

# Voice of Academia

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# Voice of Academia

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# Expanding Medicaid Coverage for Early Treatment of HIV-Positive Persons and Implications for Poverty Reduction

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## ABSTRACT

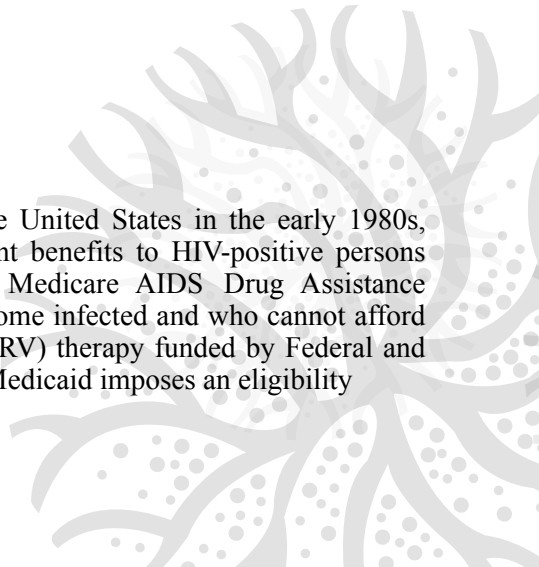
*This paper offers Medicaid assistance for early HIV/AIDS treatment as a case study in reform of the status quo administration of Federal and state health systems and undertakes to provide a compelling case for early care to low-income individuals with health needs. Since the outbreak of HIV/AIDS in the United States in the early 1980s, Medicaid (and Medicare) eligibility requirements restrict benefits to HIV-positive individuals who are completely incapacitated while access is deferred for those struggling in the interim before severe disability. De facto, HIV-positive Medicaid recipients – low-income sufferers and the majority of infected persons of color – experience shorter life expectancies and lower qualities of life than their privately-insured counterparts. Interventions addressing HIV-related illness among poor populations may also address an underlying cause of their low earnings, removing a barrier to work and encouraging employment by improving physical and emotional capacities as well as future life prospects.*

**Keywords:** HIV/AIDS, Medicaid, early treatment of HIV, Ryan White CARE Act

## 1. Introduction

### 1.1. Overview

Since the outbreak of HIV/AIDS in the United States in the early 1980s, Congress has extended in-kind treatment benefits to HIV-positive persons under Medicaid and, more recently, Medicare AIDS Drug Assistance Programs (ADAPs). People who do become infected and who cannot afford care eventually receive antiretroviral (ARV) therapy funded by Federal and state public health insurance; however, Medicaid imposes an eligibility



requirement mandating a demonstration of “severely disability” as a condition for receiving AIDS treatment. Medicaid (and Medicare) eligibility requirements restrict benefits to HIV-positive individuals who are completely incapacitated while access is deferred for those struggling in the interim before severe disability. De facto, HIV-positive Medicaid recipients – low-income sufferers and the majority of infected persons of color – experience shorter life expectancies and lower qualities of life than their privately-insured counterparts.

Unfortunately, the story of Medicaid coverage for HIV/AIDS among low-income populations in the United States is representative of Medicaid coverage for many other “disabling conditions.” That this paper undertakes to demonstrate the substantial potential gains to expanding access to early treatment for HIV symptoms should not be read as a “singling out” of HIV/AIDS to the exclusion of those illnesses also under covered by public insurance programs. On the contrary, this evaluation offers Medicaid assistance for early HIV/AIDS treatment as a case study in reform of the status quo administration of Federal and state health systems and undertakes to provide a compelling case for early care to low-income individuals with health needs.

Interventions addressing HIV-related illness among poor populations may also address an underlying cause of their low earnings, removing a barrier to work and encouraging employment by improving physical and emotional capacities as well as future life prospects. In particular, single mothers without access to health care and children of HIV-positive parents may benefit most from early ARV therapy through increased earnings. Recommendations include: (1) raising the clinical threshold for care to enroll HIV-positive individuals in the “interim” before severe disability in early drug therapy and (2) raising the eligibility threshold for earnings to include those earning at or below 250 percent of the Federal poverty line. Strategies for prevention outreach to disadvantaged populations of color and a discussion of macro (Federal- and state-level) and micro (individual-level) fiscal projections will locate these recommendations in the context of contemporary shifts in HIV infection and careful considerations of cost-effectiveness.

## **1.2. Research Methods**

An extensive literature review constitutes the substance upon which the analysis contained within this paper is built. Rigorous evaluations of the effectiveness of early HIV treatment and its cost-effectiveness for policymakers were given particular attention. Recommendations are situated, as far as possible, within the limitations of extant knowledge and relative to present policy.

## 2. Overview of Federal HIV/AIDS Legislation

### 2.1. Medicaid Eligibility

Antiretroviral therapy for HIV is recommended for all patients whose CD4 cell counts have dropped below 350 per mL, yet Medicaid-insured HIV-positive persons must wait to develop incapacitating physical symptoms before receiving treatment, though they meet clinical criteria for drug therapy. (Shapiro, 1999; Levi & Kates, 2000; Kahn, Haile, Kates & Chang, 2001) This population is not enrolled in treatment at critical stages in the progression of its viral load toward full-blown AIDS because eligibility for Federal- and state-funded care requires that symptoms be “severe enough” to jeopardize one’s capacity to work and to be self-sufficient (SSI for People Living with HIV/AIDS, 2009). To qualify for Medicaid or Supplemental Security Income, an HIV-infected person must be no longer able to earn at least \$700 per month as a result of disease complications (Graydon, T. Randolph, 2000). Thus people in the early stages of HIV, for whom early treatment clinically predicts the postponement of AIDS disability, “face the catch-22 of having eligibility [deferred] until they become disabled” (Kahn, Haile, Kates & Chang, 2001).

For persons whose HIV status has developed into full-blown AIDS (the fatal, final manifestation of HIV infection), Medicaid is the catch-all for end-of-the-line care. Medicaid covers 50 percent of all people and 90 percent of all children in the United States living with AIDS. The majority of HIV-infected people qualify for Medicaid several years after becoming infected because they are both poor and incapacitated; 70 percent of those eligible meet the criteria of being low-income and permanently disabled (Kaiser Family Foundation, 2009). An estimated 200,000 to 240,000 persons with AIDS are covered by Medicaid (Fleishman, 2005).

Since the 1990s, overall Federal and state spending on Medicaid-covered HIV/AIDS treatments has grown steadily in proportion to rising numbers of positive diagnoses, from \$3 billion to \$4.1 billion in 2000 (Health Care Financing Administration, 2000), while Medicaid expenditures on antiretroviral drugs almost tripled between 1996 and 1999 alone – increasing from \$68 million to \$160 million, representing the largest increase in ARV expenditures in the period since 1984 (Health Care Financing Administration, 2007). Total Federal spending on HIV/AIDS has grown enormously, and the FY2010 budget includes \$25.9 billion for HIV programs (Kaiser Family Foundation, 2009). Funding for Medicaid-covered ARV therapy has grown incrementally with reported infection rates, yet there has emerged a substantial cause for concern. What appears to show a decline in the rate of new infections may in reality describe a demographic shift in prevalence: previously, young, white



homosexual-practicing men comprised the highest proportion of infected individuals; now, black women and homosexual-practicing black males are at the center of the epidemic. As is discussed further below, these populations are “disconnected” from treatment services and are less likely to receive ARV therapy than whites, possibly accounting for the halt in the rise of outlays for treatment.

Despite the enormous increase in funding for HIV/AIDS-related programs, the majority of these increases continue to be “discretionary” – i.e., allocated to prevention and education efforts both within the United States and globally (Alagiri, Summers & Kates, 2002). Changes in Medicaid regulations have made meeting the requirements for receiving antiretroviral drugs increasingly difficult: In 1996, new welfare restrictions implemented under the Personal Responsibility and Work Opportunity Act (PRWORA) also limited the access to Medicaid for certain groups at-risk of HIV infection: women transitioned from “welfare to work” under the new Temporary Assistance to Needy Families (TANF) program lost the Medicaid coverage that was part of a pre-1996 Aid to Dependent Families with Children (AFDC) assistance package; regulations removing substance abuse as a disabling condition excluded injecting drug users from receiving HIV treatment by virtue of their addiction (Levi & Kates, 2000). Both of these populations find themselves at high risk, though recent rises in the infection rates of low-income women of color coupled with exclusion from access to Medicaid-funded early treatment and health-related attention that may identify HIV infection itself or drops in CD4 cell count could predict declines in life expectancy and health measures for low-income single mothers without health insurance.

## ***2.2. Medicare Coverage of HIV/AIDS***

The passage of Medicare Part D in 2006 brought substantial changes in coverage to the lives of many HIV-positive individuals previously covered by Medicaid. One quarter of the HIV-infected Medicaid-eligible population – 50,000 to 60,000 people – were transferred to Medicare Part D, ex-President Bush’s prescription drug plan (Piper Report, 2005). Demographics again account for part of this shift: low-income homosexual-practicing men who were infected in the early 1980’s have recently become “elderly” and eligible for Medicare drug coverage, though barriers to receiving drug assistance are differentially strict with respect to Medicaid coverage: harsher formulas determine need and increasingly complicated applications mediate access drug regimens (Piper Report, 2005). HIV-positive people under 65 may also qualify to receive Medicare benefits if (1) “they are deemed disabled due to a physical or mental impairment that prevents them from working for a year or more or that is expected to result in death” and (2) “they have earned enough work credits to receive SSDI [Social Security Disability Insurance] payments ... [after] a

5-month waiting period after becoming disabled before receipt of SSDI benefits and then a 24-month waiting period before an SSDI beneficiary can receive Medicare coverage, resulting in a total of 29 months before receipt of health benefits through Medicare for SSDI recipients” ( Kaiser Family Foundation, 2006).

At present, the Centers for Medicare and Medicaid Services estimate that Medicare costs for HIV/AIDS drug therapy exceeds Medicaid costs, through Medicaid remains the “gateway” to receiving coverage as those who qualify for Medicare drug assistance become eligible, first, by being identified as “severely disabled” by Medicaid criteria and, second, as “in need” of a specific drug regimen by Part D according to the standards described above for possessing an “impairment exceeding one year” and having waited the necessary 29 months (OMB, CMS Office of the Actuary, HHS Office of Budget, 2008). Equivalent disability restrictions apply for those who pass directly Medicare without being assessed for Medicaid eligibility.

The percentage of HIV-positive people who are covered by Medicaid and Medicare has not changed much since 1990. In 1990, 40 percent of HIV-infected people were covered by Medicaid (Kozak, McCarthy & Moien, 1993); by 1996, this figure had risen to 44 percent (Kaiser Family Foundation, 2006). In 2008, this number has not changed (Chang, 2009). Dual coverage under Medicaid and Medicare varies at the state level, yet the proportion of those covered under Medicaid consistently comprises the majority of cases for those enrolled in some form of public care (Kaiser Family Foundation, 2006). It is not the magnitude of the “safety net” that is at issue – Federal funding of Medicaid and Medicare amounted to \$4.1 billion and \$4.5 billion, respectively, in 2008 (Kaiser Family Foundation, 2009) – but rather the form in which it is extended. Postponement of eligibility until “severe disability,” coupled with the absence of regulatory compensations in coverage for rises in “new types” of HIV-infected populations among populations of color (discussed below), leave a worrisome delay in need-for-care and access to life-sustaining treatment.

### ***2.3. Ryan White CARE Act***

The focus of HIV policy has shifted to prevention. To complement the substantial treatment “safety net,” innovative outreach programs – funded by discretionary outlays - emerged in urban centers seriously affected by viral spread in the mid-1990s as aggressive prevention efforts. The Ryan White CARE Act was passed in 1990 to create a flexible source of funding for the changing requirements for intervention and treatment among low-income, uninsured persons affected by HIV/AIDS. The Ryan White Act “fills in the gaps” in treatment for disconnected HIV sufferers while providing financial

support to prevention and education campaigns targeted to at-risk populations (United States Department of Health and Human Services, Health Resources and Services Administration, 2009); funding for the Act has grown since 1990 as focus has shifted away from a Medicaid-based support system. State- and city-level AIDS Drug Assistance Programs (ADAPs) seek greater flexibility in provision of services to HIV-infected populations and HIV-affected geographic regions, most commonly high poverty urban centers like Detroit, Chicago, Los Angeles, and New York City.

Under Ryan White, the Federal government subsidizes states and private non-governmental organizations in efforts to reach those HIV/AIDS sufferers not enrolled in Medicaid and to promote awareness about the virus in affected communities. It is difficult to estimate the number of persons “covered under” Ryan White because prevention efforts, for example, extend to those already infected and in treatment as well as those who may pick up a provider’s pamphlet. However, states may “clientize” the Ryan White funds they receive to target services to HIV-positive individuals. In 2007, the State of North Carolina reviewed its services to Ryan White aid recipients and found that 7,891 patients were provided direct assistance, most often in the form of medical care (“N.C. Epidemiologic”, 2008). Funding for Ryan White in FY2008 amounted to \$2.2 billion, which was divided among states and then subdivided among programs dedicated not only to treatment but also to vaccine research, advertisements, education programs, and evaluations of current programs (HRSA, n.d.).

The Ryan White CARE Act does not invest in extending early treatment services to HIV sufferers but seeks to “connect” them to medical care centers once they have neared Medicaid eligibility. The “steering function” of Ryan White programs means that initiatives more often explore the effects of cultural stigma on an individual’s life with HIV/AIDS (Millbourne, 2009a) instead of addressing the gap in infection and access to treatment, with ambiguous implications for the HIV epidemic. When Ryan White-funded ADAPs do occasionally attempt to provide early drug access to patients, assignment of treatment is often ad hoc and scaled to community need – i.e., only the most needy may receive care; those making decisions about treatment must allocate Medicaid and Ryan White dollars to cover everyone in need, and more often than not funds are “woefully inadequate” (Cordena, 2004; Levi & Kates, 2000). The laudable “stopgap” functions have been under increasing stress as the “demands on Ryan White funding have increased” to meet the needs of those who are uninsured, requiring treatment, but not yet severely incapacitated by AIDS (Graydon, 2000).

In the end, funds are zero-sum: spending on ARV therapy for low-income HIV-positive individuals who will eventually end up on Medicaid may seem

like a poor investment compared to the possible gains to community prevention efforts or the equally necessary attention to “steering” recently-eligible people into care. However, the allocation of funds and energy to stigma and education effectually universalizes an encounter with “interim” disability for low-income uninsured HIV-positive people.

### **3. Medicaid and Living with HIV/AIDS**

#### ***3.1. Medicaid Coverage for Disabling Conditions***

The limitedness of Medicaid coverage for HIV/AIDS is not unique to the virus and its health effects; rather, “interim” illness and deferral of treatment until severe disability is symptomatic of most Medicaid services to low-income persons suffering from ailments. A 2008 study by Andrew B. Bindman, et al., finds that state requirements to demonstrate Medicaid eligibility itself caused 62 percent of Medicaid recipients to experience an interruption in care that predicts a higher risk of hospitalization for heart failure, diabetes, and chronic obstructive pulmonary disease (Bindman, Chattopadhyay, & Auerback, 2008). Persons living in poverty experience higher probability of hospitalization: those respondents receiving Temporary Assistance to Needy Families are found to be at a “hazard risk” more than two times the risk of the general population of Medicaid beneficiaries surveyed.

The issue is not that Congress is not allocating enough to diseases affecting low-income individuals who may qualify for Medicaid but that eligibility requirements prevent individuals in need from accessing vital care. While the “necessity” of care ultimately resolves itself as a clinical question, the health-related disadvantages of living at, below, or near the poverty line for sick persons offers a compelling case for reassessing the way in which access to care is presently extended.

Why HIV/AIDS? The focus of this paper on HIV seropositivity, the gains to early treatment, and the cost-effectiveness of eligibility expansion (discussed below) does not deprioritize the needs of HIV-negative Medicaid recipients suffering from other diseases but seeks to offer a particularized evaluation in the vein of what should, ideally, form part of a broader program of public health insurance reforms.

#### ***3.2. Limitations of Medicaid Coverage for HIV-Infected Persons***

Medicaid remains the primary care program for low-income HIV-infected persons; indeed, because the majority HIV-positive people are low-income (see footnote 7), Medicaid is the primary provider for all persons living with AIDS in the United States (Kahn, Haile, Kates & Chang, 2001). Despite its

inclusiveness for those whose viral load has progressed to full-blown AIDS, an HIV Cost and Services Utilization Study, beginning in 1996, found that HIV-infected persons enrolled in Medicaid fared worse (compared to privately-insured persons) in a nationally representative sample on six measures determinate of general health and access to basic HIV/AIDS treatment:

- (1) Fewer than two office or outpatient visits in 6 months
- (2) Emergency department visit without an associated hospitalization in 6 months
- (3) Hospitalization in 6 months
- (4) Did not receive PI or NNRTI therapy by December 31, 1996 if recommendations for treatment were met
- (5) Never received antiretroviral treatment
- (6) Did not receive prophylaxis in the last 6 months for pneumocystis carinii, a type of pneumonia to which persons with AIDS are susceptible, if CD4 count was less than 200 (Health care financing administration, 1996 - 1998).

Measures (4) – (6) demonstrate the comparative inaccessibility of ARV treatment to Medicaid beneficiaries. Measures (1) – (3) indicate that HIV-infected persons on Medicaid are generally sicker than those on private insurance plans – they are more likely to visit a doctor, emergency room, or hospital for HIV-related complications. The disparity between public-funded and private-funded HIV health care is a statistical function of eligibility criteria: fewer HIV-infected Medicaid beneficiaries were receiving treatment compared to HIV-infected non-beneficiaries because the progression of their disease did not yet qualify them for ARV regimens. That Medicaid recipients are also, on average, more prone to hospitalization indicates that beneficiaries experience more negative health shocks by virtue of their exclusion from early treatment. Moreover, because all those identified as “HIV-infected Medicaid beneficiaries” by HCSUS include also those already receiving ARV drug regimens through Medicaid, these findings additionally indicate that Medicaid-funded AIDS care for eligible recipients is inferior to private care. While qualitative disparity in public/private care exists for almost all disease treatments, the HCSUS’s finding demonstrating a lower probability of having ever received ARV therapy among AIDS sufferers is an is particularly troubling. This data indicates that low-income people diagnosed with full-blown AIDS are having their treatment deferred or that (as Bindman’s more general finding indicate) eligibility requirements interrupt the process through which drug regimens are obtained.

Medicaid has become an option of last resort in two senses: (1) for those whose HIV symptoms have finally qualified for benefits, and (2) for those

unable to access private care that meets the clinical standards for appropriate quality. Comparisons of the health of HIV-positive, privately-insured persons and that of publicly-insured HIV-positive persons reveals that the “sicker” one gets the more likely a person is to be covered by Medicaid than a private insurance plan. In a 2003 follow up study to the HCSUS survey Dana Goldman, et al., investigated

*“the impact of disease severity on insurance coverage, the investigators used HCSUS data to develop a model to adjust for factors (for example, race, sex, HIV exposure route, education, time since diagnosis, and lowest CD4 lymphocyte count) that might affect insurance outcomes. Their findings indicate that the probability of having private insurance falls gradually from about 0.37 with a CD4 count of 700 (the normal count for healthy people is usually 600-1200) to 0.23 as lowest CD4 count approaches zero. On the other hand, the probability of having public insurance rises dramatically from 0.36 to 0.67” (2003).*

A rule emerges in these analyses: low-income people living with HIV must wait until their symptoms become “so severe that they are disabled” (Levi & Kates, 2007). The qualification of disability is linked explicitly to earnings, and the level at which it is set (\$700/month) makes it paradoxically impossible for poor HIV-infected persons to pay for their own care in the interim. The de facto result is a system by which Medicaid coverage is withheld until an AIDS sufferer is no longer able to support herself/himself, with “self-sufficiency” being defined as earning an annual income of at least \$8,400 (\$700/month) – a standard \$2,430 below the official poverty threshold for a single earner, or (e.g.) for single mothers, \$6,170 (one child) and \$9,910 (two children) below the poverty line (Federal Register, 2009). For HIV-infected persons living at, marginally above, or below the poverty line, there exists no real support for early treatment, though HCSUS demonstrates its potential for preventing unexpected hospitalizations (and their associated costs) and despite the illogicalness of waiting until an AIDS sufferer’s income drops far below the poverty line before addressing the cause of her/his low earnings.

However, the counterfactual to the current “interim” delay is not immediately clear. The effectiveness of reformed interventions offering access to early care will largely depend on the efficacy of treatment itself; cost-effectiveness will also be variable to drug prices and number of new enrollees such a change would invite into care. Understanding the particular needs of HIV-positive, low-income persons will be essential to the recommendations extended below and should be an integral part of all reform efforts directed towards diseases affecting Medicaid recipients or potential Medicaid-eligibles.

The current health needs of the population of low-income, HIV-positive persons are directly related to the present gap in treatment. A 2000 study by Katz et al. evaluated the needs of a nationally-representative sample of HIV-infected persons, those receiving Medicaid or Medicare assistance, those on private insurance plans, and those whose care was covered under the Ryan White CARE Act. Respondents were asked to self-identify with five unmet needs: (1) income assistance or health care benefits (benefits advocacy), (2) a place to live (housing), (3) home health care, (4) mental health or emotional counseling (emotional counseling), and (5) drug or alcohol treatment (substance abuse counseling). Sixty-seven percent of respondents possessed at least one unmet need, and 34.6% lacked necessary income assistance or health care benefits (benefits advocacy need), with declining requirements for each need included in the list above. Most startlingly, only 60.3% of the sample had contact with a case manager in the past 6 months, meaning that only this percentage of HIV-positive adults were connected with a medical professional who was monitoring their health (Katz et al., 2000). Some variability was found across states as is common to Medicaid coverage in general. However, the nature of Ryan White funding, which is allocated based on perceived need, means that states with large, urban-based HIV epidemics receive more aid and show greater coordination among HIV-related interventions while states with rural populations of HIV-positive people are often particularly deprived of any meaningful care system.

### ***3.3. Disproportionate Disadvantage for HIV-Infected Persons of Color***

Disconnection is a serious problem for African American communities. HIV/AIDS infection rates have reached epidemic proportions among African American men and women. Urban populations of black men who have sex with men (MSM) have HIV prevalence rates between 24.2 and 37.8 percent (City of Chicago Department of Health, 2008); young black MSM aged 13-19 have seen their incidence of infection double since 2004 within the urban areas (Nikhil, 2009) - a rate more than twice that of white MSM (Centers for Disease Control, 2005). Hank Millbourne, Director of the AIDS Partnership of Detroit, asserts that “behaviors are just not lining up with knowledge about the disease” (2009b), and young black men are getting infected and avoiding much-needed treatment out of fear of stigma and exorbitant costs. Additionally, women of color living in areas of low socioeconomic status also find themselves the victims of a colluding combination of infection risks: high incarceration rates that deplete the pool of available males, sex for survival, and fluid sexual networks are prevalent in conditions of poverty. Black men and women nationwide are at “approximately ten times” greater risk for HIV infection than whites (Centres for Disease Control and Prevention, 2007). The racialized impact of HIV/AIDS, however, is not new. HIV prevalence in urban black communities boomed in the early 1990s when crack use and sexu-

ally transmitted infection rates remained absent from the Center for Disease Control's (CDC) AIDS interventions, creating a breeding ground for sexual interactions with high risks of infection (Levenson, 2004). Presently, 68 percent of HIV-positive females nationwide are African Americans, the majority of whom live below the poverty line (Ibid, n.d.).

William Julius Wilson's hypothesis predicting the exponential circulation of "poverty ills" in areas of concentrated disadvantage here appears to have a particularly pertinent application. Research suggests linkages between neighborhood factors – or "ecologic stressors" – and the rate at which HIV progresses into AIDS. Aiello, et al., report that "concentrated disadvantage, unequal income distribution, residential segregation, and poor quality of [one's] built environment" produce statistically significant, positively associated effects for the progression from HIV to AIDS through "stress-related hormonal changes" (2008). In the City of Detroit, 84 percent of people infected between the ages of 13 and 24 are black (Medical News Today, 2008). While no studies have yet attempted to measure prevalence specific to race within the City of Detroit itself (due to complications involving movement to and from the suburbs and the large intermixing of the suburban and urban gay male populations), Richard Lichtenstein, Ph.D., compared prevalence for one Eastside zipcode within the city (48213) to prevalence for the city as a whole and found that the HIV infection rate has over 10 percent higher (24.92 percent) than for the city population; this zipcode is almost entirely African American (Lichtenstein, 2007).

These findings attest to the influence of environmental factors in HIV-related health problems beyond those traditionally-conceived to originate from individual sexual behaviors, socioeconomic status, or genetic markers. Additionally, HIV-positive African Americans and Latinos are overall more likely to rely on Medicaid than HIV-positive whites (Kaiser Family Foundation, 2006; 2004): in 2003, 59 percent of African Americans with HIV/AIDS relied on Medicaid, compared with 32 percent of whites (Fleishman, 2002; Ruiz, 2003). Even within Medicaid African American HIV-infected Medicaid beneficiaries suffer greater disconnection from services: those eligible for HIV care on average enter treatment 8 months later and spend 8% less time on PI or NNRTI therapy than their non-Hispanic white counterparts (, Stephen, Sambamoorthi, Moynihan, & McSpiritt, 2001). Low-income HIV-infected African Americans on average are at higher risks for HIV infection and receive lower quality treatment on Medicaid than Medicaid recipient, HIV-positive whites. Addressing these disparities will require focusing special efforts on identifying differential racial characteristics attending to community composition, culture, and socioeconomic status that uniquely disadvantage this population to infection and exclusion from quality care.



#### **4. Poverty, HIV/AIDS, and Medicaid**

As noted above, Medicaid eligibility requirements extend benefits only to “severely disabled” HIV-infected individuals earning below the poverty line, leaving low-income HIV sufferers to fend for themselves or to seek support in the patchwork of programs (under)funded by Ryan White outlays.

Those in the “interim period” before developing severe disability and those newly alienated from public care have entered a burgeoning class of HIV-infected persons living without any connection to medical assistance: of the 850,000 to 950,000 people living with HIV in the United States, between 42% and 59% are estimated to not be in care (Kaiser Family Foundation, 2004). Rising HIV prevalence in areas of concentrated poverty and in limitations to access for at-risk, low-income populations increasingly make HIV/AIDS a disease of poverty, and Medicaid eligibility criteria ensure that if individuals are not already poor, they will become poor before being able to enroll in treatment.

What this “waiting game” means for households supported by HIV-infected adults is troubling. In 2000, Shuster et al. estimated that 28% of HIV/AIDS sufferers had one or more children living with them; of that group, 75% had previously registered CD4 cell counts between 0 and 199 per mL, far below clinically recommended levels, and 30% (included within that 75% group) had full-blown AIDS (Shuster et al., 2000). Of all respondents sampled, 83.3% earned less than \$25,000/year; 56.5% earned less than \$10,000/year. The households – containing approximately 100,000 children (Shuster et al., 2000) – of low-income HIV-infected parents are likely to experience income shocks and rising health care costs as primary earners go without access health insurance, and it is not until many of these caregivers become functionally incapacitated that Medicaid care will finally be extended. Maine and Massachusetts (AIDS Action Council, 2004) have approved extending early treatment to HIV-infected mothers, but evaluations have yet to be conducted regarding the number of new enrollees and effectiveness of treatment. Moreover, income eligibility requirements are set at the poverty line and may not provide for the largely unpredictable health needs of those adults earning just above.

#### **5. Gains to Early Treatment**

##### ***5.1. Life Expectancy and Costs per Life Year Gained***

Life for HIV-infected, low-income adults in the “interim” is not a life free from health problems, nor is deferring ARV therapy lack implications for future treatment outcomes. Early treatment for HIV infection can signifi-

cantly forestall the advent of AIDS and address the symptoms of HIV infection as they arise. Medical advances since the early 1980s have “transformed [HIV/AIDS] from a rapidly fatal infection diagnosed at a late stage of the disease to a chronic progressive illness that affords many years of productive life under complex treatment regimens” (Graydon, 2000).

Kahn et al. (2000) modeled the health effects of extending Medicaid to HIV-infected persons for early access to antiretroviral therapy. The study found that if implemented nationwide the plan (over 5 years) would enroll 38,000 more HIV patients in Medicaid, reduce AIDS diagnoses by 13,000, prevent 2,600 deaths, and 5,816 life years to the population of HIV-infected Medicaid beneficiaries. Over a 10 year period, life year gains are projected to increase by a magnitude of five, and the decline in AIDS deaths is expected to more than double.

Federal costs for each five year period at current eligibility levels are estimated by Kahn et al. to be \$24.3 billion; expanding early treatment is estimated to cost an additional \$739 million over five years: Medicaid costs would rise by \$1.43 billion, but decreases in costs for other programs (state ADAPS and SSI) would offset are projected to offset this rise (Kahn et al.,2000). The cost for quality adjusted life year gained (after five years) would be \$879.97. Kahn et al. offer two options for Federal budget neutrality: (1) bargain for lower drug prices, and (2) transition early treatment recipients back onto employment-based insurance – by subsidizing the purchase of “community-rated health insurance (i.e., by paying premiums for COBRA [Consolidated Omnibus Budget Reconciliation Act] to continue employment-based health coverage or for state high-risk pools)” insurance administration could replace inefficient plans that would continue to regulate HIV-positive Medicaid recipients as “high-risk” despite health improvements (2000).

A study conducted by Bruce Schackman et al. (2001) used a state-level simulation model to estimate life expectancy and quality of life year gains for early antiretroviral treatment for HIV-infected persons nearing the CD4 cell count level at which treatment is clinically recommended. Average gains in life expectancy for initiating early treatment at an intermediate CD4 level of 500 per mL was 2.08 years (1.98 years when adjusted for quality of life). Gains to initiated treatment at an early stage in disease progression have yet to be evaluated but could offer greater life expectancies and improved quality of life for those interim years before full-blown AIDS develops.

Schackman et al. estimate the Federal cost per quality-adjusted life year gained to be approximately \$17,300, but over a 5 year period total increases in taxpayer cost would amount to \$11,500 per patient because early treatment

would simply require an earlier payment of the cost that is deferred at current Medicaid eligibility levels (2001). The disparity in Kahn's and Schackman's measures is explained, first, by Kahn's discounting of declines in costs to state ADAPs and SSI and, second, by Kahn's assumption of rising Medicaid HIV/AIDS costs in the next five years without expansion of early treatment.

### **5.2. *Quality of Life and Increased Economic Productivity***

For HIV-infected persons earning at the margins of the poverty line, basic improvements in health can produce increases in number of hours worked, level of productivity, motivation, and future life prospects. While average gains of 2 years of additional life must not be taken out of proportion, at the very least, early treatment will help HIV sufferers avoid costly and unpredictable hospitalizations and will offer an opportunity to take their health under control. Goldman et al. (2001) find that providing access to early treatment may show the greatest cost-effectiveness through reducing the high costs of hospitalizations. Adding productive years to the lives of HIV-infected earners can also encourage savings and planning for inability to work. For thousands of children, extending the working life of an HIV-infected parent could mean the difference between growing up in poverty and not.

The costs of early therapy could also be offset by the contributions to GDP of HIV-infected workers given several extra years of working life as well as the additional taxes these workers may pay. However, real cost gains accrue to HIV sufferers themselves: the high out-of-pocket costs of hospitalization, doctor visits, and uninsured health treatment that are common occurrences in the "interim" before severe disability put stress on already low incomes, and early treatment and coverage for health shocks could offer HIV-positive earners reprieve from unpredictable expenditures or burdensome debt to medical providers.

### **5.3. *Cost-Effectiveness***

The Medicaid program functions by making matching Federal funds available to states meeting the Congressional standards for provisions of care. Since 1982, states have participated, though there is substantial variation in the generosity of benefits, eligibility requirements, and provider payments (Kaiser Family Foundation, 2004). Only one state, Maine, has extended early access to drug therapy, though this change has yet to be evaluated. Yet it seems that Congressional regulation mandating early treatment would impose costs variable to states' populations of HIV-infected persons.

Kahn's and Schackman's conflicting estimates, rather than testifying to the indecipherability of early treatment costs, make a case for a more systematic

reform to Medicaid coverage for eligible HIV/AIDS sufferers. Bargaining for lower ARV costs should be explored: In 2007, Simpson et al. estimated the daily cost of ARV regimens to be between \$52.75 per day (clinically symptomatic) and \$65.55 per day (severely symptomatic) based on the 50th and 75th percentile of Medicaid mean drug costs for patients in South Carolina (Goldman et al., 2001). Annually, ARV costs on average are projected to be between \$19,253.75 per patient and \$29,925.55 per patient. Medicaid covers these costs currently, and so the question becomes regarding the cost of extending ARV therapy earlier to HIV-positive persons.

In light of current spending, Kahn et al.'s consideration of falling "alternative" program costs post-early treatment expansion and the proposals to bargain for reduced drug prices and to transition stabilized HIV-positive workers onto employment-based insurance present a compelling case for expanding coverage. Additional costs of \$879.97 per additional quality adjusted life year gained appears a marginal expense given the potential for increased earnings and reduced hospitalization costs. Though it is difficult to model, tax revenues collected from populations of HIV-positive low-income individuals who may not be working as much or at all without early treatment could partially offset or even exceed Federal investment in their drugs regimens.

Public health insurance systems in Canada and the United Kingdom do provide early access to treatment for HIV-positive persons, though the effectiveness of this care is mediated by general characteristics of care provision in each nation. For example, it is difficult to access coverage, in general, for "high cost treatment for chronic or life-threatening diseases and conditions for Canadians who are working but have limited or no private insurance," and ARVs are no exception (Kaiser Family Foundation, 2004). Recommendations for Medicaid coverage reform must inevitably be considered in the United States context, and limitations in the ability of other developed nation, public insurance system governments suggests the need for a comprehensive approach to individual insurance coverage and approaches to the potentially high costs of ARV regimens for those who are in need of intensive treatment.

#### ***5.4. Prevention Gains, Containment of Epidemic***

For areas of concentrated disadvantage and high HIV prevalence, early antiretroviral therapy could address the rising rates of infection among disconnected populations. HIV-positive persons in high-poverty centers, substance abuse is often also a problem (Katz et al, 2000), and given the spread of HIV through networks of crack cocaine distribution and use in largely African American urban communities, comprehensive health care for HIV-positive persons including drug and alcohol counseling could remove the enabling conditions for risky sexual behavior or unsanitary needle use. Recent

randomized clinical studies evaluate to the effectiveness of alcohol and drug treatment in reducing HIV risk behaviors: Chawarski et al. (2008) found statistically significant 26 percent reductions in HIV risk behaviors among heroin dependent individuals in Muar, Malaysia, while an ongoing study (to be completed in 2010) measures the HIV risk behaviors of methadone patients (heroin users) in Wuhan, China (Katz. Et al., 2000.).

Moreover, extending treatment to members of disadvantaged communities of color could combat perceptions of alienation among others who are HIV-infected. Seeing HIV-positive persons receiving treatment with perceptible gains in life quality and life expectancy may encourage others to seek care. The disproportionately low levels of HIV care enrolment among seropositive African Americans (whether due to significant barriers to access or to cultural issues) requires attention. Beyond the possibilities of preventing new infections and promoting the attractiveness of care enrolment, early treatment could also connect “disconnected” communities of low-income African Americans to medical centers and HIV education outlets in a way that promotes greater awareness about HIV/AIDS, sexual safety device availability, and knowledge strategies for infection risk aversion. If there is a cultural or informational divide contributing to the epidemic-scale rates of infection among young men and women of color in urban settings, linking HIV-positive community members to sources of not only treatment but also prevention knowledge and tools could make them empowered advocates for prevention and accessible resources for HIV-positive individuals curious about treatment options.

## **6. Recommendations**

Congress should mandate that HIV-positive persons unable to afford private care be provided with early antiretroviral therapy funded by Medicaid:

(a) Individuals will be eligible if their CD4 cell counts are 600 per mL or lower and will have access to medical case worker evaluations to determine appropriateness of various treatment regimens and to monitor the health of patients. Kitahata et al. (2009) find that withholding treatment for CD4 counts of 500 per mL and above increases a patient’s risk of death by 94 percent (Chawarski, Mazlanb & Schottenfeld, 2008); because 500 CD4 cells per mL is the standard for evaluating the clinical appropriateness of care (Haller, Chawarski and Wang, n.d.), beginning evaluations of need for ARV therapy before this level may offer health returns for those patients whose CD4 counts may fluctuate and compromise immune systems.

(b) Income baselines should be set at 250 percent of the Federal poverty threshold for the recipient’s household type to compensate for illness occurring before full-blown AIDS that may compromise the earnings of even those

with incomes above the poverty line. Two hundred and fifty percent of the Federal poverty line is the current standard for access to Medicaid care for persons with cancer living in the State of New York, and the New York Department of Health's assertion that this standard allows individuals to "gain access to life saving treatment and services" (Kitahata & Mari, 2009) translates informatively as a model for Medicaid coverage for HIV-positive, Medicaid eligible persons. To understand early treatment as a support for earnings in the "interim" before severe AIDS-related disability is to conceive of an HIV-positive earner as economically self-sustaining. However, current eligibility requirements tied to an earnings level below the Federal poverty line does not allow medical support to intervene in critical stages of disease progression. If evaluations for care eligibility begin at 250 percent of the poverty line, severe income shocks and enforced interim-period poverty can be dealt with before they redound not only to the HIV-positive persons immediate subsistence, but also his/her future earnings and the prospects for his/her family and children. H.R. 3962, the Affordable Health Care for America Act bill recently approved by the U.S. House of Representatives, establishes a criteria for Medicaid coverage at 150 percent the Federal poverty line (Kahn et al., 2000) however, the marginal costs of extending treatment for HIV/AIDS (and its attendant costs) at an earlier stage in disease progression simply transfer the bulk of expenditures per patient to a period before severe disability. Per Kahn et al.'s discussion of transferring HIV-positive earners onto private, employer-based insurance plans, a higher threshold for HIV-positive, low-income persons could oddly keep such "eligible's" off of Medicaid by stabilizing their health and helping them to afford private insurance.

(c) To facilitate the inevitable transition into severe illness and incapacitation for low-income, HIV-infected persons, Congress should also fund assistance programs that help early treatment recipients to save and plan for the future. Caseworkers should also be assigned to monitor the income status of families supported by an HIV-positive Medicaid-recipient earner and to coordinate eligibility and access to other means-tested income transfers (unemployment insurance, social security/disability insurance) and in-kind benefits (food stamps, subsidized child care). This service would meet the "benefits advocacy" need identified by more than one-third of HIV-positive persons and address the lack of access to caseworker review reported of 39.7% of this population (MCTP, n.d.). Though lack of caseworker access is a problem for other sick Medicaid recipients, enforcing new standards for care that are tied to income level and clinical definitions of treatment need (CD4 counts) may streamline access and make contact with caseworkers more readily enforceable.

(d) Congress should also fund investigative inquiries (1) into Medicaid-funded HIV/AIDS care provider programs that demonstrate lower quality

services compared to private providers, and (2) into the gap in Medicaid enrollment in high-poverty African American communities with a guarantee that recommendations would be reflected in Medicaid eligibility rules and care standards or elsewhere in prevention education and HIV outreach program funding.

These changes will require Congressional legislation modifying current eligibility requirements, for Federal policy requires that expansions in eligibility be budget neutral without explicit increases in expenditures allocated to cover increased program costs (H.R. 3962, Section 1017). A provision should also be included to link the scope of Medicaid-funded HIV/AIDS coverage medical advancements in treatment; as new technologies offer improvements to life expectancy and life quality, low-income HIV-infected persons should not be denied the same treatment options available to their privately-insured counterparts.

## **7. Discussion of Political Feasibility**

The political feasibility of extending Medicaid coverage to include early antiretroviral therapy for low-income HIV-infected persons may encounter resistance. Medicaid recipients lack political capital as an interest group: receiving increases in care funding must overcome general antipathy to increased welfare spending. HIV-positive populations in particular face stigma that draws on moral and religious justifications. However, HIV awareness has made significant headway since the 1980s, and Congress has proved receptive to considering early treatment (as evidenced by its approval of Maine's early ARV initiative).

The greatest resistance may focus on the costs of early treatment, but his concern, too, may not be convincing given the current political climate. H.R. 4972 includes significant changes to Medicaid and Medicare law that may affect HIV coverage for low income people (Katz et al., 2000). The inclusion of this provision reflects the receptiveness of Congressional representatives to Medicaid extension to at-risk HIV sufferers and an implicit awareness of the unlikelihood of states to take action themselves. Still, an authorization is far from a requirement mandating eligibility reform, though the provision may allow for funding leeway in states that choose to follow Maine's example.

Winning mandatory requirements for early treatment will require strong advocacy for reform, though generating substantial political will may depend on demonstrating success in individual states. With the possible arrival of more accessible access to publicly-funded health care in the United States under the Obama administration, local and state actors should pursue funds that may become available to provide early treatment to those suffering in the interim

period before they become eligible for Medicaid.

## 8. Conclusion

Given the cost-effective gains in life expectancy and quality of life for low-income HIV-positive persons of early clinical interventions for HIV-infected individuals, changes in Medicaid eligibility may carry substantial implications for the poverty that persists in the “interim” period before severe AIDS-related disability. The partial incapacitation of HIV-positive earners jeopardizes not only personal health but also the wellbeing of the households that are supported by their labor. Extending additional, productive years of life to low-income, HIV-positive persons may be the difference between living in poverty and not, with attendant implications for quality of life, ability to save, and child development. Undeniably, the status of Medicaid coverage for HIV/AIDS among low-income populations in the United States is representative of Medicaid coverage for many other “disabling conditions.” Though this paper “singles out” HIV/AIDS to the exclusion of those other illnesses also under covered by public insurance programs, the case for early treatment for HIV/AIDS is a study in dynamic potential that lies in reforming the Medicaid system in a more comprehensive fashion.

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