CommunicationFIRST
Because communication is a human right.

Comments of CommunicationFIRST

in response to the

U.S. Census Bureau's

Information Collection Request (ICR):

American Community Survey (ACS) and Puerto Rico Community Survey

USBC–2023–0009; 88 Fed. Reg. 72,424 (Oct. 20, 2023)

Submitted via ***Regulations.gov*** and ***acso.pra@census.gov***

https://www.regulations.gov/document/USBC-2023-0009-0001

December 19, 2023

CommunicationFIRST, the nation's only disability-led, civil rights organization dedicated to protecting the rights and advancing the interests of people with significant speech-related disabilities, is pleased to submit these comments in response to the U.S. Census Bureau's recent Information Collection Request (ICR) regarding proposed changes to the disability-related questions on the American Community Survey (ACS).

While CommunicationFIRST is pleased that the Census Bureau is addressing a critical issue that we have been advocating for since we launched in 2019 — the need for this country to begin for the first time to systematically count our population, as is done for people with the other two main communication disabilities (hearing and vision) — we have significant concerns both about the proposed new speech question, as well as the lack of engagement and transparency employed by the Bureau with this proposal.

I. Key Points

A. Procedural

1. The Census Bureau **did not adequately engage the broader disability community** before releasing this proposal. Before proceeding, it must remedy that procedural flaw.

2. The Bureau **did not seek input from the specific communities that would be most impacted by the proposed changes**, even when the agency's own estimates



indicated the change would drastically reduce the headcount of people with disabilities. The agency thus appears to believe this proposed change and its resulting reduced headcount is of little consequence.

3. The ICR does not indicate whether an **economic impact analysis or a data equity analysis** were conducted to rigorously examine the downstream effects of the proposed changes.

4. The notice contains **no information about the proposed "new question"** ("Additionally, a new question will ask about difficulties related to psychosocial and cognitive disability **in addition to problems with speech**."). CommunicationFIRST had to contact the agency to obtain more information to enable us to prepare meaningful and responsive comments to this ICR.

5. In response to our request for more information about the "new question" regarding "problems with speech," CommunicationFIRST was sent four documents (a total of 88 pages). **None of these supporting materials were included in the public docket for stakeholder review** to help inform other potential commenters. We attach these four documents here for inclusion in the record.

6. In terms of the responsiveness of the four documents, **the word "speech" appears only once within those 88 pages**. One document includes the wording of the proposed "new question" (although the word "speech" does not actually appear in that new question). Besides this information, **we were unable to locate a rationale, impact analysis, or other deliberative information to indicate the reasoning behind the proposed changes**.

B. Substantive

1. While the existing ACS disability questions ask about two communication disabilities (hearing and vision), the ACS completely ignores and omits the third major communication disability — speech. CommunicationFIRST **strongly encourages the Census Bureau to include a question that will *accurately* count the number of people in the United States who cannot rely on speech to be heard and understood**, a number that we estimate is at least 5 million.

2. The wording of the **Washington Group question**, while a slight improvement to the status quo because it at least acknowledges the existence of people with significant



speech-related communication disabilities in the United States, **still radically fails to count us** with any kind of accuracy. We recommend the following formulation be used instead: "**Do you have difficulty speaking or using speech to be understood by others?**"

II. About CommunicationFIRST and its Members

CommunicationFIRST is our nation's only organization led by and for, and dedicated to protecting and advancing the rights of, the estimated five million people of all ages in the United States who need communication tools and support to be heard and understood due to speech-related disabilities and conditions. CommunicationFIRST is a cross-disability, cross-generational, and disability-led civil rights organization.

CommunicationFIRST seeks to represent all children, young people, working-age persons, and older adults who have little to no understandable speech and must use one or more modes of augmentative and alternative communication (AAC) tools or support to express ourselves and be heard and understood. People may use AAC all the time, most of the time, or episodically. AAC includes gesturing; pointing to or looking at letters, words, and images; relying on a personal assistant to repeat one's speech; using assistive commercially available digital devices and apps; brain-computer interface technology; and a growing number of other emerging technologies.

Our diverse members include those who have had disabilities since birth — such as Down syndrome, rare genetic syndromes, cerebral palsy, and autism — as well as those who acquire speech loss at other points in life, including due to ALS, Parkinson's disease, stroke, traumatic brain injury, and other conditions or injuries. Everyone who needs AAC endures multiple forms of discrimination and oppression throughout life — based largely on their speech disability — that must be recognized and eradicated.

In addition to having disabilities that limit or make it impossible to physically produce any understandable speech, most of us who need AAC have other disabilities that may be counted through one or more of the six existing ACS disability questions. By not asking about speech disabilities in particular, however, the Census Bureau has failed and, in effect, refused to identify the unique as well as compounded health disparities, inequities, lack of equal opportunity, and lifetime toll that children, youth, working age, and older persons who require AAC frequently endure, all stemming largely from our communication disability and failure by others to provide sufficient AAC to ensure we can



be understood. These compounded health disparities include a range of often misdiagnosed behavioral, cognitive, expressive, health-related, independent living, mental health, motoric, receptive, sensory, and traumatic disabilities and conditions.

III. Comments of Other Disability Organizations

CommunicationFIRST shares the deep concerns of many other disability civil rights organizations and others that changing the six disability questions on the American Community Survey (ACS) to the Washington Group Short Set questions will significantly undercount people with disabilities in this country, with harmful effects.[1]

Before the Census Bureau takes any further action, we call on the agency to consult with a diverse group of disability leaders and data experts to inform its reconsideration of disability-related questions in Census survey instruments.

The Census Bureau cannot carry out its statutory mission to collect and report accurate data about the population of the United States based on the way both the ACS's six disability questions and the Washington Group questions are phrased. There appears to be a dearth of interest, knowledge, and commitment within the Census Bureau regarding effective methods of defining as well as collecting and reporting accurate data on people with disabilities. This is untenable. CommunicationFIRST, therefore, resolutely urges the Bureau, the Commerce Department, and the Office of Management and Budget to make a mid-course correction, including by meeting with disability community leaders and others to chart a better way forward.

IV. Major Revisions Needed to New Speech Question

We are pleased that the Census Bureau proposes to begin to address the data inequities faced by our population by adding a "new question" to the 2025 American Community Survey, which the ICR states is meant to identify people who have "problems with speech." 88 Fed. Reg. at 72,425. We appreciate the fact that this action by the Census Bureau is intended to remedy a flaw in the agency's overly circumscribed definition of disability and the harm it causes. However, while we applaud the Bureau's intent, the wording of the proposed question is fundamentally flawed and would only exacerbate the existing lack of adequate and accurate data if adopted.

[1] CommunicationFIRST separately joins the comments of the Consortium of Constituents with Disabilities (CCD), submitted today, in response to this ICR.

Because the ICR included no additional information about this "new question," to allow us to meaningfully comment, CommunicationFIRST reached out to the Census Bureau contact listed in the Federal Register notice to obtain more information. About a week after our initial request, CommunicationFIRST received four documents entitled:

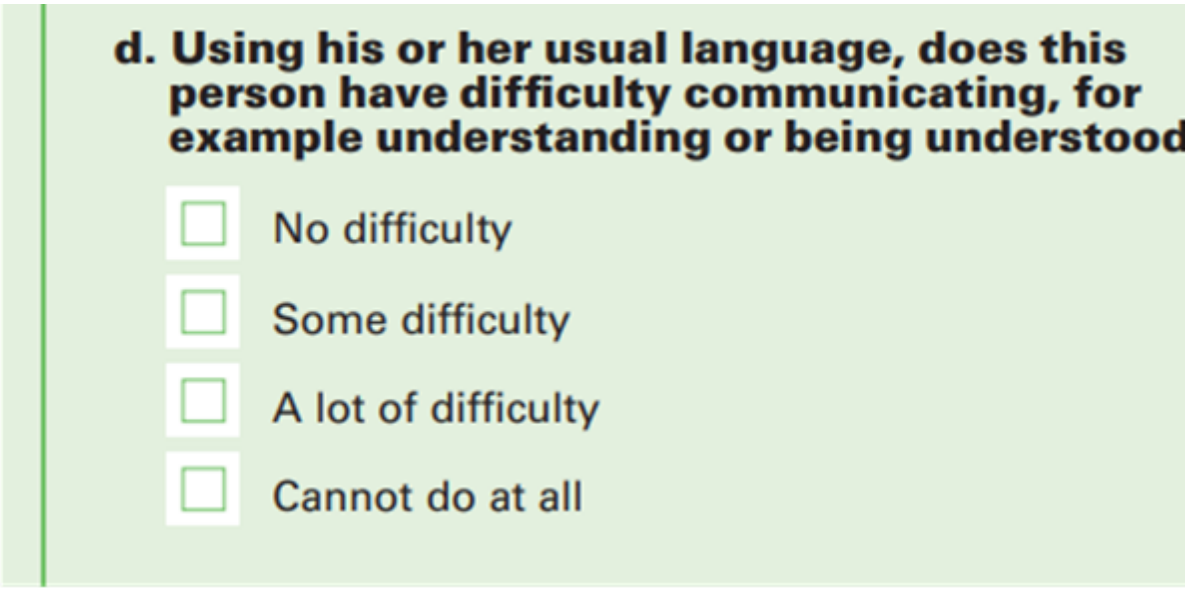
- **ACS Housing-Unit Self-Response Paper Questionnaires; Stateside English-Language New Question Comparison 2024 v 2025 (5 pages)**
- **Supporting Statement B - Draft Collections of Information Employing Statistical Methods (12 pages)**
- **Supporting Statement A - Draft Abstract and Justification (23 pages)**
- **2024 American Community Survey (48 pages)**

We attach each of these documents below.

We acknowledge the concerns of the disability advocacy community about changing the potential responses from "Yes" or "No" to a system that will enable the respondent to choose among four possible responses based on their self-reported level of disability. This change is the main driver for the estimated reduction of the overall headcount of disabled people that will result if this proposal is adopted. We share these concerns.

However, because our population has never been counted systematically by the federal government, CommunicationFIRST at the same time believes it is important to allow respondents with speech-related disabilities to describe their reported level of disability. Posing the speech-related disability question in this manner will yield more accurate and relevant data which policymakers, the disability community, and others can utilize to understand the demographic, diversity, needs, and abilities of people with disabilities and to assure laws like the Americans with Disabilities Act are effectively enforced.

Proposed new Question 19(d) in the 2025 American Community Survey (see page 4 of Attachment A below) reads: "**Using his or her usual language, does this person have difficulty communicating, for example understanding or being understood?**" (A screenshot of this question, with alt-text embedded) follows.



Screengrab of a proposed American Community Survey question that reads: "d. Using his or her usual language, does this person have difficulty communicating, for example understanding or being understood?" Below that text are four lines with empty check boxes before the following text on each line: "No difficulty"; "Some difficulty"; "A lot of difficulty"; and "Cannot do at all."

We have the following concerns and suggestions regarding this proposed question.

First, it is not clear why this question regarding communication disabilities is **separated from the other two communication disability questions** (in proposed Question 18), and lumped together with proposed Question 19, which addresses mobility, memory, concentration, and self-care disabilities.

Second, if the survey questions are being answered by another person or proxy for the person with a speech disability, if the person has no way of expressing or understanding language (e.g., with AAC or sign language), how does the Bureau expect that question to be answered? Is it acceptable for the proxy to simply guess what that person's language is?

Third, and most critically, the question as posed — contrary to the Census Bureau's assertion — will fail to clearly identify people with speech difficulty. Instead, it will identify and conflate people with three types of (and varying levels of) functional disabilities and difficulties:



(a) People who have difficulty having other people understand them when they communicate using their usual language;

- This question addresses difficulty with **expressive** communication.
- Expressive, language-based communication can include speech, sign language, writing, typing, using language-based augmentative and alternative communication. (Expressive, non-language-based communication includes facial expressions, noises, gestures, pointing, and moving differently than the person normally does.)
- Depending on how the survey-taker interprets this part of the question, they may assume that the Census Bureau is asking about whether the person can be understood with speech, whether they have access to AAC, whether they can type or handwriting, or whether they have difficulty communicating using sign language.
- Thus, this part of the question will not accurately capture people who have speech-related communication disabilities.

(b) People who have difficulty understanding when others communicate with them;

- This question deals with **receptive** communication.
- Receptive communication can involve hearing, vision, and tactile senses, as well as cognition, including language processing.

(c) People who have difficulty both being understood by and understanding others.

- This question deals with both **receptive** and **expressive** communication.
- But "understanding others" is a **cognitive** function rather than a speech or hearing function.



The WG question as worded conflates the concepts of speech, language, expressive communication, receptive communication, cognitive processing and more. The data this question would yield if added to the ACS as proposed would further skew policymakers' and the public's understanding of such individuals. It also would perpetuate the fallacy that having little to no understandable speech is certain evidence that a person cannot understand others. Thus, the question in its current form provides almost no actionable information for policymakers, public health officials, the disability and aging communities, or the public. It must be substantially changed and replaced in a timely manner that will enable its inclusion in the 2025 version of the ACS. The fact the proposed question is flawed demands urgent action and must not be used as a reason for delay or to take no action at all.

To this end, CommunicationFIRST calls on the Census Bureau to add the following questions or similar ones to the 2025 version of the ACS in consultation with people who need AAC:

> "**Does the person have difficulty speaking or using speech to be understood by others?**"[2]
>
> **"Does the person use gestures or an aid to be understood?" Never. Sometimes. Always.**

Similar questions should be added pertaining to persons with difficulty understanding others. This should be done because such information is equally important for policymakers and the public, and hopefully could be disaggregated in a manner that provides data and information regarding people who have varying levels of difficulties in both being understood and understanding others.

V. Procedural Issues

In addition to our concerns noted above that the Census Bureau did not adequately engage the broader disability community before releasing this proposal, we have several additional procedural issues with this ICR:

[2] A variation of this question has been used by Canada's Participation and Activity Limitation Survey.



1. The ICR does not indicate whether an **economic impact analysis or a data equity analysis** was conducted to examine the downstream effects of the proposed changes, including how a reduction in the headcount of disabled people might impact policies, services, budgets, and other factors of critical importance to most disabled people's lives.

2. The ICR contains **absolutely no information** about the proposed "new question" about "problems with speech" other than those words. This lack of information made it **impossible for us to prepare responsive comments**. We were forced to contact the agency to obtain additional information to learn even what the proposed phrasing of the question would be.

3. In response to our request for information about the "new question," CommunicationFIRST was sent four documents (a total of 88 pages). Unfortunately, the word "speech" appears only once within those 88 pages. In addition, only one of the documents includes the wording of the proposed new question (although the word "speech" does not in fact actually appear in that new question). Based on the wording of that new question (contained in Attachment A), we were able to deduce that the question mirrors the wording of the corresponding Washington Group question, information that was necessary to prepare these comments.

4. In addition to insufficient information about the wording and placement of the new speech-related question (i.e., separate from the other communication-related questions), we were also unable to locate a rationale, impact analysis, or other deliberative information to indicate the reasoning behind the proposed new question.

5. A final procedural concern is that none of these supporting materials were included in the public docket for stakeholder review to help inform other potential commenters. We attach these four documents here for inclusion in the record.

VI. Policy Implications

The American Community Survey (ACS) is the most widely used survey for population research of all types, including disability research on non-institutionalized children and adults in the United States. The data it collects can be analyzed at the

national, state, and zip code levels. A prime purpose of the ACS is to "help local officials, community leaders, and businesses understand the changes taking place in their communities" (https://www.census.gov/programs-surveys/acs/).

ACS data range from population demographics (e.g., sex, race, Hispanic or non-Hispanic ethnicity, age), to economic characteristics (e.g., employment status, work experience, occupation and industry, type of commute, educational attainment, earnings in the past year, and poverty status), to services received (e.g., health insurance, SSI, food stamps). Data can be geographically delineated by state and by local area. This information is vital for creating, enforcing, and funding effective public policy. The ACS is also one of the few federal surveys that includes people who are institutionalized or live in group settings—a significant subpopulation of people who need AAC. In 2006, it began including both institutional and non-institutional groups in its sampling frame.

A major flaw in the current ACS, however, is it only asks questions about the six types of functional limitations mentioned above. This means that it does not identify people with speech disabilities. Many people with speech disabilities may be included under the six disability categories, but some (including some members of CommunicationFIRST's Board of Directors and Advisory Council) may not be counted under any of the disability questions. As a result, it is impossible to determine from the ACS how many people in the United States have significant speech disabilities and may need AAC.

VII. Recommendations

The Executive Branch should ensure disability data equity, comparability, and continuity of these efforts by allocating sufficient and ongoing funding and by:

- Using this formulation for any speech-related question that is used in the future by the Census Bureau: "**Do you have difficulty speaking or using speech to be understood by others?**" This formulation can be used either with binary or four-part answers.
- Assuring data is gathered in a manner that:
    - Can be disaggregated by all demographic characteristics



- Serves to identify the types and magnitude of disparities and discrimination faced by people who need AAC—particularly those denied it and/or who live with other marginalized identities
- Covers all ages
- Covers all disabilities, regardless of age of onset
- Captures the same data regardless of residential setting: community-based, group living, and institutionalized
- Allows multiple agencies to use a core set of questions across surveys to meet multiple data needs
- Provides data at local, state, and national levels that is useful to policy makers, disability justice organizations, and the public in understanding and improving the equal opportunities of these persons

* * *

We appreciate this opportunity to comment. If you have any questions, please do not hesitate to reach out to Policy Director Bob Williams or Executive Director Tauna Szymanski at info@communicationfirst.org. More information about CommunicationFIRST can be found at https://communicationfirst.org/.

ATTACHMENTS

- **Attachment A**: ACS Housing-Unit Self-Response Paper Questionnaires; Stateside English-Language New Question Comparison 2024 v 2025 (5 pages)
- **Attachment B**: Supporting Statement B - Draft Collections of Information Employing Statistical Methods (12 pages)
- **Attachment C**: Supporting Statement A - Draft Abstract and Justification (23 pages)
- **Attachment D**: 2024 American Community Survey (48 pages)

Attachment A

Comparison of Proposed Question Changes from 2024 to 2025

"ACS Housing-Unit Self-Response Paper Questionnaires; Stateside English-Language New Question Comparison 2024 v 2025" (5 pages)

Attachment B

ACS Proposed Revision Supporting Statement B

"Supporting Statement B - Draft Collections of Information Employing Statistical Methods" (12 pages)

Attachment C

ACS Proposed Revision Supporting Statement A

"Supporting Statement A - Draft Abstract and Justification" (23 pages)

Attachment D

2024 American Community Survey (48 pages)