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601 Pennsylvania Avenue NW, Suite 420 
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Subject: American Community Survey and the Puerto Rico Community Survey

Docket Number USBC–2023–0009

Robert L. Santos

Director, U.S. Census Bureau

U.S. Department of Commerce

Dear Director Santos:

The Amputee Coalition expresses gratitude for the opportunity to share feedback with the U.S. Census Bureau regarding the proposed changes to the questions assessing disability status.

Established in 1986, the Amputee Coalition is dedicated to advocating for and supporting individuals who undergo limb loss and limb difference. Our mission extends to providing comprehensive support both pre- and post-amputation, ensuring assistance during the recovery process. Amputations can result from various causes, including traumatic injuries and illnesses such as sepsis. With approximately 4.2 million people in the country having experienced some form of amputation and an annual incidence of about 185,000 amputations, our advocacy for the limb loss and limb difference (LLLD) community naturally aligns with advocating for the broader disability community.

As representatives and advocates for the LLLD community, we respectfully request that the Census Bureau reconsider the proposed transition from the six disability questions used in the American Community Survey (ACS) to the Washington Group Short Set (WGSS) of questions. While we acknowledge the intent to enhance inclusivity, we express disagreement with this proposed switch due to anticipated negative impacts on the LLLD community. Additionally, concerns arise regarding the lack of consideration for distinguishing between durable medical equipment (DME) usage and non-usage, as well as the absence of meaningful community and stakeholder engagement in this decision-making process.

Negative Impacts for the LLLD Community

The WGSS comprises six questions that address the same subjects as the ACS inquiries. Instead of responding with a simple "yes" or "no," participants assess their difficulty levels for each function by choosing from four options, ranging from "no difficulty" to "cannot do at all." According to an agency spokesperson in an emailed statement, the WGSS aims to "capture information in a manner that reflects advances in the measurement of disability." However, it's important to note that the WGSS measurement gauge doesn't consider the fluctuating mobility levels experienced by individuals with limb loss and limb difference.



According to the Washington Group protocol, only those indicating "a lot of difficulty" or "cannot do at all" for one or more questions are categorized as disabled. This approach may exclude individuals using a prosthesis who, at the time of the Census Bureau survey, aren't experiencing significant mobility difficulties. This exclusion might occur even though their mobility could be limited later due to factors such as prosthesis changes, blistering, bone overgrowth, and more. The ongoing variations in functionalities for individuals with limb loss and limb difference pose genuine challenges for accurate assessment.

Implementing the Washington Group's disability categorization has the potential to undercount an already marginalized and underserved population. This unintended consequence creates a hierarchy within the LLLD community, leading to biased resource allocation that primarily benefits those with more 'severe disability' or, using a more applicable term, 'severe mobility limitations.' Meanwhile, those with disabilities but slightly limited mobility or better are overlooked in this categorization, further exacerbating the issue.

The Census Bureau provides concrete instances of how ACS disability data is utilized by federal, state, local, and tribal governments to make well-informed decisions regarding resource allocation, disaster planning and response, and the enforcement of civil rights laws that prohibit discrimination. Additionally, ACS data is employed by private sector businesses and nonprofits for diverse organizational decisions, such as selecting new workplace locations and monitoring the success of programs.

Durable Medical Equipment Dilemma

The Social Security Administration characterizes Durable Medical Equipment (DME) as "equipment which can withstand repeated use" and is primarily and customarily used for a medical purpose, generally not being useful to a person in the absence of an illness or injury, and suitable for home use.

Prosthetic devices fall under the DME benefit covered by Medicare Part B. DME items encompass essentials such as wheelchairs, walkers, leg, arm, back, and neck braces (orthotics), as well as artificial arms, legs, and eyes. DME plays a crucial role in assisting with Activities of Daily Living (ADLs), enhancing mobility/functionality, and improving the overall quality of life for the LLLD community.

Despite the significance of DME, it has historically been overlooked on the ACS. When individuals with LLLD complete the ACS, they face the dilemma of answering questions with or without considering DME usage. The use of DME can significantly impact mobility and the ability to perform ADLs, yet the ACS does not account for this variation. Specifically, Question 20, which asks about difficulties with errands, does not clarify whether the reference is to scenarios involving DME usage or non-DME usage.



The Amputee Coalition recommends that the ACS explicitly inquire about both the usage and non-usage of DME. Incorporating these distinctions will enhance the inclusivity of the ACS for individuals who rely on DME. Without such adjustments, the LLLD community will continue to grapple with the challenge of deciding which scenario is most applicable in their responses.

Lack of Community/Stakeholder Engagement

The Amputee Coalition expresses deep concern over the exclusion of vital disability stakeholders from the process of modifying ACS questions. Stakeholders assert that the bureau failed to engage in discussions about the questionnaire changes with the disability and disability research communities before proposing them. This lack of collaboration raises significant apprehensions about the accuracy and relevance of the modified questions.

In response to these concerns, the Amputee Coalition strongly recommends that the Census Bureau temporarily suspend its ongoing efforts to reform ACS questions. Instead, we advocate for a proactive approach that involves actively seeking input from a diverse range of researchers and individuals with disabilities. The goal is to create an inclusive process that results in a set of changes not only improving the precision of collected disability data but also carefully detailing the potential impact on future policymaking.

This comprehensive approach should extend to providing recommendations on how to address any potential negative outcomes associated with the modified questions. By fostering a collaborative and transparent dialogue, the Census Bureau can ensure that the voices of the disability community are heard and that the resulting changes are not only accurate but also considerate of the unique needs and perspectives within this community. This inclusive process is crucial for establishing trust and support for the modifications, ensuring that they genuinely serve the interests of individuals with disabilities.


Conclusion


In conclusion, the Amputee Coalition extends its sincere appreciation to the U.S. Census Bureau for the opportunity to voice concerns and provide feedback on the proposed changes to the disability status assessment questions. As a steadfast advocate for individuals facing limb loss and limb difference, our commitment to the well-being of the LLLD community drives our plea for a reconsideration of the transition from the ACS questions to the WGSS.


Our detailed analysis reveals potential negative impacts on the LLLD community, highlighting the need for a nuanced understanding of mobility variations and the essential role of DME. We urge the Census Bureau to consider the genuine concerns raised regarding the potential undercounting of this marginalized population






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Furthermore, the Amputee Coalition emphasizes the critical importance of community and stakeholder engagement in the decision-making process. We propose a temporary suspension of the modification efforts to allow for a more inclusive and collaborative dialogue, involving a diverse range of researchers and individuals with disabilities. This approach aims not only to improve the precision of disability data but also address the unintended consequences and ensure that modifications align with the genuine needs and perspectives of the disability community. By fostering transparency and collaboration, we believe the Census Bureau can build trust and garner support for changes that truly serve the interests of individuals with disabilities.

Best,

A handwritten signature in black ink, appearing to read "Cass Isidro".

Cass Isidro, MBA
President & Chief Executive Officer
Amputee Coalition

