

**New York State Department of Health
AIDS Institute**

**Response to Administration Principles for
Reauthorization of the Ryan White CARE Act**

Background

New York State leads the nation in cases of HIV and AIDS. More than 100,000 New Yorkers are living with HIV or AIDS. New York is home to 17% of persons living with AIDS in the U.S., but only 7% of the nation's population. New York's AIDS case rate of 34.8 per 100,000 is more than double the U.S. average of 15.2 per 100,000.

The epidemic in New York State is unique and complex. Communities of color are particularly affected, with more than 75 percent of living HIV/AIDS cases among persons of color. Almost half of the State's cases are directly or indirectly attributable to injection drug use. People living with HIV and AIDS in the State have a high percentage of co-morbidities, such as mental illness and STDs. The epidemic and the delivery of HIV/AIDS services are further complicated by poverty and homelessness.

As the number of people living with HIV and AIDS has increased over the years, so has the State's commitment to serving its citizens with HIV/AIDS. No state spends more to prevent the spread of HIV infection and care for persons with HIV/AIDS. The continuum of services in New York State is supported by about \$2.6 billion annually, including Medicaid-reimbursed health care and HIV grants supported by state and federal funds.

The Ryan White CARE Act governs the largest federal program for people living with HIV/AIDS. Enacted in 1990, the intent of the CARE Act is to provide assistance to localities disproportionately affected by the epidemic and to make financial assistance available to states for the development, organization, coordination, and operation of effective systems for the delivery of essential services to individuals and families with HIV disease.

The CARE Act is an essential source of support for HIV/AIDS services in New York State. New York State receives more than \$340 million in CARE Act funds under all titles. The Title II grant directed to the New York State Department of Health is currently funded at \$171.8 million.

Administration Principles

On July 27, 2005, the U.S. Department of Health and Human Services held a briefing to outline the Administration's principles for reauthorization of the Ryan White CARE Act. Many of the principles appear to be inconsistent with the original intent of the CARE Act – to direct assistance to the jurisdictions disproportionately impacted by the HIV/AIDS epidemic and to improve the availability, quality, and organization of health care and support services for individuals and families with HIV disease. Instead, some of the principles' goals appear to be related to equalizing inherent differences in HIV/AIDS resources among states, limiting the flexibility of states to direct Ryan White resources to meet locally defined needs while increasing the flexibility of the Administration to reprogram funds at their discretion, and shifting funds away from some heavily impacted jurisdictions and toward others through drastic changes in funding formulas and the elimination of provisions that limit the loss of resources to a jurisdiction over time. If adopted in legislation, many of the principles are likely to have a devastating impact on the State's HIV/AIDS infrastructure and on New Yorkers living with HIV/AIDS throughout the State.

Following is a summary of each principle along with the State's response.

PRINCIPLE: In recognition of the differences in access to HIV care throughout the country, a "severity of need for core services index" (SNCSI) will be established and used in revised Title I and Title II funding formulas that will take into account not only cases of HIV but levels of poverty and availability of other resources, including local, state, federal, and private resources.

RESPONSE: New York State strongly opposes this principle. This principle calls for a drastic change to the formula allocations for states and localities.

Early in the HIV/AIDS epidemic, the most heavily impacted states, like New York, rose to the occasion and brought resources to bear in order to organize and finance services for persons living with HIV disease. With a combination of resources, including State and federal grant funds and Medicaid reimbursement, New York State is providing high-quality services to its residents with HIV and AIDS. In order to continue doing so, New York, and other heavily impacted states, must at a minimum maintain existing levels of resources.

As stated above, no state spends more than New York does to care for persons with HIV/AIDS. An examination of the availability of other resources in the Title I and Title II formulas will lead to substantial losses in Ryan White funding for New York State. Considering the availability of other resources in determining Ryan White Title I and Title II allocations punishes jurisdictions that have devoted their own resources to addressing the epidemic and rewards jurisdictions that have not. In addition, the principle serves as a disincentive for jurisdictions to allocate local resources to meet the needs of their residents with HIV/AIDS.

Each state differs in terms of the resources that the state itself provides for the care and treatment of persons with HIV/AIDS. The Ryan White CARE Act cannot and should not be viewed as a mechanism for equalizing these inherent differences.

The only change to the Title I and Title II funding formulas should be the inclusion of cases of HIV – not just AIDS – in the allocation formulas.

PRINCIPLE: Eliminate the “double counting” of cases between major metropolitan areas and the states.

RESPONSE: New York State strongly opposes this principle. This principle calls for a drastic change to formula allocations. It would lead to substantial losses in funding to New York State and disruptions in services for persons living with HIV/AIDS.

The term “double counting” is misleading. It refers to the fact that AIDS cases located in Title I EMAs are considered in the Title I funding formula as well as the Title II base (non-ADAP) funding formula. However, they are not “double counted.” In reality, in the allocation of Title II base funds, states receive partial credit for the cases in EMAs, in recognition of the role of states in coordinating a statewide response to the epidemic and in complying with numerous CARE Act mandates related to coordination among Ryan White titles and statewide requirements. In addition, consistent with the intent of the CARE Act, the consideration of Title I EMA cases in the Title II formula recognizes the disproportionate impact and heavy burden of the epidemic on states and localities with the highest numbers and proportion of infected persons. The application of this principle to the Title II base formula would tie the allocation to non-EMA cases only, resulting in a 56 percent reduction to the State’s base and a drastic, negative impact on services in the hardest hit regions of the State. Other high-prevalence states will be harmed as well; eighteen states with Title I EMAs would lose more than \$76 million in Title II base funding.

The principle does not specify that it is the state count of EMA cases that will be eliminated. Another possible interpretation would give states full credit for EMA cases in the Title II base formula and eliminate Title I formula awards. Either way, this principle will lead to a formula change that will result in a devastating loss of resources to New York State and to other high-prevalence states.

This principle will disadvantage states that are hardest hit by the epidemic by shifting funds away from these states. The allocation of CARE Act funding must continue to reflect and be responsive to statistics that describe those states with the highest numbers and proportion of infected persons.

As stated above, the Title I and Title II base formulas should be retained, with the exception of including cases of HIV -- not just AIDS – in the allocation formulas.

PRINCIPLE: Establish a set of core medical services and require that 75 percent of Ryan White funds be used for core medical services.

RESPONSE: New York State strongly opposes this principle. The CARE Act has always recognized the importance of both medical and supportive services in providing comprehensive care and treatment to people living with HIV/AIDS. The range of allowable health care and supportive services has fostered the development of a variety of service programs that are critical to engage and maintain people in treatment and care. Such services include: treatment adherence support to help people stay on complex medication regimens; case management to ensure access to and coordination of care and services; outreach to identify persons with HIV and link them to care; nutrition to support the immune system and increase tolerance of medical treatments; housing assistance to promote stability and connection to health care; transportation to ensure access to care; and substance abuse counseling to support and assist persons with HIV/AIDS in accessing and staying in care and treatment.

Decisions regarding the services to be supported with CARE Act funds must be made at the local level based on need and availability of resources. While states should be required to ensure access to medical services consistent with Public Health Service guidelines, legislative mandates that “medicalize” the CARE Act by imposing a percentage set aside will be detrimental to the effective provision of comprehensive services, to ensuring access to and maintenance in care, and to the ability of states to respond to the emerging needs of persons living with HIV/AIDS.

Since the CARE Act is payer of last resort, imposing a percentage set-aside for medical services disadvantages states that have devoted other resources -- including Medicaid and state dollars -- to support medical care and clinical services for persons with HIV/AIDS. Like the two principles described above, this principle is likely to result in shifting funds away from states that have devoted other resources to the care of persons with HIV/AIDS and toward states that have not.

Flexibility must be preserved in the reauthorized CARE Act to allow funds to be used based on locally determined needs.

PRINCIPLE: Eliminate the provisions that entitle cities and states to be “held harmless” in funding reductions. (Note: The written principles refer to eliminating only the Title I “hold harmless” provision. During the briefing, however, HHS clarified that the principle applies to the Title II “hold harmless” provision as well.)

RESPONSE: New York State strongly opposes this principle. The “hold harmless” provisions limit the loss of resources to a jurisdiction over time. These provisions are crucial in order to avoid substantial reductions in funding that might accompany changes in case counts, changes in funding formulas that might be adopted in reauthorization of the CARE Act, or changes in funding resulting from appropriations language requirements, such as carve-outs and set-asides for specific services and populations.

The elimination of “hold harmless” provisions might be viewed as a means of fostering shifts in funds to address disparities. However, these disparities cannot be corrected with major shifts in resources without compromising services in jurisdictions that lose funding.

The Title II “hold harmless” provision must be retained, although New York supports a slight increase in the Title II “hold harmless” percentage.

PRINCIPLE: Unspent funds from Titles I and II will revert to HHS for discretionary reprogramming.

RESPONSE: New York State does not support this principle. This principle would eliminate the availability of carryforward funds. Prudent grants management will always result in some degree of underspending in a state as large as New York. Currently, unspent funds may be “carried forward” into the next budget period to support essential services and activities. New York State uses carryforward funds to support ADAP program growth. The availability of carryforward is crucial for the State. At a minimum, the State must have access to a percentage of its unspent funds.

PRINCIPLE: Maintain a federal list of ADAP core medications and prioritize these medications for federal funding.

RESPONSE: New York State does not support this principle as written. Establishing a “core” ADAP formulary and prioritizing these medications for federal funding is likely to create a ceiling with regard to ADAP formularies,

resulting in reduced access for states with more expansive formularies, like New York. This principle would be acceptable only with legislative language clarifying that the existence of a list of “core” medications must not be used to reduce existing formularies or limit expansion of formularies.

PRINCIPLE: Strengthen payer-of-last-resort provisions and require regular HHS audits to ensure compliance.

RESPONSE: New York State does not support this principle. First, this principle is unnecessary. The CARE Act has always included payer-of-last-resort provisions, and audits have been conducted by HHS. Second, the State recommends revising the payer-of-last-resort provision to recognize the total cost of HIV service programs and to enhance access to HIV services. Often, third-party reimbursement is not sufficient to cover the total cost of an HIV service program. The CARE Act can help overcome this barrier by allowing the use of Ryan White funds to cover the difference between the total cost of an HIV service program and the amount covered by third-party payers. In addition, states should have the flexibility to use Ryan White funds to serve clients who have coverage for services through other payers if the services covered elsewhere are difficult to access, for example if location or distance are barriers to access.

PRINCIPLE: Increase HIV prevention and testing efforts. States that accept Ryan White funding will be encouraged to adopt HIV prevention strategies, including routine opt-out HIV testing, contact tracing, and the recommendations of the CDC Advancing HIV Prevention Initiative.

RESPONSE: New York State supports the intent of this principle – enhancing prevention and testing – but some of the proposed strategies may be problematic. Article 27-F of the New York State Public Health Law requires informed consent for testing and provides confidentiality protections to HIV-infected and affected persons. In recognition of the importance of testing to preventing HIV infection and engaging HIV-positive persons in care, the State has already taken steps, within the parameters of State law, to streamline and simplify HIV counseling and testing, to integrate routine HIV counseling and testing in medical settings, and to better monitor the quality of HIV care by improving HIV surveillance to include results of resistance, viral load, and CD4 tests. Legislative “encouragement” of states to adopt specific strategies upon acceptance of their Ryan White awards has the potential to be translated into federal policy and requirements. The CARE Act must not include such language.

PRINCIPLE: Maintain the statutory requirement that all states submit HIV data by the start of fiscal year 2007.

RESPONSE: New York State supports this principle.

PRINCIPLE: Hold grantees accountable for reporting on system and client-level data and progress.

RESPONSE: New York State supports this principle.

PRINCIPLE: Require state and local care delivery coordination.

RESPONSE: New York State supports this principle. There is a tradition of coordination of HIV/AIDS services/activities among the State, localities, providers, and persons living with HIV/AIDS.