

Early Treatment for HIV Act: Expanding Care through Medicaid

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Introduction

The Early Treatment for HIV Act (ETHA) is proposed legislation that was originally introduced in the 106th and 107th Congresses, and has been reintroduced in the 108th Congress.^{i,ii,iii} ETHA, if passed, will provide states the option of expanding Medicaid coverage to individuals living with HIV. The proposed legislation is modeled after the Breast and Cervical Cancer Prevention Treatment (BCCPT) Act of 2000. The BCCPT Act amended Title XIX of the Social Security Act giving states the option of expanding Medicaid coverage to women who were found, through early intervention programs, to have breast or cervical cancer. Thus it provided these women with lifesaving medical care earlier.^{iv}

ETHA, in a similar manner, would provide resources to pay for early intervention, treatment, and health care for people living with HIV. Currently, most individuals with HIV/AIDS who qualify for Medicaid do so because they are certified as disabled. Usually, this certification comes after an individual has received an AIDS diagnosis. Unfortunately, this means that many of these people are too sick to benefit from current therapies, since, according to the standard of care guidelines, they are past the recommended point to begin treatment. Successful passage of ETHA would allow more HIV positive people to receive treatment at earlier stages of the infection.

Medicaid and HIV/AIDS

To understand ETHA, it is first important to review some of the basic components of Medicaid. Created in 1965 under Title XIX of the Social Security Act, Medicaid is an entitlement program that is jointly funded and administered by the federal government and the states. Unlike the spending for federal discretionary programs, such as the Ryan White CARE Act, federal Medicaid spending is not set in advance or on an annual basis by Congressional appropriations committees. There is no set limit on the amount of funding available each year to the Medicaid program, and there is no limit to the number of eligible beneficiaries. Actual Medicaid spending fluctuates with the cost of health care and with the number of people enrolled, which depends on a variety of factors including the poverty rate.

Medicaid covers three main groups of low-income Americans: the elderly, the disabled, and parents and children. Individuals who meet this and other eligibility criteria are entitled to have their respective states make

payments on their behalf for certain covered services. State participation in Medicaid is voluntary; since 1982, however, all states have elected to participate. States are entitled to matching funds from the federal government for their costs in covering eligible individuals, and the federal government pays at least one half of Medicaid costs through a Federal Medicaid Assistance Percentage (FMAP). The FMAP is a matching rate paid to states to reimburse the Medicaid expenditures. By law, the FMAP cannot be lower than 50 percent or greater than 83 percent of a state's Medicaid expenditures.^v

All states provide Medicaid coverage to individuals who meet specific income and asset requirements. Typically, income requirements are below 133 percent of the federal poverty level and asset levels are capped at \$2,000.^{vi} States must offer a basic benefits package that is outlined by federal law and falls under broad, general guidelines. These guidelines stipulate that each state must establish its own eligibility requirements; determine the type, amount, duration, and scope of services; set the payment rate for services; and administer its own program.^{vii} Although Medicaid benefits vary greatly from state to state, all state Medicaid programs cover some level of hospital, physician, nursing home, prescription drug, and long-term care services.

Medicaid is a vital source of healthcare for people with HIV. It is estimated that the program covers 55 percent of all people living with AIDS and 90 percent of all children living with AIDS who are receiving medical care.^{viii,ix} In fiscal year 2003 (FY 03), the federal government spent \$4.8 billion on AIDS care through the Medicaid program.^x As the largest direct payer for medical care for people with HIV/AIDS, Medicaid is a critically important program. Yet despite its importance, the structure of the Medicaid program is often ill-suited to meet the needs of people living with HIV/AIDS. Further, not all poor Americans with HIV are currently eligible for health care under the Medicaid program, since income is only one test for Medicaid eligibility. Most people living with HIV/AIDS who qualify for Medicaid do so because, in applying for Supplemental Social Security (SSI), they have been determined as disabled. Qualifying for SSI payments requires individuals to meet the definition of disability as put forth by the Social Security Administration—the federal agency that administers SSI. This definition states that an individual must be unable to

engage in “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.”^{xi} Social Security pays only for total disability. No benefits are payable for partial disability or for short-term disability. For most people living with HIV, the Social Security disability definition means that they will not be eligible for services until their immune systems have declined to the point of an AIDS diagnosis and/or they are no longer able to work.

The requirement of the Social Security Administration to have a “disability status” to qualify for Medicaid results in a dilemma for most people living with HIV. Current federal guidelines call for early access to medical care and treatment, including the use of combination antiretroviral therapy.^{xii} These advancements in treatment along with the use of antiretroviral therapies come at a high price. Treatment with antiretroviral therapy costs between \$10,000 and \$12,000 annually, and the cost of monitoring patients and other services related to antiretroviral therapy rises to \$18,000 to \$20,000.^{xiii} Low-income individuals, many of whom are uninsured or underinsured, are making up greater portions of the epidemic. Yet they are simply unable to access and pay for these life-prolonging medications.

There have been many attempts, both administrative and legislative, to decrease the limitations of Medicaid for people living with HIV/AIDS. These attempts, however, have been generally unsuccessful.

Several administrative options have attempted to expand Medicaid coverage to people living with HIV but they have severe limitations. One of these options is the Section 1115 waiver of the Social Security Act.

Section 1115 permits the Secretary of the U.S. Department of Health and Human Services to authorize demonstration projects which are likely to assist in promoting the objectives of Medicaid through the use of waivers to parts of the Medicaid program.^{xiv} These waivers allow states to create demonstration projects that explore new Medicaid policies and uses, including expanding eligibility to those who might not otherwise be entitled to Medicaid. In 1997, the Clinton Administration began to encourage states to explore the use of Section 1115 waivers to meet the needs of specific populations, including individuals living with HIV/AIDS, through a broadening of Medicaid eligibility. To date, ten states have applied for Section 1115 waivers to expand Medicaid coverage to people living with HIV who are not legally considered disabled, but otherwise meet state criteria for Medicaid eligibility. Only two of the nine states

(Massachusetts and Maine) and the District of Columbia have received final approval, however.

Another administrative program exists through the Ticket to Work and Work Incentives Improvement Act of 1999.^{xv} Title II of this legislation required the Secretary of the U.S. Department of Health and Human Services to establish demonstration projects (funded with \$250 million over six years) under which states could provide benefits similar to Medicaid’s to workers with potentially severe disabilities—conditions that, as defined by the states, are reasonably expected to cause a level of disability that meets Social Security’s requirements.

Title II of the Ticket to Work Act of 1999 also created two new state Medicaid options. These new options extended benefits to disabled workers who no longer qualify for Social Security benefits, due to improvements in their health status. These workers include: 1) any individual aged 16-64 who is working (or engaged in another defined work activity) at least 40 hours per month; and 2) any individual who ceases to be eligible for Medicaid because of health improvements identified during a disability review, but who nevertheless has severe and ongoing impairment. If a state exercises this option, working individuals with disabilities are no longer at risk for losing Medicaid benefits. This option is currently pending until the Center for Medicare and Medicaid Services (CMS) issues new regulations.

While there have been several options to expand Medicaid coverage for individuals living with HIV/AIDS, the optional nature of the Ticket to Work legislation and the budget neutrality requirements of 1115 waivers have ultimately left many low income individuals living with HIV/AIDS unable to qualify for health care under Medicaid. The result is that many of these low-income individuals do not have access to public or private health insurance and are increasingly relying on services provided through Ryan White CARE Act programs.

ETHA Legislation

ETHA was introduced in an attempt to provide treatment earlier in the course of HIV disease progression for low income Americans living with HIV. This bill has been introduced in three successive Congresses and it has gathered increasing support. In the 108th Congress ETHA was introduced in the Senate by lead sponsors Senator Gordon Smith (R-OR) and Senator Hillary Rodham Clinton (D-NY) and it currently has 19 additional co-sponsors (2 Republicans and 17 Democrats). In the House, the bill was introduced by lead sponsors Representative Nancy Pelosi (D-CA) and Representative James Leach (R-IA) and it currently has 89 additional co-sponsors (23 Republicans and 66 Democrats).

ETHA provides a more comprehensive approach to expanding Medicaid for people living with HIV than

either the Ticket to Work Act or Section 1115 waivers. ETHA would allow non-disabled individuals access to Medicaid by creating another category of eligibility based solely on HIV status. While ETHA would not change the traditional asset limits, it would allow states to adopt higher income limits for persons with HIV. Ultimately, all low-income individuals who meet a state's financial eligibility requirements would be eligible for Medicaid benefits from the moment they test positive for HIV.

One of the most important advantages of ETHA to people living with HIV is the optional prescription drug benefit that all states currently provide under Medicaid. Access to prescription drugs, specifically antiretroviral therapies, preserves the health of individuals living with HIV and reduces other health care costs associated with opportunistic infections and other co-morbidities. Further, expanding Medicaid through ETHA would transition a number of individuals to the Medicaid system, freeing up additional resources from other public programs such as the AIDS Drug Assistance Program (ADAP).

States will also benefit directly from ETHA because the legislation provides an enhanced FMAP for HIV/AIDS care. This means that states will receive a higher reimbursement from the federal government to provide HIV/AIDS related care and will expend comparatively fewer dollars on Medicaid than the rate for general disability status. Further, state Medicaid programs have the potential to purchase discounted antiretroviral drugs at lower cost than ADAP.

In 1990, Congress passed the Omnibus Budget Reconciliation Act (OBRA), which attempted to limit the price state Medicaid programs would pay for prescription drugs. OBRA created a statutory rebate program for the drugs that Medicaid purchases, which is known as the Medicaid rebate. For generic drugs, the statutory discount is 11 percent off the average manufacturer's price as reported to CMS. Name brand drugs (or innovator drugs) are purchased by the Medicaid program at a 15.1 percent discount.^{xvi}

Ultimately, ETHA would eliminate some of the barriers that low-income, uninsured individuals living with HIV face in accessing health care and prescription drugs. By creating an additional Medicaid eligibility category, ETHA would offer substantial health care benefits at an affordable cost for people living with HIV. Further, ETHA could serve as an early intervention program by encouraging people to seek health care and by delaying the progression from HIV to AIDS. In this way, ETHA could improve the quality of life for individuals living with HIV and save on treatment costs.

Health care costs associated with HIV/AIDS are highest between the onset of full-blown AIDS and death.

Under ETHA, Medicaid could provide treatment that would offset costs associated with non-drug services related to an AIDS diagnosis. Further cost savings beyond health care would also be possible under ETHA. Tax revenues would be maintained and SSI and disability insurance costs would be reduced since individuals could continue to work and disability status would be delayed.

Concerns

If ETHA were to become law, it would have the potential to alleviate many of the challenges faced by low income individuals, especially achieving access to health care. However, concerns arise regarding the legislation's limitations and its ability to have a positive impact on health care for individuals with HIV/AIDS. Further, implications arise with the cost of Medicaid expansion, availability of prescription drugs, and the national health care system.

- The passage of ETHA by Congress would not guarantee or ensure that non-disabled individuals living with HIV would receive Medicaid in all states. To provide an incentive for states to include HIV infection as an optional category, an enhanced FMAP is included, which would grant additional dollars from the federal government to provide care for people living with HIV/AIDS.

- State matching dollars are required for Medicaid, and the availability of money for Medicaid expansion is limited, due to state budget constraints. Many states therefore are being forced to reduce their Medicaid benefits in order to balance their budgets. These reductions include lowering reimbursement rates to providers and decreasing or eliminating some prescription drug benefits. The enhanced FMAP could alleviate some of the strain, but opening the Medicaid rolls to individuals living with HIV would place further pressure on already-burdened state budgets.

- The reliance of HIV care on antiretroviral therapy is an increasing concern for state Medicaid programs. Prescription drug benefits are optional, and although all states have elected to provide some form of prescription drug benefit, these benefits are limited. Some states restrict coverage to only a few prescription drugs (as few as three per month); others limit the amount of medication prescribed, the number of refills allowed, or total drug expenditures—known as a per capita cap. In addition, as a result of budget shortfalls, many states are first requiring generic drug use (currently, no antiretroviral drugs have generic versions) and prior approval by Medicaid for certain name-brand prescriptions (or for more than 4 prescriptions per month). These cost-saving measures attempt to limit the expenses that Medicaid programs pay. Given, however, that many HIV positive individuals

require four or more prescriptions in combination each month, these limitations pose serious difficulties.

▪ ETHA cannot replace the Ryan White Care Act because individuals living with HIV often require case managers to assist with adherence to drug regimens, psychosocial support, and other concerns. Medicaid programs act solely as a health care benefit and do not directly provide ancillary services; whereas the Ryan White CARE Act does.

Conclusions

In accessing health care through Medicaid, the greatest challenge for low-income individuals living with HIV is the meeting the program's limited eligibility requirements. The only avenue of eligibility that is currently available for many HIV positive people—no matter what their poverty level—is total disability status, as determined by the Social Security Administration. This requirement, which forces people to wait until they are disabled by AIDS to get help, robs many low-income individuals of the benefits provided by advances in HIV treatment. These advances prevent the decline of the immune system and the infections that result from this decline. Medicaid has been and will continue to be a vital part of this nation's ability to care for impoverished individuals with HIV/AIDS; however, long term strategies to improve the public health system must be incorporated into the plan.

Passage of ETHA must not supplant continued support of CARE Act programs. Instead, it should complement these services. By freeing up dollars from CARE Act programs, such as ADAP and Title III community services, ETHA would allow health care access for more people. Further, those receiving health care through ETHA, and subsequently through Medicaid, would continue to rely on CARE Act programs to meet other critical needs.

Using a published model that has served as the basis for assessing Medicaid expansion in several states at state

option, researchers at the University of California, San Francisco have calculated that expanding Medicaid coverage to low-income individuals with HIV prior to disability would amount to an additional federal expense of \$393 million over a five-year period. Yet such an expansion would extend coverage to 18,000 people by the end of the five-year period.^{xvii} This expansion is quite cost-effective when compared to the \$10,000 to \$12,000 per patient it costs annually to pay for antiretroviral therapy and the \$34,000 it can cost annually to treat someone with advanced AIDS.^{xviii}

The anticipated social and financial benefit of the expansion is further bolstered by the success of the Breast and Cervical Cancer Prevention Treatment Act of 2000, which has, to date, been implemented by 48 states plus the District of Columbia. The widespread acceptance and implementation of the BCCPT Act shows that states are interested in expanding Medicaid coverage beyond the current federal mandate so that low-income individuals dealing with life-threatening illnesses can receive support. State-level demonstration projects have provided some relief to the low-income, HIV positive population, but the time limits imposed on these projects and budget constraints have severely limited their efficacy. ETHA's simplicity and permanency provide the best solution.

AIDS Action Position

- AIDS Action supports the passage of ETHA to allow states the option of extending Medicaid to people living with HIV who would not otherwise qualify.
- AIDS Action supports wide co-sponsorship of ETHA.
- AIDS Action believes it is critical to ensure that the optional prescription drug benefits provided under Medicaid are not limited for people living with HIV.
- AIDS Action believes that Medicaid expansion through ETHA must not supplant other programs providing care for people living with HIV/AIDS, including the Ryan White CARE Act.

ⁱ H.R. 1591/S. 902 (106)

ⁱⁱ H.R. 2063/S. 987 (107)

ⁱⁱⁱ H.R. 3859/S. 847 (108)

^{iv} Public Law No. 106-354 *Breast and cervical cancer prevention and treatment act of 2000*.

^v Centers for Medicare and Medicaid Services (CMS). (2002). *Medicaid Services* (Web page). <http://www.cms.gov/medicaid/mservice.asp> [retrieved: January 17, 2003].

^{vi} CMS. (2002). *Medicaid eligibility* (Web page). <http://www.cms.gov/medicaid/eligibility/criteria.asp> [retrieved: January 17, 2003].

^{vii} CMS. (2002). *Medicaid services* (Web page). <http://www.cms.gov/medicaid/mservice.asp> [retrieved: January 17, 2003].

^{viii} Bozette, S. et al. (1998). *The care of HIV infected adults in the United States*. *New England Journal of Medicine* (336) no. 26.

^{ix} Kates, J. (2004). *Financing HIV/AIDS Care a Quilt with Many Holes*. The Henry J. Kaiser Family Foundation.

^x Kates, J. (2004). *Financing HIV/AIDS Care a Quilt with Many Holes*. The Henry J. Kaiser Family Foundation.

^{xi} Social Security Administration. (2002). *What we mean by "disability"* (Web page). <http://www.ssa.gov/dibplan/dqualify4.htm> [retrieved: January 19, 2003].

^{xii} U.S. Department of Health and Human Services. (2000). *Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents* (Web page).

http://www.aidsinfo.nih.gov/guidelines/adult/AA_032304.html [Retrieved: June 3, 2004].

^{xiii} Kates, J. (2004). *Financing HIV/AIDS Care a Quilt with Many Holes*. The Henry J. Kaiser Family Foundation.

^{xiv} CMS. (2002). *1115 waiver research and demonstration projects* (Web page). <http://www.cms.gov/medicaid/1115/default.asp> [retrieved: January 16, 2003].

^{xv} Public Law No: 106-170. *Ticket to work and work improvement incentives act of 1999*.

^{xvi} Public Law No: 101-508. *Omnibus budget reconciliation act*

^{xvii} National Alliance of State and Territorial AIDS Directors. (2002). *Early treatment for HIV act of 2001 (S 987/HR 2063)*.

^{xviii} Feig, Kristy. (2002). *Study explores high cost of HIV care in U.S.* (Web page). <http://www.cnn.com/2002/HEALTH/conditions/07/10/aids.costs/> [retrieved January 22, 2003].