August 11, 2006

Citizens’ Health Care Working Group
Attn: Interim Recommendations
7201 Wisconsin Ave., Rm. 575
Bethesda, MD 20814
Submitted via email: citizenshealth@ahrq.gov

Dear Citizens’ Health Care Working Group:

The undersigned organizations are members of the HIV Medicare and Medicaid Working Group (HMMWG)—a coalition of organizations and individuals that provide HIV care, prevention and supportive services to persons living with HIV/AIDS (PLWH) across the U.S. We are writing to strongly endorse your recommendations published on June 1 that call for all Americans regardless of income to have access to affordable and comprehensive health care services.

The HMMWG works to protect and expand access to Medicaid and Medicare for PLWH, which together provide health care coverage to a majority of the PLWH in care. However, the disparate Medicaid eligibility requirements and the disability standard generally required of both programs leave many PLWH uninsured and with limited or unreliable access to comprehensive health care services until they become sick with AIDS.

Implementation of these recommendations would greatly reduce the health care disparities experienced by PLWH across the country. Under today’s current patchwork approach to health care, access to life-saving HIV/AIDS therapy and treatment so often unfairly depends on where people live.

We appreciate the Working Group’s thoughtful approach to outlining key tenets for strengthening and improving the current system. We offer the following comments in support of your recommendations.

- It is vital that a “core” benefit package is defined so that it meets the diverse health care needs of Americans. PLWH require a range of services to effectively suppress HIV, alleviate treatment complications and treat co-occurring conditions. Access to the appropriate services when they are needed prevent the use of more costly interventions, such as hospitalization. Recognition of limited resources in developing the “core” benefits package should mean providing early, effective, comprehensive and affordable care which is both cost effective and improves the lives of PLWH. “Shared social responsibility” should not be misconstrued to stigmatize PLWH and undercut efforts to control the spread of HIV.

- Protecting people from financial instability and impoverishment because they or a family member become sick and incur high health care expenses is essential to improving the value and effectiveness of our health care system. It is unacceptable that health care costs contribute to financial bankruptcy for so many in the U.S. For PLWH, this can mean being forced to choose between taking the medications that keep them alive or paying their rent. With this in mind, we recommend strengthening this recommendation by outlining specific measures to protect individuals such as caps on out-of-pocket expenses and other strategies with an eye to ensuring that low and middle-income Americans with multiple health care needs and costs are protected.

- Integrated networks, such as HIV centers of excellence, have proven successful at more effectively delivering quality HIV care and are models to consider when developing
integrated community networks. Coordinated networks are vital for addressing HIV as it presents often with other health conditions in need of concurrent care.

- Ensuring that people regardless of income are able to control the environment, care and support available to them at the end of their lives would seem a basic and humane component of any developed health care system. We strongly support this recommendation and the Work Group’s recognition of the significant reform needed with regard to how we finance and administer services at the final stage of the continuum of care.

We look forward to your final recommendations and thank the Working Group for its contributions to improving access to health care for all.

Sincerely,

AIDS Action, Washington, DC
AIDS Action Baltimore, Baltimore, Maryland
AIDS Foundation of Chicago, Chicago, Illinois
The AIDS Institute, Washington, DC
AIDS Project Los Angeles, Los Angeles, California
Advocacy Project, Houston, Texas
American Academy of HIV Medicine, Washington, DC
Community HIV/AIDS Mobilization Project / CHAMP, New York, New York
Dooley House, Inc., Camden, New Jersey
The Florida Keys HIV Community Planning Partnership, Key West, Florida
Gay Men’s Health Crisis, New York, New York
HIV/AIDS Law Project, Phoenix, Arizona
HIVictorious, Inc., Madison, Wisconsin
HIV Medicine Association, Alexandria, Virginia
Health and Disability Advocates, Chicago, Illinois
Housing Works, Inc., Brooklyn, New York
Human Rights Campaign, Washington, DC
Hyacinth AIDS Foundation, New Brunswick, New Jersey
International AIDS Empowerment, El Paso, Texas
JSAS Healthcare, Inc., Asbury Park, New Jersey
Lifelong AIDS Alliance, Seattle, Washington
L.A. Gay and Lesbian Center, Los Angeles, California
NAMES Project Foundation, Central New Jersey Chapter, Piscataway, New Jersey
National Alliance of State and Territorial AIDS Directors, Washington, DC
National Minority AIDS Coalition, Washington, DC
New Mexico POZ Coalition, New Mexico
Project Inform, Inc., San Francisco, California
San Francisco AIDS Foundation, San Francisco, California
South Carolina Campaign to End AIDS, Columbia, South Carolina
Title II Community AIDS National Network, Washington, DC
Treatment Access Expansion Project, Boston, Massachusetts
United Progress, Inc. (UPI), Trenton, New Jersey