

# 2009 Health Care Reform Policy Platform

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*It is essential that all people have access to health care when they need it. Currently in the U.S., many persons living with HIV/AIDS lack access to medical care due to significant financial and programmatic barriers in both publicly-funded and private health care systems. Of the one million people in the U.S. estimated to be living with HIV, about half are not currently in care.*

*Access to care must be a universal right, and not dependent on financial status. Federal health policy should be reformed to eliminate inequities in access to quality care based on race, ethnicity, gender, gender identification, sexual orientation, actual or perceived disability, age, primary language, immigration status, and geography. Federal policy should encourage innovation in models of health care delivery and facilitate rapid access to new treatments and improvements in care that reflect sound scientific principles.*

*Providing comprehensive coverage for people living with HIV, regardless of their ability to pay, is crucial and long overdue. **With the goal of increasing access to affordable, comprehensive, and quality health care for persons living with HIV/AIDS, the HIV Health Care Access Working Group has identified the following ten priorities for national health care reform in 2009:***

## **1. Increase access to health care by broadening Medicaid's eligibility requirements.**

In the context of HIV, Medicaid coverage is often limited to those individuals disabled by AIDS with income below the federal poverty level. Eliminating the disability requirement and expanding coverage to individuals with income up to 200% of poverty are measures essential to ensuring early access to comprehensive health care for persons living with HIV. Under current Medicaid rules, people living with HIV/AIDS must generally wait until their health has deteriorated to an AIDS diagnosis—qualifying them as categorically "disabled"—to be eligible for Medicaid. Delay in access to care for people living with HIV/AIDS jeopardizes their health and well-being. It also ends up being more costly to the health care system, as more complicated and expensive medical interventions are required once a person has progressed to an AIDS diagnosis. To fix these counterproductive and life-threatening policies, the categorical eligibility requirement should be eliminated for low-income individuals with income under 200% of poverty.

In addition to changes in general Medicaid eligibility requirements, given the extremely high cost of HIV care, the proposed Early Treatment for HIV Act (ETHA) is a critical tool to providing early access to care. Under ETHA, states could extend Medicaid coverage to individuals living with HIV but with incomes above the federal Medicaid income eligibility limit.

## **2. Ensure access to quality health care by establishing a mandatory minimum Medicaid benefits package.**

Currently, the services that Medicaid covers vary state by state. It is critical that all persons living with HIV/AIDS in the United States have affordable access to qualified providers—including HIV specialists. Health care must be culturally and linguistically appropriate, and protections must be built in to ensure privacy. The public health care system must be transparent and accountable in order for the public to assess its effectiveness.

## **3. Make health care more affordable by limiting Medicaid and Medicare cost-sharing.**

People living with HIV/AIDS often depend on access to 8 to 14 prescriptions drugs a month to suppress HIV, manage treatment side effects, and treat co-conditions. Cost-sharing for prescriptions and doctor visits can easily add up to a significant portion of monthly income for

those struggling to live on very low incomes, and can force them to choose between food, shelter, and lifesaving health care. The federal government should minimize variability across states and implement affordable limits on cost-sharing in both Medicaid and Medicare to protect low-income beneficiaries.

Additionally, to ensure that unaffordable cost-sharing expenses for low-income Medicare beneficiaries do not continue to present a barrier to access, any plan for reform should include extending the full Low Income Subsidy program to beneficiaries with income below 200% of the federal poverty level, and the partial subsidy to beneficiaries below 300% of poverty.

#### **4. Increase the federal Medicaid matching rate to states in economic crisis.**

In response to serious budget challenges, states often cut Medicaid budgets by narrowing eligibility and reducing coverage, thereby imposing barriers to affordable health care for those most in need. Federal health policy should ensure that in times of economic crisis, those most in need do not lose access to life-saving care due to state budget cuts. Specifically, the federal government should increase the Federal Medical Assistance Percentage (FMAP) for Medicaid on a state-by-state basis, as indicated by economic factors such as unemployment and state revenues. This action would help ease fiscal pressure on the states and prevent or reverse program cuts that reduce access to critically-needed health care services.

#### **5. Help slow the HIV epidemic by implementing routine HIV screening.**

Late diagnosis of HIV has serious implications for both individual and public health. Nationally, 39% of people newly diagnosed with HIV receive an AIDS diagnosis within a year. More than 20% of individuals in the U.S. infected with HIV are unaware of their infection. Infected individuals who remain undiagnosed are responsible for 56% of all new HIV infections. The grave problems for individual treatment and protecting the public health demand that both public and private health systems be mandated to encourage screening for HIV. Routine HIV testing for all individuals age 13-64 is critical to address the epidemic. The federal government should mandate that Medicaid and Medicare programs as well as private insurers cover routine, voluntary HIV screening and counseling.

#### **6. Improve access to health care by eliminating the two-year Medicare waiting period for people with disabilities.**

Current law requires individuals with disabilities to wait two years before becoming eligible for Medicare. For many persons living with HIV, this requirement jeopardizes their access to lifesaving care and treatment. Without reliable and continuous access to care during the two-year waiting period, individuals can become sicker and require more intensive and more costly medical interventions when they do finally qualify for coverage.

#### **7. Protect vulnerable Medicare beneficiaries facing donut hole coverage gaps.**

Medicare Part D prescription drug plans contain a gap in coverage known as the “donut hole” for costs between \$3,000 and the true out-of-pocket spending limit (“TrOOP”) that triggers catastrophic coverage. ADAPs are discretionary HIV/AIDS health programs funded by annual federal and state appropriations. While ADAPs may cover HIV-related costs for individuals in the donut hole, their contributions are currently barred from counting toward TrOOP. The result is that many Medicare beneficiaries living with HIV/AIDS lack affordable, comprehensive access to lifesaving medications—including those necessary to treat other conditions, such as high blood pressure or diabetes. Any plan to reform the national health care system should address this problem by counting ADAP expenditures toward TrOOP.

In addition, to minimize life-threatening disruptions in drug coverage for individuals with complex, chronic conditions such as HIV/AIDS, the federal government should administer and subsidize a mandatory enhanced Medicare Part D option that provides comprehensive coverage for generic and brand name prescription drugs through the donut hole.

## **8. Promote stability by investing in the clinical workforce.**

Throughout the country, health care institutions that serve Medicaid patients are struggling financially because reimbursement rates and payment mechanisms do not support the cost of providing care. This is particularly true in the case of health care for complex, chronic conditions such as HIV disease. The federal government should ensure that the reimbursement systems under Medicaid, Medicare, and private insurance reflect the true cost of care and mandate that providers in fact receive adequate payment promptly.

To further strengthen the clinical workforce of HIV providers, it is critical that any plan for health care reform address HIV medical provider workforce needs by expanding federal loan forgiveness programs, such as the National Health Service Corps, to include HIV medical providers and Ryan White-funded clinics as designated sites.

## **9. Increase health care options by improving access to private health insurance and implementing a public insurance plan option.**

For many persons living with HIV, access to private market health insurance is prohibitively expensive, and provisions against covering pre-existing conditions render most policies meaningless. For persons living with HIV or other chronic, complex health conditions to have real access to private health insurance, federal policy must require insurers to: provide coverage regardless of health status, not charge exorbitant premiums for coverage, cap total out-of-pocket spending, and eliminate the practices of not covering pre-existing conditions and imposing annual or lifetime caps on benefits. It is critical that coverage be portable so that persons living with HIV do not lose coverage or have to re-build their care networks when they change jobs.

In addition to improving access to useful private health insurance, the federal government should implement a public insurance plan option so that people living with HIV/AIDS have more access to comprehensive, quality health care. The goal of equitable health protection demands that any plan for health care reform must include provisions to ensure patients' privacy and that coverage, whether private or public, is comprehensive and that insurers are accountable—for example through set medical loss ratios, and community ratings.

## **10. Increase access by expanding the role of Ryan White community-based programs.**

The Ryan White program should continue to play an integral role in a reformed health care system. It is vital in supporting the delivery of care, treatment and important social services through community-based organizations and clinics. These programs have developed model systems for delivering high quality, comprehensive coordinated care and services, and have helped build minority communities' capacity to provide primary care and critical services to underserved populations. A reformed health care system should integrate the network of these community-based providers into the broader health system. The federal government should strengthen and expand these programs by providing them with cost-based reimbursement and ensuring that Medicaid programs and private insurers build these providers into their networks.

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*This report was prepared by staff of the WilmerHale Legal Services Center of Harvard Law School and the Treatment Access Expansion Project for the HIV Health Care Access Working Group (HHCAWG). The Working Group is a coalition of nearly 100 national and community-based AIDS service organizations representing HIV medical providers, advocates and people living with HIV/AIDS and providing critical HIV-related health care and support services. For more information, contact co-chairs Laura Hanen, of the National Alliance of State and Territorial AIDS Directors, at 202.434.8091, or Robert Greenwald, of the Treatment Access Expansion Project, at 617.390.2584.*

