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HIV Health and Human Services Planning Council of New York Responds to the Bush Administration's Principles for Reauthorization of the CARE Act

New York City – New York City remains the epicenter of the HIV/AIDS epidemic nationally, with an estimated 92,000 New Yorkers diagnosed and known to be living with HIV or AIDS and an estimated 25,000 additional people living with HIV but not diagnosed. A cumulative total of 143,354 New Yorkers have been diagnosed with AIDS since 1981. As of December 2003, 15.3% of AIDS cases nationwide had been diagnosed in New York City.

The HIV Health and Human Services Planning Council of New York is extremely troubled by a number of Principles for Reauthorization of the Ryan White CARE Act released by U.S. Health and Human Services (HHS) Secretary Mike Leavitt on Thursday, July 27, 2005.

Patrick McGovern, Community Co-Chair of the mayoral-appointed planning body that oversees the allocation of Title I funding for the New York eligible metropolitan area (EMA), which includes the five boroughs of New York City, and Westchester, Rockland and Putnam counties (Tri-County), states, "I am very concerned with some of the principles outlined by the Bush Administration. The Administration's proposal to develop a 'severity of need' for core services index (SNCSI) that would factor in the availability of local and state support will be a devastating loss for New York."

"Through the generosity of New Yorkers and a strong sense of social contract, New York's Medicaid program provides a comprehensive set of medically necessary health services to the most vulnerable New Yorkers, including people living with HIV/AIDS. If it is the intention of the Administration to reduce the CARE Act funding to EMAs based on availability of local and state resources, this will create a perverse incentive for states and cities to dedicate fewer resources to care for people with HIV/AIDS, and, in effect, penalize states like New York, that have made the right decision to care for their citizens by contributing local resources."

"In addition, the requirement that 75% of CARE Act funds be allocated to 'core medical care services' would virtually eliminate the flexibility that Title I EMAs currently have to make decisions on the appropriate allocation of funds based on local community needs.

Local EMAs best understand their own needs and this unique aspect of the CARE Act should be maintained. “

“Life-sustaining and life-enhancing health services extend beyond primary medical care. Other crucial services include mental health, substance abuse treatment, case management and housing. I urge that a comprehensive list of ‘core medical care services’ that includes all crucial services be developed.”

The proposed SNCSI will negatively impact New York in additional ways. The principle only considers incidence, not prevalence, in determining the index. Prevalence is the accurate indicator for the need for HIV/AIDS treatment services. Furthermore, the currently stated formula to calculate the severity of need index will penalize those areas with decreasing incidence, which is a sign of successful prevention efforts.

Steve Hemraj and Felicia Carroll, Co-Chairs of the People Living with HIV/AIDS Advisory Group of the Planning Council, share Mr. McGovern’s concerns. “The New York EMA has built a comprehensive and integrated HIV/AIDS service system to meet the needs of New Yorkers living with HIV/AIDS through collaborative efforts with New York State and other service providers. Many New Yorkers living with HIV/AIDS receive essential primary medical services, including medications, through Medicaid and the Ryan White Title II-funded ADAP program. However, there are a number of people with HIV/AIDS who do not have access to such services. Ryan White CARE Act funds are used to assist such individuals and help them access necessary medical services and help them remain in the health care system. We believe that all persons living with HIV/AIDS deserve to receive high quality health services no matter where they live. But this cannot be achieved without the federal government’s commitment to adequately fund the CARE Act.”

The Planning Council urges the members of Congress to work together to reauthorize the Ryan White CARE Act with the goal of improving the lives of people living with HIV/AIDS in a timely manner.

Below are the HIV Health and Human Services Planning Council of New York’s responses to the principles.

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Serve The Neediest First

- **Establish Objective Indicators To Determine Severity Of Need For Funding Core Medical Services.** Those in greatest need of HIV/AIDS assistance, including African-American and low-income individuals, have the fewest resources available to meet them. There are also significant differences in access to HIV care throughout the country. Recognizing the circumstances that contribute to different care needs is an important part of assisting those hardest to reach. To address the needs of these populations, the Secretary of Health and Human Services (HHS) would develop a "severity of need" for core services index (SNCSI). This index would be based upon objective criteria and be focused on core services. It would take into account not only HIV incidence, but levels of poverty, availability of other resources including local, state, and federal programs and support, and private resources. This SNCSI would determine formula allocations among states and eligible metropolitan areas. When combined with a requirement of maintenance of effort on the part of state and local governments, the SNCSI would address the differences in HIV/AIDS care.

Response: The Planning Council supports establishing a fair and objective formula to ensure equitable distribution of funds. However, the Council is extremely troubled with the proposal to include local and state support in determining a "severity of need" index. The federal government risks creating a disincentive for localities and states to dedicate their own resources in the fight against HIV/AIDS if their intention is to deduct from Ryan White funding local commitment to services for people living with HIV/AIDS. New York State, with contributions from New York City and Tri-County, has wisely chosen to create a rich public health insurance program (Medicaid) for the poor and most vulnerable of our population. A funding formula that includes local resources such as Medicaid as a factor for funding distribution may result in substantial loss of Ryan White funding. The State as well as the three eligible metropolitan areas (EMAs) in New York State (New York, Dutchess County and Long Island) should not be penalized in their Ryan White funding because the State took a responsible route in ensuring access to health care for poor New Yorkers. Efforts should be made on the federal level to encourage states to develop as comprehensive and extensive a public health insurance program as possible; this effort is a movement in the opposite direction.

In addition, the proposed principle considers incidence, not prevalence, in determining the "severity of need" for core services index (SNCSI). Prevalence is the accurate indicator for the need for HIV/AIDS services. Furthermore, the articulated formula to calculate the index will penalize those areas with decreasing incidence, which is a sign of successful prevention efforts.

Focus on Life-Saving and Life-Extending Services

- **Establish A Set Of Core Medical Services.** It is essential to identify the basic, primary medical care and medication needs of individuals with HIV/AIDS.
- **Require That 75 Percent Of Ryan White Funds In Titles I-IV Be Used For Core Medical Services So That Federal Funds Are First Used To Support Life-**

Saving Services For The Most Impoverished Americans. A person living with HIV/AIDS receives benefits from a range of services. Some of these are clearly life prolonging and essential to maintaining physical and mental health; others are not. Services that are essential (core services) should be prioritized for Federal funding.

Response: A unique and successful feature of the Ryan White CARE Act that has been proven effective is the concept of local control and localities making decisions based on local need of appropriate usage of Ryan White Title I and II funds. The epidemic in New York varies significantly from the epidemic in other EMAs. Each locality and state must have the flexibility to make decisions on the appropriate allocation of these funds based on the data in their own region.

Limiting funding to a set of core services or prescribing a minimum percent of funding for specific services at the federal level may adversely impact the ability of grantees to fund services that enhance access to and maintenance in HIV-related medical care. Local variations in services supported by other funding streams, such as State Medicaid programs, substance abuse treatment, or mental health services for persons with multiple diagnoses, require flexibility in CARE Act-funded programs. All services supported with CARE Act funds should be linked with improvements in health outcomes related to access and appropriate utilization of health services by people living with HIV/AIDS.

New York's Medicaid program has provided important life-saving and life-extending services and medications to people living with HIV/AIDS. Ryan White funds are used to complement the strong basic primary care infrastructure by filling gaps in medical care services and to provide crucial services such as mental health, substance abuse, and housing that enable people living with HIV/AIDS to access and remain in the health care system and adhere to medication regimens. For example, at any given time, 1 in 4 New Yorkers with HIV/AIDS is unstably housed. Homelessness or unstable housing significantly reduces health care utilization, impedes treatment adherence, and exposes immune-suppressed individuals to conditions that threaten their health and well being. Ensuring that homeless and unstably housed persons receive adequate housing helps to ensure that these individuals are allowed to access care and adhere to treatment. To combat this problem, the HIV Health and Human Services Planning Council of New York has devoted \$2.5M to provide emergency and transitional supportive housing. The requirement of 75% of Ryan White Funds in Title I-IV used for "core" medical services would result in a significant decrease in RWCA Title I funds in New York. The Planning Council strongly recommends that the appropriate mix of HIV/AIDS services be determined locally based on assessment of local needs.

- **Maintain A Federal List Of AIDS Drug Assistance Plan (ADAP) Core Medications.** The HHS Secretary will develop and maintain a list of core ADAP drugs based upon those included in the U.S. Department of Health and Human Service's Public Health Service HIV/AIDS Clinical Practice Guidelines for use of HIV/AIDS Drugs, drugs needed for the treatment and prophylaxis of opportunistic

diseases and drugs needed to manage symptoms associated with HIV infection. These medications should be prioritized for Federal funding.

Response: Insufficient federal funding is the primary reason some states have been unable to maintain an adequate formulary and/or provide assistance to most low-income people living with HIV/AIDS. After an initially robust federal response to the growing costs of pharmaceuticals and the unmet treatment needs of AIDS Drug Assistant Program (ADAP) clients, the ADAP line item has received only modest increases over the past several years, falling well short of the levels needed for states to provide appropriate service. Another factor is the ability of a state to provide funding to make up for federal budget shortfalls. Some states, such as California, have contributed generously to their programs to ensure access to HIV medications. Other states, such as Alabama, have also contributed substantially to their ADAPs and still have waiting lists and/or limited eligibility standards. Other factors include: (1) the ability of the state's Medicaid program to serve people living with HIV/AIDS in need, (2) the ability to direct pharmaceutical rebate funds for drugs bought with ADAP funds back into the ADAP rather than to the state's general fund, (3) the level of discounts negotiated with the distributors of ADAP drugs, and (4) contributions from other sources.

ADAP formularies vary broadly among the 57 jurisdictions receiving Ryan White ADAP earmarked funding in FY 2004. The Planning Council is concerned that a national formulary would create an artificial ceiling on the number of allowable medications. This may result in a substantial reduction to the number of drugs available in New York and persons with HIV/AIDS will no longer be able to access necessary life-saving and life-extending medications. The Planning Council urges Congress and the Administration to support full funding for ADAP so that all states receive adequate funding for their ADAP programs.

Increase Prevention Efforts

- **Require States To Implement Routine Voluntary HIV Testing In Public Facilities And Work With Private Healthcare Providers To That Same End.** With an estimated 250,000 HIV-positive individuals unaware of their HIV-positive status, testing is a key element in prevention efforts. States will be encouraged, upon receipt of their Ryan White allocations, to adopt various important HIV prevention strategies, such as routine opt out HIV testing, contact tracing, and the recommendations of the CDC Advancing HIV Prevention Initiative.

Response: The Planning Council supports the implementation of HIV prevention strategies, including routine voluntary HIV testing in primary care and public facilities, to identify people living with HIV/AIDS and to effectively address the unmet need in New York. New York State has already implemented new HIV counseling and testing guidelines and HIV reporting requirements for laboratories that will reduce barriers to HIV testing and entry into care, as well as provide important information to better monitor the effectiveness of HIV treatment and the development of HIV antiviral resistance in persons with HIV.

An aggressive nationwide strategy to effectively identify persons who are infected with HIV and not aware of their status must include making voluntary HIV testing routinely available in all medical settings and a standard part of medical care, as well as other public venues.

Increase Accountability

- **Maintain The Current Statutory Requirement That All States Submit HIV Data By The Start Of Fiscal Year 2007.** Having a full picture of the scope of HIV is critical to successful care and treatment programs that prevent people from advancing to AIDS; because newer infections are increasingly likely to take place among minorities, this provision will better target funds to heavily impacted communities and aid in getting people into care sooner.

Response: The State of New York has already implemented named-based HIV reporting and supports this provision.

- **Hold Grantees Accountable For Reporting On System And Client-Level Data And Progress.** Accurate counts of those served and those receiving core services will help better serve those in need, as well as enable caregivers to define performance measures and evaluate progress.

Response: The Planning Council understands the need for client-level data to help the Council better understand the epidemic and clients who access CARE Act services. Since 2004 the Council has funded a client-level data collection initiative, which will be fully implemented system-wide by the end of 2005.

- **Maximize Investments Through Stronger And More Specific Payer-Of-Last-Resort Provisions And Require Grantees To Seek Alternative Payment Sources Before Using Ryan White Funds.** The Ryan White program is to be used as a last resort for only HIV-positive individuals who are not able to access medical care through other means. To ensure that this is the case, other payers of care need to be exhausted before turning to Ryan White funds. HHS would conduct regular audits to ensure RWCA funds are used as the payer of last resort. Federal and state investments would be directed to fill gaps in the existing health care system rather than duplicate existing public or private activities. The Grantee ensures through multiple means that Title I always serves as the payer of last resort.

Response: In order to ensure that CARE Act funds are the payer of last resort, during its annual priority setting and resource allocation process, the Planning Council reviews the capacity and availability of HIV/AIDS services provided by other payment sources. Working with local community partners, including State and City agencies such as the HIV/AIDS Services Administration of the New York City Human Resources Administration, other Titles of the CARE Act, and CDC-funded prevention providers, the Planning Council identifies service priorities and allocates resources to address unmet

need and fill gaps without duplicating services provided by existing public or private payers.

- **Require State And Local Care Delivery Coordination.** A coordinated effort between the states, cities, and other care providers is essential to effective, comprehensive care and prevention services. HHS would consult with state AIDS officials on discretionary grants and would provide to state AIDS officials all information necessary for states to coordinate HIV care and treatment with other Federally funded projects to maximize efficiency and effectiveness of AIDS services.

Response: The Planning Council has a strong collaborative relationship with external partners, including city agencies, state AIDS officials, and other care providers to coordinate HIV care and treatment services in New York.

- **Eliminate The Double Counting Of HIV/AIDS Cases Between Major Metropolitan Areas And The States.** Currently, in major metropolitan cities, AIDS cases are counted once as part of a city count and a second time in the overall state count. Therefore, HIV/AIDS cases in major metropolitan cities are counted twice. In an effort to ensure that every AIDS case is counted equally and to make sure that Federal funds are distributed fairly to those most in need of assistance, we must eliminate this double counting.

Response: This principle may eliminate the Title I EMA AIDS cases from the Title II base funding formula. Currently, the Title II base formula consists of: 1) a statewide component, based on the number of statewide AIDS cases compared to the number of AIDS cases in the nation, which is given a weight of .8 or 80%; and 2) a non-EMA component, based on the number of cases in the state outside of Title I EMAs compared to the number of cases in the nation outside of Title I EMAs, which is given a weight of .2 or 20%. The proposed revision to the Title II base formula -- i.e., tying the Title II base allocations to non-EMA cases only -- will result in a 56 percent reduction to the State's base and will have a drastic, negative impact on Title I EMAs.

Furthermore, the current structure of the CARE Act, with resources devoted to localities as well as states to combat the epidemic is a deliberate design in the Act and was intended to give both state and local government each the resources to address the epidemic. HIV/AIDS disproportionately impacts major urban areas around the nation; local governments, whose health care infrastructure has been hardest hit by the epidemic must have the tools at their disposal to provide services and health care locally. In addition, urban areas such as New York City have unique challenges that make addressing the epidemic that much harder, including larger substance using populations, high concentration of poverty, lower education levels, and high health care and housing costs. The epidemic's concentration among the very poor substantially adds to the cost and complexity of care. For example, 21% of New York City residents (compared to 12% nationally) live below the poverty line. The CARE Act provides resources through Title I and II to ensure that both state and local governments have the federal support it needs to address the needs of their citizens.

- **Eliminate Current Provisions That Entitle Cities To Be "Held Harmless" In Funding Reductions.** Today, because of the way the existing formulae count the number of AIDS cases (by including cases spanning the last 10 years), metropolitan areas with newer epidemics receive disproportionately less than those with more longstanding problems. In order to more accurately reflect the current status of the epidemic, we must eliminate provisions that entitle cities to be "held harmless" in funding reductions.

Response: The Planning Council supports equitable distribution of the CARE Act funds across EMAs. However, it is equally important to ensure that currently existing systems of care are not decimated overnight by radical reductions in funding. Cities and states must be given adequate time to gradually anticipate and plan for any potential reductions in funding. The Planning Council recommends that the "held harmless" provision be maintained but with an accelerated percentage reduction from 15% over five years to 21% over five years. The Council agrees with the comments made by Senator Coburn that reform of the hold-harmless provision must be done in a way that "minimizes harm to existing systems of care."

Increase Flexibility

- **Allow The Secretary Of HHS To Redistribute Unallocated Balances Based On Need As Determined By Severity Of Need Measures.** To maximize all Ryan White funding, unspent funds from Titles I and II would revert to the Secretary of HHS for discretionary reprogramming to state ADAP programs with the greatest need.

Response: Given the New York EMA's large portfolio, even the most efficient administration of the grant will result in some degree of underspending. Over the years, the New York EMA has successfully implemented a mechanism to minimize any underspending of Title I funds. Through aggressive contract monitoring, the New York EMA manages to spend over 97% of its total award. Any unexpended funds are then used to provide essential health services for people with HIV/AIDS. Under the proposed principle, the New York EMA may lose access to its carryover money. The Planning Council opposes this principle and recommends that localities be allowed to determine the best use of unallocated funds to meet their HIV/AIDS service needs.

- **Allow Planning Councils To Serve As Voluntary And Advisory Bodies To Mayors.** State and local officials need maximum flexibility to respond to the epidemic and to direct funding to those in greatest need. Planning councils would be structured at the discretion of the mayor; could not have conflicts of interest; and would no longer be required to set priorities for spending.

Response: The Planning Council strongly objects to the elimination of the councils' mandated roles and responsibilities to set service priorities and allocate resources. The Ryan White CARE Act has always required that Title I planning councils include people living with HIV/AIDS to ensure that individuals with firsthand experience as consumers

of Title I services have a role in fulfilling the council's planning and priority-setting mandates.