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September 13, 2006

The Honorable Mike Enzi
Chairman
Health, Education, Labor and Pensions Committee
United States Senate
Washington, DC 20510

The Honorable Joe Barton
Chairman
Energy and Commerce Committee
United States House of Representatives
Washington, DC 20515

The Honorable Edward Kennedy
Ranking Minority
Health, Education, Labor and Pensions Committee
United States Senate
Washington, DC 20510

The Honorable John Dingell
Ranking Minority
Energy and Commerce Committee
United States House of Representatives
Washington, DC 20515

Dear Senators Enzi and Kennedy and Representatives Barton and Dingell:

The New York AIDS Coalition (NYAC), a statewide advocacy group presenting over 150 HIV/AIDS organizations across New York State, remains very concerned about the current draft of the HIV/AIDS Treatment Modernization Act of 2006 and its impact on New York. As the bill now stands, NYAC cannot support this legislation and is urging all New York Members of Congress to remain united in their opposition to this bill, unless significant changes are made.

New York is home to more persons living with HIV/AIDS than any state in the nation, with approximately 110,000 New Yorkers diagnosed with HIV/AIDS. One in five Americans living with HIV/AIDS resides in New York.

Our major concerns with the pending legislation are listed below. Please note that NYAC has a number of additional concerns/issues with the legislation not mentioned in this letter, but the items below are critical.

Failure to Support the Dutchess County EMA as a Title I Eligible City

Despite repeated requests from HIV/AIDS advocates from across the nation to use prevalence instead of incidence data, this legislation still uses AIDS incidence as a measure for cities to qualify for Title I funds. The legislation does not take into consideration persons who are living with AIDS who were diagnosed over five years ago. Using AIDS incidence as the sole criteria for qualification as a Title I Eligible Metropolitan Area (EMA) unfairly discriminates against cities that have older epidemics and have managed to prevent individuals living with HIV disease from progressing to an AIDS diagnosis. Furthermore, individuals living with AIDS who were diagnosed five or more years ago are still very much alive and have continued need for services. It is completely unconscionable that this legislation would choose to ignore countless individuals in the determination of which cities qualify for funding.

The Dutchess County EMA currently has over 1,600 individuals living with HIV/AIDS. However, because the legislation will only recognize new cases of AIDS in order to determine eligibility for Title I funding, the Dutchess EMA will cease to exist in three years.

NYAC strongly urges that the legislation be amended to change the qualification for eligibility as a Title I city from newly diagnosed cases of AIDS over the past five years to persons living with HIV and AIDS (prevalence). A threshold of 1,500 or more cases of HIV and AIDS would allow the Dutchess County EMA to continue to receive Title I Tier 2 funds. This solution allows all individuals living with HIV and AIDS will be fairly counted in the eligibility criteria for Title I.

NYAC is very much aware of the challenges that exist around using data from HIV surveillance systems not certified by CDC. We recommend that the legislation use the same methodology to determine eligibility for Title I funds that applies to the distribution of funds. This would allow cases of HIV and AIDS, not just AIDS, from across the nation to be considered.

Projected Cuts in Funding to All Three EMAs in New York

NYAC continues to be concerned that proposed formula changes and the inclusion of HIV data in the distribution of Title I funds will result in significant shifts in funding. The data charts released by the bicameral, bipartisan process indicate that all three EMAs in New York State will experience some reduction in formula funding. This merely highlights the need for a continued hold harmless that is retained for the life of the act. (See comments later on hold harmless.)

In addition, we remain very concerned about the total overall grant that all three EMAs in New York will receive next year under this legislation. Based on conservative fiscal estimates using Government Accountability Office (GAO) report, the City of New York predicts that it stands to lose more than $17.8 million in FY 2007. The Nassau-Suffolk EMA will lose $320,650 and the Dutchess County EMA $30,5000 in formula funds alone under the projections released by your own bipartisan, bicameral process. However, the projections for Nassau-Suffolk and Dutchess County do not even take into consideration any potential loses in the overall grant due to the reduced availability of supplemental funds, which could amount to additional loses that will amount to thousands of dollars.

Projected Cuts in Funding to New York's Title II Program

For many parts of New York State, persons living with HIV/AIDS rely exclusively on Ryan White Title II funds to provide them with access to primary medical care and supportive services. In addition, there are over 16,000 New Yorkers who depend on the Title II funded AIDS Drug Assistance Program (ADAP) for access to life saving HIV anti-Retrovirals. Without the ADAP program, countless individuals in New York would be unable to afford the cost of these expensive medications.

The projected cut in funding to the State's overall Title II grant, based on the bicameral, bipartisan data recently released, will be $8.7 million in FY 2007 alone. The cuts in future years will only get worse and are projected to exceed $30 million by the fourth year of authorization. Once again, without a hold harmless that exists for the life of the act, New York State is poised to lose untold millions after FY 2009.

For the over 110,000 New Yorkers living with HIV/AIDS, this scenario is completely unacceptable. A solution to the State's funding challenges must be found; this legislation must make provisions to keep whole the State's Title II funding. The current distribution of funds that are proposed in this legislation must be amended. The thousands of New Yorkers who rely on services provided through Title II funds must not be left without access to critically needed services.

Threat to Title II HIV CARE Consortia's

It is through the consortia that states receive input from service providers on the front lines and persons living with HIV/AIDS. The consortia are the foundation of the Ryan White tradition of participatory planning. They give regional representatives, providers, and consumers a voice in program and policy

development, and they play an important role in meeting legislative mandates around needs assessments and state plans.

The current proposal to place the spending of Ryan White funds under the State's administrative cap would mean the elimination of this important planning mechanism in New York. NYAC requests that spending on HIV CARE consortia's be moved to the supportive services category and not considered administrative expenses of the grantee. This would gives states that chose to continue consortia's the flexibility to do so.

Lack of Title I or Title II Hold Harmless Beyond 2009

As repeated several times in this letter, the failure to continue hold harmless protection for Title I and II formula funds is highly problematic. Without hold harmless, health care and supportive services funded through these titles could be potentially destroyed by wide and unpredictable fluctuations in grant awards. The principle behind hold harmless, to ensure that service systems built over the past decade and a half with CARE Act funds are not decimated, is an important principle that should be maintained during this reauthorization. Especially in light of a number of other changes in the provision of formula funds, such as the new inclusion of HIV case data, the role of hold harmless is even more critical at this juncture.

The Creation of a Severity of Need Index Without Adequate Congressional Oversight

NYAC remains baffled why Congress would give the Administration a "blank check" to enact wholesale modification to the allocation of Title II base funds without appropriate Congressional oversight. Furthermore, because the Administration has not yet finalized the creation a Severity of Need Index, there exists no understanding of what changes the Administration will make and how they will impact on individual states. The redistribution of funds could be quite severe; NYAC respectfully requests that the implementation of a Severity of Need Index (SONI) be delayed until the next reauthorization. NYAC strongly urges that the legislation only direct the Administration to develop a SONI, with Congress making the final determination whether or not a SONI should be fully implemented.

Thank you for your consideration of these issues. Please remember that thousands of New Yorkers living with HIV/AIDS rely on Ryan White funds to provide critical medical and supportive services and access to life-saving medications. The changes made in this legislation will have tremendous consequences.

Sincerely,

Joey B. Pressley
Executive Director

Cc: Senators Clinton and Schumer
NY Members of Congress

September 19, 2006

The Honorable Michael B. Enzi
Chairman
Health, Education, Labor, and Pensions Committee
835 Hart Senate Office Building
Washington, DC 21510

The Honorable Edward M. Kennedy
Ranking Member
Health, Education, Labor, and Pensions Committee
527 Hart Senate Office Building
Washington, DC 21510

The Honorable Joe Barton
Chairman
Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable John D. Dingell
Ranking Member
Energy and Commerce Committee
2322 Rayburn House Office Building
Washington, DC 20515

Dear Chairmen Enzi and Barton and Ranking Members Kennedy and Dingell:

CAEAR Coalition greatly appreciates your dedicated efforts and those of your staff to develop Ryan White CARE Act reauthorization legislation that responds to the needs of people living with HIV/AIDS in the U.S. CAEAR Coalition has been at work on the reauthorization process for over three years and is pleased that each iteration of the reauthorization legislation has reflected positive movement in addressing many of CAEAR Coalition's key policy concerns.

One of the strengths of CAEAR Coalition is its diverse geographic constituency. With respect to the reauthorization, this diversity allows us to see the bill from many different angles, but regretfully the variety in perspectives does not allow us to reach consensus on unanimous endorsement of the bill. Although many of the provisions are acceptable to us, there are still provisions in this legislation that, if passed in their current form, have the potential to negatively impact some of our constituents.

Many of our members also are concerned about the potential funding scenarios if the CARE Act is not reauthorized before the beginning of Fiscal Year 2007. We are committed to working with you and your staff to address our outstanding concerns so that we can reach our shared goal of a reauthorized bill by September 30. We believe that all parties have worked in good faith and we are committed to continuing this process in the days ahead.

In addition to completing the reauthorization process, it is crucial that Congress provide additional resources to the CARE Act. As you know, many of the community's key concerns with the current legislation could be resolved with appropriate funding and we ask you to stand with us in seeking those funds.

Sincerely,

Patricia Bass
Chair

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Washington, DC 20009-1361
(202) 789-3565
fax: (202) 332-7087
www.caear.org

until it's over
AIDS ACTION

September 18, 2006

The Honorable Michael B. Enzi
Chairman
Health, Education, Labor, and Pensions Committee
835 Hart Senate Office Building
Washington, DC 21510

The Honorable Edward M. Kennedy
Ranking Member
Health, Education, Labor, and Pensions Committee
527 Hart Senate Office Building
Washington, DC 21510

The Honorable Joe Barton
Chairman
Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable John D. Dingell
Ranking Member
Energy and Commerce Committee
2322 Rayburn House Office Building
Washington, DC 20515

Dear Chairmen Enzi and Barton and Ranking Members Kennedy and Dingell:

I am writing on behalf of AIDS Action Council to say thank for the hard work that you and the members of your staff have done on behalf of reauthorizing the Ryan White CARE Act. We thank you also for listening to the members of the community who spoke to your staff at the "stakeholders meeting" on September 11, 2006 and said that they could not support the bill in this form. The changes to eligibility including the use of actual living AIDS counts, broader acceptance of data from code-based states and changes to consortia requirements that resulted from that meeting, along with the offer of report language clarifying the terminology on "medical case management" have given AIDS Action reason to support the bill.

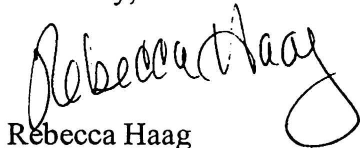
The resolution passed by the Board of Directors reads as follows:

> The AIDS Action Council Board adopted the following statement at its meeting of September 19, 2006:
>
> AIDS Action Council supports the draft of the Ryan White HIV/AIDS Treatment Modernization Act of 2006 as released on September 18, 2006. While AIDS Action Council supports the bill, we continue to advocate that the committees make additional changes on the following issues: Hold Harmless, Funding Concerns, the Early Diagnosis Grant Program and Data Concerns (detailed in the recommendations of the community coalition – see attached document) and to ensure that states that have recently adopted name based systems and who have not fully reported HIV cases are able to avoid destabilization of their services.

We reiterate AIDS Action's May 30 comments on the manager's amendment marked up in the Senate. At that time we stated that, "AIDS Action notes that there may be one or more states which switched to names based reporting after 2000 and whose HIV data has not fully matured despite being certified by the CDC. AIDS Action recommends that the committee seek to avoid major funding swings due to introduction of the new system either through a transition system or other mechanism." We now know that New York, New Jersey, Texas and Florida and possibly other states each appear to have low HIV counts, most likely due to undercounting of some sort. Therefore we remain concerned about the potential impact of this bill and support efforts to ensure that services desperately needed by people living with HIV will not be destabilized by this change.

Therefore, although we support the bill, we continue to ask that you consider making the changes listed above. We stand ready to work with you to find a position that will help all people living with HIV in the United States. Again, we thank you for your work and for your continuing efforts to improve the bill.

Sincerely,



Rebecca Haag
Executive Director

CC: Marty McGeein, Department of Health and Human Services

Greater New York Hospital Association
555 West 57th Street / New York, N.Y. 10019 / (212) 246-7100 / FAX (212) 262-6350
Kenneth E. Raske, President

September
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The Honorable Joe Barton
Chairman, Energy & Commerce Committee
U.S. House of Representatives
Washington, D.C. 20515

The Honorable John Dingell
Ranking Member, Energy & Commerce Committee
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairmen Barton and Ranking Member Dingell:

On behalf of the nearly 300 not-for-profit hospitals and continuing care facilities in the greater New York area (including many in New Jersey), I am writing to share my concerns on the latest version of the Ryan White CARE Act Reauthorization bill. Many of our members provide an extensive array of HIV- and AIDS-related services and many of their programs receive funding through the Ryan White CARE Act. As such, the Greater New York Hospital Association (GNYHA) is troubled to learn that, under last Monday's version of the bill, New York State would still lose tens of millions of dollars as a result of the proposed changes to the funding formulas. I strongly urge you to reconsider the funding formulas before proceeding with reauthorizing this important piece of legislation.

Specifically, GNYHA is very concerned that New York State—the state with the largest number of HIV cases in the country—would be among the hardest hit under the proposed changes in the grant allocation process. As you may know, New York City alone represents over 15% of the entire country's HIV/AIDS population. According to recent analysis performed by the Government Accountability Office (GAO), New York City would essentially receive a 15% funding cut—amounting to nearly $18 million loss—in 2007 alone under the proposed legislation. These losses only worsen in subsequent years.

If enacted, the proposal would significantly shift money away from states with existing substantial need by altering the funding formula for Title I and Title II grants to include an HIV case "proxy" that is ratio-based (i.e., a ratio of HIV cases to AIDS cases). However, the "proxy" relates more to the age of a state's name-based reporting system than to the number of people with HIV in need of services. As such, states like New York and New Jersey will be inadvertently punished by dramatically decreased funding. Conversely, states that have not made

the commitment to develop and implement name-based surveillance systems won't be disadvantaged since they will be able to take advantage of—a significantly higher—"proxy" figure for HIV cases. I ask that you protect states from devastating losses that, if enacted, would undoubtedly have a disastrous impact on the ability of those living with HIV/AIDS to access important and necessary care. Therefore, I ask that the hold harmless provisions included in Titles I and II should be strengthened and be available to states during the entire period of reauthorization (i.e., through FY 2011).

It is important to address states with emerging populations of HIV cases; however, it should not be at the detriment of those states with existing, significant populations of persons living with HIV and AIDS. Moreover, states that have significantly invested in HIV/AIDS infrastructure should not be penalized for having done so; this would set a dangerous precedent for future Federal funding.

My best.

Sincerely,

Kenneth E. Raske

cc: The Honorable Michael Enzi
The Honorable Ted Kennedy

Greater New York Hospital Association
555 West 57th Street / New York, N.Y. 10019 / (212) 246-7100 / FAX (212) 262-6350
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The Honorable Michael Enzi
Chairman, Health, Education, Labor, and Pensions Committee
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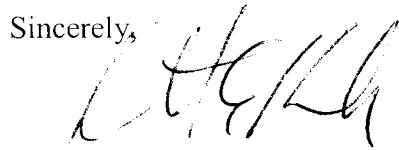
My best.

Sincerely,



Kenneth E. Raske

cc: The Honorable Joe Barton
The Honorable John Dingell

Recommendations to the Bipartisan Bicameral Committee on The House Version of Reauthorization of the CARE Act

Recommendations Endorsed By:
AIDS Action Council
AIDS Alliance for Children, Youth and Families
Communities Advocating Emergency AIDS Relief Coalition
National Alliance of State and Territorial AIDS Directors
National Association of People with AIDS
National Minority AIDS Council
Project Inform
Southern AIDS Coalition
Title II Community AIDS Network

Hold Harmless Provisions

There are areas of the country which appear to lose far more than 4 percent of funding under the bipartisan bicameral bill, particularly when Titles I, II, and Title I supplemental funding levels are included in calculations. Such losses will severely disable care and treatment systems upon which those living with HIV/AIDS depend. In particular, jurisdictions which are in good faith in transition to HIV name-based reporting will lose hold harmless status in three years. In the 1996 and 2000 reauthorizations, the concept of "hold harmless" was historically correlated with the age of the epidemic and therefore the presumed level of need of those living with HIV and AIDS. In the current House draft, it has been generally acknowledged that transition to a new reporting system can take significant time despite best efforts by state and local officials. A hold harmless provision for the full length of the reauthorization is essential to avoid loss of service to those in need of care and treatment as well as those receiving these services.

Funding Concerns

In order to ensure stabilization of current services and to meet the needs of the growing epidemic, we applaud the committee for adding additional funding to the Title II base. However, with the important changes to the ADAP supplemental, we believe there must be an increase in funding for the ADAP earmark to ensure that the increase in the setaside amount for the supplemental does not result in significant losses for other ADAP programs. Our coalition has endorsed a recommendation for higher authorization levels for each component of the CARE Act and annual increases tied to the rate of health care inflation and the overall cost of living.

EMA, Transitional Area and Emerging Community Eligibility

Eligible Metropolitan Areas (EMAs) with a significant burden of disease should remain eligible in Title I for the length of the reauthorization period. Many of the EMAs that would drop out of Tier 2 after three consecutive years under the September 7th draft have older epidemics. As a result, the people in the EMA who have been living with AIDS for more than five years are not counted towards EMA eligibility although they are being served. Eliminating Title I eligibility for these areas, many of which have a

similar or greater number of actual living AIDS cases as new EMAs, would result in severe cuts to vital care, treatment, and support services for thousands of people living with HIV/AIDS. Therefore the coalition proposes:

Title I, Tier 1 (EMAs):
Eligibility for Tier 1 remains at the level in the September 7th draft EXCEPT if the jurisdiction has an AIDS prevalence rate of 3,000 or more actual living AIDS cases, the jurisdiction shall remain eligible for Tier 1.

Title I, Tier 2 (Transitional Areas):
Eligibility for Tier 2 remains at the level in the September 7th draft EXCEPT if the jurisdiction has an AIDS prevalence rate of 1,500 or more actual living AIDS cases, the jurisdiction shall remain eligible for Tier 2.

Title II, Emerging Communities:
Eligibility for Emerging Communities remains at the level in the September 7th draft EXCEPT if the jurisdiction has an AIDS prevalence rate of 750 or more actual living AIDS cases, the jurisdiction shall remain eligible as an Emerging Community.

Additionally, if a Title I, Tier 2 EMA drops into Title II after three consecutive years we ask that it be made explicit that funding is allocated to the EMA's respective state in either the Title II base or Emerging Communities pot, whichever is applicable.

Title II Consortia Support
We ask that consortia-related expenses be allowed in a states' 25 percent support services pot, and not restricted to the 10 percent administrative pot as suggested by the September 7th House bill. For 15 years, consortia have been one of the allowable program activities and expenses within Title II. States are not likely to be able to also absorb consortia costs within the administrative cap. We believe consortia expenses should continue to be an allowable program expense, under the support services pot.

Early Diagnosis Grant Program
As discussed in a letter of August 25 signed by many of our organizations, we are opposed to provisions which would authorize incentive grants for states that carve out existing resources from CDC HIV prevention funding. In spite of this opposition, we could accept such a provision that authorizes the grants ONLY using new money. As this provision also appears to be in direct conflict with the President's Domestic HIV/AIDS Initiative which proposes increased funding for a broad-based testing initiative, we believe that potential incentive grants should have a wider set of eligibility criteria. Therefore, we would support the collapsing of the $30 million authorization level so that the entire $30 million may be awarded to jurisdictions that comply with either of the two categories. Further, we recommend that the use of funds for "treatment of mothers infected with HIV/AIDS" be further targeted and replaced with "treatment for pregnant women to prevent perinatal transmission."

Formula Data Concerns

We understand that, for the purposes of formula funding distribution, the committee proposes to use the estimated HIV data reports from code based States and Eligible Metropolitan Areas included in their funding applications to HRSA. We would ask that this requirement be made explicit in statute as well as a requirement that HRSA establish a uniform methodology that track-two States and EMAs would be required to use to produce their HIV estimates. We remain concerned that the data runs from the Government Accountability Office (GAO) do not include any estimates on the impact to either Title I or Title II base supplemental funding. Title I communities have come to rely on supplemental funding as an essential resource to sustain their systems of care and treatment. The impact of the House bill on Title I and Title II base supplemental funding is critical for all Members of Congress and their represented communities to assess the full impact of the proposed bill.