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This brief is based on a paper completed by Nicole Heidelberg during her internship at the American Public Health Association, Scientific and Professional Affairs, Summer 2003

## Access to Antiretroviral Therapy for HIV/AIDS in the United States

### Introduction

Advances in HIV/AIDS treatment over the last decade have greatly reduced AIDS-related mortality. For a quick update on HIV/AIDS trends in the U.S., visit the [Centers for Disease Control and Prevention Website](#). More comprehensive information is available at [HIV/AIDS Statistics and Trends](#). The introduction of protease inhibitors (PIs) in 1995 transformed an HIV positive diagnosis from a death sentence into a chronic disease. These drugs, when taken in combination with two other classes of drugs called reverse transcriptase inhibitors, make up a "triple drug cocktail," or highly active antiretroviral therapy (HAART) <sup>1</sup> The widespread use of HAART has allowed HIV positive individuals to live longer, healthier lives by significantly slowing the progression of the disease. Today, there are more people in the U.S. living with AIDS than ever before—an estimated 950,000.<sup>2</sup>

But these advances have not benefited all U.S. residents. Antiretroviral therapy is very expensive and is difficult for low-income people living with HIV/AIDS to obtain without assistance. The incidence of HIV is disproportionately high in low-income communities, particularly among African Americans and Latinos.<sup>3</sup> Federal programs created to finance health care for low-income individuals are not sufficient to cover all of the persons living with HIV/AIDS.

This paper describes the limitations of existing Federal health care programs for persons living with HIV/AIDS and explores policy options for reducing financial barriers to access. **Section 1** discusses each of the three programs and their limitations. **Section 2** describes policy options to expand Medicaid coverage.

### **1. Access to Antiretroviral Therapy and Health Care**

The majority of persons living with HIV/AIDS receive support for their health care through three federal

programs: Medicaid and Medicare—both entitlement programs—and the Ryan White CARE Act, a discretionary program.

### Medicaid

The Medicaid program provides full medical assistance for certain individuals and families with low incomes and limited assets. The program covers three main groups of low-income persons: the elderly, the disabled, and families.<sup>4</sup> Individuals who meet income-related requirements are entitled to free or discounted health care services. Although the Federal government establishes general guidelines for the program, specific Medicaid requirements are established on a state-by-state basis, and as a result, differ dramatically across the country. Typically, annual income requirements are approximately \$12,000, (133 percent of the federal poverty level<sup>5</sup>) and asset levels are capped at \$2,000.<sup>6</sup> Once an individual qualifies for Medicaid assistance, benefits provided range from in- and out-patient hospital and prevention services, and family planning programs, to early and periodic screening,

diagnosis, and treatment services. Medicaid covers many AIDS treatment-related drugs and drug-related care.<sup>7</sup> Medicaid is an entitlement program, which means that its funding and long-term existence is assured unless Congress changes the law. Mandatory spending increases or decreases with the need for services. Thus, if the cost of AIDS drugs goes up because of a research breakthrough, the federal funding under Medicaid should grow to allow the purchase of these drugs for Medicaid beneficiaries who need them.<sup>8</sup>

Medicaid is the largest direct payer of HIV/AIDS related care and a vital source of prescription drugs for infected low-income individuals who qualify. It is estimated that the program covers 55% of all people living with AIDS at some point in their lives and 90% of all children living with AIDS who are receiving medical care.<sup>9</sup> Yet despite its importance, limits to eligibility and drug coverage pose significant access barriers.

### Eligibility

Eligibility is dependent upon meeting *both* the income requirements and at least one of the other criteria (old age,

disability, and spouse and/or child dependency). Most people living with HIV/AIDS who qualify for Medicaid do so because they have met both the income and disability requirements. The Federal Social Security Administration is responsible for the definition of disabled<sup>10</sup> and determining eligibility. This is usually done in the process of applying for Supplemental Security Income (SSI).<sup>11</sup> To walk through the application process, visit [Disability & SSI](#). To be found disabled, 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.”<sup>12</sup> No partial disabilities are considered. **For most people living with HIV, this definition of disability delays eligibility for Medicaid services until their immune systems have declined to the point of an AIDS diagnosis and/or they cannot work, at which point they will most likely be too sick to receive the maximum benefit from treatment.**<sup>13</sup> Those persons with AIDS who do receive effective drug

regimens often face the loss of disability status (and related health care benefits) if their health improves or they return to work. The loss of health benefits and the cessation of the drug treatments in turn would lead to a relapse in the disease and possible immunity to drug treatment.<sup>14</sup>

### Drug Coverage

Medicaid prescription drug coverage often does not cover all the drugs needed for antiretroviral therapy. State budget shortfalls have forced many states to reduce their Medicaid benefits, including lowering reimbursement rates to providers and decreasing or eliminating some prescription drug benefits. Some states restrict coverage to only a few prescription drugs, as few as three per month – not enough to ensure effective HIV treatment. Other states have a per capita cap, which limits the amount of medication prescribed, the number of refills allowed, or total drug expenditures.<sup>15</sup> Antiretroviral therapy requires more prescriptions in combination each month than Medicaid provides in these states,<sup>16</sup> so beneficiaries must seek another source of drug assistance such

as the Ryan White Comprehensive AIDS Resources Emergency Act AIDS Drug Assistance Program (ADAP). For information on Medicaid programs in the 50 states, go to [State Medicaid Programs](#).

### Medicare

Medicare is the nation's largest health insurance program. Go to [Centers for Medicaid and Medicare Services](#) for information. Individuals aged 65 or older are automatically entitled to Medicare if they have worked at least ten years; others qualify after receiving Social Security Disability Insurance (SSDI) benefits. There are no income eligibility requirements.<sup>17</sup> Medicare covers nearly 40 million Americans--35 million 65 years of age or older and over 5 million disabled and under the age of 65.<sup>18</sup> Included among these 5 million disabled individuals are people living with HIV/AIDS. Most HIV/AIDS patients covered by Medicare cannot afford private insurance but have income levels above the Medicaid income eligibility cut-off. An exception would be the so-called Medicare-Medicaid 'dual-enrollees' who have both near-poverty level incomes and at least a ten-year

long employment record. Much like Medicaid, Medicare benefits include inpatient hospital services, physician services, outpatient hospital care, and medical equipment and supplies.<sup>19</sup> But the drug benefits differ.

Medicare is not considered an AIDS lifeline but is an increasingly important source of health insurance for people living with AIDS. Antiretroviral therapy has allowed more individuals with HIV to reach old age and therefore qualify for Medicare, heightening the program's importance for the AIDS community. An estimated 13-18% of HIV positive individuals either depend solely on Medicare for health care services or are dual enrollees.<sup>20</sup> Medicare's eligibility requirements and its drug coverage severely limit benefits for persons living with HIV/AIDS.

### Eligibility

People living with HIV/AIDS who are under the age of 65 are eligible for Medicare only if they have qualified for Social Security Disability Insurance (SSDI), which requires individuals to meet the Social Security Administration's definition of disability. SSDI usually requires individuals to

have worked at least ten years in order to qualify, with the exception of children, widows, and widowers over age 50 who are eligible for survivor's benefits.<sup>21</sup> People under 65 qualify for SSDI after the Social Security Administration determines that they are disabled, but federal law requires that individuals wait five months after a disability determination is made before receiving SSDI benefits. An additional *two years* must pass after receipt of SSDI benefits before Medicare can be received. This results in a two-and-a-half year wait before a disabled individual under 65 is eligible for Medicare<sup>22</sup>, a time lapse during which disease and disability progress.

### Drug Coverage

While Medicare pays for basic medical service, **it does not cover outpatient prescription drugs**. Medicare beneficiaries must purchase expensive supplemental insurance,<sup>23</sup> or, for those with HIV/AIDS, rely on services provided by the Ryan White CARE Act, both of which only pay for part of the cost of prescription drugs. Fully one third of Medicare beneficiaries have no drug coverage at all. Medicare also requires

significant cost sharing and has no limit on out-of-pocket expenses for other types of care.<sup>24</sup>

### Ryan White Comprehensive AIDS Resources Emergency Act (CARE)

The Ryan White Comprehensive AIDS Resources Emergency Act—a discretionary grant program—provides fixed dollar grants to states, metropolitan areas and other entities to provide medical and support services to HIV-infected persons. Title II of the CARE Act program created the AIDS Drug Assistance Program (ADAP), which provides low-income persons living with HIV/AIDS limited access to prescription drugs. For information on all Ryan White programs, visit [Ryan White CARE Act](#).

All state CARE Act programs determine eligibility requirements and drugs to be covered. All states require an individual to have a CD4 cell count less than 350 per ml in order to qualify for drug services,<sup>25</sup> the recommended level at which to start antiretroviral treatment. This is well above the level required for an AIDS diagnosis, which is 200 ml.<sup>26</sup> Clients do not experience the long process of applications and wait periods

as with Medicare and Medicaid. Income eligibility ceilings vary from \$8,000 (Arkansas and Utah) to \$30,000 (California, Hawaii, Rhode Island, Idaho).<sup>27</sup>

### **Budget Constraints**

ADAP programs are under-funded. As the number of poor people infected with HIV has increased, so has the demand for prescription drugs, resulting in almost all programs limiting access to treatment in some way: 17 states took funds from other CARE Act programs to fund drug coverage; 11 reduced the number of drugs covered, and 7 lowered the maximum income required to qualify.<sup>28</sup> 20% of people with HIV are uninsured<sup>29</sup> and can access treatment only through CARE Act programs. But treatment is often limited and short-term. Entitlement programs like Medicaid are more financially stable and provide a structure to offer consistent and complete health insurance for people living with HIV/ AIDS. The most effective way to allow people with HIV/AIDS to start antiretroviral therapy earlier is to expand Medicaid coverage. The Kaiser Family Foundation conducts extensive analyses of spending for all

aspects of the AIDS epidemic, both in the U.S. and globally. For current information about funding, visit [U.S. and Global Funding for HIV/AIDS](#).

## **II. Policy Options to Expand Medicaid Coverage for Antiretroviral Therapy**

### **State Waivers**

Waivers under Section 1115 of the Social Security Act may be used to expand Medicaid coverage to low-income people living with HIV/AIDS. These waivers allow states to create demonstration projects, including expansion of eligibility.<sup>30</sup> The Centers for Medicare & Medicaid Services (CMS) issues guidelines for developing Section 1115 demonstration waivers [1115 Waiver Research and Demonstration Projects](#).

Waivers are difficult to implement. To obtain a waiver for expanding coverage to HIV/AIDS clients, a state must show that future reductions in disability and subsequent health care costs that result from early treatment are equal to or surpass the cost of providing earlier treatment.<sup>31</sup> This barrier—the budget neutrality requirement—in combination with the optional nature of the waivers has prevented most states from using

this option. As of September 2003, Massachusetts and Maine were the only states to implement HIV waivers. Six others have considered either applying for waivers or have submitted proposals to the CMS.<sup>32</sup>

### Title II of the Ticket to Work and Work Improvement Incentives Act (TWWIIA) of 1999

Title II of [TWWIIA](#) seeks to remove the significant barriers to Medicare and Medicaid coverage for disabled persons who continue to work.

Specifically regarding AIDS, the legislation authorized funding for Demonstration to Maintain Independence and Employment grants. These grants provide funding (\$ 250 million over six years)<sup>33</sup> to states for demonstration programs that provide full Medicaid benefits to a targeted group of 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.<sup>34</sup> The demonstration programs would evaluate the effectiveness (in terms of productivity and quality of life) of preventing or delaying disabilities for a

targeted group.<sup>35</sup> This means people living with HIV would receive Medicaid benefits before the disease progresses to the point where they can no longer work, thereby maintaining their health and avoiding lost productivity.

Mississippi is initiating a [Demonstration to Maintain Independence and Employment Grant](#) in nine counties in the lower Mississippi River Delta where there is a relatively high occurrence of HIV/AIDS and limited health care resources. Up to 500 individuals aged 16 to 64 years old with a diagnosed HIV infection or a diagnosis of AIDS who are employed but do not meet the Social Security Administration’s disability eligibility requirements are able to participate.<sup>36</sup> While the program is not yet operational, it is expected to demonstrate that early medical and social interventions are key to delaying disease progression. Also, it will encourage individuals living with HIV to seek employment and maintain self-sufficiency as long as possible.<sup>37</sup>

Title II of TWWIIA 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 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.<sup>38</sup> The first option would allow individuals living with HIV/AIDS to go back to work without losing benefits. The second option would allow people living with AIDS to continue to receive treatment after losing disability status but before going back to work. This option is still pending until the CMS issues new regulations. Title II also extends *Medicare* benefits to individuals who return to work for a total of six-and-a-half years. It also permits an individual to suspend Medicare coverage if he or she receives access to employer-sponsored health insurance, or to reinstate it if the worker loses health care through their employer.<sup>39</sup>

### **The Early Treatment for HIV Act (ETHA)**

If enacted, ETHA would allow HIV positive, non-disabled individuals permanent 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. All low-income individuals who meet a state's financial eligibility requirements would be eligible for Medicaid benefits, including prescription drugs, from the moment they test positive.<sup>40</sup>

The Early Treatment for HIV Act provides a more comprehensive approach to expanding Medicaid for people living with HIV than either the Ticket to Work or Section 1115 waivers. Upon passage of ETHA, every state could immediately implement the program. ETHA includes no requirement that participants be working, nor is there a stipulation for budget neutrality within the state Medicaid program in order to implement the program. ETHA eliminates the need for the burdensome process of applying for a state waiver or demonstration project.<sup>41</sup> ETHA would allow all states to easily expand eligibility to low-income, non-disabled people living with HIV. Expanding Medicaid through ETHA would transition a number of individuals

to the Medicaid system, freeing up additional resources from other public programs such as ADAP.<sup>42</sup>

ETHA was first introduced in the 106<sup>th</sup> Congress. It was reintroduced in the 108<sup>th</sup> Congress (S. 847), and currently has 19 co-sponsors. To find out the status of Congressional legislation, go to <http://thomas.loc.gov>.

Researchers at the University of California, San Francisco have calculated that expanding Medicaid coverage to 18,000 low-income individuals with HIV who have not yet qualified for disability would amount to an additional Federal expense of \$393 million, which is cost-effective, considering that the cost of treating 18,000 patients with advanced AIDS is almost double.<sup>43</sup> Expanding health coverage could also encourage HIV testing and provide access for HIV positive individuals to medical care and other services, including prevention case management.

## LINKS

### General

- [CDC Division of HIV/AIDS Prevention](#)
- [NIH](#)
- [UNAIDS](#)
- [DHHS Minority AIDS Initiative](#)

### Advocacy

- [APHA HIV/AIDS Section](#)
- [AIDS Action](#)
- [AIDS Education Global Information Center \(AEGIS\)](#)
- [AIDS.org](#)
- [National Minority AIDS Council](#)
- [Project Inform](#)

### Policy

- [American Public Health Association  
HIV/AIDS Section  
Policies on AIDS](#)
- [Families USA](#)
- [Kaiser Family Foundation](#)

### Health Care Programs

- [Social Security Administration, Benefits for People Living with HIV/AIDS](#)
- [Medicare Coverage Database](#)
- [HIV/AIDS and Minorities: A Guide to Federal Programs](#)
- [Ryan White Care Act Programs](#)

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*Medigap programs are supplemental insurance programs that individuals can buy from private insurance companies to fill in Medicare's gaps and provide a more comprehensive benefit package. Three of the ten Medigap' benefit packages include limited prescription drug coverage that has a \$3000 annual limit on drug costs.*
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