FOIA Number: 2018-0758-F

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Subgroup/Office of Origin: National AIDS Policy Office

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Subseries:

OA/ID Number: 21083

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Folder Title:
Budget - FY [Fiscal Year] '99 - HHS [Health and Human Services] - NORA [National Organizations Responding to AIDS] - OMB [Office of Management and Budget] - Reports

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S	66	6	1	2

until it's over
AIDS ACTION

1875 Connecticut Avenue NW
Suite 700
Washington, DC 20009
202-986-1300 (P) 202-986-1345 (F)

FOR IMMEDIATE RELEASE:
October 20, 1998

CONTACT: STEVEN FISHER
202-986-1300, ext. 3065

Record AIDS Funding Won in FY99 Budget

Eight hundred million dollar increase will help modernize arsenal in fight against AIDS

WASHINGTON, D.C. – AIDS Action praised record AIDS funding in the Fiscal Year 1999 omnibus budget package expected to be passed by Congress Tuesday night. These funding levels will help modernize AIDS programs to better serve those affected by the new era of the epidemic. In particular, $110 million secured by the Congressional Black Caucus (CBC) will help fight the epidemic in the African-American community and help address the CBC's declared "State of Emergency" on AIDS.

An increase in prevention funding that is more than both the President's request as well as funding passed by the House and Senate earlier this year sends a strong message of support for FY2000 funding levels that can launch a reinvigorated national prevention effort. AIDS Action called this summer for a 25% increase in prevention funding to help fight both rising infection rates and complacency among those at risk; the budget package increases prevention by about 5%, twice last year's increase.

"These are extraordinary funding levels that meet extraordinary changes in the AIDS epidemic," said Daniel Zingale, AIDS Action's executive director. "These levels of funding will help support better deployment of new AIDS drugs, improved care, better physician training as well as the development of better and less expensive drugs and treatments."

The budget package includes $4.087 billion for AIDS research, treatment and prevention, including $261 million in increases for Ryan White funding, $184.9 million more for AIDS research and $225 million more for the Housing Opportunities for People with AIDS Program (HOPWA). AIDS and AIDS-related funding for FY99 is about $800 million more than what was appropriated in FY98, including $297 million more for substance abuse prevention and treatment programs.

The spending package brings total prevention funding in FY99 to $657.8 million, $32.9 million more than FY98 and about $25 million more than what President Clinton requested. While this increase falls far short of what's necessary for a reinvigorated HIV prevention effort, it nonetheless sends a strong message for better prevention funding in the FY2000 budget.

"This year, the President and Congress reinvented AIDS spending to better meet the needs of increasing numbers of people living with HIV and AIDS. Next year, we must adapt to meet the needs of those at risk for infection," added Zingale.

AIDS Action also expressed deep concern about the bill's inclusion of language barring federal funds to District of Columbia organizations that operate needle exchange programs, even if those programs are operated with local or private money. AIDS Action will fight for creative solutions that allow continuation of needle exchange programs in D.C.

FUNDING CHART FOLLOWS

FY99 Appropriations Levels for Federal AIDS Programs

(as of October 20, 1998; increases or decreases from FY 98 numbers are shown in parentheses)

PROGRAM	FY 98 FINAL	FY 99 President's Budget Request 2/2/98	FY 99 House Mark Labor/HHS Full committee 7/14/98 VA/HUD Final 10/6/98	FY 99 Senate Mark Labor/HHS Full committee 9/3/98 VA/HUD Final 10/7/98	FY 99 FINAL[3] 10/20/98
CDC: Prevention	$634.3m	$632.3m (-$2m)	$624.9m[1] (+0m)	$631.7m[1] (+$6.8m)	$657.8m[1] (+$32.9m)
HRSA: Ryan White CARE Act Total	$1,150.2m	$1,315.2m (+$165m)	$1,331m (+$181.1m)	$1,218.4m (+$68.2m)	$1,411.6m (+$261.4m)
Title I	$464.8m	$489.8m (+$25m)	$500.2m (+$35.4m)	$478m (+$13.2m)	$505.2m (+$40.4m)
Title II: Care Services	$257.5m	$284.5m (+$27m)	$284.5m (+$27m)	$277.3m (+$19.8m)	$277.3m (+$19.8m)
Title II: ADAP	$285.5m	$385.5m (+$100m)	$385.5m (+$100m)	$311m[2] (+$25.5m)	$461.0m (+$175.5m)
Title III	$76.3m	$86.3m (+$10m)	$91.3m (+$15m)	$82m (+$5.7m)	$94.3m (+$18m)
Title IV	$41m	$44m (+$3m)	$44m (+$3m)	$44m (+$3m)	$46m (+$5.1m)
Title V: AETCs	$17.3m	$17.3m (+0)	$17.3m (+$84,000)	$18.0m (+$784,000)	$20.0m (+$2.7m)
Title V: Dental Reimbursement	$7.8m	$7.8m (+0)	$7.8m (+$37,000)	$7.8m (+$37,000)	$7.8m (+$37,000)
NIH: AIDS Research	$1,608m	$1,732m (+$124m)	9.1% NIH increase overall; OAR increase uncertain	15% NIH increase overall; OAR increase uncertain	$1,792.9m (+$184.9m)
SAMHSA (Substance Abuse Prevention & Treatment Blockgrant)	$1,310m	$1,510m (+$200m)	$1,585m (+$275m)	$1,310m (+0m)	$1,607m (+$297m)
HUD: HOPWA	$204m	$225m (+$21m)	$204m (+0m)	$225m (+$21m)	$225m (+$21m)

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[1] New number ($624.9m) reflects a Congressional accounting change. In the past, amount going directly to the office of the CDC director was included in the CDC total ($634.3m). This change does not represent any loss in money for prevention programs.
[2] The Subcommittee has proposed an additional $150 million increase in forward funding for ADAP for FY'99-2000.
[3] The final totals reflect $52 of $110 million dollars secured by the Congressional Black Caucus. The remaining $58 million is allocated for emergency spending to eliminate racial and ethnic health disparities and the Office of Minority Health.

# # #

Clinton Presidential Records
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N O R A

NATIONAL ORGANIZATIONS RESPONDING TO AIDS

AIDS APPROPRIATIONS RECOMMENDATIONS FISCAL YEAR 1999

A Coalition Convened by AIDS Action Council
1875 Connecticut Ave. NW, Suite 700, Washington, DC 20009
202-986-1300

Office of National AIDS Policy

Analysis of FY99 Budget - HHS Discretionary

Community Agency Requests

PROGRAM	FY98 Enacted	FY99 Community Request	Agency	Last Year's Increase		Community Request Increase		Notes
HRSA								
Ryan White CARE Act								
Emergency Relief	464,800	570,000	CAEAR	14,857	3%	105,200	23%	
Block Grants	257,500	342,500	NASTAD	7,546	3%	85,000	33%	
ADAP	285,500	459,000	AAC	118,500	71%	173,500	61%	
Early Intervention	76,300	113,000	AAC	6,732	10%	36,700	48%	
Women, Children, Youth	41,000	65,000	AAC	5,000	14%	24,000	59%	
Special Projects	0			0				
AIDS Educ. & Training Centers	17,300	24,300	AAC	1,013	6%	7,000	40%	
Dental Reimbursement	7,800	9,000	AAC	300	4%	1,200	15%	
Subtotal	**$1,150,200**	**$1,582,800**		**$153,948**	**15%**	**$432,600**	**38%**	
CDC								
HIV Prevention	634,300	754,300	NASTAD	17,510	3%	120,000	19%	$90 prevention, $30 surveillance
SAMSHA								
Substance Abuse Block Grant	55,122	55,122	none	0	0%	0	0%	accountability
NIH								
AIDS Research	1,607,000	1,607,000	none	107,000	7%	0	0%	Maintain OAR support
Subtotal	**$2,296,422**	**$2,416,422**		**$124,510**	**6%**	**$120,000**	**5%**	
TOTAL	**$3,446,622**	**$3,999,222**		**$278,458**	**9%**	**$552,600**	**16%**	

AIDS Policy Center
For Children, Youth & Families

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December 11, 1997

The President
The White House
1600 Pennsylvania Avenue, NW
Washington, D.C. 20500

Dear Mr. President:

On behalf of 350 affiliate care projects serving 35,000 infected and affected children, youth and families living with HIV/AIDS, **we are writing to strongly urge increased funding for Title IV of the Ryan White CARE Act in your FY 1999 budget request.**

The Ryan White CARE Act Title IV program has a unique mission to provide comprehensive HIV care for children, youth, women and families living with HIV and AIDS, and to link patients to clinical research programs throughout the United States.

Youth Services Directive

On World AIDS Day, you issued a directive to the head of each United States department and agency to find ways to integrate HIV prevention, education, care, and services into federal programs serving youth. Mr. President, we applaud your recognition of the needs of today's youth. We understand that the budget request is under final consideration, and are certainly aware of the federal budget constraints. However, in a year of enormous focus by The White House on the growing needs of youth who are at-risk or infected with HIV/AIDS, it is imperative that Title IV of the Act, which supports youth-focused services and primary medical care, be an absolute priority for additional funding.

Decrease in AIDS Deaths Disproportionate

The Centers for Disease Control and Prevention recently reported a 19% decrease nationally in the AIDS death rate in the first nine months of 1996. The decrease in death rate for women with AIDS was reported as one-third less than the death rate for men with AIDS. Youth and women living with HIV and AIDS now constitute the fastest growing group of people diagnosed with HIV and AIDS in the United States, served in large numbers by the Ryan White CARE Act. We have great hopes that the decline in AIDS deaths for women and children will dramatically improve in the near future, especially as Title IV services and access to drug trials are expanded, and more AIDS drugs are approved for use in children, youth, and adults.

Children's Health as a National Priority

Mr. President, we applaud your efforts to work with Congress to prioritize children's health initiatives as a national priority. A recently developed national pediatric drug labeling policy that will require pharmaceutical companies to test new drugs for children living with devastating diseases like HIV and AIDS continues this national priority. We are hopeful that this will increase the safe availability of promising new AIDS drugs for children. With the new drug labeling policy and more resources for Title IV, our unique mandate to provide care and access to clinical research – including drug trials – will be significantly improved.

Reduced Perinatal Transmission

The Centers for Disease Control and Prevention (CDC) recently reported a 43% decline during 1992-1996 in the number of children diagnosed with perinatally acquired AIDS. This new data demonstrates a direct result of increased care, services, and treatment made possible by increased funding for Title IV. The reduction of perinatally acquired AIDS remains a success story, but we must continue to invest in Title IV in order to continue our recent success in reducing perinatal HIV transmission.

Specifically, we recommend that your FY 1999 budget request include an additional $20 million for Title IV programs over the FY 1998 funding level of $41 million. This request reflects three priorities in FY 1999: (1) $8.5 million to expand social services and primary medical care for women, and to continue to reduce perinatal HIV transmission; (2) $8.5 million to expand outreach services and primary medical care for youth infected with HIV/AIDS; and (3) $3 million to support a basic program increase for existing Title IV projects.

Mr. President, thank you for your leadership on HIV and AIDS issues and for your consideration of this important request. For further information, we attach a Title IV funding rationale. Your support of Title IV funding will greatly impact the lives of children, youth, women and families living with HIV/AIDS throughout the United States.

Sincerely,

Mildred Williamson
President

David C. Harvey
Executive Director

AIDS Policy Center
For Children, Youth & Families

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FAX COVERSHEET

TO: Todd Summers

FAX #: 632-1096

FROM: Heidi Eckert

DATE:

SUBJECT: President's Budget

NUMBER OF PAGES (including cover): 3

Notes: FYI, please find the new letter to the President. Thank you for your comments!

CAEAR
CITIES ADVOCATING EMERGENCY AIDS RELIEF

$570 MILLION NEEDED IN FY '99 FOR CARE ACT TITLE I

Promise of new treatments – require commitment of new resources.

- The CAEAR Coalition is requesting a minimum of $570 million in FY '99 funding for Title I of the Ryan White CARE Act. **This would be an increase of $105 million over FY '98 appropriations.**
- The 49 metropolitan areas eligible to receive emergency assistance under Title I provide care to at least 74% of all reported cases of AIDS in the United States.
- According to the Centers for Disease Control and Prevention, AIDS prevalence will continue to increase. This fact underscores an increasing need for medical and other services for people living with AIDS. As the number of AIDS deaths has begun to decrease, the number of people living with AIDS has grown, rising 10% since mid-1995.

Federal HIV treatment guidelines call for enhancement of care – increased out-patient office visits and diagnostic tests.

Viral Load Testing

- A decade and a half of research has brought significant breakthroughs in the treatment of HIV. These breakthroughs have led to the quick approval by the Food and Drug Administration (FDA) of one class of new antiretroviral drugs, protease inhibitors, which offer treatment of unparalleled potency.
- The National Institutes of Health (NIH) guidance in the use of antiretroviral therapy calls for viral load testing for people living with HIV/AIDS. With the release of the NIH and Public Health Service guidelines, early treatment of HIV infection, the use of protease inhibitors and the accompanying viral load testing have become the standard of care.
- Currently, the lowest estimated cost for measuring a person's viral load is $100 per test, and quarterly monitoring is recommended. Test costs, in some locales, are as high as $250 per test. The Health Resources and Services Administration (HRSA) reports that there were approximately 562,400 Title I clients in FY 1995, the latest year for which data is available. A conservative estimate is that at least 30% of these clients are expected to use Title I funding to pay for viral load testing. **To provide quarterly viral load testing just for the number of people in 1995 living with HIV in Title I areas requires a minimum FY '99 increase of $67 million.**

Federal health officials recommend early treatment of HIV infection.

Increased Cost of Primary Care

- New drug breakthroughs and the quick approval by the FDA of a new class of drugs, protease inhibitors, have led the National Institutes of Health to recommend early treatment of HIV infection. The new standards of care have placed significant pressure on Title I areas to ensure that access to these drugs is available and continuous. A person who fails to take these medications as prescribed runs the risk of rapidly developing resistant viral strains. The annual cost per person for the new combination therapy including these drugs is $10,000 to $16,000. In FY 1995, Title I communities expended at least $35.5 million on direct pharmaceutical drug purchases. The majority of this sum does not include transfers of Title I funds to state-run, Title II AIDS Drug Assistance Programs (ADAPs).

Epicenter EMAs struggle to respond to flood of new patients seeking medical care.

- **New Primary Care Clients.** HRSA estimates a 60% increase in the number of new Title I clients between 1994 and 1995. This flood of new clients has continued as a result of the availability of the new combination drug therapies. Title I communities across the country have documented client increases ranging from 13% to as high as 74%, and the typical Title I community has client increases somewhere in the 40% range. The provision of primary health care services accounts for 58% of Title I funds. **A minimum FY '99 increase of 10% in Title I primary care funds, or $27 million is required to provide for these new Title I clients.**

Title I Clients Use More Primary Care.

- **Increased Overall Primary Care Utilization.** Preliminary HRSA data reveals astoundingly large increases of 59% in primary care utilization by existing clients of Title I between 1994 and 1995. CARE Act services are predominantly used by symptomatic people with AIDS who require significantly more and more complex medical visits. The number of primary care visits per AIDS case also increases as people with HIV live longer. **The CAEAR Coalition requests a very conservative FY '99 increase of $11 million for primary care utilization. These funds are necessary, in addition to the requested increase for viral load testing, in order to begin to respond to this increase in overall primary care utilization.**

For further information contact, H. Alexander Robinson, Administration of Federal Affairs, CAEAR Coalition, 1413 K Street, NW, Suite 700, Washington, D.C. 20005, 202.789.3565 fax 202.789.4277 or *Grayson Fowler,* The Sheridan Group, 1808 Swann Street, NW, Washington, D.C., 20009, 202.462.7288 fax 202.786.1964

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December 9, 1997

The President
The White House
1600 Pennsylvania Avenue, NW
Washington, D.C. 20500

Dear Mr. President:

On behalf of 350 affiliate care projects serving 35,000 infected and affected children, youth and families living with HIV/AIDS, **we are writing to strongly urge increased funding for Title IV of the Ryan White CARE Act in the President's FY 1999 budget request.**

The Ryan White CARE Act Title IV program has a unique mission to provide comprehensive HIV care for children, youth, women and families living with HIV and AIDS, and to link patients to clinical research programs throughout the United States.

Youth Services Directive

On World AIDS Day, President Clinton issued a directive to the head of each United States department and agency to find ways to integrate HIV prevention, education, care, and services into federal programs serving youth. The President, recognizing the needs of youth, directed that each federal agency identify youth programs that can provide HIV prevention services and care, and to develop a specific plan to increase access to these services. We understand that the budget request is under final consideration, and are certainly aware of the federal budget constraints. However, in a year of enormous focus by The White House on the growing needs of youth who are at-risk or infected with HIV/AIDS, it is imperative that Title IV of the Act, which supports youth-focused services and primary medical care, be an absolute priority for additional funding.

Decrease in AIDS Deaths Disproportionate

The Centers for Disease Control and Prevention recently reported a 19% decrease nationally in the AIDS death rate in the first nine months of 1996. The decrease in death rate for women with AIDS was reported as one-third less than the death rate for men with AIDS. Youth and women living with HIV and AIDS now constitute the fastest growing group of people diagnosed with HIV and AIDS in the United States, served in large numbers by the Ryan White CARE Act. We have great hopes that the decline in AIDS deaths for women and children will dramatically improve in the near future, especially as Title IV services and access to drug trials are expanded, and more AIDS drugs are approved for use in children, youth, and adults.

Children's Health as a National Priority
The Administration has tirelessly worked with Congress to prioritize children's health initiatives as a national priority. Recently, the Administration crafted a national pediatric drug labeling policy that will require pharmaceutical companies to test new drugs for children living with devastating diseases like HIV and AIDS. We are hopeful that this will increase the safe availability of promising new AIDS drugs for children. With the new drug labeling policy and more resources for Title IV, our unique mandate to provide care and access to clinical research – including drug trials – will be significantly improved.

Reduced Perinatal Transmission
The Centers for Disease Control and Prevention (CDC) recently reported a 43% decline during 1992-1996 in the number of children diagnosed with perinatally acquired AIDS. This new data demonstrates a direct result of increased care, services, and treatment made possible by increased funding for Title IV. The reduction of perinatally acquired AIDS remains a success story, but we must continue to invest in Title IV in order to continue our recent success in reducing perinatal HIV transmission.

Specifically, we recommend that the President's FY 1999 budget request include an additional $20 million for Title IV programs over the FY 1998 funding level of $41 million. This request reflects three priorities in FY 1999: (1) $8.5 million to expand social services and primary medical care for women, and to continue to reduce perinatal HIV transmission; (2) $8.5 million to expand outreach services and primary medical care for youth infected with HIV/AIDS; and (3) $3 million to support a basic program increase for existing Title IV projects.

Thank you for your leadership on HIV and AIDS issues and for your consideration of this important request. For further information, we attach a Title IV funding rationale. Your support of Title IV funding will greatly impact the lives of children, youth, women and families living with HIV/AIDS throughout the United States.

Sincerely,

Mildred Williamson
President

David C. Harvey
Executive Director

AIDS Policy Center
For Children, Youth & Families

RYAN WHITE CARE ACT TITLE IV

FY 1999 Funding Rationale Additional Primary Care Needs

Memorandum

- Title IV supports confidential social services, primary medical care and access to research for children, youth, women and families.

- Over 75% of Title IV projects provide direct primary medical care to children, youth, at-risk youth and pregnant women with HIV and AIDS. Medicaid does not fully reimburse Title IV projects for costs of primary medical care. Over 65% of Title IV projects are the principle source of primary medical care for children, youth, at-risk youth and pregnant women with HIV and AIDS living in their geographic area.

- Title IV reaches 338 sites in 27 states, the District of Columbia and Puerto Rico. Title IV is administered by the HIV/AIDS Bureau of the Health Resources and Services Administration.

- Title IV sites serve an estimated 50,000 HIV infected and affected children, youth, at-risk youth, women, men, and families. Demand for services has tripled during the past three years.

Funding Rationale

- Women and youth are the fastest growing population infected and affected with HIV in the United States and need greater access to Title IV projects.

- Additional funding for Title IV will support increased primary medical care and participation in clinical research by children, youth and women with HIV, particularly African-Americans and Latinos.

- $25 million in additional Title IV funds are needed to: (1) expand women's HIV care programs; (2) expand youth focused HIV care programs; and (3) expand existing programs.

FY 1999 Title Budget Request Summary

I. Women's Special Initiative	**$8.5 million**
II. Adolescent Special Initiative	**$8.5 million**
III. Basic Program Increase	**$3 million**
FY '99 Subtotal	**$20 million**
FY'98 Appropriation 41	**$45 million**
FY '99 Total Request 61	**$65 million**

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AIDS Policy Center
For Children, Youth & Families

RYAN WHITE CARE ACT
TITLE IV

Memorandum

FY 1999 Funding Rationale
Additional Primary Care Needs

- Title IV supports confidential social services, primary medical care and access to research for children, youth, women and families.

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III. Basic Program Increase	**$3 million**
FY '99 Subtotal	**$20 million**
FY'98 Appropriation	**$41 million**
FY '99 Total Request	**$61 million**

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THE WHITE HOUSE

Office of the Press Secretary

For Immediate Release December 1, 1997

December 1, 1997

MEMORANDUM FOR THE HEADS OF EXECUTIVE DEPARTMENTS AND AGENCIES

SUBJECT: Integration of HIV Prevention in Federal Programs Serving Youth

Adolescence marks a major rite of passage, a transition from childhood to adulthood. It is a period of significant physical, social, and intellectual growth and change. It is also a period of experimentation and risk-taking. The choices that young people make during these years profoundly affect their chances of becoming healthy, responsible, and productive adults.

Unfortunately, too many young people lack the support and self-esteem needed to make sound decisions, and end up putting their lives and their futures at risk. Today, it is estimated that one-quarter of all new HIV infections in the United States occur in young people between the ages of 13 and 21. This means that two Americans under the age of 21 become infected with HIV every hour of every day. The Centers for Disease Control and Prevention reports that in some communities as many as one in thirty 18- and 19-year olds may be HIV-positive.

For young people who become infected, there are promising new treatments available to help them live longer and more productive lives. Yet these treatments only forestall the progression of the disease; they do not constitute a cure. In fact, AIDS is the sixth leading cause of death among young people 15-24 years old (and the leading cause of death among African Americans of the same age group). The loss of so many young Americans to this terrible epidemic is a threat to this Nation and should serve as a call to action.

My Administration is firmly committed to doing everything within its power to end the AIDS epidemic. That includes finding a cure for those already infected as well as a vaccine to keep others from developing the disease. This commitment also includes reaching out in new ways to enable young people to protect themselves from acquiring or spreading HIV infection.

Accordingly, I hereby direct:

- That each Federal agency, within 90 days, working with the Department of Health and Human Services (HHS) and the Office of National AIDS Policy (ONAP) identify all programs under its control that serve young people ages 13-21 and that offer a significant opportunity for preventing HIV infection; and

- That each Federal agency, in collaboration with the HHS and ONAP, develop within 180 days a specific plan through which said programs could increase access to HIV prevention and education information, as well as to supportive services and care for those already infected.

WILLIAM J. CLINTON

# # #

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FAX COVERSHEET

TO: Sandy Thurman

FAX #:

FROM: Heidi Ecker

DATE:

SUBJECT: FY99 Title IV funding

NUMBER OF PAGES (including cover): 6

Notes: Please find the following letter about FY99 funding and a Title IV funding rationale. Please call me at 785-3564 ext 13 with any questions.

Thanks

Memorandum

To: Todd Summers
Re: CAEAR's FY '99 Budget Request
From: H. Alexander Robinson
Date: November 25, 1997

On September 4, 1997, the CAEAR Coalition delivered an urgent appeal for substantial increases in CARE Act funding for Title I eligible metropolitan areas. In a sharply worded letter to President Clinton, CAEAR Coalition Chairperson Ernest Hopkins, called President Clinton's request for a $5 million increase in FY '98 Title I funding "woefully inadequate," and noted that "despite the decline in AIDS deaths, the scope of the AIDS epidemic continues to expand relentlessly in racially and ethnically diverse communities, and increasingly in injection drug users and their partners."

Detailing the need for additional resources, the letter, which I co-signed with Ernest Hopkins, requested President Clinton include a request for $570 million in CARE Act Title I funding for FY '99. This would provide a $120 million increase over FY '97 Title I spending and a $105 million increase over FY '98 Appropriations. Based on 1995 estimates of the number of people living with HIV, the Coalition estimated that Title I EMAs will require a minimum FY '99 increase of $67 million over FY '97 appropriations in order to provide quarterly viral load testing. In relation to the recently House and Senate passed Conference Report on the Labor, Health and Human Services, and Education appropriations legislation, that is $58.625 million increase.

Even before the new therapies, HRSA reported a 60% increase in the number of new clients between 1994 and 1995. "We believe this flood of new Title I clients has continued since 1995 as a result of the availability of new combination drug therapies," wrote Hopkins adding that "in recent years, Title I communities across the country have documented client increases ranging from 13% to as high as 74%, and client increases average in the 40% range." The provision of primary health care services accounts for 58% of Title I funds. Consequently, the Coalition concluded that a minimum FY '99 increase of 10% in Title I primary care funds, or $26 million, over FY '97 spending will be required to provide for these new Title I clients. Compared to FY '98 appropriations, that number represents a $22.75 million increase.

HRSA data revealed an astoundingly large increase of 59% in primary care utilization by Title I clients between 1994 and 1995. CARE Act services are predominantly used by symptomatic people with AIDS who require frequent and significantly more complex medical visits. As people with HIV live longer, the number of primary care visits per AIDS case grows. The CAEAR Coalition requested a very conservative increase of 15% over FY '97 spending, or $27 million, in FY '99 Title I funding for primary care. This figure is a $23.625 million increase over FY '98 appropriations. These funds are necessary, in addition to those requested for viral load testing, "in order to begin to respond to this increase in overall primary care utilization."

CAEAR Coalition Members, Mayors, community-based AIDS services providers and people living with HIV and AIDS in Title I EMAs have also written to the President and the Secretary of Health and Human Services, Donna Shalala, in support of the CAEAR Coalition's request. If you would like copies of any of those letter, please let us know.

NANCY PELOSI
8TH DISTRICT, CALIFORNIA

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(202) 225-4965

DISTRICT OFFICE:
FEDERAL BUILDING
450 GOLDEN GATE AVENUE
SAN FRANCISCO, CA 94102-3460
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Congress of the United States
House of Representatives
Washington, DC 20515-0508

COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEES:
LABOR-HEALTH AND HUMAN SERVICES-EDUCATION
FOREIGN OPERATIONS, EXPORT FINANCING AND RELATED PROGRAMS

PERMANENT SELECT COMMITTEE ON INTELLIGENCE
RANKING MEMBER, SUBCOMMITTEE ON TECHNICAL AND TACTICAL INTELLIGENCE

COMMITTEE ON STANDARDS OF OFFICIAL CONDUCT

CONGRESSIONAL WORKING GROUP ON CHINA, CHAIR

AT-LARGE WHIP

AIDS Funding

Labor-HHS Appropriations Bill for FY 98
All numbers in millions

	1997	1998	Change	
Ryan White Program				
Education & Training Centers	16.3	17.3	+1.0	(6%)
AIDS Dental Services	7.5	7.8	+.3	(4%)
Emergency Assistance	450.0	464.8	+14.9	(3%)
Comprehensive Care	250.0	257.5	+7.5	(3%)
AIDS Drug Assistance Program	167.0	285.5	+118.5	(71%)
Early Intervention Programs	69.6	76.3	+6.7	(10%)
Pediatric Demonstrations	36.0	41.0	+5.0	(14%)
Total	996.3	1,150.2	+153.9	(15%)
CDC HIV Prevention	616.8	634.3	+17.5	(3%)
NIH AIDS Research	1,501	1,608	+107	(7%)

Included in the House VA-HUD Appropriations Bill:

Housing Opportunities for Persons with AIDS	171	204	+33 (19%)

MEMORANDUM

To: Sandra Thurman
Director
Office of National AIDS Policy
Suite #820
808 17th Street, NW
Washington, DC 20006
Fax: 202-632-1096

From: Richard Jefferys, AIDS Treatment Data Network
Co-Chair, Data Subcommittee, ADAP Working Group

Date: 11/25/97

Re: **ADAP Budget Projections, FY 1999**

I enclose the ADAP Working Group Data Subcommittee's preliminary national Ryan White Title II AIDS Drug Assistance Program budget projection for fiscal year 1999, April 1, 1999 - March 31, 2000.

The following summarizes the projection:

Projected ADAP need for FY 1999 (all sources):	**$749,348,764**
Projected base budget for FY 1998:	**$532,887,033***
Current ADAP shortfall for FY 1998:	$216,461,731
Federal Increase (80%*):	**+$173,169,385**
State Increase (20%*):	+$ 43,292,346

*See last bullet point, below.

We have used the same pharmacoeconomic model employed for previous fiscal projections. This model uses real world information about the immune system status of ADAP clients to project the need for preventive and acute treatment with outpatient drugs. The expected incidence of illness is based on the Multi-AIDS Center Cohort Study (MACS). The same model has predicted individual state ADAP expenditures within 5% of the actual totals.

The entire projection is driven by numbers of current ADAP **utilizers**, not enrollees. This avoids confounding problems such as counting clients who may be enrolled in ADAP but who have chosen to wait before starting antiretroviral treatment. The assumptions for this projection are as follows:

- The number of ADAP utilizers will continue to grow at a rate of 1,000 new programs utilizers each month. Based on as yet unpublished data from a recent update to the ADAP Monitoring Project, growth in utilizers from July 1996 to July 1997 was approximately 982 clients a month. This figure is

somewhat artificially depressed by the removal of 600 clients from Mississippi ADAP and by the institution of waiting lists in Alabama and Florida prior to July 1997. The start point for the projection is 43,163 utilizers in July 1997, data also derived from the most recent ADAP Monitoring Project Survey. The projection thus estimates a total of 75,165 utilizers in March, 2000, which remains significantly below recent Centers for Disease Control and Prevention data indicating that approximately 225,000 uninsured people are currently living with HIV in the U.S.

- The projected distribution of antiretroviral therapy among utilizers is 90% receiving triple combination therapy and 10% utilizing opportunistic infection prophylaxis only. This projection is based upon both the new NIH/PHS Guidelines on the Use of Antiretroviral Agents and data from New York State ADAP, which currently shows an average of 2.65 antiretroviral prescriptions per utilizing client. The three drug regimen used in the projection is derived from the earliest study of this treatment strategy and uses two nucleoside analogs and the lowest priced protease inhibitor currently available. The Data Subcommittee acknowledges the varied distribution of different antiretroviral combinations in use and anticipates that by FY 1999 possible treatment combinations may have become yet more heterogeneous. Since there is a potential for new treatment strategies to be both more and less costly than the regimen currently used in the model, we believe that our cost projection for combination therapy is a reasonable placeholder given the uncertainty of future treatment trends.
- A rebate/discount of 20% below Average Wholesale Price is applied to all pharmaceutical costs in the model. This represents a slightly deeper reduction than the 15.8% rebate/discount used in previous projections, to take into account potentially broader ADAP access to the Public Health Service pricing schedule through a rebate mechanism.
- For the FY 1999 projection, annual inflation was estimated from the medical care services consumer price index at approximately 2.6% a year.
- For the baseline FY 1998 ADAP budget, we assume a 20% State match of the additional Federal contribution of $118.5 million. The percentage of the additional need allocated to Federal and State sources is derived from the FY 1998 Appropriations report language.

Please do not hesitate to contact me with any questions. Further details on the methodology will be provided.

CAEAR
CITIES ADVOCATING
EMERGENCY AIDS RELIEF

September 4, 1997

The President
The White House
Washington, DC 20500

Dear Mr. President:

CITIES ADVOCATING EMERGENCY AIDS RELIEF (CAEAR) is a national coalition of community members who come together with a sense of urgency to advocate on behalf of cities and localities served by Title I of the Ryan White Comprehensive AIDS Resources Emergency Act. Our members include Title I planning councils, people living with HIV/AIDS, organizations of people living with HIV, community-based AIDS service organizations, CARE Act grantees and consortia. We are civic and business leaders, straight people as well as lesbians and gay men, members of religious organizations, government representatives, local public health officials, drug treatment and mental health providers and representatives from diverse communities of color.

We write to you today regarding your Fiscal Year 1999 budget request to Congress. We ask that you request Congress to provide increases for all Ryan White CARE Act programs. **In particular, we strongly urge you to include a request for Title I funding for FY '99 in the amount of $570 million.** This would provide a $120 million increase over FY '97 Title I spending. The Administration's budget request for FY '98, we believe, was woefully inadequate.

Increased funding for the CARE Act is urgently needed to address the AIDS emergency in metropolitan areas across the nation. As you know, AIDS remains the leading killer of all Americans between the age of 25 and 44. Six years ago, Title I provided assistance to 16 communities. Today, 49 American communities receive funding under Title I. These 49 communities account for 74% of all reported AIDS cases in America. The Centers for Disease Control and Prevention (CDC) reports a decrease in AIDS deaths, which means people with AIDS are living longer. Therefore, Title I areas must have the capacity to provide more CARE Act services.

Despite the decline in AIDS deaths, the scope of the AIDS epidemic continues to expand relentlessly in racially and ethnically diverse communities, and increasingly in injection drug users and their partners. In 1985, 2% of the reported cases of AIDS were attributed to heterosexual sex. By 1995, this rate had jumped to 11%. Adding to the complexity of addressing the needs of Americans living with HIV, there have been increases in cases of AIDS in communities of color, women and IV

The CAEAR Coalition
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drug users. According to the CDC, African Americans and Hispanics comprised 40% of all AIDS cases in 1985. In 1995, the CDC reported that 59% of people living with AIDS were African American or Hispanic. Last year, the proportion of African Americans living with AIDS exceeded the proportion of Whites for the first time. Furthermore, reports show that, on average, HIV-positive African Americans, women and IV drug users are poorer than the population of gay white men who were the majority of AIDS cases in the 1980's.

Accompanying this demographic shift has been a revolution in treatment for people living with HIV. While it is far too early to declare victory over this devastating pandemic, a decade and a half of research has brought significant scientific discoveries in the United States. These medical breakthroughs have led to the quick FDA approval of one class of new antiretroviral drugs, protease inhibitors, which offer treatment of unparalleled potency. These new therapies must be provided within the context of overall primary care; failure to take these medications as prescribed runs the risk of rapid development of resistant viral strains.

The Guidelines for the Use of Antiretroviral Agents in HIV Infected Adults and Adolescents developed by the Panel on Clinical Practices for Treatment of HIV Infection and the National Institutes of Health Panel to Define Principles of Therapy of HIV Infection provide guidance in the use of antiretroviral therapy. The DHHS/NIH guidance have made viral load tests the standard of care for physicians treating people living with HIV. It is the measure by which physicians determine whether or when to commence the new combination drug therapies. Consequently, the 49 Title I communities will have to provide access to these tests as a part of a complete medical care regimen for people living with HIV. The Health Resources and Services Administration (HRSA) reported a total of 562,400 Title I clients in FY '95. The recipients of Title I services are non-Medicaid eligible, uninsured people living with HIV/AIDS. We estimate that 30% of these clients would use Title I funding for payment of viral load testing. A minimum of four viral load tests per year, per patient, will be required. Each test will cost at least $100, and in some locales the test will be as high as $250. To provide quarterly viral load testing just for the number of people in 1995 living with HIV in Title I areas requires a minimum FY '99 increase of $67 million over FY '97 appropriations.

Even before the new therapies, HRSA reported a 60% increase in the number of new clients between 1994 and 1995. We believe this flood of new Title I clients has continued since 1995 as a result of the availability of new combination drug therapies. In recent years, Title I communities across the country have documented client increases ranging from 13% to as high as 74%, and client increases average in the 40% range. The provision of primary health care services accounts for 58% of Title I funds. A minimum FY '99 increase of 10% in Title I primary care funds, or $26 million, over FY '97 spending is required to provide for these new Title I clients.

HRSA data also revealed an astoundingly large increase of 59% in primary care utilization by Title I clients between 1994 and 1995. CARE Act services are predominantly used by symptomatic people with AIDS who require frequent and significantly more complex medical

visits. Moreover, as people with HIV live longer, the number of primary care visits per AIDS case grows. The CAEAR Coalition requests a very conservative increase of 15% over FY '97 spending, or $27 million, in FY '99 Title I funding for primary care. These funds are necessary, in addition to those requested for viral load testing, in order to begin to respond to this increase in overall primary care utilization.

The AIDS epidemic has produced dangerous strains on the public health systems in our nation's major metropolitan areas. As a result, the epidemic has fueled an emergency care crisis, and it continues to spread disproportionately in historically underserved communities. Access to primary health care can prevent costly HIV/AIDS emergency room situations. Hospitals in the Title I communities have long reported average losses of $401 per day for each AIDS patient. As the financial burdens mount, responding to the needs of the AIDS epidemic grows ever more difficult. This burden imperils our ability to meet all the other health needs in our communities. With funds provided under the Ryan White CARE Act, our communities can prolong the lives of people with AIDS and save the nation millions of dollars in unnecessary hospitalizations and other health care costs. Heavily reliant upon funding for all titles of the CARE Act, the Coalition requests that your budget include adequate funds for all titles of the CARE Act, as well as other federal AIDS efforts in prevention, housing and research.

The AIDS epidemic has taken another turn in a truly dramatic decade of suffering, despair and great loss. This worldwide pandemic has engendered inhuman acts of discrimination as well as astonishing acts of selflessness and compassion. Now AIDS presents another challenge to our nation to again keep the American promise to ensure justice for all. People with AIDS are able to remain working and contributing members of their communities. Working people with HIV who cannot afford access to life saving care need your assistance. People living with HIV who are poor need your assistance. With Title I funds, we can maintain health, save taxpayer money and improve the quality of life for people with HIV/AIDS. But we need your help to do it.

In the recent budget agreement with Congress, AIDS issues generally, and the Ryan White CARE Act specifically, were de-prioritized. Your administration has hastened to assure the AIDS community that AIDS remains a high priority for you. Your budget request is the tangible means of providing this reassurance. We urge you and your administration to answer this challenge to our nation with all the passion and resources required to bring hope to Americans living with HIV.

Respectfully,

Ernest Hopkins, Chair, CAEAR Coalition
Director of Health and Treatment
National Association of People with AIDS

H. Alexander Robinson
Administrator of Federal Affairs
CAEAR Coalition

AIDS *Action* Council
1875 Connecticut Ave. NW Suite 700
Washington, DC 20009
t. (202) 986-1300 f. (202) 986-1345

Memorandum

To: Todd Summers

From: Christine Lubinski, Deputy Executive Director ext. 3046
Javier Salazar, Legislative Representative – Budget and Appropriations ext. 3051

Date: November 25, 1997

Re: AIDS Action Council FY 99 Budget requests for HIV/AIDS programs

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What follows are need numbers for HIV/AIDS discretionary funding levels and a Medicaid expansion initiative for Fiscal Year 1999. We hope you find this helpful and look forward to continuing to work with you as the FY 99 budget process proceeds.

Health Care Financing Administration
Request: +100 million for Medicaid Expansion
Medicaid is the major source of health care for people living with HIV/AIDS. Unfortunately, most people with HIV disease must become completely disabled and develop AIDS, before they can qualify for Medicaid and receive health care and drug treatments which might prevent them from progressing to AIDS. AIDS Action has called for an expansion of Medicaid eligibility, so that low-income individuals living with HIV disease can receive health care and life-prolonging prescription drugs before disease progression occurs. The Health Care Financing Administration is exploring the efficacy of an HIV Medicaid demonstration project. In the meantime, a number of states have expressed interest in submitting a Medicaid waiver to cover this population, and some of these states are developing waiver applications. Most states are having difficulty ensuring that uninsured HIV positive individuals receive the HIV standard of care endorsed by the NIH and the Public Health Service. Additional health care coverage under the Medicaid program is urgently needed.

HCFA needs additional resources to support the efforts of states to expand Medicaid eligibility for low-income HIV positive individuals. AIDS Action respectfully requests a funding level of $100 million for this expansion of Medicaid eligibility. These funds could be utilized to support health care services, including prescription drugs, under the Medicaid program for about 25 percent of the estimated number of low-income HIV positive individuals who meet income requirements, but who do not currently meet disability criteria for the Medicaid programs.

AIDS research at the National Institutes of Health
AIDS Action and the rest of the AIDS community have consistently advocated for increases in NIH-funded AIDS research commensurate with increases for NIH research overall. Because of the strong bipartisan support for the NIH on Capitol Hill and the strong commitment of the Clinton Administration to biomedical research, we choose to defer advocacy based on any specific funding level for AIDS research.

HIV Prevention at the Centers for Disease Control
Request: + $120 million increase over FY 98 for a total of $754 million in FY 99.
While CDC's HIV/AIDS budget is over $600 million, only about half of that is actually channeled to community-based HIV prevention initiatives directed toward populations at high risk for HIV infection. There are simply not enough federal prevention resources directed to community-based prevention. For example, the recent program announcement for application from community-based organizations for targeted prevention programs funded 98 CBOs although over 400 applications merited funding.

Since it's inception with the Clinton Administration, the HIV community planning process – a partnership between state and local health departments—has consistently been unable to garner the necessary resources to fund the locally-identified HIV prevention priorities.

Although it will not meet the need, an additional $120 million in FY 99 would make a critical contribution to our nation's efforts to prevention HIV and AIDS.

Housing Opportunities for People with AIDS (HOPWA)
Request: +46 million over the FY 98 funding for a total of $250 million in FY 99.
HOPWA is a formula-funded, flexible program that gives states and localities hardest-hit by the AIDS epidemic desperately needed resources and local control over the use of these resources to meet the local housing needs of people with AIDS. Stable housing is essential if individuals are to have the opportunity to access and to manage complex, but life-prolonging medications. Eight to ten jurisdictions become newly eligible for formula grants based on increases in caseload. At least $250 million would be needed in FY 99 to prevent cuts in funding to existing jurisdictions. For each $1 million in HOPWA funds, HUD estimates that an additional 269 individuals and families living with HIV and AIDS will have access to vital housing and housing-related services.

Ryan White CARE Act
Title I
Request: +$105 million over FY 98 for a total of $570 million in FY 99.
Title I provides formula and supplemental grants for the delivery of comprehensive HIV/AIDS medical care and support services to eligible metropolitan areas (EMA) disproportionately affected by the HIV epidemic. There are currently 49 EMAs. These urban areas continue to experience increases in demand for primary care and services as more individuals seek treatment. Additionally, increased longevity associated with new therapies has led to a sustained demand for current services and increased demand for viral load testing. Title I funds are also used to purchase new and costly therapeutics to treat HIV disease.

Title II –
Care and Support Services
Request: +$85 million over FY 98 for a total of $343 million in FY 99.
Title II provides formula grants to provide statewide, comprehensive HIV/AIDS services. State AIDS directors have identified enhanced case management, insurance continuation and purchasing programs, and enhanced primary medical care as high priority needs. States are needing to bolster HIV care services in rural areas as well as transportation to and from care services.

AIDS Drug Assistance Program (funded under Title II of the Ryan White CARE Act)
Request: + $173 million over FY 98 for a total of $459 million in FY 99.
Initial data from July 1996 – July 1997 suggests that state ADAP programs are experiencing up to 1,200 new enrollments per month. This figure, however, does not reflect the total number of those seeking assistance due to closed enrollments, capped programs, or other measures restricting access to state ADAPs. For FY 99, rough projections using the new federal treatment guidelines and increased enrollments suggest a total ADAP budget of about $750 million, which includes both state and federal contributions.

Title III
Request: +$36.7 million over FY 98 for a total of $113 million for FY 99.
Title IIIB provides grants to existing community-based clinics and public health providers to develop and deliver early and ongoing comprehensive HIV/AIDS services on an outpatient base. Grantees provide primary medical care in rural and underserved urban areas. In many cases, Title IIIB grantees are the only source of medical care in a given area. A healthy increase in funding is needed to ensure that rural and underserved areas, primarily those lacking Title I EMAs, have access to critical primary medical care. As more individuals seek new therapies, greater access to medical care is needed to ensure successful therapeutic outcomes.

Title IV
Request: +$24 million over FY 98 for a total of $65 million in FY 99.
Title IV provides grants to support pediatric, adolescent and family HIV/AIDS care programs and the coordination of access for these populations to clinical research programs. With over 330 sites in 27 states, the District of Columbia, and Puerto Rico, over 550,000 HIV infected and affected children, youth, at-risk youth, women, and families are served. Increased funding is needed to expand existing programs and youth-focused programs, and to better target care services for women which now make up over 21 percent of all new AIDS cases.

Title V
AIDS Education and Training Centers (funded under Title V of the Ryan White CARE Act)
Request: +$7 million over FY 98 for a total of $24.3 million in FY 99.
The AETCs are the training arm of the Ryan White CARE Act. The AETC's ensure that health care providers have access to the most up to date information and training on clinically competent AIDS care. The advent of the new treatment regimens and the newly developed Public Health Service guidelines for HIV antiretroviral treatment make the role of these federally funded trainers all the more critical. Poor medical management of HIV/AIDS patients can result in drug resistance and premature death.

HIV Dental Reimbursement Program
Request: +$1.2 million over FY 98 for a total of $9 million in FY 99.
The HIV Dental Reimbursement Program is a federal-institutional partnership that provides quality oral health care to people living with HIV while simultaneously training new professionals in the delivery of such care. Last year, this cost-effective program provided over 70,000 individuals with critical oral care.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

November 25, 1997

Joshua Gotbaum
Executive Associate Director
Executive Office of the President
Office of Management Budget
Old Executive Office Building
17th Street and Pennsylvania Avenue, NW
Washington, DC 20503

Dear Mr. Gotbaum:

In anticipation of the Administration's fiscal year 1999 budget request to Congress, the National Alliance of State and Territorial AIDS Directors (NASTAD), which represents the nation's AIDS program administrators in charge of prevention, care and support service programs in every state, would like to inform you of critical HIV/AIDS-related funding needs, including preliminary estimates of funding level requests for federal HIV/AIDS programs.

Centers for Disease Control and Prevention
HIV and STD Prevention and Surveillance

Funding recommendations for HIV prevention and surveillance programs for FY 1999 are **$120 million** greater than the FY 1998 funding level. This increase includes a **$90 million increase** for HIV prevention programs and a **$30 million increase** for HIV surveillance programs.

HIV Prevention

A **$90 million** increase over the FY 1998 funding level is required to address the high priority needs identified by state AIDS directors to support HIV prevention programs through the cooperative agreements with state and local health departments. These activities include, but are not limited to:

- **Targeted prevention for higher risk populations.** Increased funding is needed for HIV prevention targeting the "emerging" at risk groups including women of color, youth in high risk situations, and gay men of color.

- **Enhanced HIV counseling and testing.** The availability of effective treatment is prompting a renewed interest in counseling and testing programs. State and local project areas are interested in using new testing technologies - oral testing and rapid tests - in non-clinical settings and require funding for training and implementation of these new testing modalities. Funding for more targeted counseling and testing including aggressive outreach and mobile units is also needed.

- **Implementation of new CDC program guidance.** CDC is issuing new program guidance for both partner notification and prevention case management programs. Resources are needed to enable states to implement the new guidance and expand and enhance these prevention interventions. In particular, states have expressed a great interest in expanding HIV prevention services targeting HIV infected people and their sexual/needle-sharing partners through both partner services and prevention case management.

- **Enhanced funding for evaluation** of HIV prevention models and interventions and dissemination of "what works" to jurisdictions.

HIV Surveillance

Additionally, a **$30 million** increase is needed to undertake priority HIV and AIDS surveillance needs which include, but are not limited to the following activities:

- Guidance and funding from the CDC for implementation of active HIV case reporting in all jurisdictions.

- Continued funding for population-based blinded serosurveys in hospitals, drug treatment clinics, STD and adolescent health settings.

- Increased funding for behavioral surveillance to learn more about changes in behavior related to HIV prevention.

- Increased funding for perinatal surveillance in the absence of the Survey of Child Bearing Women.

STD Prevention and Surveillance Programs

Sexually transmitted disease (STD) prevention and surveillance projects continue to be severely under-funded. Yet STD prevention programs remain one of the nation's most effective methods of controlling the exploding rates of STDs among teens. Furthermore, since there is a direct correlation between decreases

in STD and HIV rates, STD treatment and prevention programs are effective in reducing the further spread of HIV.

NASTAD requests an increase of **$60 million** for STD programs for the following priority activities:

- Increased funding for syphilis elimination in areas across the country with high incidence, particularly in the south and rural areas.
- Increased funding for screening women including urine screening for GC and chlamydia and single dose therapy.
- Support for STD surveillance.
- Support for behavioral interventions for people at risk for STDs.
- Expanded partner notification services for all STDs in addition to syphilis and gonorrhea.
- Improved outreach services with incorporation of less invasive testing modalities.
- Increased flexibility for states to determine priorities for STD funding based on the state's STD epidemiology.

Health Resources and Services Administration
Ryan White CARE Act, Title II State AIDS Services

NASTAD requests an increase of an additional **$258 million over FY 1998 funding levels** to support state Title II comprehensive AIDS services funded by the Health Resources and Services Administration. This increase includes **$85 million for Title II core** funding **and $173 million** for dedicated state AIDS drug assistance program (ADAP) funding in FY 1999. Primary care and pharmaceutical assistance continue to represent key focus areas of Title II programs. This funding will augment and expand the following activities:

State Title II Core Services

- **Primary care, including viral load testing and monitoring.** Linking individuals as quickly as possible after diagnosis to primary care services is a key goal of Ryan White CARE Act Title II programs. Viral load testing continues to be an additive cost that is borne by states - particularly in providing reimbursement for lower cost state laboratory processing of viral load tests.

- **Rural primary care services.** Many states need to bolster HIV care services in rural areas which may be outside of managed care environments. In addition, transportation to and from care services for individuals eligible for Title II services is a continuing problem area in more remote areas of larger rural states. The recently identified cluster of HIV-infected women in Jamestown, a small town in northwestern New York, seemed to be an aberration to many. However, HIV/AIDS is more common in rural America than many realize. As recently cited in the November 10th issue of U.S. News and World Report, between 1990 and 1992, the number of AIDS cases grew just 8 percent in cities, but 21 percent in rural areas of the U.S. Although the total number of cases of AIDS in rural areas is still much smaller, with 4,605 cases reported in 1996 compared to 56,556 in metropolitan areas, the resulting economic impact can be devastating. Many rural areas lack clinics or doctors that are adequately prepared to deal with HIV disease. Title II of the CARE Act serves all areas of the country and is positioned to provide access to primary care and supportive services for people living with HIV in rural and urban areas.

- **Insurance continuation and insurance purchasing programs.** Approximately 30 states have high risk insurance pools for individuals who are deemed uninsurable, and approximately 20 of those states now use their high risk insurance pools as an alternative mechanism of guaranteed issue of insurance for Health Insurance Portability Protection Act eligible individuals. This option is opening up in more states and states need to augment their use of federal funds for this purpose. In the state of Minnesota, which has a well-funded state insurance program, funds are limited to those who are disabled. Use of more flexible federal dollars is viewed as critically important to fill the gap for those people who are not HIV symptomatic.

- **Enhanced case management.** Competent, well-trained case managers are needed to help people living with HIV to navigate the increasingly complex social services and medical care systems and to assist with adherence with drug treatment regimens. The complications and barriers to care which are the result of recent legislation such as welfare reform and immigration laws, the complexity and expense of therapies, and the managed care version of Medicaid, all combine to make increased case management assistance needed for many clients of Title II service programs.

State AIDS Drug Assistance Programs

NASTAD concurs with the preliminary assessment of the ADAP Working Group's data committee in recommending a **$173 million increase** in AIDS drug assistance program dedicated funding for FY 1999.

- **Implementation of Federal Treatment Guidelines.** Client utilization and costs continue to increase dramatically in state ADAPs. Nationally, state ADAPs in 1996 reported a 77% increase in client utilization with an average of almost 40% increase in expenditures. Along with these pressures, many states are in the process of or are implementing state formularies which more closely reflect the recommendations of the new federal treatment guidelines. Implementation of these guidelines will far outpace the ability of states to fill budget shortfalls in ADAP programs with state general revenues alone. A continued and intensified partnership with the federal government is needed to provide the greatest possible access to multi-drug therapies for low-income uninsured and underinsured individuals.

As you know, the HIV prevention and care programs in which Congress, the Administration, and state governments have invested are achieving promising results. We must continue our efforts to prevent individuals from becoming HIV-infected, and to provide early and effective medical treatments and services to individuals living with the disease. We thank you for your efforts and look forward to working with the Administration in the coming year.

Sincerely,

Randall S. Pope
Chair

Julie M. Scofield
Executive Director

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

December 17, 1997

The Honorable William J. Clinton
President of the United States
1600 Pennsylvania Avenue, N.W.
Washington, DC 20500

Dear Mr. President:

On behalf of the National Alliance of State and Territorial AIDS Directors representing the nation's chief state HIV/AIDS care and prevention program administrators, we ask that you—through your appropriate agency representative—issue a determination based on the preponderance of current scientific data that access to sterile syringes and needle exchange programs are effective interventions in preventing spread of HIV and do not encourage the use of illegal drugs. This determination would allow states and local governments to utilize existing federal HIV prevention funds to initiate or augment existing needle exchange programs as a part of a jurisdiction's comprehensive HIV prevention plan.

Regarding the efficacy of these programs, the current scientific data is so compelling that all of this nation's major public health and public interest organizations have stated their support for access to sterile injection equipment for injection drug users and have called for the removal of the prohibition on the use of existing federal funds for these programs.

These organizations include the:

- American Academy of Pediatrics
- American Medical Association
- American Nurses Association
- American Public Health Association
- Association of Schools of Public Health
- Association of State and Territorial Health Officials
- National Association of County and City Health Officials
- National Black Caucus of State Legislators
- United States Conference of Mayors

Because this intervention saves lives, some states have not waited for a public health determination from the Administration or funding from the Congress. However, many state legislatures need to hear a clear message from the Administration concerning the efficacy of this intervention before beginning legislative deliberations on needle exchange programs or sterile syringe availability as a part of their comprehensive efforts on substance abuse and HIV prevention

Not withstanding current data, the question remains, does the Administration have the will to make a favorable determination regarding the efficacy of sterile syringe availability and needle exchange programs.

Additionally, since the majority of injection drug use-related HIV infections occur in African American and Hispanic populations, we feel it is imperative—in light of your initiatives on race relations—that your administration quickly issue a clear statement regarding the effectiveness of sterile syringe availability, needle exchange programs and the need for greater drug treatment resources. This action will help reduce the disproportionate HIV-related mortality, morbidity and emotional suffering in communities of color.

We appreciate your attention to this matter and look forward to hearing from you.

Sincerely,

Randall S. Pope
Chair

Beth Weinstein
Chair
Committee on HIV/AIDS and
Substance Users

cc: Sandra Thruman, Director, Office of National AIDS Policy
General Barry R. McCaffrey, Director, Office of National Drug Control Policy
Donna E. Shalala, Secretary, U.S. Department of Health and Human Services

NATIONAL ORGANIZATIONS RESPONDING TO AIDS

HAND DELIVERED

June 26, 1997

The Honorable William Jefferson Clinton
President of the United States
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the NORA (National Organizations Responding to AIDS) Coalition, we are writing to request a meeting with all the principals within the Administration who are working on federal policy regarding needle exchange programs. As you know, NORA is a coalition comprised of over 175 health, labor, religious, professional, and advocacy groups representing a broad consensus on issues concerning HIV/AIDS policy, legislation, and funding.

We are extremely concerned about efforts by some members of the House Appropriations Subcommittee on Labor, Health and Human Services and Education to remove Secretary Shalala's authority to lift the restrictions on using federal funds for needle exchange programs.

We appreciate your remarks at the U.S. Conference of Mayors (USCM) meeting in San Francisco regarding HIV prevention and fully support your call for identifying sound public health strategies that enable local communities to address the twin epidemics of HIV and substance abuse. However, if the authority of the Department of Health and Human Services to determine public health policy is removed, many communities will be denied the opportunity to implement an important, proven, and life-saving HIV prevention intervention.

As you know, the USCM passed a resolution on Tuesday calling for Secretary Shalala to lift the restrictions on federal funding for needle exchange programs. In passing the resolution, the USCM is calling for a partnership with the federal government to implement these life saving programs. We agree with the mayors, as well as the scientific and public health communities that the Secretary should allow localities to use federal funds for needle exchange programs, if they so choose.

NORA
A coalition convened by
AIDS Action Council
1875 Connecticut Ave., NW
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A meeting with the principals is urgently needed to discuss the Administration's plan for preserving the Secretary's authority, the timing for lifting the restrictions on federal funding, and the strategy for ensuring that science and public health drive the discussion of this issue. In February, when Department officials met with community leaders on the day the Secretary released her report on needle exchange to Senator Specter, the Administration pledged to hold such a meeting. Given this pledge and the threat that now exists to the Secretary's authority, we feel that a meeting is necessary immediately.

Thank you for your commitment to local flexibility in implementing life-saving public health interventions. We appreciate your efforts and look forward to discussing needle exchange policy with Administration principals.

Sincerely,

Christine Lubinski, AIDS Action Council
David Harvey, AIDS Policy Center for Children, Youth and Families
Jane Silver, American Foundation for AIDS Research
Seth Kilbourn, Human Rights Campaign
Jenny Collier, Legal Action Center
Amy Slemmer, Mother's Voices
B.J. Harris, National Alliance of State and Territorial AIDS Directors
Mike Shriver, National Association of People with AIDS
Miguelina Maldonado, National Minority AIDS Council
Charles King, Housing Works

cc: Vice President Albert Gore
Secretary Donna Shalala
Erskine Bowles
Sylvia Mathews
John Podesta
Sandy Thurman
Donald Gips
Toby Donnenfeld
Bruce Reed
Franklin Raines
Nancy Ann Min DeParle
Kevin Thurm
William Corr
Marsha Martin
Eric Goosby

June 27, 1997

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

NAPWA

NATIONAL ASSOCIATION OF PEOPLE WITH AIDS

Dear Mr. President:

~~On behalf of the National Association of People with AIDS (NAPWA), I am writing in support~~ of the request submitted to you by the National Organizations Responding to AIDS Coalition (NORA) for a meeting with the appropriate officials of your Administration to develop a comprehensive plan to secure the lifting of the federal ban on needle exchange.

NAPWA was very encouraged by your comments at the U.S. Conference of Mayors (USCM) meeting in San Francisco regarding HIV disease. We fully support your call for "identifying sound public health strategies that enable local communities to address the twin epidemics of HIV and substance abuse."

This week, both the US Conference of Mayors and the American Medical Association have officially gone on record calling for the repeal of the federal ban on needle exchange. Given these events, the overwhelming amount of scientific evidence and the proven success of these programs at the local level, we now call on you and your administration to redouble your efforts in this arena and join with not only the HIV/AIDS communities, but with the scientific and public health communities to have this unsound public health policy permanently removed.

In February, the Administration agreed to work with the HIV/AIDS community in developing a comprehensive and sound strategy that will result in permanently lifting the federal prohibition on needle exchange. We look forward to this partnership.

Far too may individuals and communities at-risk for HIV disease are relying upon us to make sure that this unsound and unscientific ban be lifted. Your leadership will save lives.

Respectfully yours,

A. Cornelius Baker

A. Cornelius Baker
Executive Director

1413 K Street, N.W.,
Washington D.C. 20005
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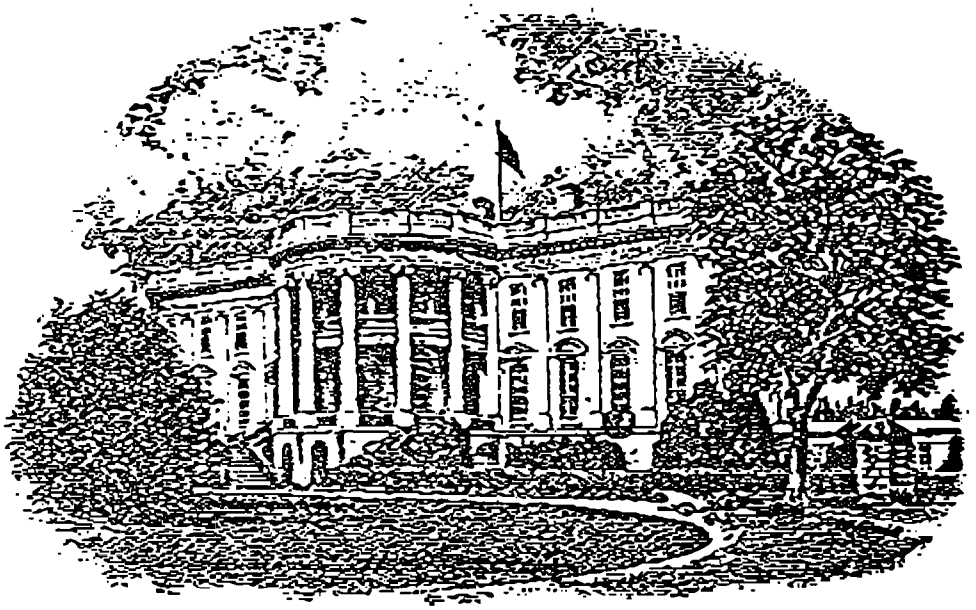
The White House
Office of Presidential Letters and Messages



facsimile from Sarah Knight
phone: 202-456-5514
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To: Todd Summers

No. of pages (including cover): 4 Date: 12/18/97

Phone: _____ Fax: 632-1096

Comments: Thanks - S.