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"Domestic HIV/AIDS Care Programs"
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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) to discuss the programs of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. We appreciate your continuing support, and that of your colleagues, for CARE Act programs. Your interest in CARE Act services is certainly welcome, given the state of today's HIV epidemic as described by the CDC.

The Ryan White CARE Act is the centerpiece of our domestic response to care and treatment needs of low income people living with HIV/AIDS. Currently funded at $2.1 billion, it provides primary health care, life saving medications, and support services to individuals who lack health insurance and financial resources to provide for themselves. On two occasions, including his most recent State of the Union Address, President Bush has addressed the importance of this program and has called for the timely reauthorization of the Ryan White CARE Act.

Since its last reauthorization we have been able to provide anti-retroviral treatment, primary care, and support services to over half a million people annually in the United States, Puerto Rico, the Virgin Islands and pacific basin. Fifty percent of these

individuals lived below the Federal Poverty Level, less than 10% had any private insurance, and less than 30% were enrolled in Medicaid. In 2002 almost half of Ryan White clients were African-American. 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 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 is not over and will be in need of our continuing 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. During the past five years we have recognized that, as essential as the CARE Act has been to serve Americans living with HIV/AIDS, it is an imperfect instrument in need of revitalization. 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

President Bush has laid out three principles for the reauthorization of the CARE Act: First, that we should focus Federal resources on life-extending medical care such as anti-retroviral drugs, doctor visits, and lab tests – core services that are critical to maintain the health and well-being of people living with HIV/AIDS; second, that we provide greater flexibility so that CARE Act resources can be targeted to areas of greatest need; and third, that we ensure accountability in all that we do.

Current State of the Disease

Based on new CDC data, it is estimated that there are between 1 million and 1.2 million people living with HIV disease in the United States. Approximately 40,000 new HIV infections and over 18,000 AIDS related deaths occur per year. Of those living with HIV/AIDS disease, 74% are male and 47% are African-Americans while 34% are White and 17% are Hispanic.

In addition to challenges related to poverty and lack of adequate health insurance, individuals living with HIV disease commonly face other problems. About 22% of those with HIV/AIDS were infected through injection drug use. An estimated 20%-50% of people living with HIV/AIDS suffer from severe mental illness both related and unrelated to their infection and co-infection with hepatitis B and C is an increasing problem.

Current State of the CARE Act

The CARE Act, funded at approximately $2.1 billion in FY 2005, funds primary health care and support services for individuals living with HIV disease who lack health

insurance and financial resources for their care. Each year, the CARE Act programs, primarily through grants to States, metropolitan areas, providers and educators, reach more than half a million underserved persons - more than half of those living with HIV/AIDS in the United States. Since AIDS was first recognized, the pattern and treatment of HIV disease have shifted. We now can now strive to manage HIV/AIDS as a chronic disease.

More than 2,700 providers funded by the CARE Act programs are providing primary care and treatment and are building networks with other public and private providers to expand the response to the epidemic. Innovative outreach programs and community-based points of entry, such as public health, faith-based, social service and substance abuse treatment organizations, help to extend CARE Act services to hard-to-reach and at-risk populations.

Since the initiation of the CARE Act programs in 1990, perinatal transmission of HIV has declined dramatically. Less than 2% of all CARE Act HIV-positive clients are children age 12 or younger due, in large part, to the advances in prevention of perinatal transmission. The CDC reports that, in 25 states with long-standing confidential name-based HIV reporting, cases of HIV/AIDS in infants born to HIV-infected mothers have declined 74% over the 10 year period from 1994 to 2003.

Access to antiretroviral therapy for the CARE Act population has been expanded through the cost-saving mechanisms being used by individual State AIDS Drug

Assistance Programs and other discount programs. Antiretroviral therapy has led to longer, healthier lives for individuals living with HIV and AIDS. As a result, almost one third of the CARE Act population is age 45 or older.

ADAP, which provides funds to States to purchase life-saving medications, is the single largest CARE Act program because of the high cost of medication and the growing number of people living with HIV/AIDS. In FY 2005, HRSA distributed in excess of $787.5 million in ADAP funds to States, and the FY 2006 President's budget request includes an increase of $10 million. The ADAP program reaches approximately 90,000 people every month. The program is State-defined and thus differs in eligibility criteria and formularies from State to State.

The epidemiology and treatment of HIV has shifted in recent years to a more chronic disease model requiring a changing continuum of services to support this model. This shift and the success of new treatments has resulted in longer life spans and an overall increase in the demand for care and related drug treatments.

Going Forward

The greatest challenge is reaching people who have nowhere else to turn - especially as HIV/AIDS prevalence, health care costs, and the burden of HIV among the uninsured and underinsured increases. Resources are likely to become more and more strained as the CARE Act's outreach efforts coupled with CDC's prevention initiatives continue to successfully identify individuals living with HIV disease.

These newly infected individuals are more likely to be low-income, to be minority, and to have complex co-morbidities such as mental health and substance abuse problems. Many will live in rural areas. Strengthening health care and community organizations capable of serving these populations will be an increasingly important role in the CARE Act's next decade.

Mechanisms to allocate funds must be cognizant of these changes: "hold harmless" provisions, formulas based on AIDS rather than HIV, and allowing funds that have not been put to work in a timely manner to "roll over" or revert to the Treasury rather than giving DHHS the necessary flexibility and authority to reprogram resources to communities in need, must be re-engineered.

We take great pride in the advances in care and support for people living with HIV/AIDS that have been made by the CARE Act programs over the last 15 years. We are thankful for your help and that of the dedicated providers and communities all over the Country. However, we are humbled by the significant challenges that remain to reach 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. We will soon be releasing an expanded set of policy points based upon President's principles. We intend these to serve as guideposts for discussion and deliberation on the very tough issues we must face together: how to ensure that the most vulnerable and needy in this country receive life

saving treatment, how to work more effectively with state and local governments and communities impacted by HIV, how to hold ourselves and our partners more accountable for use of Federal tax dollars and, importantly, how to advance HIV prevention in this Nation. We look forward to working with you to revitalize the CARE Act.