THE EARLY TREATMENT FOR HIV ACT: 
MEDICAID COVERAGE FOR PEOPLE LIVING WITH HIV

INTRODUCTION

The Early Treatment for HIV Act (ETHA) would allow states to extend Medicaid coverage to uninsured, non-disabled people living with HIV. ETHA represents a breakthrough in assuring early access to care for thousands of low-income, non-disabled people living with HIV. Currently, individuals with HIV must become disabled by AIDS and meet strict income and asset criteria in order to receive Medicaid coverage.

Medicaid is government health insurance, funded jointly by the federal and state governments and administered by state government. States have many options regarding who is covered by the program and what services are provided. Medicaid rules vary greatly from state to state, but for most people living with HIV, the path to Medicaid eligibility has been closely tied to strict Supplemental Security Income (SSI) disability rules. These rules reinforce a system where access to care and treatment lag far behind established medical standards of care for treating HIV.

Relatively new HIV/AIDS treatments, such as highly active antiretroviral therapy, are successfully delaying the progression from HIV infection to full-blown AIDS. These advancements have improved both the health and quality of life for many people living with this disease. However, without access to early intervention health care and treatment, these advances remain out of reach for thousands of non-disabled, low-income people living with HIV.

THE EARLY TREATMENT FOR HIV ACT (H.R. 2063, S. 987)

ETHA is the most comprehensive effort to date to address the early intervention health care needs of people living with HIV. The proposed legislation allows states to readily amend their Medicaid eligibility requirements to include non-disabled persons living with HIV.

The Traditional Medicaid Approach and ETHA’s Changes

Income/Asset Limits

Traditional Medicaid eligibility standards have two components – income/asset limits and categorical requirements. In general, Medicaid’s income and asset limits track SSI limits. Under current Medicaid rules an individual cannot have more than $2000 in assets, excluding a home (if the individual resides there) and a few other exceptions. There are no specific income limitations for Medicaid eligibility. In many states, however, if an individual’s countable income (i.e., income minus any applicable deductions) exceeds the SSI level (approximately $500-$700 per month), this

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will be considered surplus income and result in ineligibility for an equivalent value of medical expenses. So, for example, if a person had countable income of $1,000 per month, he or she would be presumed to have $300-$500 available for medical expenses.

While ETHA retains traditional asset limitations, it allows states to adopt significantly higher income limits. ETHA establishes minimum income guidelines for eligibility, yet allows states to set maximum income limits. In short, ETHA allows states to readily expand eligibility to uninsured, low-income, non-disabled people living with HIV and allows them to both earn income and receive Medicaid benefits.

Categorical Eligibility
In addition to strict income rules, the traditional Medicaid program also requires that people fit into a particular category to be eligible for coverage. People living with HIV/AIDS usually meet this requirement only when they are found to be “disabled” under the strict SSI definition of disability. The SSI definition of disability is “unable to engage in any substantial gainful activity by reason of a medically determined physical or mental impairment expected to result in death, or that has lasted or can be expected to last for a continuous period of at least 12 months.” Generally, this means that people with HIV are not eligible until their health has significantly worsened—often, until their disease has progressed to AIDS.

ETHA eliminates the need for people with HIV to meet this disability requirement by creating a new category of eligibility based solely on HIV status. Under ETHA, from the moment a person tests HIV-positive, he or she meets Medicaid’s categorical eligibility requirements.

Scope of Covered Services
As with the traditional Medicaid program, ETHA gives states tremendous flexibility to determine the scope of care and treatment services to be provided. All states must provide the following federally-mandated Medicaid services: inpatient hospital services, outpatient hospital services, laboratory and x-ray services, skilled nursing facility services, physician’s services, early and periodic screening, diagnosis and testing services and family planning services and supplies.

Federally-optional Medicaid services include the following: prescribed drugs, home health care services, nursing home services and intermediate care facility services, durable medical equipment, private day nursing services, clinical services, podiatry, dental services, physical, occupational and speech therapy, optometrists and hearing aids.

1 Non-disabled, low-income parents and children who meet the standards that were in place for the former welfare program Aid to Families with Dependent Children (AFDC) as of July 1996, and certain other pregnant women and children, automatically meet Medicaid’s categorical requirements.
While ETHA does not change the scope of Medicaid covered services, any successful early intervention plan must include coverage for medications, including highly active antiretroviral therapy. These drugs help preserve health, and thus reduce other health care costs, such as hospitalizations associated with opportunistic infections.

Other Early Intervention Approaches vs. ETHA

States, with the cooperation of the Centers for Medicare and Medicaid, have attempted to implement other programs that offer early access to care and treatment to non-disabled people living with HIV. Of these efforts, the two most successful have been the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) and Medicaid Expansion through Section 1115 Waivers of the Social Security Act. While both of these programs have met with some success, ETHA represents a significant step beyond these efforts.

The Ticket to Work and Work Incentives Improvement Act
TWWIIA established the **Demonstration to Maintain Independence and Employment**, which was authorized for $250 million from fiscal year 2001 through 2006, to provide early delivery of Medicaid benefits to working people with potentially severe disabling conditions. The purpose of the demonstration is to cover individuals who have a specific physical or mental impairment that, without medical assistance, has the potential to lead to disability. These individuals are not eligible to receive Medicaid benefits under traditional Medicaid rules because they do not meet the SSI standard of disability.

The legislation requires that an individual participating in the demonstration be employed at least 40 hours per month throughout the course of his/her participation in the project. To date, four states have been awarded demonstration grant funding. Mississippi and Washington, D.C. have proposed to cover individuals living with HIV.

Medicaid Expansion Waivers
Section 1115 Medicaid Expansion waivers enable states to provide Medicaid to non-disabled persons living with HIV, whether or not they are working, under state-set income and asset guidelines. Although not required by law, it has been the federal government’s policy that such waivers must be “budget neutral” within a five year time frame. This means that the program cannot result in increased federal Medicaid spending during the five years in which a given waiver is granted.

To expand coverage to people living with HIV through an 1115 waiver, states must show that the increased costs of earlier treatment access are offset by cost reductions created by prolonging health and delaying disease progression. To date, Massachusetts, Maine and
Washington, D.C. have submitted successful waiver applications.\(^2\) Georgia has an application that is awaiting final approval.

**ETHA’s Improvements**
ETHA does not include many of the restrictions that seriously limit the effectiveness of both TWWIIA and Medicaid expansion waivers. ETHA is not a demonstration project with limited funding or of limited duration. Upon passage of ETHA, every state can immediately implement the program. ETHA includes no requirement that participants be working. There are no requirements that a state demonstrate budget neutrality within the Medicaid program in order to implement the program. Finally, ETHA eliminates the need for the burdensome process of applying for a state waiver or demonstration project. In short, ETHA allows all states to easily expand eligibility to low-income, non-disabled people living with HIV.

**LEGISLATIVE HISTORY**
ETHA is modeled after the successful “Breast and Cervical Cancer Prevention and Treatment Act of 2000”, which allows states to provide early intervention access to Medicaid to women with breast and cervical cancer.\(^3\)

ETHA was originally filed in the House of Representatives of the 106\(^{th}\) Congress with sixty-one co-sponsors. Representative Nancy Pelosi (D-CA) and House Minority Leader Richard Gephardt (D-MO) were the lead co-sponsors of the bill. Immediately after its introduction, the Presidential Advisory Council on HIV/AIDS and most major national AIDS organizations came out in support of the bill. Time constraints, reauthorization of the Ryan White CARE Act, and election-related activities all worked against securing passage of the bill.

ETHA was reintroduced in the 107\(^{th}\) Congress. It was reintroduced in the House by the original lead co-sponsors and with 110 other co-sponsors. The bill now has 152 co-sponsors in the House, and is currently in the House Energy and Commerce Committee’s subcommittee on Health. Identical ETHA legislation was filed in the Senate, with Senators Robert Torricelli (D-NJ), John Kerry (D-MA) and Gordon Smith (R-OR) as lead co-sponsors. The Senate bill currently has 11 co-sponsors and is in the Senate Finance Committee.

**THE BENEFITS OF THE EARLY TREATMENT FOR HIV ACT**
As HIV moves increasingly into low-income, underserved communities, there is a pressing need to eliminate barriers to early intervention health care and drug therapy for vulnerable populations. ETHA creates a systemic approach to eliminating such barriers by providing

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\(^2\) The Massachusetts program went into effect in April 2001 enrolled over 750 people living with HIV in the first year of operation. The Maine program went into effect in July 2002. The Washington, D.C. program is expected to go on-line in the winter of 2002.

\(^3\) Forty-five states have amended their categorical eligibility requirements to implement this initiative.
substantial health benefits at affordable cost. By delaying the progression from HIV to AIDS, not only is the health and quality of life of individuals living with HIV greatly improved, but savings in treatment costs are realized.

Many studies demonstrate that the amount of HIV in the blood (HIV viral load) is a predictor of HIV disease progression and survival. By reducing viral load, which can be achieved through early access to highly active antiretroviral therapy (HAART), disease progression is slowed. Studies also show that lowering viral loads improves the quality of life for non-disabled people living with HIV, by reducing the number of opportunistic infections and increasing the numbers of years lived. Finally, early access to care and treatment, and specifically the use of HAART, have proven to be cost-effective and clearly result in significant improvements in survival and quality of life.

Delaying the progression from HIV to AIDS also saves treatment costs, since treatment costs are the highest between an AIDS diagnosis and death. Studies indicate that HAART can significantly lower the costs of patient hospitalization, community care, terminal care and the costs of treating opportunistic infections. The results of these studies range from a finding that, with the introduction of HAART, healthcare expenditures decline, to a finding that increased drug costs are offset by savings in non-drug services.

There are several other additional benefits to providing non-disabled people access to Medicaid. Lower viral loads, through the early introduction of HAART, are associated with a decreased likelihood of HIV transmission. Thus early treatment has significant prevention benefits. Additionally, expanded Medicaid coverage can ensure continuous access to medications, reducing the likelihood of developing resistance to existing drugs. This represents a significant benefit to both individuals and the general population, as drug resistant strains of HIV reduce positive health outcomes and increase the long-term costs of care. Finally, cost savings beyond health care will be realized. Increased tax revenues will be

4 With the introduction of HAART, the number of patients with undetectable viral loads increased from 6% in 1996 to 56% at the end of 1997. See Lapins, et al., Cost of Care for HIV Infection in a Managed Care Population From 1995-1997, The American Journal of Managed Care, 2000.

5 The Lapins study demonstrated that, with the early introduction of HAART, there was a reduction in mortality from 4.8% in 1995 to less than 1% in 1997. See Lapins, supra, note 4. Also, a more recent study found that a three-drug HAART regimen increases the quality-adjusted life expectancy by 1.38 to 2.67 years. See, Freedberg, et al., The Cost Effectiveness of Combination Antiretroviral Therapy for HIV Disease. N Eng J Med, 2001.

6 This study concludes that HAART is more cost-effective than many other therapies including radiation therapy for early-stage breast cancer or treatment of hypercholesterolemia. See, Freedberg, supra, note 5.


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generated, and SSI and disability insurance costs will be reduced, as individuals continue working and disability is delayed.

CONCLUSION

The Early Treatment for HIV Act addresses a cruel irony in the current Medicaid system—that is, that people must become disabled by AIDS before they can receive the health care that could have prevented them from becoming so ill in the first place. ETHA would bring Medicaid coverage into line with medical standards of care for HIV disease, by providing access to early intervention and treatment. ETHA would also help eliminate the disparities in access to care suffered by many traditionally underserved populations.

By preserving the health of people living with HIV, preventing opportunistic infections, and slowing the progression to AIDS, ETHA could ultimately save taxpayer dollars. If ETHA can garner the bipartisan support needed to become law, the United States will take an important step towards ensuring that all people living with HIV can get the medical care they need to stay healthy for as long as possible.