August 1, 2011

Garth Graham, M.D., M.P.H.
Deputy Assistant Secretary for Minority Health
The Office of Minority Health
US Department of Health and Human Services
Washington, DC 20013-73337

SUBJECT: Proposed Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status Required by Section 4302 of the Affordable Care Act

Docket ID Number: HHS-OMH 2011-0013

Dear Dr. Graham,

The National Association of Social Workers (NASW) is pleased to submit comments regarding the Department of Health and Human Services’ proposed data collection standards to reduce health disparities and the plan to begin collecting data on lesbian, gay, bisexual, and transgender (LGBT) populations as outlined by Section 4203 of the Affordable Care Act. The proposed standards and data collection would facilitate identification of health issues and reduction of health disparities.

Founded in 1955, NASW seeks to enhance the well-being of individuals, families, and communities through its work and advocacy. NASW has long advocated that an essential component of eradicating health inequities is addressing the social determinants of health. Social determinants include a person’s socioeconomic status, geographic location, employment conditions, access to health care, ethnicity, and personal behaviors.

We offer, for your consideration, the following recommendations to strengthen the data collection standards to reduce health disparities and begin data collection for LGBT populations.

1) **Include questions that address socioeconomic status and geographic region.**

NASW affirms HHS’ proposed data collection standards and encourages HHS to include in its collection questions about socioeconomic factors and geographic region. A 2010 Center for American Progress report, *Measuring the Gaps: Collecting Data to Drive Improvements in Health Care Disparities*, identified inadequate data on a person’s socioeconomic status as one gap in understanding of the causes of racial and ethnic health care disparities. Measures of individuals’ socioeconomic characteristics, such as education attained or income, are useful to understand mediators of racial and ethnic disparities. In addition to income or education, a question about geographic region or locators (such as urban, suburban, or rural) or ZIP code could assist in determining factors that contribute to health disparities.
2) **Include questions to address behavioral, cognitive, mental, and physical ability.**

The current questions do not accurately identify all people with certain limitations. For example, behavioral and mental health, speech, developmental and learning conditions, as well as limitations associated with certain types of neurological conditions, need to be identified to determine disability status.

NASW supports the right of individuals with disabilities to affordable, accessible, and comprehensive health care. A revised question on disability will help address disparities faced by people with a wide variety of cognitive, physical, and behavioral and mental health conditions.

3) **Increase data collection research.**

As stated in the 2008 Institute of Medicine Report, *Toward Health Equity and Patient-Centeredness: Integrating Health Literacy, Disparities Reduction, and Quality Improvement*, stigmatizing practices in health care delivery, a lack of racial and ethnic diversity and cultural competence among health care providers, differences in health literacy between groups, and the failure to include minority populations in medical research produce a lower quality of health services for racial and ethnic minority groups (even after adjustment for socioeconomic characteristics and other access-related factors).

NASW recommends that more research is needed to understand how an individual’s race or ethnicity, disease status, sexual orientation, and other characteristics may influence physician decision making and the experience of minority groups during health care encounters. Measures must also include familial status, gender, sexual orientation, gender identity, disability (including physical, behavioral, mental, and cognitive abilities), socioeconomic status, religion, age, and geographic location.

4) **Expand data collection on LGBT populations.**

NASW applauds the Department’s plan to integrate questions on sexual orientation and gender identity into national data collection efforts. Developing high-quality data on the diverse LGBT population is essential if federal, state, local, and nonprofit agencies are to serve LGBT communities and individuals effectively. Improved data are also necessary to allow researchers to understand the health, economic, and demographic characteristics and needs of LGBT individuals and families.

Similarly, NASW recommends that the word “gender” should be expanded to represent female, male, or transgender and sexual orientation should include bisexual, gay, heterosexual, lesbian, or other. Asking questions about gender, gender identity, and sexual orientation are necessary for scientific, practical, and policy purposes.

Addressing cultural diversity, human rights, disparities and social and economic justice constitutes a core component of the social work curriculum and practice. NASW believes that the above recommendations will help the equitable delivery of health services for all people regardless of ability, age, ethnicity, gender, geographic location, race, religion, sexual orientation, socioeconomic status, or physical, mental, and cognitive ability.
Should you need any additional information regarding our recommendations, please contact my office at 202-408-8600.

Sincerely,

Elizabeth J. Clark

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