"Reinvigorating Political Will in Washington to Help Stop the Spread of AIDS"

Statement for Rep. Maxine Waters
November 29, 2006

I am deeply honored to be here this evening at this important conference on "Opportunities for Improving HIV Diagnosis, Prevention and Access to Care in the U.S." The primary topic for this conference, issues involved in the implementation of the Centers for Disease Control's new guidelines on routine HIV testing, is dear to my heart.

I know that there are many distinguished physicians, scientists, public health experts, and community advocates at this conference; so I will not attempt to list them all. However, I would like to thank Gavin Hart, Greg Lugliani and Joanne Jablonski for inviting me.

Introduction

Twenty-five years after AIDS was discovered, the AIDS virus, continues to infect and kill thousands of Americans and millions of people around the world. At least 1.6 million Americans have been infected by HIV since the beginning of the pandemic. Half-a-million of them have died, and more than one million Americans are living with HIV/AIDS in the United States today.

The face of AIDS has changed tremendously over the past quarter-century. When the disease was first discovered, most of its victims were gay, white men. Today, they are far more diverse. Women now account for 27% of new AIDS cases in the United States, and teen girls account for half of new AIDS cases among teenagers. African Americans account for about half of new AIDS cases in the United States, despite the fact that we only make up 13% of the population. African American women represent 67% of new AIDS cases among women, and African American teenagers represent 66% of new AIDS cases among teenagers. Over 70% of new AIDS cases are people of color. Today, as often as not, the face of AIDS is black, and increasingly, it is a woman's face.

Importance of Testing

You are all familiar with the statistics, but perhaps the most disturbing statistic is the fact that about one quarter of the Americans living with HIV/AIDS do not know they are infected. This amounts to between 252,000 and 312,000 people.

The good news is that the CDC reports that many infected persons decrease behaviors that transmit the AIDS virus to sex or needle-sharing partners once they find out about their infection. The CDC theorizes that sexually transmitted HIV infections could be reduced by more than 30% per year if all HIV-infected persons found out about their infection and changed their behavior in a manner comparable to those who already know of their infection. When people know their HIV status, they are more likely to act responsibly. They are more likely to protect their sex or needle-sharing partners, and they are more likely to protect themselves.

Furthermore, medical treatment that lowers the HIV viral load could also reduce the risk of transmitting the virus to others. So identifying people who are infected and getting them into treatment not only reduces their risk of AIDS-related illness and death, it also protects the community.

That is why HIV testing is essential if we are to get a grip on this tragedy. We will never be able to stop the spread of HIV and AIDS as long as there are large numbers of Americans who don't know they are infected.

CDC's New HIV Screening Guidelines

As you all know, on September 21, the CDC published new guidelines for HIV screening in health care settings. These guidelines recommend routine HIV screening for all patients between the ages of 13 and 64, regardless of risk factors.

The guidelines recommend that routine HIV testing be performed using an "opt-out" approach. Most HIV testing is performed using an "opt-IN approach," in which patients are provided pre-test counseling and must specifically consent to an HIV test, usually in writing. Under an "opt-OUT approach," patients are notified that an HIV test will be included in their routine health care and that they can refuse to take the test. But pre-test counseling and separate, written consent for the HIV test are not required. Instead, consent for an HIV test can be included in the general consent for medical care.

CDC 2001 Guidelines on Pregnant Women

These new guidelines are an expansion of the CDC's 2001 guidelines for HIV screening of pregnant women, which were issued in 2001. The 2001 guidelines emphasized that HIV testing should be a routine part of health care for all pregnant women. Most importantly, the guidelines recommended an opt-OUT approach in order to simplify the testing process and ensure that pre-test counseling would not be a barrier to testing.

Two states, Arkansas and Tennessee, implemented opt-OUT testing for pregnant women ahead of the CDC. CDC data indicated that these states had significantly higher testing rates. States that used an opt-IN approach to HIV testing had a testing rate of 25% to 69% among pregnant woman. Arkansas, on the other hand, had a 71% testing rate and Tennessee had a testing rate of 85%.

The 2001 guidelines were an astounding success! Adoption of the CDC's recommendations for routine opt-OUT testing for pregnant women led to a dramatic 95% decline in perinatal AIDS cases. As for the pregnant women themselves, I have no doubt many of them would have died of AIDS without the treatment that they are now able to receive.

Opposition to "Opt-out" testing

There is still considerable opposition in Washington to opt-OUT HIV testing. Some AIDS activists would have you believe that people are less likely to learn how to protect themselves and their partners if they are not required to undergo pre-test counseling before an HIV test, and some civil libertarians argue that eliminating separate, written consent for an HIV test would lead to violations of patients' privacy and their right to informed consent.

When the CDC issued its new guidelines in September, the American Civil Liberties Union (ACLU) issued a press release expressing health and civil liberties concerns. Rose Saxe, an ACLU staff attorney, said, "[E]liminating the only safeguards that guarantee that testing is voluntary and informed does little to ensure that people will receive the care they need."

I have been a strong supporter of civil liberties throughout my career, and I have worked closely with the ACLU on numerous occasions, but in this case, we have a difference of opinion. Routine HIV tests are no more a violation of patients' right to informed consent than routine diabetes tests, blood pressure tests, and cholesterol tests. When you go to the doctor for a routine medical exam and sign a consent form for medical care, you do not have to sign additional consent forms for each of these procedures. You should not have to sign a separate consent form for an HIV test either.

Moreover, when doctors test for diabetes, blood pressure and cholesterol, they provide basic information about all of these conditions. More importantly, they educate their patients about living a healthy lifestyle. And if a routine test indicates that a patient actually has diabetes or high cholesterol, the doctor explains the condition and discusses treatment options.

Regarding the right to privacy, there are laws in place to guarantee patients' privacy and prohibit the use of HIV test results and other medical records for non-medical purposes. I welcome any and all efforts to strengthen privacy protections for all medical records for all people.

The stigma associated with HIV is perpetuated, in part, by those who fight against making the test routine. I would argue that one way to create a climate in which people with HIV/AIDS are not subjected to discrimination is to standardize the testing process. By singling out HIV, advocates are guaranteeing that people who are HIV positive will continue to be treated differently by society.

The Routine HIV/AIDS Screening Coverage Act

During the same month that the CDC announced its new guidelines on routine HIV screening, I introduced two bills in the House of Representatives to promote routine HIV screening.

H.R. 6309, the Routine HIV/AIDS Screening Coverage Act, would require health insurance plans to cover routine HIV tests under the same terms and conditions as other routine health screenings.

Standard health insurance plans generally cover HIV tests when there are clinical indications of infection or when there are known risk factors present. Some plans also cover HIV tests when the patient specifically asks for them. However, it is unclear whether health insurance plans will be willing to pay for the inevitable increase in the number of routine tests administered by primary care doctors all around the country as the new CDC guidelines are implemented. I hope that my legislation will encourage them to do so. If they do not, I will urge my colleagues in Congress to pass my bill and require them to do so.

For those of you who are in the medical community, as I know many of you are, allow me to give you a word of advice. If you agree that routine HIV screening is a good idea, then do it. Don't let the health insurance industry intimidate you!

The Stop AIDS in Prison Act

I also introduced legislation to address the HIV/AIDS crisis in our nation's prison system. The U.S. Department of Justice reported that the rate of confirmed AIDS cases in prisons is three times higher than in the general U.S. population. The U.S. Department of Justice also reported that 2.0% of State prison inmates and 1.1% of federal prison inmates were known to be living with HIV/AIDS in 2003. However, the actual rate of HIV infection is unknown because, currently, prison officials do not consistently test prisoners. By not testing all prisoners for HIV, prison authorities avoid paying for the treatment of prisoners who are infected but do not know it. When these prisoners complete their sentences and return to society without knowing their HIV status, there is a very real danger that they could infect their spouse or partner.

I introduced ***H.R. 6038, the Stop AIDS in Prison Act.*** This bill would make a routine HIV test part of the standard health screening regimen for prison inmates upon entry and release from federal prisons. Inmates would be allowed to opt out, and those who test positive would be provided comprehensive medical treatment, privacy protections, and referrals to community services upon their release from prison.

Funding for HIV/AIDS-related Programs

While getting people tested for HIV is critical, Congress must also ensure that those who test positive have access to appropriate medical treatment. Otherwise, some people will choose not to get tested, rather than find out they need expensive medical treatment they cannot afford. We also must fund outreach and prevention programs to stop the spread of HIV and research to find a cure.

The federal government spent approximately $21 billion on HIV/AIDS in fiscal year 2006. But this is a large and misleading figure. So I will try to break it down for you.

Almost half of the money, a total of $9.5 billion, was spent on medical treatment for people who qualify for Medicare and Medicaid. Medicare and Medicaid are entitlement programs, meaning that everyone who qualifies for benefits gets treatment. As a result, Congress has no discretion over the amount of money spent on them.

Smaller amounts of money were spent on a variety of miscellaneous programs related to HIV/AIDS including Social Security payments to people living with HIV/AIDS, medical treatment for veterans at the Department of Veterans Affairs, medical treatment for prisoners at the Bureau of Prisons, and international programs run by the State Department and the Agency for International Development.

Most of the programs that were developed by Congress specifically for HIV/AIDS prevention, research, and treatment in the United States are administered by the various agencies of the Department of Health and Human Services. The primary agencies involved in HIV/AIDS programs are the CDC, which as you all know does excellent prevention work; the National Institutes of Health (NIH), which does medical research; and the Health Resources and Services Administration (HRSA), which provides emergency relief and health services to patients under the Ryan White CARE Act.

Funding for the Department of Health and Human Services' HIV/AIDS prevention, research, and treatment programs increased significantly between 1996 and 2003. In fiscal year 1996, Congress provided $2.9 billion for these programs. By fiscal year 2003, funding had more than doubled to $6.1 billion. Since then, however, funding has hardly increased at all, and Congress provided only $6.2 billion for Health and Human Services' HIV/AIDS programs in fiscal year 2006. That's a mere 1.6% increase over a three year period.

While HIV/AIDS funding has stagnated, HIV infections have not. Every year, another 40,000 people are infected with HIV. All of these people are going to need medical treatment.

Unfortunately, Congressional leaders have shown little interest in HIV/AIDS issues – or indeed in any of the nation's health care issues. There are, of course, many Democrats as well as some Republicans in Congress who are deeply concerned about the HIV/AIDS crisis. But the Republican leaders who have been responsible for setting budget priorities have not considered our nation's health care to be one of those priorities.

The Gay Community

Of course, the lack of funding for HIV/AIDS programs is only part of the problem. We must constantly reevaluate HIV/AIDS programs to ensure that the funding is being used as effectively as possible. Most of the HIV/AIDS outreach, treatment and prevention programs developed by Congress and administered by Health and Human Services agencies were designed when the face of AIDS was white and gay.

I have to say a word about the gay community. When gay Americans became aware of the threat that AIDS posed to their community, they responded. They got organized. They educated themselves and their peers. They reached out to the medical community, and they got involved in the political process. They became advocates. They demanded action to stop the spread of this disease, and they got it. If it were not for the efforts of the gay community, I dare say that we would be in a far worse situation than we are today.

Minority AIDS Initiative

Unfortunately, the HIV/AIDS programs that have been successful with the white gay community have not been nearly as successful among other groups, especially African Americans. As a result, education and awareness have been substituted by stigma and a lack of knowledge about HIV/AIDS within the black community.

We need to develop new approaches to AIDS prevention – approaches that will work for African Americans and approaches that will work for all Americans. That is one of the reasons that I led congressional efforts to establish the ***Minority AIDS Initiative*** in 1998.

The Minority AIDS Initiative provides grants to community-based organizations and other health care providers for HIV/AIDS treatment and prevention programs serving African American, Hispanic, Asian American and Native American communities. The Initiative was designed to enable health care providers serving minority communities to expand their capacity to deliver culturally and linguistically appropriate care and services.

Funding for the Minority AIDS Initiative grew considerably during its first few years and then leveled off. In fiscal year 2003, the Initiative was funded at $411 million. Since then funding has been reduced and now stands at about $399 million.

Congressional support for the Minority AIDS Initiative has increased steadily since its founding. For each of the past six years, I circulated appropriations request letters to the Chairman and Ranking Member of the Subcommittee on Labor, Health and Human Services and Education Appropriations, in support of funding for the Initiative. My most recent request letters were sent on May 1, 2006. These letters requested $610 million for the Minority AIDS Initiative in fiscal year 2007. A record number of 119 Members of Congress signed the 2006 letters. Most, but not all, were Democrats.

The Current Situation in Congress

This year, Republican leaders never even brought the fiscal year 2007 Labor, Health and Human Services and Education Appropriations bill to the House Floor for a vote. Theoretically, they could still do so next week during the lameduck session before we adjourn for the year. However, since the Democrats won control of Congress in the November elections, the Republicans are more likely to pass a Continuing Resolution that would allow all programs to be funded at last year's levels until January, when the Democrats will take control.

Now that Democrats will be in the majority, it will be up to us to govern effectively and address our nation's problems – problems like the HIV/AIDS pandemic. I will be working with my colleagues to pass legislation that will require insurance companies to be responsible, encourage people to get tested, simplify the testing process, educate the public, and ensure quality medical care for people living with HIV/AIDS. I will also be working with my colleagues to provide effective oversight to ensure that HIV/AIDS programs meet the tremendous needs in communities all across America.

This will be a difficult challenge, but we must succeed. The lives of our families and communities depends on it.

Community involvement will continue to be essential. The advocacy community must reach out to people throughout the United States and tell them to get tested and protect themselves and their partners. The medical community should educate their patients and implement the CDC's new guidelines. And each and every one of us must take personal responsibility for our own lives and the lives of others in our community.