The NAPWA/TAEP HIV/AIDS Policy Report-April 2008

AIDSWatch: Time to take action on HIV/AIDS in the U.S.

April 1, 2008 By Robert Greenwald , Megan Hughes , Lindsey Murtagh and Amy Rosenberg

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From April 28–30, HIV-positive people and their supporters will come from around the United States to make their voices heard in Washington, DC, during the 16th annual AIDSWatch advocacy program. As they do each year, participants will visit Capitol Hill to educate their members of Congress about the needs of people living with HIV and AIDS and to seek support for important legislation and funding. But this year, AIDSWatch delegates will also tell Congress that it's time to refocus on HIV/AIDS in the U.S., and time for a coordinated national strategy to fight the epidemic. AIDSWatch participants will call on Congress to recommit to a domestic AIDS agenda.

A coordinated national AIDS strategy must incorporate efforts to implement evidence-based prevention and education, expand access to health care and treatment, provide supportive services (including housing, case management, and substance abuse treatment among other services), and adequately fund research. Some specific goals include lifting the ban on immigration for HIV-positive people, ending abstinence-only sex education funding, addressing HIV/AIDS in prisons, eliminating the ban on federal funding for needle-exchange programs, and building on the successes of the first 10 years of the Minority AIDS Initiative.

To be successful in implementing a national strategy, AIDS advocates must recognize the importance of working together with substance abuse and mental health advocates toward common goals. AIDSWatch will initiate efforts to work in coalition with others to create a broader national agenda for improved public health and social justice. As well as calling on Congress to commit generally to a national plan to fight AIDS, AIDSWatch participants will also discuss specific policy areas. Two of the areas in which participants will emphasize the need for change are access to health care and treatment and the necessity of adequate funding for key prevention, care, services and research programs.

It goes without saying that access to quality health care and treatment is critical for people living with HIV and AIDS. The Early Treatment for HIV Act (ETHA) would greatly expand access to health care by giving states the option to extend Medicaid coverage to low-income people who are HIV positive, but who do not yet have AIDS. Current Medicaid rules require people to become disabled by AIDS before they can receive access to care and treatment through Medicaid that could have

prevented them from becoming so ill in the first place. This not only creates a cruel irony for low-income HIV-positive people, but also puts Medicaid policy at odds with federal treatment guidelines, which recommend early and aggressive treatment of HIV.

In addition to the health benefits for HIV- positive people themselves, ETHA would also bring significant broader public health and economic benefits. Several studies have shown that early treatment lowers viral levels and the potential for HIV transmission by over 60 percent, thus helping to prevent the spread of HIV. Early access to care reduces annual treatment costs, high-cost medical interventions, and reliance on government programs, and allows people with HIV to remain productive, work and pay taxes. ETHA illustrates the maxim that "an ounce of prevention is worth a pound of cure."

ETHA legislation is pending in both the House and Senate. The House bill (H.R. 3326) counts Eliot Engel (D-NY), Ileana Ros-Lehtinen (R-FL) and Speaker Nancy Pelosi (D-CA) as lead sponsors and as of February has an additional 87 cosponsors. Senators Hillary Clinton (D-NY) and Gordon Smith (R-OR) are the lead sponsors of the Senate bill (S. 860), which has 33 co-sponsors. Despite bipartisan support in both the House and Senate, the ETHA bills remain in committee.

The Medicare prescription drug benefit (Part D) began in 2006. Since then, problems of access and affordability of medications have plagued the program. Two key changes sought by advocates would improve the situation for people living with HIV and AIDS. The first is to codify into law special protections for six specific categories of prescription drugs, including those used to treat HIV/AIDS, mental illness, cancer, epilepsy and autoimmune diseases. Antiretroviral medications had been protected from measures that could restrict their use, such as requiring prior authorization before a prescription could be filled. However, these protections are subject to annual review. Advocates want to ensure access to critical medications by writing the protections into the law for the long term.

The second change to Medicare Part D involves trying to help people out of the enormous coverage gap (commonly called the "doughnut hole") in the program. Under Part D, Medicare beneficiaries pay deductibles, coinsurance, and/or co-payments for medications until they reach a threshold amount ($2,510 in 2008). Once the threshold is reached, beneficiaries fall into the doughnut hole, and must pay 100 percent of the cost of their drugs out of their own pockets until they reach the level where Medicare catastrophic coverage begins. In 2008, that level is $5,726, meaning that beneficiaries have to come up with $3,216 of their own to bridge the gap, before the costs of medications are covered by insurance and the government.

State AIDS Drug Assistance Programs (ADAPs) can and do help people living with AIDS to pay their Part D expenses. The problem is that ADAP contributions do not count toward meeting the beneficiaries' True Out-of-Pocket (TrOOP) expenditures—the $3,216 required to get to catastrophic coverage. Without being able to count the ADAP contributions, many beneficiaries remain stuck in the doughnut hole. ADAPs continue to pay as beneficiaries are unable to reach the other side of the hole where catastrophic coverage begins. If ADAP expenditures could count toward TrOOP, more beneficiaries could reach the catastrophic coverage "shore," thus freeing up ADAP resources

to help others living with HIV/AIDS. Other state contributions, such as State Pharmacy Assistance Program payments, count towards TrOOP; advocates contend that it's only fair to allow ADAP contributions to count as well.

Language codifying protections for the six protected classes of drugs and counting ADAP contributions toward TrOOP is included in several bills in both the House and Senate. These two changes were also part of the State Children's Health Insurance Program (S-CHIP) bill that was twice vetoed by President Bush. As of February, all of the bills containing the two key Medicare Part D changes remain in committee.

Along with expanded access to care, more funding for domestic HIV/AIDS programs is key to effectively addressing the epidemic in the U.S. The Bush administration's lack of focus on domestic AIDS programs is once again evident in the President's proposed fiscal year 2009 budget. President Bush's budget proposal for FY 2009 would freeze or reduce funding for many domestic AIDS programs. While the Centers for Disease Control and Prevention (CDC) HIV/AIDS programs would be flat-funded overall, HIV prevention programs would be cut by $40 million. National Institutes of Health (NIH) research and the Housing Opportunities for People With AIDS (HOPWA) program would have no funding increases under the administration's proposal. The Ryan White CARE Act would receive a $1.1 million increase (an increase of 0.004 percent), while AIDS Drug Assistance Programs would get $6 million more, far short of the $133 million increase that advocates estimate is needed. In addition to the HIV/AIDS-specific programs, the president has called for a $200 billion reduction in Medicaid and Medicare spending over the next five years. Advocates have already called on Congress to reject the administration's proposed budget and adequately fund important AIDS programs.

AIDSWatch participants bring real stories to lawmakers and their staffs and show them the real consequences of government policy decisions. We invite you to join us in Washington from April 28–30 to share your concerns.

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