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and  
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## **Recommendations for Ryan White CARE Act Reauthorization**

Good morning. My name is Guthrie Birkhead. I am the Director of the AIDS Institute at the New York State Department of Health. The AIDS Institute administers the Ryan White CARE Act Title II funds that come to New York State. I am pleased to have the opportunity to speak to you regarding reauthorization of the Ryan White CARE Act.

### **I. The HIV/AIDS Epidemic in New York State**

Let me begin by telling you a little about the HIV epidemic in New York State. Despite what you might have heard about HIV/AIDS in the rest of the country, New York State still leads the nation in the number of persons living with HIV and AIDS – now more than 100,000 – and the number of new HIV and AIDS cases each year. New York also has seen a sustained drop in the number of HIV/AIDS deaths each year, so the number of people living with HIV and AIDS in New York in need of services continues to grow. The number of new AIDS cases reported in 2004 increased by 15.5 percent over the number reported in 2003.

New York bears a disproportionate share of the epidemic, with 17 percent of all persons living with AIDS but just seven percent of the U.S. population. At 39.7 per 100,000, New York's annual rate of new AIDS cases in 2004 was the highest of any jurisdiction other than the District of Columbia. The epidemic in New York State is dominated by HIV/AIDS in people of color. More than 75 percent of living HIV/AIDS cases in New York State are persons of color.

Unfortunately, as these data indicate, New York's epidemic has not "stabilized." There are approximately 6,000 new HIV infections each year in New York, and in 2004, New York State reported more new AIDS cases and more new HIV cases than any other state.

Some have claimed that the HIV epidemic in the U.S. has "shifted". Certainly, the epidemic has expanded, but it has not shifted. More than half of all people living with AIDS in the U.S. still are concentrated in just five states. Ten jurisdictions are home to almost 70 percent of all persons living with AIDS in the U.S. New York and California continue as major epicenters of the epidemic, followed by

Florida, Texas, and New Jersey. These five states accounted for more than 52 percent of all new AIDS cases in 2004. More than 40 percent of all Blacks or African Americans living with AIDS reside in four states: New York, Florida, California, and Texas. More than 60 percent of all Hispanics living with AIDS reside in these four states.

These data illustrate the disproportionate impact of this epidemic on a few jurisdictions. If Ryan White resources are to follow the epidemic, they must continue to flow to all jurisdictions and be increased. It does not make sense to reduce funding to the most heavily impacted states, which continue to see increases in persons living with HIV/AIDS in need of services.

## **II. Comments on Administration's Reauthorization Principles**

I would like to offer comments on the Administration's principles for reauthorization of the CARE Act. The principles, if implemented fully and without an increase in the appropriation, would have the effect of redistributing Ryan White funds – that is, shifting funds away from some jurisdictions and toward others – and limiting flexibility at the state and local levels to direct Ryan White resources to meet locally defined needs. An examination of the principles indicates that funds would be redistributed in a manner that will harm persons living with HIV/AIDS in the states with the largest number of persons living with HIV/AIDS. This would have devastating consequences for people living with HIV and AIDS in New York State. There are grave concerns about four aspects of the reauthorization principles.

Principle 1. Severity of Need for Core Services Index (SNCSI). Under the first principle, a “severity of need for core services index,” or SNCSI, would be developed and used in revised Title I and Title II funding formulas. The Index is to take into account, among other measures, the availability of funding from other sources, such as local, state, federal, and private sources, in determining the Title I and Title II funding amounts.

Early in the HIV/AIDS epidemic, New York State brought resources to bear in order to organize and fund services for persons living with HIV and AIDS. With a combination of resources, including State and federal grant funds and Medicaid reimbursement, New York State is providing high-quality services. No state spends more than New York does to care for persons with HIV/AIDS. These resources, when

included in the severity of need index, would result in substantial losses in Ryan White Title I and II funding for New York State. By considering the availability of other resources in determining Ryan White Title I and Title II allocations, the Index ends up punishing jurisdictions that have devoted their own resources to addressing the epidemic and rewarding jurisdictions that have not. Thus, the severity of need index principle serves as a disincentive for jurisdictions to allocate local resources to meet the needs of their residents with HIV/AIDS.

An underlying assumption behind the severity of need principle seems to be that differences in Ryan White Title I and II funding to states are responsible for different levels of HIV/AIDS services among states. This is not correct. The variances between states are largely attributable to differences in the resources that the states themselves provide for the care and treatment of persons with HIV/AIDS as well as the services available through Medicaid. The Ryan White CARE Act cannot and should not be viewed as a mechanism for equalizing these inherent differences.

An additional issue is the proposal to use HIV incidence – or new cases of HIV per year -- in the severity of need index. This is not appropriate. The true indicator of need for Ryan White services is HIV/AIDS prevalence – the total number of persons living with HIV and AIDS. Elsewhere, the principles recognize that counting all cases of HIV and AIDS is the best way to gauge the current status of the epidemic, and New York strongly supports this view. The goal of addressing the epidemic can only be achieved by recognizing prevalence – not incidence – as the indicator of need.

HRSA has begun the development of a Severity of Need (or SON) Index for Title I supplemental awards even though this principle has not been adopted in legislation. New York State participates in two of the expert panels that have been convened by HRSA to assist in the development of the SON index. It is our understanding that the groups are having difficulty identifying reliable, universally available data that might be used to make allocation decisions.

Principle 2. The second principle that is deeply concerning is the proposal to eliminate the so-called “double-counting” of cases between Title I Eligible Metropolitan Areas (EMAs) and states, which the principle maintains contributes to an unequal distribution of federal funds. This conclusion is incomplete

and not appropriate. It exaggerates the inclusion of EMA cases in Title II base formula awards as “double counting,” and it suggests that an equal dollar-per-case distribution of Ryan White funds can be achieved by adjusting the Title I and Title II formula awards only, thus disregarding the rest of the CARE Act -- including Title I supplemental awards as well as Title III, Title IV, and Part F awards. Any meaningful assessment of fair and equitable distribution of CARE Act resources must include funding from all titles. For this reason, the principle cannot achieve its goal – to count every AIDS case equally and ensure the fair distribution of federal funds.

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. When the Ryan White CARE Act was first authorized, 15 years ago, Congress saw the wisdom of providing direct funding to the major metropolitan areas impacted by the epidemic, New York City, Los Angeles, Miami, Houston, and other EMAs, to ensure a coordinated local response. At the same time, Congress recognized the key role of the states, which administer Medicaid and regulate the health care, health insurance and other key sectors, in coordinating a statewide response. These considerations are equally valid today. The solution that Congress arrived at, which has stood the test of time through two reauthorizations of the CARE Act, is to give states partial credit for AIDS cases in EMAs, in recognition of the role of states in coordinating a statewide response to the epidemic and in complying with numerous mandates on States contained in the CARE Act. 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.

It has been suggested that this principle might be operationalized either by eliminating Title I formula awards, or by eliminating the statewide component of the Title II base formula. Either application of the principle will lead to a devastating loss of resources to high-prevalence states. For example, eliminating the statewide component of the Title II formula would lead to a loss of about \$54 million in Title II base funding in the five highest prevalence states -- New York, California, Florida, Texas, and New

Jersey – and a loss of more than half of the Title II base funding in six additional jurisdictions -- the District of Columbia, Massachusetts, Connecticut, Missouri, Nevada, and Minnesota. In all, 18 states would lose more than \$76 million in Title II base funding. Thus, this principle hits jurisdictions the hardest that are already hit hard by the epidemic. While some areas undeniably need additional funding, this is not the way to achieve it. It is important to note that states are expected to ensure the availability of services for persons with HIV/AIDS statewide and to carry out statewide CARE Act mandates. As such, all statewide cases must be considered in the Title II formula awards.

Principle 3. The third principle that would harm the State is the establishment of core medical services and a requirement to use 75 percent of Ryan White funds for core medical services.

Since its inception, the CARE Act has 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.

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 principles discussed above, this principle is likely to result in shifting funds away from states that have devoted other resources to the direct medical 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 4. Finally, the principle that calls for the elimination of provisions that entitle cities and states to be “held harmless” in funding reductions is a major concern. The “hold harmless” provisions limit the extreme service disruptions that would result from the precipitous loss of resources to a jurisdiction and give time for a local response to ensure that no one loses critical services. In light of the apparent intent of the previously mentioned principles to redistribute CARE Act funds, hold harmless provisions are crucial in order to avoid substantial reductions in funding. 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 through major shifts in resources between states without compromising services in jurisdictions that lose funding. Rather, there should be a concerted effort to increase Ryan White funding to keep pace with the continued growth of the HIV epidemic.

### **III. New York State’s Recommendations for Ryan White Reauthorization**

There are alternatives to the Administration’s principles which can achieve increased resources to areas where current support is particularly inadequate without withdrawing support from other jurisdictions, which, as has been pointed out in this testimony, also have major needs. These alternatives are contained in the recommendations of the National Alliance of State and Territorial AIDS Directors (NASTAD), which the New York State Department of Health fully supports. These recommendations offer more effective and equitable alternatives that address overall increased need for resources in all jurisdictions. A brief summary of some key recommendations follows:

1. Retain the structure of the CARE Act. Proposals to drastically change the structure of the CARE Act – including eliminating some titles -- have been suggested by some. Modifications to the basic structure of the CARE Act could alter service delivery systems and disrupt services in many jurisdictions. The current CARE Act structure has stood the country in good stead for 15 years, and provides an appropriate mix of funding and local decision making to state and local governments, and health care and community organizations. It should not be abandoned, but rather new provisions added and overall funding increased (see below) to address the current concerns.

2. Retain the existing framework for Title II funding to states, with the base formula related to cases in the entire state and with earmarked ADAP funds as a component of Title II. Statewide cases should continue to be included in the Title II base formula, maintaining the “80-20” component of the formula.
3. Enhance the availability of ADAP resources in all areas of the nation through a guaranteed minimum annual increase to the ADAP appropriation. If sufficient new resources are not forthcoming, redirect funds from all Titles of the CARE Act to address the need for life-saving medications for persons with HIV/AIDS.
4. Enhance the availability of Title II base resources in jurisdictions in severe need through a Title II Supplemental Fund established by redefining the existing “emerging communities” provision and directing increased funding to these areas. In the absence of sufficient new resources, redirect funds from other components of the CARE Act to address severe need for health care services in some jurisdictions.
5. Include living HIV cases, in addition to living AIDS cases, in Ryan White formulas. This change must be phased in to accommodate states that are transitioning to names-based HIV reporting.
6. Maintain flexibility to allow CARE Act funds to support a range of health care and supportive services based on locally determined needs. 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. Legislative mandates that limit fundable services will not support states in responding to the existing and emerging needs of persons living with HIV/AIDS, whose circumstances differ from state to state.
7. Increase the stand-alone Title II base and ADAP earmark hold harmless provision to reflect a 1.5 percent loss each year, with a maximum possible loss of 7.5 percent over the five-year authorization period.

These are some key NASTAD recommendations. I understand NASTAD might have presented additional recommendations in their testimony yesterday.

I hope my comments have illustrated the disproportionate impact of the epidemic on New York, the importance of the CARE Act to New York State, and the potential catastrophic effect on New Yorkers living with HIV/AIDS if the Administration's principles were to be adopted in legislation. It is important to remember that the state of emergency associated with this epidemic is not confined to one region but is ongoing, particularly in the most heavily impacted states, as well as throughout the nation. Ryan White reauthorization must acknowledge that the epidemic remains concentrated in a few jurisdictions and must consider need in the states and major metropolitan areas with the largest numbers and proportions of persons in need of HIV services. It should also recognize the needs of areas currently without adequate resources through significant increases in appropriations targeted to these areas.

Thank you for the opportunity to speak with you today.