July 21, 2010

Senator Daniel Inouye, Chair
Senate Committee on Appropriations
Room S 128, The Capitol
Washington, DC 20510

Senator Tom Harkin, Chair
Subcommittee on Labor, Health and Human
Services
Senate Committee on Appropriations
Room S 128, The Capitol
Washington, DC 20510

Senator Thad Cochran, Ranking Member
Senate Committee on Appropriations

Re: Appropriations for data collection provisions to address disparities in the ACA

Dear Senators Inouye, Harkin and Cochran:

The undersigned organizations, dedicated to the eradication of health disparities and the promotion of health equity, are writing to express our strong support for the immediate implementation of Section 3101—Data Collection, Analysis, and Quality of the Public Health Services Act (42 U.S.C. 201, as amended by the Patient Protection and Affordable Care Act (ACA)). This section requires that, no later than 2 years after the date of enactment of the ACA, any federally conducted or supported health care or public health program, activity or survey (including Current Population Surveys and American Community Surveys conducted by the Bureau of Labor Statistics and the Bureau of the Census) collects and reports to the extent practicable data on race, ethnicity, sex, primary language, and disability status for applicants, recipients, or participants.

As the new health reform law is implemented, more individuals will obtain coverage and changes to the health care delivery system will improve quality. It is essential that data on race, ethnicity, sex, primary language, and disability status are collected to ensure disparities in health care access and quality are identified and addressed, and that programs are designed from the outset to serve the most vulnerable populations. The Institute of Medicine in its groundbreaking report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, included data collection and monitoring as a key recommendation to identify factors associated with health disparities, help health plans monitor performance, ensure accountability to enrolled members and payors, improve patient choice, allow for evaluation of intervention programs, and help identify discriminatory practices. Similar data collection provisions were included in the bipartisan health equity legislation, S. 1576 (Kennedy/Cochran)/H.R. 3333 (Jackson), and H.R. 3014 (Solis) introduced in the 110th Congress. This data collection is also a critical component for ensuring enforcement of Section 1557, the nondiscrimination provisions, of the ACA.

In order to facilitate the immediate implementation of Section 3101, we urge you to:

- **Strike the section that conditions implementation of Section 3101 on direct appropriation of funds.** Section 3101(g) authorizes such sums as may be necessary for each of fiscal years 2010 through 2014 for the purposes of carrying out Section 3101. However, the following section 3101(h) states that: "notwithstanding any other provisions of this section, data may not be collected under this section unless funds are directly appropriated for such purpose in an Appropriations Act." Subsection (h) is unnecessary and ostensibly blocks HHS from taking any steps to collect the critical data it needs to provide quality care for all communities and address disparities in health status. We urge you to include language in appropriations legislation to strike this provision so that there is no question that HHS may allocate existing resources and begin implementation immediately.

- **Appropriate $50 million in FY 2011 to begin implementation of Section 3101.** We recognize that to implement Section 3101, appropriate resources must be allocated either directly or as part of existing programs. We propose that $50 million be appropriated for implementation within the Agency for Healthcare Research and Quality (AHRQ), the Centers for Medicare & Medicaid Services and the Office of Minority Health, three agencies that play an integral role in addressing disparities and assuring high quality health care.

- **Adopt the Institute of Medicine standards for collection of ethnic subgroup and language needs.** Section 3101(a)(2) requires the Secretary to develop data collection standards including for sex, primary language, and disability status. In 2009, the IOM was commissioned by AHRQ to develop standards for collection of race, ethnicity and language data. The report, *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*, recommended variables for standardized collection of race, ethnicity, and language need, including that HHS develop and make available nationally standardized lists for granular ethnicity categories, and spoken and written languages, as well as rules for aggregating granular ethnicity categories to the broader OMB race and Hispanic ethnicity categories. These standards should be adopted by HHS for use by all public health and health care agencies that are either Federally supported or conducted.

Requiring that these data are collected, reported, analyzed and disseminated is consistent with the goal of transparency and accountability of the public health and health care systems. We urge you to prioritize the above recommendations through the appropriations process for FY 2011 and FY 2012.

Sincerely,

Aetna
Alliance for Prostate Cancer Prevention (APCaP)
American Association of Colleges of Nursing
American Association of People with Disabilities
American Association of University Women (AAUW)
American Association on Health and Disability
American Cancer Society Cancer Action Network
American Congress of Obstetricians and Gynecologists
American Dance Therapy Association
American Diabetes Association

American Heart Association
American Nurses Association
American Society of Transplantation (AST)
Americans for Democratic Action
Amputee Coalition of America
Asian & Pacific Islander American Health Forum
Asian Pacific Islander Caucus of the American Public Health Association
Association for Ambulatory Behavioral Healthcare
Association of Clinicians for the Underserved
Association of Language Companies
Association of Professional Chaplains
Association of University Centers on Disabilities
Autism Society
Bazelon Center for Mental Health Law
Bronx Health REACH
California Pan-Ethnic Health Network
California Public Health Association-North (CPHA-N)
California Rural Legal Assistance Foundation
Catholic Healthcare West
Center for Immigrant Healthcare Justice
Centro Binacional para el Desarrollo Indígena Oaxaqueño
CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder
Coalition on Human Needs
CommonHealth ACTION
Community Catalyst
Consumer Action
Council on Social Work Education
Defeat Diabetes Foundation
Disciples Justice Action Network (Disciples of Christ)
Easter Seals
Faithful Reform in Health Care
Families USA
Having Our Say Coalition
Hawai'i Public Health Association
Intercultural Cancer Council Caucus
Japanese American Citizens League
Ke Ali`i Maka`ainana Hawaiian Civic Club
Khmer Health Advocates, Inc
La Clinica del Pueblo
La Fe Policy Research and Education Center
Learning Disabilities Association of America
National Asian American Pacific Islander Mental Health Association
National Asian Pacific American Families Against Substance Abuse
National Asian Pacific American Women's Forum
National Association of Pupil Services Administrators
National Association of School Nurses
National Black Nurses Association
National Congress of the American Indians

National Council of Asian and Pacific Islander Physicians
National Council of Jewish Women
National Council of La Raza
National Education Association
National Health Law Program
National Latina Institute for Reproductive Health
National Minority Quality Forum
National Multiple Sclerosis Society
National Partnership for Women & Families
National Senior Citizens Law Center
National Women's Law Center
National Youth Advocacy Coalition
New Jersey Association of Pupil Services Administrators
Northwest Federation of Community Organizations
OCA
Out of Many, One
Papa Ola Lokahi, Native Hawaiian Health Board
Pennsylvania Prostate Cancer Coalition (PPCC)
Premier Healthcare Alliance
Raising Women's Voices for the Health Care We Need
REACH Charleston and Georgetown (SC) Diabetes Coalition
REACH Southeastern African American Center of Excellence for Elimination of Disparities
RESULTS
Society for Public Health Education
Society of Professors of Child and Adolescent Psychiatry
Southeast Asia Resource Action Center
Spina Bifida Association
Sullivan County Public Health Services (NY)
The Endocrine Society
The National Consumer Voice for Quality Long-Term Care
The Praxis Project