

HIV Health Care Access Working Group

June 10, 2009

Dear Representative:

We urge you to support the goal of expanding early access to affordable health care for all low income people with HIV by ensuring that the Medicaid disability requirement is eliminated and that states are given the option to further expand Medicaid access. We urge you to support the following health care reform priorities to ensure that health care reform does not leave out those most in need of better access to affordable health care:

1. Eliminate the Medicaid disability requirement to ensure that all low income individuals – including childless adults – have early access to affordable, quality care through Medicaid.
 - Eliminating the disability requirement will give hundreds of thousands of people living with HIV who are currently uninsured immediate access to life-saving health care through Medicaid.
2. Give states the option to further expand early access to Medicaid for low-income people living with HIV by having Early Treatment for HIV Act (ETHA) language included in health care reform.
 - If states opt into ETHA and expand coverage to families and individuals with income up to 200% of the federal poverty level, Medicaid coverage will be available to approximately 75% of people living with HIV who are currently uninsured.

The attached document outlines why the elimination of the Medicaid disability requirement and inclusion of the Early Treatment for HIV Act (ETHA) are top health care reform priorities of the HIV Health Care Access Working Group (HIVHCAWG). HIVHCAWG is a coalition of 84 national and community-based AIDS service organizations representing HIV medical providers, advocates and people living with HIV/AIDS and providing critical HIV-related health care and support services.

For more information, contact the HIVHCAWG co-chairs Laura Hanen of the National Alliance of State and Territorial AIDS Directors at 202.434.8091 or Robert Greenwald of the Treatment Access Expansion Project at 617.390.2584.

Respectfully submitted by the,

**HIV Health Care Access Working Group
Steering Committee**

AIDS Action, Washington, DC
AIDS Action Baltimore, MD
AIDS Alliance for Children, Youth and Families, Wash., DC
AIDS Foundation of Chicago, Chicago, IL
The AIDS Institute, Washington, DC
AIDS Project Los Angeles, CA
American Academy of HIV Medicine, Washington, DC
Community AIDS National Network, Washington, DC
Community HIV/AIDS Mobilization Project, New York, NY
Gay Men's Health Crisis, New York, NY
Health & Disability Advocates, Chicago, IL

HIV Medicine Association, Arlington, VA
Housing Works, New York, NY
Indiana Minority Health Coalition, Indianapolis, IN
Lifelong AIDS Alliance, Seattle, WA
National Alliance of State and Territorial AIDS Directors, Washington, DC
National Association of People With AIDS, Silver Spring, MD
National Minority AIDS Council, Washington, DC
New York AIDS Coalition, New York, NY
Project Inform, San Francisco, CA
San Francisco AIDS Foundation, CA
Treatment Access Expansion Project, Boston, MA

HIV Health Care Access Working Group

Strengthening Medicaid and Expanding Coverage for Pre-Disabled, Low-Income HIV Positive Individuals by Incorporating ETHA into Health Care Reform Legislation

As Congress and the Administration consider ways to overhaul the nation's health care systems, we urge them to ensure that low income people living with HIV and AIDS have early access to affordable, quality, comprehensive care through Medicaid. Early access to Medicaid-based comprehensive care would preserve health, prolong productivity and not force people into the untenable position of choosing between health care and work. This is a key principle of the Early Treatment for HIV Act (ETHA) (H.R.1616, S.833). Incorporating ETHA into broader reform efforts is critical to creating health care reform that will be meaningful and effective for people living with HIV.

To date, many proposals are considering modifying the current Medicaid program as one vehicle for health care reform. It is vital that improvements are made to the Medicaid program as part of the reform process to ensure that our country's low income residents with intense medical needs are not left behind. Medicaid has historically played, and must continue to play, a unique role in serving low income people with serious, chronic medical conditions. In particular, as opposed to private health insurance, its benefits and cost-sharing structures are better designed to meet the health care needs of low-income people living with HIV and AIDS. Unlike private insurance systems, its strength is in its ability to address ongoing health conditions like HIV disease, by providing consistent treatment and services in ways that specifically address the unique needs and circumstances of low income citizens.

Key components of the Medicaid program must be maintained through the reform process, such as the option to cover a wide range of vital benefits and services and beneficiary protections that prevent denial of services for inability to pay. Disparities in Medicaid reimbursement rates must be addressed and through the reform process states must be encouraged to cover a standard benefits package that includes critical services, such as prescription drugs and mental health and substance abuse treatment, without arbitrary and harmful limits being applied to these services. This type of comprehensive coverage is the standard envisioned by ETHA.

Some current health care reform proposals, supported by HIV/AIDS advocates, call for strengthening the Medicaid program and eliminating the categorical eligibility rule. In the context of HIV disease, categorical eligibility generally means that low-income people living with HIV disease must become disabled by AIDS before they can access care that could have prevented them from becoming disabled in the first place. Any meaningful health care reform legislation needs to include a provision enabling expanded, early access to Medicaid for low-income HIV positive individuals. Such a provision would remedy the current illogical situation that often forces people living with HIV to choose between work and health care. It would bring a critical federal health insurance program in line with federal treatment guidelines calling for early intervention and access to care, and would have both individual and public health benefits. This approach is an idea that advocates have put forth for years and is the core provision of ETHA.

In addition to eliminating categorical eligibility, major Congressional health care reform proposals consider expanding Medicaid's income eligibility standard nationwide to between 100% and 133% of the federal poverty level (FPL). While this is a step in the right direction to improve health care access, it is not enough. To be effective for people living with HIV disease, many of whom work in low-wage jobs, income limits would need to be expanded to 200% - 300% of FPL, another key principle of ETHA.

AIDS Drug Assistance Program (ADAP) utilization patterns reveal why expanded eligibility rules for people living with HIV are so critical: 74% of ADAP clients (low-income individuals living with HIV and AIDS who are otherwise uninsured or underinsured) have incomes at or below 200% FPL—with 42% at or below 100% FPL and 32% between 101-200% FPL.¹ These numbers demonstrate that by

¹ See, Kaiser Family Foundation and National Alliance of State and Territorial AIDS Directors, National ADAP Monitoring Project Annual Report, April 2009.

expanding Medicaid eligibility to at least 200% FPL, ETHA will dramatically increase access to secure health care for low-income people living with HIV and AIDS compared to current reform proposals. Further support for the importance of expanded access includes the ETHA-like Medicaid 1115 Waivers implemented in Massachusetts and Maine. Both programs expand eligibility rules for those living with HIV, with Massachusetts income eligibility at 200% FPL and Maine eligibility at 235% FPL. The higher income eligibility levels of these state-based HIV early intervention health care programs recognize that expanded access is necessary to maximize the benefits of early health care access to low-income HIV positive people who could not otherwise afford the high costs associated with HIV care and treatment.

Strengthening and expanding coverage under Medicaid in the current economic climate will require incentives to states. ETHA recognizes this and provides a model for how to do so. Under ETHA, states would receive an enhanced FMAP for Medicaid services provided to individuals only eligible for Medicaid under the ETHA option. These key aspects of the bill—no disability requirement, enhanced income eligibility and an enhanced FMAP to states—are modeled after the successful Breast and Cervical Cancer Prevention Act (BCCP Act) enacted in 2000. The BCCP Act provides immediate Medicaid coverage for women diagnosed with breast or cervical cancer at income levels higher than traditional Medicaid income eligibility levels, and provides enhanced FMAP to states for providing such access.

Expanding access to Medicaid coverage for early treatment of HIV disease will garner significant individual health, public health and economic benefits by:

- **maintaining wellness** through chronic disease management;
- **reducing the death rate** of persons living with HIV;
- **decreasing Medicaid spending and avoiding more costly medical interventions** that result when the disease progresses to an AIDS diagnosis;
- **reducing reliance on government income support programs** by keeping residents healthy and in the workforce;
- **addressing growing waiting lists** for access to life-saving medications and limited access to comprehensive health care in many parts of the country; and
- **slowing the spread of HIV disease** through both health care-supported behavioral change and reduction of viral load and transmissibility of HIV.

Lack of access to reliable health care services can be problematic even for healthy individuals. But going without consistent, comprehensive health care and prescription drugs is unduly risky for those who live with HIV disease—which is why HIV/AIDS advocates have been working to see ETHA enacted for nearly a decade. In light of recent CDC data showing that the rate of new HIV infections is growing nearly 40% faster than previously estimated, the need to enact ETHA is even more urgent. Congress appears poised to pass sweeping health care reform legislation this session, and it is only logical that ETHA be incorporated into such legislation. ETHA represents a necessary shift—as is being called for as part of health care reform more broadly—in the nation's health insurance and health services delivery paradigms toward early access to care and treatment, wellness maintenance, and coordinated comprehensive care. Failure to include ETHA into health care reform places the lives of low income people with HIV across the country at risk.

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