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April 28, 1997

AIDS Action council

Anne Wade
Health Care Financing Administration
Office of State Health Reform Demonstrations
7500 Security Boulevard
Baltimore, MD 21244

VIA Facsimile

Dear Anne:

Thank you for offering us the opportunity to comment on the 4/23/97 draft solicitation for Section 1115 HIV/AIDS Demonstration. Although the turnaround was short, we did have some opportunity to share the draft with a number of our community-based members who participated in the initial meeting on this subject with Bruce Vladeck and Nancy-Ann Min. Their comments have been incorporated here.

While the draft document does offer a first sketch of a demonstration, it is just a start. We have attempted to offer specific comments on each section of the draft, but perhaps our most important concerns focus on what is not in the draft. From our perspective, the Health Care Financing Administration (HCFA) must offer states substantially more guidance and data about a whole range of issues -- from how to best determine and capture the HIV-infected population for this demonstration to how they might best proceed to develop a program which is budget neutral. We are heartened by Vladeck, Min, and subsequently Vice-President Gore's commitment and expression of federal leadership to this initiative. In order to succeed with this initiative, true federal leadership must continue. This leadership will: create incentives and support mechanisms for states to participate in the demonstration, allow the maximum amount of flexibility in terms of budget neutrality, and permit access to federal databases and other information sources to facilitate the data analysis necessary to proceed further to implement HIV Medicaid expansion programs.

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Clearly, we face a number of challenges in expanding access to early intervention services under Medicaid for people with HIV. This initiative requires us all to think outside of the box. Many of our challenges center around creating incentives for states to move forward and apply for participation in the demonstration. In an effort to identify issues not included in the draft document, we are highlighting the following issues:

- Financial, operational, and technical support is needed to encourage states to respond to this demonstration project. Discretionary funding and other assistance should be identified to support the design, implementation, operational, and administrative components of the demonstration.
- We might explore the feasibility of a complementary Medicare only demo which provides prescription drug coverage to individuals with HIV/AIDS who are not dually eligible for Medicaid.
- To the degree that it is permissible, we must be creative and flexible

with states on issues of budget neutrality. For example, we might examine the implications of making the timeframe for budget neutrality longer or shorter.

- We need to look at using savings from other programs to demonstrate budget neutrality. For example, reductions in Medicare, SSI, and SSDI costs can be achieved by preventing or delaying disability.
- We need access to all the information and data that is available to determine the costs and potential savings of the services which might be offered in an early intervention expansion.

AIDS Action and its community-based partners have retained consultants to do some research on cost-effectiveness, which we will share with HCFA upon its completion. However, the scientific literature is limited and invaluable information currently exists in federal databases. These data sources include the Medicaid and Medicare databases, the VA AIDS database which tracks clients by disease marker and service, and some survey data at the CDC which is garnered through in depth interviews with individuals living with HIV/AIDS (SHAS). We need to identify service and cost trends in these programs since the introduction of combination therapy. Other useful data are the costs for the average person with AIDS in the first year on Medicaid or Medicare.

Addressing these issues will not only be vital to engage states to participate in this demonstration, but will also give them critical guidance about how to approach their respective populations for the purposes of program development. Without some in-depth attention to and analysis of these questions and others, we have doubts about whether this demonstration can be successful.

It may not be necessary to have the answers to all of the questions before promulgating a solicitation. A demonstration, by definition, suggests that the answers to all pertinent questions are not known. Nevertheless, before we can even begin to implement the demonstrations which will grapple with questions for which there are not current answers, we must provide states with a great deal of additional information and technical assistance about the range of questions they must answer to even begin. HCFA must do a great deal more than draft a solicitation. HCFA must utilize its own databases and those of other federal agencies as resources to inform the solicitation and its work with the states to develop and implement the demonstrations. HCFA must more aggressively explore the budget neutrality questions associated with this proposed expansion before shifting that burden to individual states.

From the vantage point of the AIDS community, this Medicaid expansion is urgently needed. But AIDS Action and its partners believe that it is in all our interests, but most particularly in the interests of low-income individuals living with HIV who may benefit from a well-crafted demonstration program, that this initiative be done carefully and thoughtfully.

Sincerely,

Robert Greenwald
Director of Public Policy and
Legal Affairs
AIDS Action Committee (Boston)
Co-Chair, Early Intervention
Working Group

Christine Lubinski
Deputy Executive Director
for Programs
AIDS Action Council
Co-Chair, Early Intervention
Working Group

**AIDS Action Comments on Draft Solicitation for Section 1115 HIV/AIDS Demonstration**

## Section I. General Solicitation Issues

Given the challenges states will face in assessing the nature and scope of the demonstration population, not to mention developing a model for budget neutrality, the one-year time period seems unnecessarily limited and limiting. (bullet #3)

We have concerns about the solicitation actively encouraging a blending of Ryan White and Medicaid funding in light of the discretionary nature of Ryan White funding and the fact that Ryan White funding decisions under Title I, for example, are based on an annual local decision-making process. Instead, we suggest that states demonstrate some effort to coordinate services developed under this solicitation with other current sources of HIV funding. (bullet #4)

We should explore flexibility with the five-year approval period for demonstration projects. More detail on the renewal process should be included in the solicitation. (bullet #5)

Budget neutrality issues: (bullet #6)

- What definition of budget neutrality will we used to evaluate applications?
- What data do states need to have in order to prepare demonstration applications and prove budget neutrality?
- What is the baseline (how will current Medicaid recipients with AIDS affect the baseline, since they should already be receiving combination therapy)?
- What is the timeframe for demonstrating budget neutrality (pros and cons of longer and shorter timeframes)?
- Can savings in other programs be used in demonstrating budget neutrality? (Medicare cost reductions can result from the delay or prevention of disability; reduction in SSI and SSDI costs for the same reason)
  Expanded eligibility can reduce Ryan White ADAP costs; Title III costs can be reduced given that 67% of clients are at or below the Federal Poverty Level.

(Add a bullet #9)
The linkages with academic institutions or organized HIV service coalition primarily speak to data collection and evaluation functions. We would argue for additional requirements for public participation from AIDS community-based organizations, state AIDS directors, and other entities providing health care and social services to individuals living with HIV/AIDS in the development, implementation and monitoring of the demonstration.

## Section II. Objectives

We continue to challenge a narrow view of cost-effectiveness tied only to the Medicaid program, and suggest serious consideration of assessing savings to SSI and Medicare as components of the cost-savings equation. A demonstration should offer some latitude to explore savings from a

variety of federal programs heavily utilized by individuals with HIV infection in the later stages of the disease.

Since there is no precedent for SSI eligible individuals with AIDS losing SSI eligibility relative to improved health from protease inhibitors, we object to this inclusion because of its implication that decertification efforts are underway. The intent here could be stated more affirmatively by targeting individuals who return to work and/or are not currently eligible for SSI or other mandatory or optional coverage categories on the basis of health status.

**Section III. Eligibility Options**

**1. HIV+ and income standards**

Since the Public Health Service/National Institutes of Health HIV/AIDS standard of care guidelines are scheduled to be published in the federal register over the next month, this document should be the primary reference point in the solicitation for discussing standard of care. (paragraph #1)

We support an eligibility option of HIV positive, regardless of risk factors and symptoms. Use of surrogate markers such as CD-4 counts or viral load testing have too much variation to utilize for eligibility purposes. In regard to the income standard, it is important that it not be too stringent, certainly not lower than current SSI levels. (bullet #1)

We have concerns with the exclusion of individuals receiving federal payments for medical services from other sources, including Ryan White. Since Ryan White is the payer of last resort, this is not necessary. Moreover, while individuals may receive some services from some publicly funded entities, they would not necessarily be receiving the comprehensive primary health care/prescription drug regimen vital for effective early intervention services. Therefore, they should not be excluded from demonstration eligibility based on other program participation. (bullet #2)

The eligibility section must clarify the treatment of resources for the purposes of determining inclusion in the demonstration population. We support allowing states to utilize "spend-down" options for eligibility purposes.

Modify the paragraph to be responsive to earlier comments regarding improved health and loss of SSI. Replace "a protease inhibitor drug regimen" with "effective treatments." (4th paragraph)

**2. HIV+ but with revised definition of "disability" State flexibility on income standards**

We do not support the use of an HIV "marker" to determine eligibility for an early intervention HIV demonstration project.

**Section IV: Benefit package**

1. At a minimum, the package of benefits and services in the demonstration must include: primary medical care (outpatient services and primary medical management), diagnostic testing, prescription drugs, and other services (such as mental health counseling and outpatient substance abuse treatment) that will facilitate compliance with new drug regimes. The benefit package must be flexible enough to respond to new treatment advances.

   If states are allowed to offer a limited benefit package to demonstration participants, there must be a clear prohibition against states transferring other categorically eligible Medicaid beneficiaries with HIV/AIDS into the demonstration in an effort to achieve cost savings.

   States must demonstrate that individuals in the demonstration have access to experienced HIV practitioners.

**Section VII**

Expand the QA requirements to be responsive to HIV/AIDS practice guidelines.

Should there be a plan to monitor access to care and services?

AIDS Action Council

July 14, 1997

The Honorable William Jefferson Clinton
The White House
Washington, DC 20500

VIA FACSIMILE

Dear Mr. President:

I am writing on behalf of AIDS Action Council, the national voice for 1400 community-based AIDS service organizations and the people living with HIV/AIDS whom they serve.

As you know, the Budget Reconciliation Conference Committee is currently considering options to deal with the disparities between the House-passed and Senate-passed Budget Reconciliation bills. The House and the Senate bills differ on key provisions that could profoundly restrict the quality and access of health care and welfare programs for millions of Americans, particularly the most vulnerable among us. Some of the provisions clearly defy the Budget Agreement that was struck between the Clinton Administration and Congressional leaders.

As the Conference Committee considers the Medicare, Medicaid, and welfare components of the bills over the next few days, we would like to draw your attention to a number of provisions. I urge you to work with the Congressional Leadership and Conference Committee members to ensure that the conference report of the Reconciliation bill does not undermine access to quality health care for people living with HIV/AIDS.

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**Cost Sharing/Medicaid**

The Senate Budget Reconciliation bill includes a provision allowing states to impose cost sharing on optional Medicaid beneficiaries. Current law allows only "nominal" cost sharing to be imposed on Medicaid beneficiaries. The Senate provision unfairly targets vulnerable optional beneficiaries with potentially burdensome costs that could, in fact, serve as barriers to health care. This cost sharing provision would disproportionately affect people living with HIV/AIDS. Many Medicaid beneficiaries with HIV/AIDS qualify for the program through optional beneficiary categories, especially the medically needy category. It would be extremely inappropriate if individuals who have already "spent down" into poverty were to be faced with premiums and copayments which prevented them from receiving all the health care services they needed. People living with HIV/AIDS and Medicaid beneficiaries with other chronic illnesses need a variety of health care services on a regular basis. Cost-sharing unfairly penalizes the sickest beneficiaries.

**Managed care quality protections in Medicaid and Medicare**
Both the House and Senate bills eliminate the 1915(b) waiver requirement for mandatory managed care enrollment. This is a significant change and must be coupled with strong managed care consumer protections ensuring the access and quality of care available to Medicaid and Medicare beneficiaries. I urge you to ensure that the conference report includes language requiring that all Medicaid and Medicare managed plans meet the following basic standards:

- demonstration of adequate capacity
- protections against marketing abuses
- grievance and appeals procedures
- OB/GYN and specialists as gatekeepers
- access to emergency and specialty care services
- due process requirements for enrollees and providers
- external quality review
- no preemption of state managed care standards that are stronger than federal standards.

While both the Senate and House bills include some managed care consumer protections, the Senate version is stronger than the House bill.

The District of Columbia and Puerto Rico are faced with increasingly high HIV/AIDS case loads. We support the inclusion of the much-needed increase in the Federal Medical Assistance Percentage (FMAP) for these jurisdictions in the legislation.

**Access to care and services/private health insurance market**
The House-passed Budget Reconciliation bill includes a MEWA provision that would allow small employers to band together to purchase health insurance and, in the process, exempt the plans from state insurance regulations. While AIDS Action is in favor of small employers banding together to purchase insurance, we are against exempting these plans from state regulations, including state mandated benefits and consumer quality protections. The MEWA exemption could limit the access of individuals living with HIV/AIDS to essential benefits and services. People living with HIV/AIDS have multiple health care needs including needs for substance abuse and mental health services. Many state insurance regulations mandate benefits such as substance abuse treatment and mental health coverage. Further, state laws aimed at protecting the quality of health care available to patients in managed care plans are vital to people with HIV and AIDS because of the complex and costly nature of HIV disease. I urge you to reject the MEWA provision because it would erode access to comprehensive benefits and consumer quality protections and undermine state laws.

**Welfare Issues:**
The House Budget Reconciliation bill breaks with the Budget Agreement on the issue of restoring SSI and Medicaid eligibility to legal immigrants. The Budget Agreement ensures legal immigrants who were in the country as of August 22, 1996 to be eligible for SSI benefits. The House bill limits eligibility to only those legal immigrants who were receiving SSI benefits as of August 22, 1996, leaving legal immigrants who may become disabled sometime in the future with no opportunity to receive disability income support or desperately needed Medicaid benefits.

Fortunately, the Senate Budget Reconciliation bill is in line with the Budget Agreement and extends SSI eligibility to legal immigrants in the country as of August 22, 1996, including those receiving benefits at that date and those who will become disabled in the future. We urge you to accept the Senate provision and meet the terms of the Budget Agreement by allowing legal immigrants who become disabled in the future to qualify for income assistance and Medicaid benefits.

**Disproportionate Share Hospital (DSH) payments**
As you know, the majority of spending reductions in the Medicaid program occur through DSH payment reductions. It is imperative that public hospitals which provide the majority of care to indigent and Medicaid clients do not bear the brunt of the cuts. All too many hospitals now receiving DSH payments provide little or no care to these populations. Neither the Senate nor the House bill goes far enough to protect critical health safety net hospital providers. Many people with HIV/AIDS rely on these hospitals for their health care. We urge you to ensure that the DSH funding reductions in the conference report do not undermine the ability of hospitals to provide quality health care to uninsured individuals and Medicaid beneficiaries.

The Budget Reconciliation bill makes significant changes in the way health care is reimbursed and delivered in the public sector; and in the case of MEWA's, in the private sector as well. We believe that the budget savings targeted in the Budget Resolution can be made without depriving people living with HIV/AIDS, including legal immigrants, the quality health care they need. We respectfully request that you ensure that the issues we have identified are addressed in the conference report of the Budget Reconciliation bill, before you agree to sign this measure into law.

Sincerely,

Daniel Zingale

Daniel Zingale
Executive Director

AIDS Action council

November 13, 1997

Honorable Donna Shalala
Department of Health and Human Services
200 Independence Ave, SW
Washington, DC 20201

Dear Secretary Shalala:

On behalf of the over 2,400 community based organizations we represent, AIDS Action urges you immediately to make the determination that needle exchange programs are both effective in preventing the spread of HIV and do not encourage the use of illegal drugs. Furthermore, we strongly request that you and your department expeditiously develop the conditions and guidelines under which these exchange projects would operate without compromising the operation of existing programs.

AIDS Action and the NORA (National Organizations Responding to AIDS) coalition have actively and successfully worked with the Congress to preserve your authority from legislative attack. The American Medical Association as well as the American Bar Association, and the American Public Health Association joined us in this effort. We all agree with the NIH Consensus Panel finding that there is overwhelming scientific data to prove the effectiveness of needle exchange programs in reducing HIV transmission and not increasing the use of illegal drugs. We hope to continue this momentum to ensure your determination.

Although Congress ultimately preserved your authority, a moratorium on the flow of federal funds was established, along with several program parameters. It is critical that you take action before the expiration of the moratorium on March 31, 1998, to signal to Congress your unequivocal resolve to put science ahead of politics and to allow the use of federal funds for these programs. We pledge to work with you to lay the groundwork for you to exercise your authority on April 1, 1998. Furthermore, it is our expectation that federal funds will then be made available for needle exchange programs.

In addition, your prompt and aggressive action would signal to leaders on Capitol Hill that the Administration will oppose any attempts to revisit the removal of your authority. In the long legislative battle over the preservation of your authority, there was tremendous education on Capitol Hill about needle exchange programs. We are encouraged that you, the National Institutes of Health and Dr. Varmus, the Centers for Disease Control and Prevention and Dr. Satcher, Office of National AIDS Policy and Ms. Thurman have all endorsed needle exchange programs. This is a strong list of qualified individuals who can join AIDS Action and NORA in assisting your efforts to implement needle exchange programs and do battle, if necessary, on Capitol Hill.

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I look forward to your cooperation and expeditious work on this important matter. If we can be of assistance, please call on me. Thank you for your consideration.

Sincerely

Daniel Zingale

Daniel Zingale
Executive Director

cc: Mr. Bruce Reed
Mr. Chris Jennings
Mr. John Hilley
Ms. Maria Echaveste
Ms. Sylvia Mathews
Mr. Donald Gipps
Mr. Kevin Thurm
Mr. Bill Corr
Ms. Sandy Thurman
Mr. David Satcher
Ms. Helene Gayle

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Thurm -
Corr
Satcher - Gayle

until it's over
AIDS ACTION

# Memo

To: David Beier
Eric Goosby
Chris Jennings
Daniel Mendelson
Lawrence Stein
Kevin Thurm
✓Sandy Thurman

From: Daniel Zingale, Executive Director x3011

Date: 09/24/98

Re: FY 1999 Appropriations End Game

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Enclosed is a letter I sent to the four Congressional principals of the House and Senate Labor, Health and Human Services Appropriations Subcommittee. As you know, AIDS Action is one of the few HIV/AIDS organizations dedicated to the entire HIV/AIDS portfolio --- prevention, care, research, and substance abuse treatment. We would like to strongly urge you to support our recommendations in your negotiations with the four principals as you wrap up work on the final Labor, HHS package.

Our request is timely because it appears that the FY99 Labor, HHS bill will be part of an omnibus appropriations package. The final product will certainly reflect some of your public health priorities. The Surgeon General has done a magnificent job in getting the message out that the HIV/AIDS epidemic is not over. We remain hopeful that the programs that serve people living with HIV/AIDS and those not infected will continue to be this Administration's priority.

Thank you for you consideration.

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until it's over
AIDS ACTION

September 23, 1998

Honorable Arlen Specter
Chairman, Labor, Health and Human Services Appropriations Subcommittee
184 Dirksen Senate Office Building
Washington, DC 20510

Honorable Tom Harkin
Ranking Member, Labor, Health and Human Services Appropriations Subcommittee
123 Hart Senate Office Building
Washington, DC 20510

Dear Chairman Specter and Ranking Member Harkin:

On behalf of AIDS Action, the national voice on AIDS, representing all Americans affected by HIV/AIDS and the 3,200 community-based service organizations that serve them, I am writing to commend the work of both the House and Senate Labor, Health and Human Services Appropriations Committees in providing funding and increases for HIV/AIDS prevention, care, research, and substance abuse treatment. It appears that the FY 1999 Labor, HHS Appropriations bill may be part of a broader package that contains funding for several different appropriation bills. Regardless of the legislative outcome, AIDS Action is writing to urge you to support the highest possible levels of funding for HIV/AIDS in your final package.

The programs that make up the HIV/AIDS portfolio are interwoven and demand a balanced approach.

**PREVENTION** Since new infections continue unabated, it is time we invest more in scientifically-proven prevention programs to lower the numbers of people who will later need more expensive services. There are 40,000 – 60,000 new HIV infections a year, half of which occur among people under the age of 25. Therefore, **AIDS Action urges you to support the $6.8 million increase that the Senate provided for HIV prevention at the Centers for Disease Control and Prevention**.

**CARE** Thanks to dramatic new treatments and improvements in care, the numbers of AIDS-related deaths have decreased for two straight years, increasing the prevalence of people living with AIDS. However, the fact remains that not all communities have realized the dramatic rates of decline in AIDS deaths. These two scenarios highlight the need for more access to treatment. Therefore, **AIDS Action urges you to support the House increases for the Ryan White CARE Act except for the AIDS Drug Assistance Program and the AIDS Education and Training Centers, where the Senate funding level is higher.** As you know, $150 million of the Senate's $175 million increase for ADAP is in forward-funding. We are concerned about the

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effects of forward-funding on FY 2000 funding, therefore we urge you to appropriate the highest possible amount for ADAP for FY 1999.

**RESEARCH** AIDS research funding increases help to prevent disease, prolong health, improve quality of health, and extend survival. Disease-based research conducted at the National Institutes of Health is extremely important in the quest to find vaccines, cures and to relieve individual's disease burden. AIDS research at NIH has had multiple benefits for other areas of research. Therefore, **AIDS Action urges you to support increased funding for NIH with a commensurate increase for AIDS Research.**

**SUBSTANCE ABUSE TREATMENT** There is a dual epidemic of substance abuse and HIV/AIDS, and it is unmistakable that drug and alcohol dependency contributes to unsafe behavior. Treatment for substance abuse is essential if rates of HIV infection are to be lowered. This treatment also helps contribute to improving the health of existing HIV infected individuals. Therefore, **AIDS Action urges you to support the House funding increase of $275 million for the Substance Abuse and Mental Health Services Administration treatment and prevention block grant.**

**RIDERS**

**NEEDLE EXCHANGE** Nearly one-third of AIDS cases are attributed to injection drug use, and almost half of new HIV infections are directly or indirectly related to injection drug use. This startling data has led the NIH and professional groups such as the American Medical Association, American Public Health Association and others to support the implementation of needle exchange programs. That overwhelming scientific consensus notwithstanding, the Administration and the Congress have agreed that no federal funds should be used for needle exchange programs at this time. As you know, no current federal funds are used for the implementation of needle exchange programs. Therefore, **AIDS Action urges you to support the Senate language that preserves local and state authority to use their funds for needle exchange programs, and does not contain extraneous language that jeopardizes other federal dollars.**

Thank you again for your commitment to individuals living with HIV/AIDS. We appreciate your consideration of our views.

Sincerely,

Daniel Zingale

Daniel Zingale
Executive Director