

HIV Health Care Access Working Group

December 16, 2008

The Honorable Max Baucus
Chairman
Finance Committee
United States Senate
Washington, DC 20510

Dear Senator Baucus:

We are writing on behalf of the Health Care Access Workgroup of the Federal AIDS Policy Partnership, a coalition of more than 100 HIV/AIDS advocacy organizations and service providers. We would first like to applaud you for your ambitious proposal to reform the nation's health care delivery system with the goal of ensuring universal access to health insurance for all Americans. For persons living with HIV/AIDS (PLWHA), prompt access to quality medical care is critical to one's survival and to maintain a decent quality of life. Currently, far too many persons living with HIV in the U.S. remain unconnected to medical care, and in many areas of the country, publicly funded health care programs are unavailable to individuals until far too late. Your proposal offers hope for countless PLWHAs as many will finally have affordable access to medical care.

Regarding an urgent issue that demands attention, we applaud your efforts to address the countercyclical nature of Medicaid by tying the federal matching rate to a variety of economic conditions. Given the immediate economic crisis we express our strong support for a temporary increase in the federal matching rate.

We are writing to highlight key components of your proposal that are especially important to ensuring access to care and treatment for persons living with HIV. Many of these are critical to all individuals with complex health care needs, not just persons living with HIV.

1) Maintain and Strengthen the role of Medicaid

Medicaid is the single largest payer of health care services for persons living with HIV/AIDS and is a vital source of care. Estimates are that approximately 40% of all PLWHAs rely on Medicaid.

We applaud your proposal to mandate that states extend Medicaid to all individuals up to a defined income level. In most states, coverage for persons with disabilities is limited to those with incomes of around \$640/month (74% of poverty). It is time to raise the bar and ensure all low-income people with disabilities are guaranteed access to Medicaid. While we acknowledge that your proposal to cover all people below poverty through Medicaid represents important progress, we remain concerned that the high cost of HIV-related health care and the potential for unaffordable cost-sharing and out-of-pocket costs would leave many people above the poverty level vulnerable to inadequate access to lifesaving health care. Therefore, we ask you to consider modifying your proposal to cover low-income people through Medicaid up to a higher income level, such as 200% of the poverty level.

We also strongly support your proposal to eliminate the categorical eligibility requirement. Low-income individuals should not be forced to develop a disability to gain access to the health care that could have prevented the disability in the first place. This is particularly important to people living with HIV/AIDS who in most states must wait until they have progressed to an AIDS diagnosis and are therefore considered disabled before they qualify for Medicaid. Delaying

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access to care and treatment jeopardizes the lives and well-being of PLWHA and can be more costly to the health system.

As you may know, the HIV community has worked for many years for the enactment of the Early Treatment for HIV Act (ETHA, S. 860/H.R. 3326). If all people below 200% of poverty were covered through Medicaid, this would cover many uninsured people with HIV. At the same time, we believe there still remains a role for an ETHA state option in a reformed health system. We ask you to consider incorporating into your reform plan a Medicaid state option that would allow states to cover higher income pre-disabled people with HIV through Medicaid. This would give states the ability to extend Medicaid to people with HIV above whichever federal Medicaid income standard is established should states determine that low-income individuals, with HIV, with incomes higher than the new federal income standard, are best served by a Medicaid benefits package and cost-sharing system.

We also are supportive of your proposal to eliminate the five-year ban on legal immigrants accessing Medicaid. An effective response to the HIV epidemic requires that all persons residing within the U.S. receive appropriate care and treatment.

(2) Make Critical Improvements to Medicare

After Medicaid, Medicare is the second largest payer of health care for persons living with HIV with an estimated 100,000 PLWHA relying on it for access to health care, including prescription drugs.

We strongly support your proposal to phase-out the current disability waiting period. The current statutory requirement that individuals with disabilities must wait two years before becoming eligible for Medicare coverage is a major barrier to many persons living with HIV having reliable and continuous access to lifesaving care and treatment. The current delay in access to health coverage that is built into the Medicare program for people who are disabled is cruel and counter-productive. In the absence of access to care during the two-year period, individuals will become sicker and require more intensive medical interventions when they do finally qualify for coverage.

We ask that when considering fixes to the Medicare program, you allow expenditures made by AIDS Drug Assistance Programs (ADAPs) to count toward the True-Out-of-Pocket (TrOOP) limit. ADAPs are discretionary programs funded through the annual federal and state appropriation processes with 40 states contributing to their ADAP budgets. While ADAPs may wrap around Medicare Part D by helping people with HIV/AIDS cover their Medicare Part D cost sharing, their contributions are barred from counting toward the true out of pocket cost limit known as TrOOP. TrOOP is critical because it triggers the end of the coverage gap and initiates catastrophic coverage. The Congressional Budget Office scored a provision to allow ADAP and Indian Health Services (IHS) expenditures to count toward TrOOP at \$100 million over 5 years. Making this relatively inexpensive policy change would improve access to lifesaving medications for Medicare beneficiaries with HIV/AIDS and persons who receive services from the Indian Health Services (IHS).

We also ask that you consider legislative action to impose a nominal monthly cap on cost-sharing for people eligible for the low income subsidy (LIS) program within Medicare Part D. People living with HIV/AIDS generally depend on access to 8 to 14 prescriptions a month to suppress HIV, manage treatment side effects and co-occurring conditions. Co-payments and other cost sharing disproportionately burden people who are the sickest, the most in need of drugs and struggling to live on very low monthly incomes that range from \$600 to \$1,200. Even

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co-payments as low as \$3 and \$5 require them to spend a significant portion of their incomes on medications forcing them to make difficult choices between food, shelter and lifesaving health care and treatment.

(3) Reform the Private Health Insurance Market

We also applaud your proposal to make major changes to the way Americans can access the private market for health insurance and the responsibilities that plans would have under your plan. For many persons living with HIV, access to private market health insurance is prohibitively expensive and often not even possible, especially if one is seeking coverage as an individual and not through their employer or other group purchasing arrangement. In addition, provisions in most insurance policies against covering “pre-existing conditions” render policies meaningless for many persons living with HIV. In order for persons living with HIV to have access to private health insurance, it is critical that insurers are required to cover persons regardless of health status, not charge exorbitant premiums for coverage, cap total out-of-pocket spending and eliminate the practice of not covering pre-existing conditions. Only through these changes can persons living with HIV, as well as individuals with other health conditions, be able to enjoy the benefits of private health insurance.

(4) Promote Access to Population Based HIV Screening

We want to congratulate you for including prevention as part of healthcare reform and urge you to include coverage of routine voluntary HIV testing under Medicaid and Medicare. More than 20% of persons infected with HIV in the U.S. are unaware of their infection. Previously, access to HIV testing has been largely limited to circumstances when an individual is perceived to be at high-risk for HIV infection. Current CDC recommendations, however, call for routine testing in healthcare settings for adolescents and adults ages 13-64. We ask that ensure that HIV screening is available through your RightChoices Program and that you consider legislative actions to require reimbursement by public and private insurers for routine HIV screening, consistent with CDC recommendations.

(5) Strengthen the Clinical Workforce

We applaud you for recognizing the need to address the primary care workforce shortage in your proposal. We are facing a similar crisis in the HIV clinical workforce and are deeply concerned that this will soon serve as a barrier to people with HIV/AIDS having access to the level of HIV experience that is vital to successful management of HIV disease. We strongly support your proposal to expand existing programs, such as the National Health Service Corps, and to develop programs that devote special attention to increasing the number of racial and ethnic minorities that enter the healthcare workforce. We urge you to ensure the HIV medical workforce issues are addressed in developing the details of your proposal.

As you know, addressing inadequate reimbursement levels for primary care services and ensuring prompt payment is critical to shoring up Medicaid-based health care systems. This is particularly true for complex, chronic conditions, such as HIV disease, where the current reimbursement systems do not support the cost of providing care. We urge you to develop reimbursement systems under Medicaid, Medicare and private insurers that reflect the true cost of care for serious, complex, chronic conditions, such as HIV disease.

(6) Recognize the Critical Role of Community-Based Programs

The Ryan White program should continue to play an integral role in a reformed health care system. The Ryan White program has been vital in supporting the delivery of care, treatment and important social services through community-based organizations and clinics. Although in recent years these programs have struggled to meet the needs of uninsured and underinsured

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people living with HIV/AIDS, many have developed model programs for delivering high quality, comprehensive, coordinated care and services. Additionally, a major challenge of racial disparities in access to appropriate medical care remains very significant. The Ryan White programs have made an important contribution to building the capacity of racial/ethnic minority communities and other communities to provide primary medical care and other critical services that help bring into care underserved populations. It is critical for these programs to continue to play a role in the health care system and for the range of services provided by these programs to continue to be supported through Ryan White. Therefore, we ask you to support a continued role for the Ryan White programs in a reformed health system. We ask you to consider ways to facilitate the integration of the network of Ryan White-funded community-based providers into the broader health system, such as providing them with cost-based reimbursement and considering other ways to ensure that Medicaid programs and private insurers will build these providers into their networks.

We thank you for your ambitious proposal to reform the nation's health care delivery system and look forward to working with you on this critical issue in 2009. For more information on the issues contained in this letter please contact the HIV Health Care Access Work Group co-chairs Laura Hanen with the National Alliance of State and Territorial AIDS Directors at 202.434.8091 or Robert Greenwald with the Treatment Access Expansion Project at 617.390.2584.

Sincerely,

AIDS Action
AIDS Action Baltimore
AIDS Alliance for Children, Youth & Families
AIDS Foundation of Chicago
The AIDS Institute
AIDS Project Los Angeles
AIDS Treatment Data Network
American Academy of HIV Medicine
Community HIV/AIDS Mobilization Project
Gay Men's Health Crisis
Health and Disability Advocates
HIV Medicine Association
HIVictorious, Inc.
Housing Works
The International Community of Women Living with HIV
LA Gay & Lesbian Center
National Alliance of State and Territorial AIDS Directors
National Association of People With AIDS
National Minority AIDS Council
Project Inform
San Francisco AIDS Foundation
South Carolina Campaign to End AIDS
Title II Community AIDS National Network
Treatment Access Expansion Project
Village Care of New York