

Public Comment to the Senate Committee on Health, Education, Labor and Pensions and the House Committee on Energy and Commerce Regarding the White House and HHS Ryan White CARE Act Reauthorization Principles



January 19, 2006

Thank you to the Senate Committee on Health, Education, Labor and Pensions and the House Committee on Energy and Commerce for providing this opportunity to officially respond to the White House and United States Department of Health and Human Services Ryan White CARE Act reauthorization principles.

AIDS Action In Mississippi (AAIM) is a statewide grassroots AIDS advocacy organization, and a joint advocacy project with Housing Works, Inc, the nation's largest AIDS service organization. AAIM has representatives from all regions of the state of Mississippi and 66% of our members are persons living with HIV. AAIM is also affiliated with the nationwide grassroots advocacy movement, the Campaign to END AIDS.

We are here to call, on behalf of all the members of AIDS Action In Mississippi, for a swift reauthorization of the CARE Act that does not divide Americans.

The President's Ryan White CARE Act principles are too often divisive, and they threaten to endanger the lives of people living with AIDS and HIV in the United States. We at AAIM believe citizens should not be forced to fight each other for access to lifesaving AIDS medications, health care, and supportive services. Both of us as Mississippians understand how important Ryan White funding is to ensure emergency survival needs to those of us who are living with HIV. Thus we greatly appreciate this opportunity to speak on this matter.

ROBIN WEBB

My name is Robin Webb. I am a person living with AIDS in the state of Mississippi. I was diagnosed in New York City fifteen years ago during a time when people were getting extremely ill and dying on a daily basis. It was a dark and terrifying time during those early years of HIV/AIDS, with very little to hang on to, certainly no effective medications. Chances of surviving for three or more years were less than 30%. Miraculously, I survived but I could not have done so without Ryan White assistance.

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When antiretroviral medications came onto the scene in the mid-90s, I started a combination of HIV meds and my health stabilized. I didn't die. I was grateful to be alive. I stuck with the program; I kept taking medicines. If one set of medicines failed, I would try other medicines. For the past several years -- even after moving home to Mississippi -- my health has progressively improved, in fact, I am now in excellent condition, strong as ever, and am committed to spending my days voicing HIV prevention messages, helping my fellow Mississippians who are HIV-positive in managing their health so they do not become sick and speaking out to demand an end to this epidemic.

There is a profound difference in living with AIDS in Mississippi as compared to living with AIDS in Manhattan, particularly in the areas of access to care and services.

I could not have survived without the Ryan White services I received in New York City during the 1990s. I am deeply concerned about fellow HIV-positive Mississippians who too often get far less than what I received in New York. I got good standard medical care, safe and adequate housing, transportation assistance into care and mental/emotional support services which motivate people to take assertive action when it comes to their own healthcare.

Today in Mississippi, people living with HIV/AIDS can't get these things they need to survive. Our nation has the resources to provide these lifesaving essentials to our state -- without reducing the resources that are saving lives in other states.

AIDS Action in Mississippi was formed out of a need for Mississippians living with this virus to become pro-active. AAIM represents a substantial number of people of color and people who live in poverty. Since most AAIM members use Ryan White services, our mission is to serve in turn, by becoming vital voices of HIV prevention. Furthermore, we are strong advocates of HIV testing, quality HIV disease management, and full access for everyone to HIV care and services, particularly underserved rural communities.

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We want AIDS and HIV transmission to come to a halt in Mississippi. We want HIV positive people in Mississippi to be contributing members of society, to stay healthy and out of hospitals, and certainly out of graveyards.

In our state, there are an estimated 11,324 persons living with HIV/AIDS, compounded by the estimated sixty percent of infected persons who have yet to be tested. While African Americans represent 37% of Mississippi's population, they account for a staggering 80% of new infections. Women in Mississippi represent 30% of all new AIDS cases. Thirty-nine percent of AIDS cases in Mississippi were reported among those younger than 35 years of age. Mississippi has an emerging number of new infections among Latinos, Asians, Pacific Islanders, teenagers and young mothers.

Part of our goal here today is to stress the importance of equaling the care and services field for persons living with HIV or AIDS in the United States. There should be no competition for care between an African-American mother living in Jackson Mississippi, and an African-American mother living in Chicago. Money should not be taken away from the mother in Chicago to pay the mother in Mississippi, nor should the mother in Mississippi suffer from lack of HIV funds because she lives in the rural South, which is the case at present. Joining me today is my friend, Almetha Williams."

ALMETHA WILLIAMS

My name is Almetha Williams; I am 34 years old and have been living with AIDS for over ten years. I represent the homeless community where HIV/AIDS is hurting so many. The AIDS Drug Assistance Program and Housing Opportunities for Persons With AIDS have saved a lot of our lives. Without these programs I would not be here today.

Though I have been positive for ten years and have been homeless for many of these years, I have been told I am not eligible to receive Medicaid and other government assistance programs. At the moment, I currently receive all my needed medications through the state of Mississippi's Ryan White funded AIDS Drug Assistance Program. Without it I would not have access to the medication that keeps me alive. The Housing Opportunities for Persons

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With AIDS program has taken me from sleeping in an abandoned house to living in a home where I can nourish myself, and focus on my health.

When I first applied for the AIDS Drug Assistance Program and Housing Opportunities for Persons With AIDS they didn't have enough funds to take on any new cases. I didn't give up; I thought that I should wait to see what would become of the situation. While waiting, my health went downhill. I wasn't on medications; I wasn't sleeping at night or eating right, all the while I was homeless and prostituting my body for survival. My CD4 was a low as 51 and my viral load as high as 200,000. I was also diagnosed with cancer.

Needless to say, during this waiting period, which happens often in Mississippi and around the nation, I could have died. This waiting period increased the chances of me infecting others. Luckily, my provider felt that I was an emergency case and did all they could to get me the assistance that I needed.

I am alive and functional only because of these programs. The most important affect of Ryan White funding keeping me alive is I am now assisting our communities in preventing the contraction of this virus and am here to ask you to help continue life success stories like mine.

A lot of the programs in Mississippi that would assist persons like me in bettering ourselves and our situations are not available because of funding cuts and shortfalls. These programs are a matter of life and death for many Americans -- I am the living proof. I am deeply concerned about the next time someone like me is told funding is short we can't help you?

Organizations like AAIM listen to the needs of the people living with this disease and help us find out what we need to do to stay alive and functional members of society. All most of us want is a chance to be real citizens to our nation. I hate hearing that someone can't get needed meds because initiatives are short funded.

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I have seen what the Ryan White programs have done for me and I know that it will help many more...as long as funds are available.

RESPONSE TO PRESIDENT’S PRINCIPLES

AAIM agrees with aspects of the president’s reauthorization principles that would have the CARE act serve the neediest first, focus on lifesaving and life-extending services – but not if it means a nationwide fight for lifesaving funding. We have the following concerns over certain reauthorization principles.

On establishing Objective Indicators To Determine Severity Of Need For Funding Core Medical Services:

AAIM believes that any indexes (SNCSI) that would determine formula allocations amongst states should be developed by a consortium of state HIV/AIDS directors and grass roots organizations and not primarily by the secretary of Health and Human Services. This consortium could assist the administration in defining “severity of need”, core services, and the objective criteria. If there is to be measure of differences in HIV/AIDS care the manner of determining these differences should be the voice of those who receive care and are most intimately affected by current and proposed policy changes.

On the Requirement That 75 Percent Of Ryan White Funds In Titles I-IV Be Used For Core Medical Services

AAIM opposes any percentage mandate to dictate funding of “medical” services. Setting mandates for medical spending will limit the provision of life-saving non-“medical” services where funds are short. Many of the hardest-hit states have expanded Medicaid and other programs to ensure comprehensive medical care for a majority of people living with AIDS and HIV. These states should be able to use Ryan White dollars for housing and other life-saving services.

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In Mississippi where one in five people live below the federal poverty level, it is critical that we have access to as many dollars outside of “medical” services to assist persons in accessing all life saving services. Many non-“medical” services maintain stability in health care and address mental/emotional health issues. We want to guarantee our citizens adequate resources to be productive citizens living with HIV/AIDS. AAIM believes firmly in comprehensively funding service and treatment and allowing states to determine the levels of such funding.

On A Federal List Of AIDS Drug Assistance Plan (ADAP) Core Medications

AAIM supports a list of comprehensive 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 as a minimum AIDS drug formulary. Such a list should not create an artificial ceiling- or minimum AIDS drug formulary- at the exclusion of other life-saving drugs and psychotropic medications.

On the “Double Counting” Of HIV/AIDS Cases Between Major Metropolitan Areas And The States

This authorization principle is exactly what we are talking about when we request that the President’s principles not pit one region against another. Non EMAs need more money to address the rising epidemic, but it should not come at the expense of other persons living with HIV in EMA zones.

On the Redistribution of Unallocated Balances

AAIM opposes any loss of local control over distribution of unallocated balances. Redistribution of unallocated balances should be determined by a consortium of state AIDS directors and grassroots organizations. The same group that assists with “severity of need” measures should assist with redistribution of unallocated balances. HHS, the hardest impacted communities, and the future of the epidemic would benefit greatly from a community decided policy verses a top down policy.

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On Flat Funding for the Ryan White CARE Act

Lastly AAIM must address the issue of flat funding with a growing epidemic. With over one million Americans living with AIDS and HIV, and 40,000 plus new HIV infections each year, we cannot afford another five years of a CARE Act that does not receive additional funding to meet the needs of newly infected uninsured and underinsured people living with AIDS and HIV in every part of the country. The south currently has 46 percent of all new infections and receives only 34 percent of funding. The south is growing at disproportionate rates yet EMAs are also experiencing a growth in the epidemic. To cut/re-distribute current funding leaves all regions of the country unable to handle current cases and completely unable to dealing with emerging cases. Currently, the CARE Act is funded at \$2.1 billion level and has essentially been flat-funded for five straight years, except for small insufficient increases to the AIDS Drug Assistance Program.

AAIM, together with a substantial number of other AIDS organizations, insists that the Ryan White CARE Act be funded at the community request of \$2.56 billion for fiscal year 2006-- a \$513 million increase from fiscal year 2005.

AAIM echoes the call for advocates and legislators to build a consensus around a reauthorization plan that would ensure quality provision of care to everyone in our nation living with AIDS and HIV. Our nation's AIDS budget cannot be balanced on the back of poor people of color- whether in urban or rural America. We are one nation, and we are all impacted by AIDS. The CARE Act works and now we need to fully fund it so that we may live and continue to be productive members of society.

AAIM supports the **Ryan White Legislative Group -- Key Recommended Legislative Changes to the Ryan White CARE Act** as the best starting point for a Ryan White CARE Act reauthorization plan that improves quality care and treatment for everyone in our nation living with AIDS and HIV.

Thank you.

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