

Ryan White CARE Act Reauthorization

Written Comments Submitted to:

The CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment
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The New York City Department of Health and Mental Hygiene thanks the members of the CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment for holding these hearings on this important piece of federal legislation. The Ryan White CARE Act has been a critical law that has over the past decade helped improve the lives of thousands of People Living with HIV/AIDS.

HIV/AIDS in the New York Eligible Metropolitan Area (EMA)

HIV/AIDS is still a crisis in this country. Federal emergency assistance in the form of the Ryan White CARE Act is essential to help jurisdictions address the needs of the diverse and highly complex populations living with HIV/AIDS. Without federal assistance, localities would be unable to meet the needs of persons living with HIV/AIDS.

New York City remains the epicenter of the epidemic nationally, with at least 80,000 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 134,504 New Yorkers have been diagnosed since AIDS case reporting began in 1985. In 2001, 1,770 persons first learned they were HIV positive when they were diagnosed with AIDS, a sad and very avoidable situation.¹ According to the Centers for Disease Control and Prevention (CDC), the New York EMA (which includes the five boroughs of NYC and the counties of Westchester, Rockland and Putnam) has more persons living with AIDS than the cities of Los Angeles, Washington DC, Houston and West Palm Beach combined.² Further complicating the epidemic, New York, like many large urban areas, has a complex epidemic that contains a high percentage of comorbidities (such as intravenous drug usage, serious mental health problems, and other sexually transmitted diseases) that are concentrated in traditionally marginalized populations. The AIDS crisis is far from over, especially in New York City.

CARE Act Title I Funding

The New York Eligible Metropolitan Area (EMA) does not receive its equitable share of Title I funding. With 20% of all living AIDS cases among the 51 EMAs, and a much greater share of AIDS cases with co-morbidities which make access to care particularly challenging, New York City only receives 17% of the total Title I award. Furthermore, Title I spending per living AIDS case in New York is approximately \$2,062 versus a national average of \$2,311. That places New York's per capita share of the Title I award at the 12th lowest in the nation among EMAs (see attachment), lower than cities such as Miami FL, Fort Worth TX, and Baltimore MD.

This past year, the New York EMA experienced a 13% reduction in our grant award, in the amount of \$13.8 million, all of which was from the supplemental portion of our application. The recent cut in our award has placed great stress on the ability of New York to provide a consistent level of quality services to the People Living with HIV/AIDS (PLWHAs). Many other Eligible Metropolitan Areas have also been severely impacted by wide fluctuations in their award. We know we are not alone in trying to meet greater needs with fewer resources. For example, in 2002, 17 EMAs suffered cuts in their Title I award, and in 2003, 13 EMAs received cuts in their award. NYC lost the most at: \$13.8 million. Such significant funding reductions do great harm to the populations we serve. HRSA expects municipalities to provide a consistent level of quality care and services for PLWHAs. HRSA must then be prepared to provide consistently stable funding to make this a reality. In New York, the \$13.8 million reduction in our award resulted in

the cancellation of contracts with some service providers, the reduction of our contribution to primary health care services, and across-the-board cuts to programs. Many are predicting that these measures will result in serious reductions in services from providers who are already stretched thin while trying to meet ever-growing demand. HRSA should re-visit the policies that caused the negative fluctuations in the supplemental awards. An alternative solution needs to be identified by which EMAs are not severely penalized in their supplemental award.

The newly introduced CDC HIV prevention initiative holds the promise of identifying many individuals who did not previously know their HIV status. As these individuals enter systems of care, Ryan White-funded programs, many of which are already strained, will struggle to meet the growing need for their services. In New York City, the \$13.8 million cut in our award will make this challenge particularly difficult to address.

Local Decision Making

Local decision-making is an important part of the CARE Act and must be preserved in the Reauthorized Act. Local Planning Councils are responsible for needs assessment, priority setting, and resource allocation. An important feature of the CARE Act is its ability to rapidly disburse funds to address the epidemic locally. Frontline community planning is challenging, but it is critical that voices of disenfranchised and marginalized individuals be an integral part of the planning process.

In a jurisdiction such as New York, with a large disproportionately impacted HIV/AIDS population representing all facets of the HIV/AIDS community, there are frequent opportunities for input into the CARE Act planning process. We believe that this process maximizes community input and allows us to be truly able to adapt scarce resources to ever-changing HIV care and support needs. We support continued improvement of coordination across all titles of the Ryan White CARE Act, as well as collaboration with other federal, state, and local partners. In addition, we recommend greater flexibility in the reauthorized CARE Act to allow Persons Living with HIV/AIDS who work with AIDS service organizations to be members of Planning Council bodies.

The Changing HIV/AIDS Epidemic

Each year, during our annual planning process, the New York HIV Health and Human Services Planning Council, through the careful review of data and with input from the community, determines that there is a substantially greater need for additional services than is available with the resources provided by the Federal government. Examples of programs recommended for funding by the Council but lacking the necessary resources include: Housing for PLWHAs in Need of Harm Reduction, Emergency and Transitional Housing for Special Populations, Mental Health Services in Primary Care Settings, Mental Health Services Targeted to Persons Over 50, the expansion of Assessment Teams in Emergency Rooms, and Ambulatory/Outpatient Services targeted to Women and People over 50. While the CARE act provides us with a significant level of assistance to help respond to the needs of our community, the inability to fund additional needed services demonstrates that this assistance is still woefully short of demand.

One of the most significant HIV service gaps that has been identified in our community is the need for medically appropriate housing and related supportive services. The low housing

vacancy rate in the City, now about 3%,³ coupled with the low quality of some of the available housing stock, has provided a particular challenge to the New York EMA. For rental units under \$700, the vacancy rate is even lower, at 2.0%, which means that affordable apartments are in very short supply. The CARE Act can help the New York EMA fill this gap by allowing flexibility in the use of CARE Act funds to meet this vital need. In addition, as the U.S. Department of Housing and Urban Development (HUD) moves away from using HUD and Housing Opportunities for Persons With Aids (HOPWA) dollars for supportive services, it is extremely important that the Ryan White CARE Act remain flexible enough to allow us to support units of housing for PLWHAs and tie this in to a support system that connects consumers to appropriate medical care and treatment. It is abundantly clear that for PLWHAs, the utmost priority to HIV care is first having a stable, medically appropriate place to live.

The New York EMA works hard to identify barriers to accessing services by PLWHAs and finding ways to overcome these barriers. As we have found from epidemiological data, our own longitudinal study of persons with HIV/AIDS called the Community Health Advisory Information Network (CHAIN) from Columbia University, as well as other data elements, the HIV/AIDS epidemic in New York City disproportionately affects certain specific populations. In particular, certain individuals that have co-morbidities such as alcohol and substance abuse problems, as well as certain populations (inmates/releasees, immigrants/ undocumented populations, men of color, the homeless and those unconnected to care) have greater difficulty accessing existing HIV/AIDS health care. In many areas, a lack of suitable drug treatment programs and affordable mental health counseling poses a barrier to accessing HIV/AIDS services.

For populations that have a dual diagnosis of HIV-infection and a history of substance abuse or mental health problems, the substance abuse or mental health problems alone can impose barriers to accessing Ryan White services. For active substance users, drug use often takes priority over seeking medical and other health care services and additional self-care behaviors. Persons with serious and persistent mental health problems may be unable to maintain strict highly active antiretroviral therapy (HAART) drug adherence requirements or manage activities of daily living. Often consumers are not aware they have mental health needs, or even if they are aware, they are not in care. Recent CHAIN studies indicate that at least 40 percent of the cohort has been experiencing clinically relevant, mental health symptoms. Of these clients, approximately 50 percent do not receive any type of mental health treatment.⁴ The New York EMA is working to overcome these barriers through the funding of mental health and harm reduction programs designed to assist People Living with HIV/AIDS with a dual diagnosis.

For immigrant and undocumented populations, fear of disclosure, social stigma and fear of contact with governmental entities can prevent HIV-infected immigrants from accessing services. A significant subset of HIV-infected immigrant, migrant and refugee populations require a broad range of culturally sensitive services to help them address issues including HIV/AIDS denial and stigmatization.⁵ The CARE Act works best to address this issue by allowing local jurisdictions to develop their own policies to allow immigrants to access Ryan White services. For example, in New York, Title I funded organizations are encouraged to develop programs that are culturally and linguistically appropriate for New York's diverse immigrant communities living with HIV/AIDS.

For the inmate population, large numbers of HIV+ inmates are discharged without receiving counseling, testing, drug treatment or referrals to the community before discharge. Without information on the availability of services in their community, many HIV-infected recently released inmates are left with inadequate information on where to turn to for help. The New York EMA is working hard to address barriers experienced by the inmate and releasee population, including the recent opening of a post-release drop-in center. Rikers Island has upwards of 100,000 persons incarcerated per year, and the most recent survey concluded that 19.4% of female and 9.9% of male detainees were HIV infected. Additional federal funding and support would allow the New York EMA to increase these services to adequately address the needs of this population.

Structure of a Reauthorized CARE Act

There has been much discussion of ideas to block grant or merge the titles of the CARE Act. It is essential that direct federal funding to cities and counties in the form of Ryan White Title I dollars be maintained, as it is uniquely designed to meet the needs of diverse populations and Eligible Metropolitan Areas. Municipalities are on the front-line of the epidemic, and are best equipped to provide core public health services to those impacted by HIV/AIDS. A comprehensive range of services that supports access to and maintenance in HIV-related primary medical care needs to be a focus of the CARE Act.

A reauthorized CARE Act needs to include a provision devoting resources to outcome evaluation (similar to the Minority AIDS Initiative) to demonstrate the efficacy of Title I programs. It is important for local planning councils to have the tools and resources they need to develop systems of care that focus on high quality services for PLWHAs.

Currently, the Minority AIDS Initiative (MAI) is not part of the Ryan White Care Act (RWCA) legislation. Incorporation of MAI into the reauthorized RWCA would ensure the continuation of this program.

In closing, it is imperative that EMAs continue to receive critically needed Title I funding, and substantial cuts in funding amounts must be avoided. In order for municipalities to be able to maintain a stable and reliable system of care for PLWHAs, it is of utmost importance that support from HRSA be reliable and consistent. No jurisdiction should experience a drastic reduction in its supplemental funding from year to year. Speaking from the experience here in New York, any reduction can and will have serious consequences for the ability of the EMA to provide a reliable level of high quality services to their PLWHAs.

We hope that these comments prove valuable to HRSA, CDC and public policy leaders as future decisions are made about appropriations and reauthorization of the Ryan White CARE Act. New York City looks forward to continuing our partnership with government officials and national HIV/AIDS organizations such as the Communities Advocacy Emergency AIDS Relief (CAEAR) Coalition and AIDS Action Council. Everyone must work together to help improve the lives of persons living with HIV/AIDS.

The New York City Department of Health and Mental Hygiene would like to once again thank the members of the CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment for listening carefully to what the public has to say about this vitally important law.

¹ New York City Department of Health and Mental Hygiene, *HIV Surveillance and Epidemiology Program 2nd Quarter Report*, Vol. 1 No. 2, April 2003

² U.S. Centers for Disease Control, *AIDS Cases and Person Living with AIDS by State and Metropolitan Area Provided for the Ryan White CARE Act, HIV/AIDS Surveillance Supplemental Report* Vol. 8 No. 3, June 2001

³ NYC Office of the Mayor, Press Release dated February 7, 2004, *Mayor Michael R. Bloomberg Releases Initial Findings of 2002 New York City Housing and Vacancy Survey*, PR-041-03.

⁴ Aidala, Angela A., *Pathways to Mental Health Care*, CHAIN Update Report #40, Columbia University, December 2001.

⁵ New York HIV Health and Human Services Planning Council, *Immigrant Planning Group Recommendations and Priorities Report*, February 2002.