



**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 for the opportunity to comment before the Senate Committee on Health, Education, Labor and Pensions and the House Committee on Energy and Commerce and to officially respond to Ryan White CARE Act reauthorization principles released by the White House and United States Department of Health and Human Services.

Housing Works is the nation's largest community-based AIDS service and advocacy organization. We are a minority-controlled agency dedicated to providing housing, healthcare, job training, and vital supportive services to nearly 2,000 homeless people with AIDS and HIV in New York City. Housing Works also operates a federal advocacy office in Washington, DC, a State advocacy office in Albany, New York; a New York City advocacy office in Brooklyn, New York; and a statewide advocacy affiliate in Jackson, Mississippi called AIDS Action in Mississippi (AAIM). Housing Works is a part of the Campaign to End AIDS, a diverse coalition of people living with HIV/AIDS, their advocates and their loved ones demanding that our leaders exert the political will to stop the AIDS epidemic, in the U.S. and abroad. Additionally, Housing Works is a member of the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition and the Ryan White Legislative Group.

Our submitted comments will consist of three parts: our Housing Works Ryan White Reauthorization Principles; testimony from Housing Works staff and clients whose lives have been touched by CARE Act services; and an analysis and response to the White House/HHS reauthorization principles.

**HOUSING WORKS RYAN WHITE CARE ACT REAUTHORIZATION PRINCIPLES**

On July 27, 2005, U.S. Health and Human Services Secretary Mike Leavitt called on Congress to reauthorize the Ryan White CARE Act, which expired on September 30, 2005, and included "reauthorization principles" for moving forward with this important work.

In response, our organization distributed our own principles – foremost of which is a need to make sure that reauthorization of the CARE Act that does not pit Americans against one another for access to lifesaving AIDS medications, health care and supportive services. To end AIDS in our country, we must save all Americans. There should be no competition for HIV care between an African-American mother living with AIDS in Memphis, Tennessee, and an HIV-positive white injection drug user from Batavia, Illinois.

**Ensure Universal HIV Treatment Nationwide**

According to the Institute of Medicine's recent report "Public Financing of HIV/AIDS Care," over a quarter of a million Americans living with HIV can't get access to HIV treatment. In recent years, thousands of Americans have languished on waiting lists for the AIDS Drug Assistance Program, and some have died before they made it to the top of the list.



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RECOMMENDATION: Ensure stable access to HIV treatment for everyone in the United States who needs it, regardless of where they live. *Geography should not be a death sentence for people with AIDS.*

### **Support Adequate Funding Now**

With over one million Americans living with AIDS and HIV and 40,000 Americans, mostly African American and Latino, newly infected each year, we can't afford another five years of flat & inadequate AIDS funding. We must meet the needs of uninsured and underinsured people living with AIDS and HIV in every part of the country – particularly when and where Medicaid is cut.

RECOMMENDATION: Increase Ryan White CARE Act funding by \$513 million to a total of \$2.56 billion for fiscal year 2006 – more if Medicaid is cut. Increases should not be forced offsets from other vital programs, and the CARE Act should be protected from across-the-board cuts. *People with AIDS are not budget offsets.*

### **Establish a Standard for HIV Care**

Current program standards allow unreasonable variations in services and benefits for public HIV care programs across the country. Doctors, frontline providers and public health officials know what it takes to keep people living with AIDS and HIV alive and healthy – we need to make sure needed services are provided nationwide.

RECOMMENDATION: Guarantee a quality standard of care for all people living with AIDS and HIV through “mandatory minimum” care and formulary standards – and support states and localities that use higher standards. *A high standard of care for people with AIDS is a right.*

### **Coordinate Federal, State and Municipal Investments in HIV Care**

A national response is required to provide HIV care nationwide, and we need to help poor states and regions get care where it's badly needed. An equitable funding model would recognize variations in wealth while requiring states to do their share – a good place to start is the proposal of the Ryan White Legislative Group to establish \$80 million in additional CARE Act Title II base funding for treatment and care that would be targeted to non-Eligible Metropolitan Area states and states in which over fifty percent of the AIDS epidemic is outside of an EMA. To adequately address emerging needs will requires increases in funding, not the redistribution of already-inadequate resources.

RECOMMENDATION: Develop funding mechanisms to create more equitable distribution of CARE Act funds and leverage state and local investments. *Taking care of low-income people with AIDS is a shared responsibility.*

### **Strengthen Commitment to Supportive Services**



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Particularly for poor and homeless people, families with children and those living with HIV and mental illness or chemical dependency, HIV treatment will succeed only if supportive AIDS services are available when and where they're needed. Studies show case management by CARE Act providers ensures access to care and improves health.

**RECOMMENDATION:** Preserve and strengthen the federal commitment to coordinated supportive AIDS services, including housing, food & nutrition, transportation and legal services. *The success of HIV care depends on vital support services.*

### **Require Meaningful Participation of People Living with AIDS and HIV**

The CARE Act is a model for the active engagement of health care consumers -- people living with HIV/AIDS -- in the assessment of their own needs, priority-setting for services and resource allocation that directly impacts their lives. This participation improves access and helps make sure the public gets the most bang for the buck in HIV/AIDS programs.

**RECOMMENDATION:** Require meaningful participation of people living with AIDS that receive CARE Act services in all CARE Act planning efforts, including priority-setting and program oversight of all CARE Act programs.

### **Develop a New Comprehensive Domestic AIDS Response within Five Years**

By 2010, the CARE Act will have been in existence for twenty years. Originally conceived as an emergency response, the CARE Act needs to be improved upon if our nation is to build a comprehensive twenty-first century public health response to the growing epidemic. This year's reauthorization should be the last.

**RECOMMENDATION:** Create a more comprehensive, effective and efficient response to the domestic AIDS epidemic for low-income and uninsured people living with AIDS and HIV by 2010 to ensure access to HIV care, treatment and supportive services for all. *People with AIDS need more than the Ryan White CARE Act to survive.*

**Housing Works calls on advocates, legislators, and the Bush administration to build support for a consensus reauthorization plan that will ensure lifesaving quality HIV care to everyone in our nation living with AIDS and HIV.**

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

### **TESTIMONY OF HOUSING WORKS STAFF AND CLIENTS**



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Hello. My name is Alandra Mitchell. I am HIV positive and I reside in Brooklyn, New York. I work with Housing Works as a Peer Advocate on federal issues, and I am before you today because the Ryan White CARE Act saved my life. The Care Act is important to me and my community. It provides access to life-saving health care and supportive services. We are all Americans, and as Americans we care for our own in a time of need. I hope you consider our comments today as you move forward to craft a reauthorized CARE Act that addresses the needs of marginalized African Americans and everyone on the United States who is HIV positive, uninsured or underinsured, and locked out of access to critical services.

Hello. My name is Larry Bryant. I am the National Field Organizer for Housing Works. I work to strengthen local and state advocacy networks and leadership of people living with HIV/AIDS, communities of color, women and young people in impacting AIDS policies throughout the country.

In 1986 I was diagnosed HIV positive while a freshman at Norfolk State University. As a terrified 18 year old, I believed that my life was over. I believed that my goals, plans, and dreams of having a “normal” life were over. At times, in my darkest moments, I prayed that my life would be over than have to deal with the stigma and fear that surrounded being HIV positive in my community. Being a heterosexual, Black college student and athlete, I didn’t fit the “profile” of what general society believed someone with AIDS looked like. Over time I was able to reconstruct my life from the inside out. Clinics funded by the Ryan White Care Act allowed me the opportunity to access medical care to have regular blood work done to monitor my T-cell count and viral load. Support services such as peer counseling and case management gave me a chance to assess my needs and direction so that I could reach independence. After reaching my own independence, I have also had the opportunity educate others about needed services. As a member of the Ryan White Planning Council in Houston, Texas, I worked to help direct funding to the people who need it most. There are many cities and towns across the country that is losing the battle of matching affordable and appropriate services to need. With the help of these CARE Act services, I have been able to not just survive the last twenty years of being HIV positive, I am succeeding. I work everyday to overcome the AIDS-related fear and stigma which has survived as well.

**RESPONSE TO THE WHITE HOUSE/HHS “REAUTHORIZATION PRINCIPLES”**

Housing Works agrees with aspects of the president’s principles that would have the CARE act serve the neediest first, focus on lifesaving and life-extending services – but not if it means the government will rob Peter to pay Paul. A number of the president’s reauthorization principles would have a harmful impact:

**Allow Planning Councils to Serve As Voluntary And Advisory Bodies to Mayors**

Housing Works vehemently opposes any attempt to diminish the authority of independent planning councils to set binding funding priorities in eligible metropolitan areas. The planning councils are the only significant venue for the participation of oftentimes marginalized people living with AIDS and HIV who receive Ryan White CARE Act-funded services to participate in the process to prioritize life-saving services and to target limited CARE Act resources to address local epidemics.

**Establish a Set of National Core “Medical” Services**



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Housing Works supports the inclusion of locally-defined supportive services that facilitate access to medical care, including housing, in any set of core services. Medical care and medications are critical, but they won't save lives if we eliminate services that get people into care while helping them to maintain adherence to complex treatment. Particularly for homeless people and people with children, housing, transportation and other support services are essential to making health care effective.

### **Require That 75 Percent of Ryan White Funds in Titles I-IV Be Used for Core "Medical" Services**

Housing Works opposes any percentage set aside that dictates the funding of medical services. 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 not be penalized from using Ryan White dollars for housing and other life-saving services.

### **Maintain a Federal List of AIDS Drug Assistance Plan (ADAP) Core Medications**

Housing Works 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.

### **Stronger and More Specific Payer-of-Last-Resort Provisions That Increase Auditing**

Housing Works acknowledges that the CARE Act is an emergency relief program and has always been intended to be the payer of last resort -- but endless federal audits won't make sure we get the most bang for the buck. While increased auditing might identify marginal misuses of funds, it avoids the real issue. The largest obstacles to the Ryan White CARE Act being the payer of last resort are State restrictions on Medicaid eligibility and State limitations on services that Medicaid will provide. President Bush could save many lives by expanding Medicaid coverage for HIV nationwide.

### **Allow The Secretary Of HHS To Redistribute Unallocated Balances Based On Need**

Housing Works opposes any loss of local control over distribution of unallocated balances without a full commitment from all states, territories and municipalities to provide supplemental resources to address the unique epidemics in each area of the country, including the ADAP crisis. A national response is required, but it must be matched by State and local tax dollars if we are to adequately respond to AIDS around the country.

### **Eliminate Current Provisions That Entitle Cities To Be "Held Harmless" In Funding Reductions**

Housing Works opposes the destabilization and drastic yearly shifts in funding that a complete elimination of the current protection period provision would create in the highest incidence areas of the country. Particularly during this period of a shift from AIDS cases to inclusion of HIV cases to determine formula awards, eligible metropolitan areas (EMAs) should be protected against wild swings in funding.

EMAs are disproportionately impacted by HIV/AIDS – they've got three-quarters of the AIDS cases in the country, an overwhelming majority of whom are people of color. Emerging AIDS hot-spots that don't include EMAs must receive their fair share without negatively impacting other localities. To adequately



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address emerging needs requires increases in funding, not simply the redistribution of an already inadequate pot of resources.

**Eliminate the Double Counting of HIV/AIDS Cases between Major Metropolitan Areas and the States**

So-called “double counting” was intentionally authorized as a part of the initial Ryan White legislation in order to allow the hardest hit areas of the country to develop comprehensive systems of care. Housing Works supports funding mechanisms that would create more equitable distribution of CARE Act funds but strongly opposes cuts that are administered in a destabilizing manner to any area of the country. If this provision were implemented precipitously, it would result in devastating cuts to many hard-hit states and territories including Texas, Missouri, Illinois, Pennsylvania, New York, New Jersey, California, Washington, DC, Puerto Rico and others.

Over one million Americans living with AIDS and HIV, and the 40,000 plus that are infected with HIV each year, 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. 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. **Housing Works 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.**

As noted previously, Housing Works 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.