

## **Comment on Notice of Availability of Proposed Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status Required by Section 4302 of the Affordable Care Act (Document ID HHS-OMH-2011-0013-0001)**

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The National Association of County and City Health Officials (NACCHO) is pleased to comment on the Proposed Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status Required by Section 4302 of the Affordable Care Act.

NACCHO represents the nation's 2800 local health departments. These city, county, metropolitan, district and tribal departments work every day to ensure the conditions that promote health and equity, combat diseases, and improve the quality and length of all lives for all people in their communities through public health policies and services. NACCHO, with support from the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention, convenes a Health and Disability Workgroup dedicated to the inclusion and engagement of people with disabilities in the planning, implementation, and evaluation of public health programs. This workgroup provided input for these comments.

NACCHO supports the proposed data collection standards for race, ethnicity, sex, primary language and spoken language. NACCHO also appreciates the inclusion of disability in the new data collection standards, and is grateful for the opportunity to work with the Department of Health and Human Services (HHS) to assure that the data collected be as useful as possible.

The currently proposed data collection standards are an excellent starting point, and NACCHO supports the proposal to use a standard set of questions on disability that span all federal surveys that gather demographic data. However, in order to gather the best and most useful information, and to reflect the diverse needs of people with diverse disabilities, **NACCHO strongly encourages HHS to make crucial additions to the proposed data standard for disability status.**

It is essential that the data gathered by HHS be valuable and useful to HHS, the public, and to those who provide services to the public. In their current format the questions focusing on disability status do not adequately allow for the data collected to appropriately identify respondents with different types of physical disabilities or distinguish between those with physical, mental, or emotional disabilities. Further, the questions may inadvertently overlook or exclude people with intellectual, developmental, mental health, speech, learning, neurological,



and other disabilities. The proposed questions are not exhaustive of the categories of disability; therefore the data collected will be of limited utility.

In order to properly identify health disparities across distinct groups of people with disabilities, **NACCHO recommends that HHS expand the question set to collect much more definitive information about disability status to include the missing categories.** These additions would allow for a much more exhaustive set of circumstances to be identified and thus greatly enhance the usefulness of the data. Without this extension, the data gathered will continue to fail to capture all available data on people with disabilities.

NACCHO appreciates that the process of identifying the correct questions will be time-consuming. NACCHO urges HHS to form a workgroup that includes representatives from local health departments that have a stake in collecting and using this critical health information. Together, we can make this a more meaningful data collection instrument. NACCHO strongly encourage you to consider this addition. Thank you for your consideration of our comments.

Contact for further information:

Eli Briggs

Director of Government Affairs

National Association of County and City Health Officials

202/507-4194

[ebriggs@naccho.org](mailto:ebriggs@naccho.org)