Testimony
Before the Committee on Homeland Security and Governmental Affairs
Subcommittee on Federal Financial Management, Government Information and International Security
United States Senate

HRSA Efforts to Ensure Early Diagnosis and Improve Access for Persons Living With HIV/AIDS

Statement of

Deborah Parham Hopson, Ph.D.

Associate Administrator
HIV/AIDS Bureau
Health Resources and Services Administration
U.S. Department of Health and Human Services

For Release on Delivery
Expected at 2:30 pm
Wednesday, April 26, 2006

Mr. Chairman, Members of the Subcommittee, thank you for the opportunity to meet with you today on behalf of the Health Resources and Services Administration (HRSA). Last year, I testified before the Subcommittee regarding the Domestic HIV/AIDS Care Programs and I am happy to be here today to discuss ways to ensure early diagnosis and improve access to treatment for Americans living with HIV/AIDS. I appreciate your continuing support of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Programs.

Introduction

The Ryan White CARE Act is the centerpiece of our domestic response to care and treatment of low income, uninsured and underinsured individuals living with HIV/AIDS. Currently funded at $2.06 billion, it provides primary health care, life saving medications, and support services to individuals who lack health insurance and financial resources to provide adequate health care for themselves. The Ryan White CARE Act was enacted in 1990; it was amended and reauthorized in 1996 and again in 2000. The authorization for the CARE Act programs expired on September 30, 2005. President Bush in his State of the Union Address stressed the importance of this program and asked Congress to "reform and reauthorize the Ryan White Act and provide new funding to states so we can end the waiting lists for AIDS medicines in America."

Since its last reauthorization, we have been able to provide antiretroviral treatment, primary care, and support services to over half a million people

annually in the United States, Puerto Rico, Guam, the U.S. Virgin Islands, and eligible U.S. territories. In 2004, an estimated 65 percent of these individuals were racial minorities, 33 percent were women, and 87 percent were either uninsured or received public health benefits. The Ryan White CARE Act programs have provided important benefits to these populations. Overall, AIDS mortality is down and lives have been extended with HIV/AIDS medications purchased through the AIDS Drug Assistance Program (ADAP). Pregnant HIV positive women have been provided with care that has allowed them to give birth to children free from HIV infection, and thousands have received support services that have allowed them to access and remain in health care.

Although we are making progress in providing services to people living with HIV/AIDS, the epidemic continues and will be in need of our attention for some time to come. The President and the Secretary understand the dynamics and severity of the epidemic and they are committed to ensuring the Department's HIV/AIDS programs are as effective as possible in preventing infection and treating those who become infected. We have recognized that, as essential as the CARE Act has been to serve Americans living with HIV/AIDS, it is in need of revitalization to safeguard its critical mission. Despite record levels of funding, we continue to face waiting lists for life-saving drugs through the ADAP program, and there are marked disparities in access to quality medical treatment across the country. As minority populations are increasingly and disproportionately impacted by HIV/AIDS, changes to existing systems of care designed for an

earlier epidemic are increasingly urgent. We are challenged as never before to make sure that Federal funds are directed where they are most needed and used for the most vital purposes.

Advancements

When AIDS was first recognized in the United States in the 1980s, medications to effectively treat the underlying immune deficiency did not exist. Today, although a cure has not been found, the introduction of Highly Active Antiretroviral Therapy (HAART) has had a tremendous impact on the morbidity and mortality associated with AIDS. Life-saving treatments have led to an increasing number of persons with HIV in the United States living longer lives. From 1999 to 2003, the number of persons in the U.S. living with AIDS rose from 311,205 to 405,926 – an increase of 30 percent.

Currently, 27 medications have been approved by the Food and Drug Administration (FDA) for the treatment of HIV/AIDS, including NRTIs (nucleoside reverse transcriptase inhibitors), PIs (protease inhibitors) and fusion inhibitors. A total of 84 HIV/AIDS related drugs, including vaccines, antivirals, antiinfectives, cancer treatments, immunomodulators, antifungal, gene therapies, and nine other medicines are currently in clinical trials or before the FDA awaiting approval. These life-saving treatments and related primary care services, however, come with a stiff price tag, ranging from $18,000 - $30,000 per year per patient.

Today, care and treatment advances have significantly reduced AIDS mortality, yet there has not been a corresponding reduction in the number of new infections, still estimated at 40,000 each year. In addition, of the estimated 1,039,000 – 1,185,000 persons in the U.S. with HIV/AIDS, 252,000 – 312,000 are undiagnosed and unaware of their HIV infection. HRSA's collaboration with the Centers for Disease Control and Prevention (CDC) on the Advancing HIV/AIDS Prevention Initiative together with the President's 2007 Domestic HIV/AIDS Initiative will go a long way in diagnosing and bringing these individuals into care. We must assure that the CARE Act programs are in a state of readiness to receive a growing number of newly diagnosed persons and link them into effective primary care and treatment.

Current State of the Disease

The HIV/AIDS epidemic is growing most rapidly among minority populations and is a leading killer of African-American males ages 25 to 54. African-Americans account for 50 percent of all HIV/AIDS cases diagnosed in 2004. The disease is also taking an increasing toll on women in the U.S., accounting for a growing percentage of new AIDS cases, rising to 27 percent of the cases diagnosed in 2004. Women of color, particularly African-American women, have been hard hit and represent the majority of new AIDS cases among women, an estimated 82 percent. The primary mode of HIV transmission is sexual contact, followed by injection drug use for women.

Current State of the CARE Act

The CARE Act, with appropriations of $2.06 billion, funds primary health care and support services for individuals living with HIV disease who lack health insurance and financial resources to pay for their care. HIV/AIDS health care is the largest component of Federal funding for people living with HIV/AIDS in the U.S. Each year, the CARE Act programs, primarily through grants to States, metropolitan areas, providers and educators, reach an estimated 571,000 underserved persons – more than half of those living with HIV/AIDS in the U.S. Medicare and Medicaid, the largest payers of HIV/AIDS health care, served an estimated 355,000 persons in FY2005 at a projected cost of $8.6 billion dollars in Federal funds. Since AIDS was first recognized, the pattern and treatment of HIV disease has shifted. We now strive to manage HIV/AIDS as a chronic disease.

The CARE Act is often the first line of defense for persons living with HIV/AIDS who are uninsured or underinsured. Early diagnosis and improved access to HIV care and treatment is key to what the CARE Act stands for. Funding under Titles I and II of critical early intervention services that include counseling, testing, and referral services for persons at high risk for HIV infection was expanded in the 2000 amendments. In 2004 alone, over 121 organizations received CARE Act funds to provide early intervention services under Titles I and II (or Parts A and B); a total of 359 organizations were funded under Title III (or Part C), a majority of which were community based health centers. An additional 91 programs were funded under Title IV (or Part D), a program designed with a focus on providing

access and early entry to care for HIV infected women, infants, children and youth, as well as supportive services to affected family members.

CARE Act funded programs are successful at counseling and testing. In 2004, over 800,000 HIV tests were administered in CARE Act sites. Over 85 percent of persons tested in CARE Act sites returned for their results. This was primarily because the CARE Act sites also were primary care settings which linked persons testing positive into immediate care and treatment.

Prevention and early intervention go hand in hand. Our medical care providers reported serving 5,375 HIV-positive pregnant women in 2004. Fifty-one percent were in care during the first trimester of their pregnancy. The percentage of pregnant women receiving prenatal care rose to 76 percent by the second trimester. Eighty-one percent received antiretroviral (AVR) treatment to prevent transmission of HIV to their child. The significant decline in perinatal transmission of HIV is a true success story and testament to the impact that targeted efforts such as those made by CARE Act programs can have, especially within our Title IV program. Early intervention services also include efforts to reach and provide early access to people living with HIV/AIDS who know their status but are not receiving HIV-related health services. In 2004, 506 CARE Act programs were funded to provide these outreach services, facilitating enrollment or re-entry into care and treatment efforts for over 35,000 HIV-positive clients and additional 59,000 HIV-affected persons. However, even with this successful

outreach effort, less than half of all HIV infected persons who know their status are in care.

Going Forward

We take great pride in the advances in HIV/AIDS care and treatment that have been made by the CARE Act programs over the past 16 years. However, we are humbled by the significant challenges that remain for people living with HIV/AIDS who have nowhere else to go for care in an age of increasing HIV/AIDS prevalence, increasing health care costs, and a growing burden of HIV among the uninsured and underinsured. With authorization of the Ryan White CARE Act pending, now is the time to make the necessary changes to ensure that individuals living with HIV/AIDS are better served by the Act.

The Administration has emphasized five key principles for reauthorization of the Ryan White CARE Act: (1) serve the neediest first; (2) focus on life-saving and life-extending services; (3) increase prevention efforts; (4) increase accountability; and (5) increase flexibility. The President has made fighting the spread of HIV/AIDS a top priority of his Administration, and he will continue to work with Congress to encourage prevention, and provide appropriate care and treatment to those suffering from the disease.

The President's fiscal year 2007 budget request for the CARE Act HIV/AIDS activities is $2.16 billion, an increase of $95 million for several elements of a new

Domestic HIV/AIDS initiative (further elements of that initiative, focusing on testing in the areas of greatest need, are requested outside the CARE Act). The request will support a comprehensive approach to address the health needs of persons living with HIV/AIDS, consistent with reauthorization principles. The budget also includes a new authority to increase program flexibility by allowing the Secretary to transfer up to five percent of funding provided for each Part of the Ryan White CARE Act to any other Part if the need warrants it. Of the new $95 million requested, $70 million will address the on-going problem of State waiting lists and provide care and life-saving medications to those newly diagnosed as a result of increased testing efforts. The remaining $25 million will be used to expand outreach efforts by providing new HIV community action grants to intermediaries including faith and community-based organizations, and to provide technical assistance and sub-awards to grassroots organizations.

Today, people with HIV/AIDS are living longer and healthier lives in part because of the CARE Act. In order to make the legislation more responsive in the future, the Administration urges Congress to take into account the above stated principles in the reauthorization of the Ryan White CARE Act.

Thank you for the opportunity to discuss the Ryan White CARE Act today and for your dedication and interest in such an important piece of legislation.