

STATEMENT OF THOMAS R. FRIEDEN, M.D., M.P.H.,
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ON THE
RYAN WHITE CARE ACT REAUTHORIZATION PRINCIPLES

RWCA FEEDBACK MEETING

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Good morning. I am Dr. Thomas Frieden, Commissioner of the New York City Department of Health and Mental Hygiene (NYCDOHMH). My agency is responsible for administering all funding under Title I of the Ryan White CARE Act in New York City, which has the largest and most diverse HIV epidemic in the United States and is home to one in six people in this country living with AIDS. I appreciate this opportunity to comment on the Ryan White reauthorization.

While there are some proposed principles we wholeheartedly support, there are others for which details will be crucial, and some that are simply wrong.

Among the principles we support are increasing accountability and increasing prevention efforts. In fact, the proposal to expand prevention efforts can be further strengthened by making voluntary HIV testing a routine part of health care not only in public health facilities but in private practices as well. To that end, the provision in Title III that requires pre-and post-test counseling must be amended and streamlined. With the advent of rapid testing, whereby patients can learn their HIV status in 20 minutes, these requirements are an unnecessary barrier to promoting voluntary HIV testing as a normal part of medical care. They are also at odds with CDC's *Advancing HIV Prevention* initiative, which places a high priority on removing barriers to HIV testing.

The CARE Act Title I formula must also be updated, but definitely not in the manner proposed by the Administration. The current Title I formula grant uses the number of cases diagnosed in the most recent 10-year period to estimate the number of people living with AIDS in a given area. The current formula has serious flaws:

- It does not account for the care that Ryan White provides to persons living with HIV who have not been diagnosed with AIDS. HIV case data should be used to determine awards, particularly as at present effective treatment can delay onset of AIDS diagnosis for many years.

- It does not account for people living with AIDS diagnosed more than 10 years ago. In New York City, 12,698 individuals diagnosed with AIDS before 1995 are alive today. They represent more than 1 in 5 people living with AIDS, and because of their advanced illness require the most intensive services, yet **they are not counted at all in the current formula.** This formula began, I believe, when AIDS was not much more than 10 years old, and when few patients lived more than a decade with the disease. Today, the formula essentially denies the existence of many of the most deeply affected people living with HIV/AIDS in New York City and throughout the United States. This is unethical and undermines the core principle of caring for those with HIV/AIDS who are most in need.

Simply put, the Ryan White allocation formula does not accurately reflect the full scope of the epidemic. Prevalence, not incidence, should be used to calculate the size of the award.

A viable alternative to this method of determining need would be to define a minimum package (e.g., the federal ADAP formulary) and minimum eligibility criteria (e.g., analogous to the federal standards for Medicaid eligibility for pregnant women), and to make state funding of these standards a prerequisite for receipt of Title I funds. This would ensure both a basic level of care for all Americans living with HIV/AIDS, and would avoid the misguided public policy of rewarding jurisdictions that do not support care for the patients in their jurisdiction and punishing jurisdictions with established effective care systems.

Similarly, the proposal to base future funding on a “severity of need” for core services index (SNCSI) that would take into account HIV incidence, levels of poverty, and availability of other resources, including local, state, federal and private programs, is simply wrong. It would undermine treatment and care for PLWHA. Basing the index on availability of local and state resources would reward localities and states that do not spend their own funds on HIV/AIDS care. The proposed principle would create incentives for states to limit benefits for PLWHA and would penalize jurisdictions that provide more effective services and which successfully contain the epidemic.

In addition, basing the SNCSI on HIV incidence rather than prevalence would recognize only new cases entering the system rather than all people living with HIV/AIDS. Prevalence, not incidence, is the accurate indicator of caseload. The number of prevalent cases, adjusted for levels of poverty, is the appropriate index.

Other principles will require careful attention to detail in implementation. For instance, one of the Administration’s reauthorizing principles seeks to establish core medical services; 75 percent of Ryan White funds would be used for these core medical services. The HHS Secretary would also develop and maintain a list of core AIDS Drug Assistance Program, or “ADAP” medications.

Given the diversity of the epidemic in this country, flexibility in the local determination of medical need and the definition of core medical services is important. For example, treatment of mental illness and drug addiction is crucial to effective AIDS treatment in many areas, including in New York City. A federal list of ADAP core medications has the potential to be useful, but ensuring that it is comprehensive is critical. Rather than limiting medications that states can provide, this provision should instead improve the basic level of care by requiring all states to offer a minimum formulary that is comprehensive and current. It is also crucial that ADAP programs are guaranteed the lowest price. Any federal ADAP list must include psychotropic medications and

drugs such as buprenorphine. Only by treating the medical illnesses that HIV/AIDS patients face will we be able to maintain patients in effective care.

Another troubling principle seeks to eliminate the method by which HIV/AIDS cases are counted between major metropolitan areas and states. The current funding formula for Title I and Title II funding involves what is referred to as “double counting.” The current funding formula does not actually “double count”; rather, it gives partial credit in statewide counts for cases in major metropolitan areas within a state. The formula was developed to acknowledge the complexity and expense of serving individuals in high-impact urban areas where co-morbidities and poverty factors are disproportionate. The current structure of the Act gives both state and local governments the necessary resources to combat the epidemic by recognizing the unique challenges faced by urban areas, such as high housing costs, high health care costs, low educational levels, high poverty levels, large immigrant populations, and language and social barriers. This provision would reduce New York State Title II base funding, which supports primary care through ADAP Plus by 56 percent, or about \$20 million. Moreover, New York State is not alone; 18 states with EMAs would also lose a significant amount of Title II base funding. Such a reduction would reduce services in the hardest hit regions. State initiatives, which are mandated by the CARE Act, are important and include coordination and gap-filling.

There are other Ryan White CARE Act reauthorization principles proposed by national AIDS advocacy groups, among which is restructuring the CARE Act by combining titles of the Act. The City of New York strongly opposes this proposal. It is essential that direct federal funding to cities and counties in the form of Ryan White Title I dollars be maintained, as cities are uniquely designed to meet the needs of diverse populations on the front line of the epidemic and are best equipped to provide core services to those impacted by HIV/AIDS.

I urge you to consider the serious impact that the various proposals you are being asked to consider would have on the treatment and care of HIV/AIDS patients, especially in metropolitan areas disproportionately affected by this epidemic such as the City of New York. Giving localities the resources and flexibility to address their unique needs and challenges is critical to providing effective care. The Administration’s principles were a start. There are aspects of the Ryan White Legislative Groups draft which are a better beginning point for discussion. Before any changes are implemented, the concerns raised above must be addressed. Careful consideration and deliberation is needed because the impact of these actions will have far-reaching consequences.

New York City has the largest and most diverse HIV epidemic in the United States. Today, more than 95,000 people in New York City are known to be living with HIV/AIDS and nearly one in every six AIDS patients in the U.S. lives in New York City. Every action considered by you will have a dramatic effect on the HIV/AIDS epidemic in New York City.

Thank you again for this opportunity to speak to you today. I look forward to working with you to reauthorize the Ryan White CARE Act and ensure that effective services are equitably provided, with accountability for outcomes. I would be happy to answer any questions you may have.

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