text	ACS Response Options	Proposed Set	WG-SS Response Options
Are you <u>deaf</u> or do you <u>have serious difficulty</u> hearing?	1. Yes 2. No	Do you <u>have difficulty</u> seeing, even when wearing glasses?	1. No - no difficulty 2. Yes - some difficulty 3. Yes - a lot of difficulty 4. Cannot do at all
Are you <u>blind</u> or do you <u>have serious difficulty</u> seeing even when wearing glasses?		Do you <u>have difficulty</u> hearing, even when using a hearing aid?	
Because of a physical, mental, or emotional condition, do you <u>have serious difficulty</u> concentrating, remembering, or making decisions?		Do you <u>have difficulty</u> remembering or concentrating?	
Do you <u>have serious difficulty</u> walking or climbing stairs?		Do you <u>have difficulty</u> walking or climbing stairs?	
Do you <u>have difficulty</u> dressing or bathing?		Do you <u>have difficulty</u> (with self-care such as) washing all over or dressing?	
Because of a physical, mental, or emotional condition, do you <u>have difficulty</u> doing errands alone such as visiting a doctor's office or shopping?		Because of a physical, mental, or emotional condition, do you <u>have difficulty</u> doing errands alone such as visiting a doctor's office or shopping?	
n/a		Using your usual (customary) language, do you <u>have difficulty</u> communicating, for example understanding or being understood?	

Where are we in the Process?



Proposal

A federal agency proposes a new or changed question.

Requests undergo legal, technical, and policy review.

OMB, Census Bureau, and the Interagency Council on Statistical Policy (ICSP) Subcommittee on the ACS (SACS) decide whether the change has merit.



Testing

Interagency topical subcommittees are formed to develop wording options for cognitive testing.

Federal register notice posted to announce question performance will be evaluated in a field test.



Evaluation

Test results are reviewed by the Census Bureau and requesting federal agency.

The Census Bureau solicits public comment through a Federal Register Notice.



Decision

In consultation with the OMB and ICSP-SACS, decisions are made on what changes will be included in the OMB clearance package.

A final decision is made by OMB.

If approved, the Census Bureau implements the change.

Note: The Paperwork Reduction Act requires OMB approval of data collection that would impose a burden on the American public. It also requires a public comments period via the Federal Register.

Common Issues Raised on Disability

- Need for more comprehensive public engagement
- Concern that existing and proposed questions do not include more or all types of disabilities (for example, measures do not capture long COVID diagnoses)
- Concern regarding break in series, a gap in data availability and comparisons across measures
- Requests for more estimates that reflect the WG-SS graded response categories, including: no difficulty, some difficulty, a lot of difficulty, and cannot do at all
- Requests for a different cutoff, concern that the proposed use of the international standard cutoff for disability, which does not include people reporting “some difficulty,” would decrease the estimate of people living with disabilities
- Concern that the proposed change in data will impact program funding and services

Current & Recent Engagement

- September 21 – Presented test results to the Census Scientific Advisory Committee
- November 16 – Presented test results to the Census National Advisory Committee
- December 6 — Briefing with the Leadership Conference Coalition
- December 8 — Director met with disability stakeholders
- December 14 — Presentation at the White House’s Office of Public Engagement’s biweekly aging and disability community call
- January 19 — Census and NCHS met with staff from the Senate Subcommittee on Health, Education, Labor, and Pensions and the Subcommittee on Aging
- February 8 — Census and NCHS meet with the National Council on Disability
- A few individual stakeholder letters to the Director received and responses sent
- Meetings with other federal agencies and ICSP

ACS Disability Stakeholder Meeting

- Comments were received from:
 - Over 150 organizations
 - 20 local & state governmental groups
 - Over 300 people with university affiliation
 - Thousands of people with disabilities
 - Several federal agencies
 - Some were part of the disability interagency subcommittee for the test
 - Some were not part of the interagency subcommittee and were not involved in the content test

We will soon convene an all-day hybrid meeting in early Spring.

Objectives of the Meeting:

- Provide clarification about the ACS proposed question
- Address concerns raised in the FRN
- Develop a path forward for understanding the holistic data needs for this community.

Additional Communication Plans

Ongoing

- Briefings with partners and stakeholders across government and beyond, including with disability community

February 2024

- Blog published announcing current disability content plans to the public

March 2024

- Stakeholder meeting(s) planning

April 2024

- Publish 2025 ACS 30-day FRN to solicit final round of public input on the 2025 ACS content changes

May 2024

- OMB review and approval of 2025 ACS content changes

Thank You