Approved: Feb. 16, 1998
Date

MINUTES OF THE SENATE COMMITTEE ON WAYS AND MEANS.

The meeting was called to order by Chairperson Dave Kerr at 11:00 a.m. on February 9, 1998 in Room 123-S of the Capitol.

All members were present except:

Committee staff present: Alan Conroy, Legislative Research Department
Russell Mills, Legislative Research Department
April Holman, Legislative Research Department
Norman Furse, Revisor of Statutes
Michael Corrigan, Revisor of Statutes
Judy Bromich, Administrative Assistant
Ann Deitcher, Committee Secretary

Conferees appearing before the committee: Dale Brunton, Deputy Director, Division of Accounts & Reports
Gary Mitchell, Secretary of Dept. of Health & Environment
Betsy Topper of NE Kansas Aids Partnership
Cindy Wiklund of Douglas County Aids Project

Others attending: See attached list

SB 465 — **An act concerning cancelled state warrants**

Michael Corrigan, Revisor of Statues, spoke to the committee, explaining the workings of the bill. Dale Brunton, Deputy Director, Divison of Accounts and Reports spoke before the committee strictly to provide any information they might need. (Attachment 1).

Mr. Brunton told the committee that SB 465 proposed a fee structure based on the greater of 5% or fifteen dollars. This is the same as SB 100 from 1997, which passed the Senate and remains in the House Judiciary Committee awaiting recommendation.

Asked if he believed that the purpose of this was to discourage people from holding their warrants too long, or is it to recover the cost of issuing, Mr. Brunton said he wasn't sure. He also said that during FY 97, 76% of the warrants were under $400.

Senator Kerr said the way he would represent the committee's concern was that they were not sure last year's bill was correct so we would suggest they not leave the upper end uncapped. In the bill, the words "greater of" means uncapped so you have the possibility of a very large number. The bill will be held.

SB 545 — **An act making and concerning appropriations for FY ending 6/30/98 for Department of Health & Environment.**

Gary Mitchell, Secretary of Kansas Dept. of Health and Environment spoke regarding a plan for Child Care Licensing and Registration. (Attachment 2)

The Secretary told the committee that in the past, the Legislature has put limits on the amount that Health and Environment can spend even if it is Federal money. There's been concern about how they've been spending money, so they now have a cap on the amount they can spend. Because it's Federal money being transferred from SRS to Health and Environment, the cap has to be raised for FY 98 to spend the million dollars available in Federal money.

Senator Salisbury asked if this would allow the agency to have approximately $1.8 million to appropriate to local health departments in FY 98.

Secretary Mitchell said that since this money came at them so quickly, the Governor put it all in aid to local governments. The Secretary felt it would be wiser if it was split 80-20. Eighty percent would go to locals with 20 percent going to KDHE. He thought this ratio would ultimately have to be changed.

The appropriations asked for in SB 545 amounts to $235,000. The Secretary said they have access to $232,000 from the federal government.

Senator Kerr asked if they actually only needed the $84,000 shown on the ADAP Fact Sheet as the "remaining deficit". (Attachment 3).

The Secretary said that would cover this year but he would start April 1 in the hole by $232,000. This is the date the Ryan White aids money is available but the federal appropriation isn't done until October. He pointed out that what the Ryan White program addresses is those people who don't qualify for Medicaid funding and don't have enough money to continue their medication which costs $1,000 a month.

Next to testify before the committee was Betsy Topper, Executive Director of NE Kansas Aids Partnership. (Attachment 4).

Cynthia Wiklund, a Student Intern with the Douglas County AIDS Project read from a copy of her testimony in support of SB 545. (Attachment 5).

Senator Kerr said that the bill turned out to be more complicated that originally anticipated so there would not be a vote at this time.

The meeting was adjourned at 12:15 p.m.

The next meeting is scheduled for Tuesday, February 10, 1998.

SENATE WAYS AND MEANS COMMITTEE GUEST LIST

DATE: 2/9/98

NAME	REPRESENTING
Cynthia Wiklund	Douglas County AIDS Project
Betsy Topper	AIDS Council of Greater Kansas City
Nusheen Ameenuddin	KS Public Health Association
Sally Finney	"
Carol A Sprague	State Treasurer
Jerry Serk	Dept of Admin
Dale Brunton	✓ — ✓
Dennis Gros, Intern	Sen. Huelskamp
Julie Eberwein Social work student	—

TESTIMONY BEFORE THE
SENATE WAYS AND MEANS COMMITTEE
February 9, 1998, 11:00 a.m., Room 123-S

Presented by Dale Brunton
Deputy Director of Accounts and Reports

Mr. Chairman, Members of the Committee:

I am providing testimony today on behalf of the Department of Administration on SB 465. The Department has no position on the bill and today's testimony is strictly for information.

The bill appears to be an effort to provide a fee structure which more fairly assesses to claimants the administrative and processing costs incurred to re-issue warrants not cashed within one year from the issuance date. These warrants are automatically canceled one year from issuance date. However, if the payee subsequently discovers that the warrant was not cashed, a claim may be filed within four years from the cancellation date, to allow the warrant to be re-issued. The proposed statutory amendment reduces the fee for processing such claims from the *greater* of ten percent or $15, to the *lesser* of five percent or $25, based on the original warrant amount.

The Division of Accounts and Reports administers this process but receives no portion of either the re-issuance fee nor funds restored from warrants canceled which are never claimed. The cost to re-issue this type of warrant is estimated at $20. Thus, the proposed fee structure would not recover costs for any warrants less than $400, based on 5% of the original warrant amount to a maximum fee of $25. The fee structure would accomplish a more equitable fee assessment to claimants for warrants of any amount, with a lesser fee to those requesting smaller claims.

The Department of Administration agrees that a revision to the fee structure is appropriate and proposed SB 100 during the 1997 Legislative Session. The bill proposes a fee structure based on the *greater* of five percent or $15. The bill passed the Senate and remains in the House Judiciary Committee awaiting recommendation.

Thank you for the opportunity to provide testimony to the Committee. I would be happy to address any questions the Committee may have.

S W+M
3/9/98
Attachment 1

Child Care Licensing and Registration
A Plan

Presented to the Senate Ways and Means Committee
Gary Mitchell, Secretary
Kansas Department of Health and Environment
February 9, 1998

S W+M
2/9/98
Attachment 2-1

Child Care Licensing and Registration

Kansas Department of Health and Environment

Program Goal

To correct the deficiencies identified in the Post Audit report on Child Care Licensing.

Objectives

1. Increase the resources of the child care licensing bureau within KDHE to ensure the provision of quality child care in the state.

2. Increase the resources of local government child care licensing programs to ensure the provision of quality child care in the state.

Strategy

Utilize available federal monies to KDHE and local governments to meet the human resource and technology needs necessary to improve service delivery.

Action Plan

1. By April 1998, appropriate $1 million Child Care Development Funds to KDHE to be used to increase the human resource and technology needs of the child care licensing bureau and local government aid for child care.

2. By May, 1998 increase the state's funding of child care licensing and registration activities to 75%.

3. By May 1998, hire six trainer/program specialists in KDHE's district offices; one legal assistant to assist with the performance of KBI background checks and with the legal enforcement action workload; and one performance auditor to establish performance standards for local government compliance for future fiscal years.

4. By June 30, 1998, invest about 70 percent of the appropriated monies in infrastructure needs including hardware and software upgrades in local government and KDHE child care licensing programs.

5. By October, 1998, hire 2.5 end-user support positions to support the child care inspectors and maintain systems and a 0.5 performance auditor to measure performance standards for local government compliance with the fiscal year 1999 contract requirements.

S W+M
2/9/98
Attachment 2-2

Background

Through a Federal grant to SRS, the Federal government has made available $1 million in FY 98 and $1.5 million in FY 99.

The Local Health Departments in a letter to the Kansas Department of Health and Environment (7-28-97) asked for $474,300 increase for FY 99 in child care licensing money from the state. This would increase the state "share" of child care licensing and registration activities to 70 percent; i.e., the State would fund 70 percent with local governments responsible for 30 percent. On a 12 month basis this is a $39, 525 per month increase.

The Kansas Department of Health and Environment contracts with 98 local health departments or private contractors to license and inspect child care facilities. With the current infusion of federal money the state could pick up nearly a 100 percent of the cost of licensing. However, in the registration and licensing of day care centers it is essential to have that local commitment and involvement. Recognizing the counties need to have more and better trained inspectors KDHE is proposing the following:

> Raise the level of the state's commitment to 75 percent, as long as the county maintains its effort. This year will become the base year. If the county does not reduce its funding for child care then the state will increase its commitment.

Fiscal Year 1998

If the legislature completes action and KDHE has access to the money by the April 1 (3 months in FY 98), based on the FY 99 increase, the amount equals $46,836 per month X 3 months = $140,508 for the locals. This will be distributed based on the current formula.

Fiscal Year 1999

$562, 035 increase to locals; note this is $87,734 above what the local health departments requested but this would raise the state "share" to 75 percent. Counties will be required to maintain their effort; i.e., the increased State aid cannot be offset by reductions in county resources devoted to child care activities.

The State plans on adopting a new "Effort based" formula that will be based on :

- 10 percent - population (children <16 years)
- 30 percent - number of child care facilities per county
- 60 percent - number of child care slots per county

S W+M
2/9/98
Attachment 2-3

Human Resources

Fiscal Year 1998

New inspectors in the counties; 6.0 trainers/program consultants (one in each KDHE district office); 1.0 legal assistant to help with the KBI background checks, increased legal activity and draft enforcement orders; and 1.0 performance auditor position.

Fiscal Year 1999

Add 2.5 end-user support positions in the state to support the child care inspectors and maintain systems and 0.5 performance auditor position.

Budget Plan

To accomplish the child care licensing initiative, the department proposes the Child Care Licensing budget outlined below:

	FY 1998	FY 1999
SRS Transfer	1,000,000	1,500,000
Budget		
Salaries and Wages (KDHE)	93,136	445,629
Other Operating Expenses		
KDHE	207,098	226,871
Local Governments	444,000	62,500
Subtotal Operating Expenses	**651,098**	**289,371**
Aid to Local	140,508	562,035
Performance Bonus	50,000	75,000
Subtotal Aid to Local	**190,508**	**637,035**
Total Expenses	**934,742**	**1,372,035**
Balance - If needed, will be spent in 1998 or carried forward to fiscal years 1999 or 2000.	65,258	127,965
FTE -If possible, KDHE intends to use existing unclassified temporary positions to fulfill proposed staffing needs.	8.0	11.0

5 cw+m
2/9/98
Attachment 2-4

The Legislative Post Audit Recommendations:

1. To ensure that it knows about problems affecting the safety and well-being of children in child care homes and facilities, the Department of Health and Environment should do the following:

a. ensure that county health departments and private contractors conduct new and renewal inspections and complain investigations in a timely manner.

HOW THE BUDGET PLAN ADDRESSES (a)

- *Adds more than $500,000 for additional inspectors/increased local efforts.*
- *Adds more than $500,000 for hardware/computerization of child care licensing/registration to provide local health departments with a computerized tickler system.*
- *Invests in Internet linkage between KDHE and the 98 contractors so complaints and follow-ups can be processed quickly.*

b. ensure that investigations are thorough

HOW THE BUDGET PLAN ADDRESSES (b)

- *Adds 1 KDHE trainer/program consultant in each district office to provide on-site training to local health departments to assist in performing thorough investigations and inspections.*
- *Establishes a Performance Auditor to review counties' (as contractees of the state) performance of the child care licensing function.*

c. take steps to reduce the degree to which providers can anticipate the timing of regular inspections.

HOW THE BUDGET PLAN ADDRESSES ©

- *While this is not a resource item, in FY 99, KDHE will re-design the aid to local formula based on effort and also establish performance criteria and goals; one of those criteria will be unannounced inspections.*
- *With additional resources the counties should have the resources needed to inspect in a timely manner, which will assist in preventing child care providers "anticipation" of the inspection time.*

d. take steps to reduce the backlog causing delays in getting background checks for staff in the large child care facilities.

HOW THE BUDGET PLAN ADDRESSES (d)

- *Establishes a legal assistant to help with processing/evaluating background checks and handle the projected increase in enforcement appeals as result of this effort.*

- *Investment in computer hardware allows the clerical staff at KDHE's Child Care Program Internet access and will provide counties with an electronic means to immediately transfer files to KDHE.*

- *Prior to this budget plan (February '98) KDHE moved one clerical position to the Child Care Program to assist with the work load. NOTE: By December '97 KDHE had eliminated the background check backlog by utilizing temporary staff.*

e. reassess its regulations and the adequacy of State law relating to such things as child-adult ratios in family day care homes and training hours for child care workers, which currently are less stringent than national standards or other states, to identify areas where more stringent requirements may be needed.

HOW THE BUDGET PLAN ADDRESSES (e)

- *Establishing training/program consultants in the district offices to work with local child care inspectors allows KDHE staff in Topeka to address such issues as updating and changing regulations to monitor shortfalls in regulations and focus on timely and appropriate enforcement actions.*

2. To ensure that child care providers correct violations of child care regulations, and are dealt with appropriately if they don't make the needed corrections, the Department of Health and Environment should do the following:

a. take enforcement actions that are consistent with the severity and history of violations found.

b. initiate enforcement actions in a more timely manner.

c. follow up on enforcement actions taken to make sure providers correct problems found.

S Ways
2/9/98
Attachment 2-6

HOW THE BUDGET PLAN ADDRESSES 2. a, b & c

- *Provides additional resources to the local county health department which perform inspections and requires counties to maintain their current efforts; this should result in more inspectors and more timely inspections.*

- *Establishes training/program consultants each KDHE district offices to enhance the professionalism of the counties' effort by providing training KDHE human resources for assistance and guidance.*

- *Designing an integrated information system allows counties to transfer files to Topeka for prompt enforcement actions improves KDHE's timeliness of enforcement actions and better protects children who may be endangered by unsafe day care facilities.*

- *Computerizing the entire local health care network (ultimately through the KIPHIS system) enhances timeliness of enforcement actions and improves day care in the state. By the state committing to end-user support positions in the field we address concerns local health departments have had with KDHE in the past and ensures the integrated information system will work.*

- *Because the state will supply direct staff resources and provide a higher level of funding for child care licensing and enforcement (75 percent), the state can demand and expect a higher level of service from its child care enforcement contractors. In addition, the funding of a performance auditor will also provide mechanism for continuous monitoring of inspections and enforcement.*

3. To better ensure the safety and well-being of children in the State's child care facilities, the Legislative Post Audit Committee should consider introducing legislation to do the following:

a. require regular inspections of all registered child care homes.

b. amend KA 65-526 (1966 Sup.) Regarding civil fines for child care providers who violate regulations to make it clear whether the fine amount applies on a per provider, per violation, and per day basis.

This is a legislative/policy issue.

5 W+M
2/9/98
Attachment 2-7

4. The Department of Health and Environment should work with the Governor, the Legislature, and other parties involved in child care (such as local health departments, child care providers, and the Department of Social and Rehabilitation Services) to identify any additional funding that may be needed to provide high quality child care and to maintain an effective child care regulatory program. If additional funding is needed, the sources available would include increased licensing fees, or increased State or federal funding.

SRS has made available $1 million in FY 98 and $1.5 million in FY 99 from Federal child care grants (Child Care Development Funds).

5 W+M
2/9/98
Attachment 2-8

AIDS Drug Assistance Program (ADAP) Fact Sheet

1997 ADAP Budget	847,620
1997 ADAP Expenditures (April 1997 - December 1997)	848,848
	(1,228)
Estimated Expenditures (January, 1998 - March 31, 1998)	315,000
Estimated Deficit	(316,228)
25 Percent Advance Request from 1998 ADAP Budget	232,219
Remaining Deficit	(84,009)

S w+ 7n
2/9/98
Attachment 3-1

AIDS Drug Assistance Program
Comparison of Clients and Expenses
April, 1996 through December, 1997

Period	Clients	Expenses
Dec 97	148	113,215
Nov 97	137	92,511
Oct 97	136	105,830
Sep 97	128	100,259
Aug 97	135	101,302
Jul 97	132	101,820
Jun 97	113	76,223
May 97	118	81,893
Apr 97	110	75,796
Mar 97	89	65,584
Feb 97	91	65,887
Jan 97	90	60,102
Dec 96	68	44,499
Nov 96	61	35,753
Oct 96	67	38,414
Sep 96	63	38,218
Aug 96	83	42,627
Jul 96	86	40,525
Jun 96	49	29,747
May 96	57	30,662
Apr 96	29	15,351

5 W+M
2/9/98
Attachment 3-2

THE AIDS COUNCIL
OF GREATER KANSAS CITY
A CATALYST FOR A COMPREHENSIVE RESPONSE TO HIV DISEASE

BETSY TOPPER
Executive Director

(816) 751-5166
FAX 751-4623

Testimony before Senate Ways and Means Committee
February 9, 1998

In Support of Senate Bill 545

In January 1998 Kansas health officials ran out of federal AIDS Drug Assistance Program (ADAP) dollars that pay for AIDS drugs for Kansans with HIV or AIDS.

ADAP is a state-administered program that provides access to the drugs used to treat HIV and prevent the onset of related opportunistic infections for low-income people living with HIV and AIDS who do not have adequate private or public health insurance. The program forms one link in the continuum of publicly-funded HIV care and services that includes the Ryan White CARE Act, Medicaid, Medicare, and local indigent health care programs. The 52 ADAPs receive federal dollars through the Ryan White CARE Act. In 1997, 30 states contributed supplementary funding. In 1997 total federal and state ADAP spending was $385 million. States set the income eligibility, determine which drugs will be covered and how they will be purchased and distributed. *(Source: Henry J. Kaiser Family Foundation)*

In 1997, Kansas provided AIDS drugs to 225 people living with HIV or AIDS statewide. Approximately 1/4 were on protease inhibitors, the new powerful class of drugs that have reduced the presence of the AIDS virus to undetectable levels in 70% of people who take them in combination with other drugs. The drug combinations must be taken according to strict dosing regimens; missing even one dose may make the person resistant to that combination and may produce resistance to drugs the person has not taken yet. *(Source: Kansas Department of Health and Environment)*

Of the 52 states and territories that receive ADAP funding, 30 contribute state general revenue dollars. Among states that border Kansas, Missouri and Colorado both contribute state general revenue dollars. Kentucky, Maine, Utah and Vermont -- with total AIDS budgets similar to Kansas' -- also contribute state general revenue dollars to ADAP. *(Source: National Alliance of State and Territorial AIDS Directors)*

Drug therapy is cost effective. Studies have shown that the drug combinations reduce the total cost of care for people with HIV and AIDS by reducing the need for home health services, care in long term care facilities and the number and length of inpatient hospital stays. Many people who have taken the drug combinations for some time feel well enough to return to work. *(Source: Glaxo Wellcome)*

S W+M
2/9/98

2801 WYANDOTTE, SUITE 167, KANSAS CITY, MISSOURI 64108-3345

Attachment 4-1

CATALYST

JANUARY · FEBRUARY
1 9 9 8

THE AIDS COUNCIL OF GREATER KANSAS CITY ■ 2801 WYANDOTTE ■ SUITE 167 ■ Kansas City, Missouri ■ 64108-3345 ■ 816/751-5166 ■ FAX 751-4623

Crisis in CARE Act Funding

For nearly six years, the Ryan White CARE Act program accomplished what Congress intended it to do: provide a much-needed safety net for HIV-infected individuals who had little or no public or private insurance. As a payer of last resort, the program picked up the tab for physician visits, medications and other vital services that people living with AIDS typically require.

The CARE Act was a relatively modest program by federal standards. That all changed in 1996, when protease inhibitors — a family of antiretroviral medications that substantially improve the quality of life of those struggling with HIV/AIDS — came into widespread use.

This expensive new medication, which costs about $10,000-$16,000 annually per client, is stretching CARE Act resources to the limit. Between fiscal 1995 and fiscal 1998, the CARE Act's budget nearly doubled, from $633 million to nearly $1.2 billion.

It is not enough. States and cities administering CARE Act funds have been forced to cut back on other program services in order to meet the growing demand for medications. And still there are waiting lists for medications as well as for a host of other services.

This issue of *Catalyst* will look at various aspects of the CARE Act funding crisis.

Demand for Protease Inhibitors Overwhelms ADAP

In fiscal 1997, $167 million in federal funds were earmarked for the AIDS Drug Assistance Program (ADAP) to provide protease inhibitors and other medications for HIV-infected clients. That's more than triple the amount allocated in fiscal 1996.

Nonetheless, ADAP funding is in short supply. To date,

- at least 14 states are slated to run out of ADAP funds before the close of the fiscal year, which technically ends in March 1998.
- another 15 states have already capped ADAP enrollments, meaning they won't allow anyone else to be served by the program.
- most other states have instituted at least one cost-containment measure — such as reducing income guidelines or limiting the number of protease inhibitors on their drug formularies — to keep their ADAPs solvent.
- 30 state and territorial ADAPs have supplied more than $109 million in general revenue funds to supplement ADAP resources.

Despite these massive efforts, there are hundreds, perhaps thousands of low-income people who qualify for CARE Act services (no nationwide tracking of ADAP waiting lists exists) who can't get the protease inhibitors they need. That's the assessment of a recent study on the status of ADAP by the National Alliance of State and Territorial AIDS Directors (NASTAD). The report was prepared by NASTAD in conjunction with the Henry J. Kaiser Family Foundation and the AIDS Treatment Data Network.

Demand for Protease Inhibitors Is Escalating

A primary reason for the ADAP shortfall is the efficacy of protease inhibitors (PIs). They work for a lot of people. The good news is that those using PIs are feeling better; many are able to maintain their jobs or even return to work. The bad news is that the pool of people wanting PIs — which cost about $14,000 a year per user — is growing exponentially.

There are several reasons for this phenomenon. First, the nation's AIDS caseload is expanding rapidly (20 percent between the end of 1995 and June 1997)

Continued on page 2

S WM 2/9/98
Attachment 4-2

...nd for Protease Inhibitors — Continued from page 1

due to declining mortality rates. Second, since the National Institutes of Health (NIH) recommended in mid-1997 that PI combination therapy be introduced early in the disease cycle, before HIV progresses to AIDS, more and more HIV-infected individuals want access to PIs. How many? Nobody knows for sure. About 14,000 people or 35 percent of ADAP's average monthly client load of 40,000 were receiving at least some financial support for PIs in late summer, according to the Health Resources Service Administration. HRSA oversees ADAP and other CARE Act programs.

Other Existing and Potential Medication Resources

Federal officials respond to the "not enough money for HIV/AIDS medications" alarm with a frustrated sigh. They know. But there are no easy answers. The federal government has done more than its fair share, they insist, increasing ADAP by some $233 million over the last two years.

State Support

"Everybody has to step up to the plate and do his share," explains Warren Buckingham, deputy director of the division of service systems for HRSA, which oversees ADAP and other CARE Act programs. He adds that more states need to initiate or expand their support of ADAP and other programs serving people with HIV/AIDS. Last year, for example, California and New York supplemented ADAP by $27 million and $10 million respectively. Although 30 states and U.S. territories provided an estimated $109 million in ADAP supplements in fiscal 1997 (Missouri contributed $600,000; Kansas, nothing), Buckingham believes many states could do more.

Compassionate Use Programs

Several thousand destitute HIV-positive individuals are believed to be receiving protease inhibitors (PIs) and other AIDS-related drugs through compassionate use programs operated by drug manufacturers. Drug companies refuse to publicize the number of people being served by compassionate use initiatives or to release the financial and other eligibility requirements for program participation. AIDS activists say that people on ADAP waiting lists are good candidates for compassionate use programs because drug companies can reasonably anticipate that their support will be short term.

PHS Drug Pricing Program

A drug discount program operated by the Public Health Service (PHS) is not available to most state ADAPs because they do not purchase HIV/AIDS medications directly from drug manufacturers. HRSA recently persuaded the PHS to adopt a policy requiring pharmaceutical companies involved in its discount program to provide rebates to ADAPs. The rebates, which will be available in early 1998, are expected to save state ADAPs more than 10 percent on PIs and related medications.

Medicaid

Vice President Gore, at the urging of AIDS advocates, recently asked the federal government to consider expanding Medicaid to cover HIV+ people whose disease has not yet progressed to AIDS. (At present, only those with a CDC-defined AIDS diagnosis — and very low incomes — qualify for Medicaid.) The preliminary response was negative, based on the assumption that the initiative would not be cost-effective within five years, a prerequisite for any change in Medicaid eligibility. AIDS Action is currently working with several states to secure waivers for Medicaid demonstration projects designed to prove that serving people with HIV can be cost-effective. (See *Rich ADAP Formularies Are a Health Care Bargain* on page 4.)

"In the past few months, ADAP caseloads have been expanding by about 1,000 people per month on a nationwide basis. This year, we believe that at least 35,000 ADAP clients will request support for PI therapy."

AIDS advocacy groups expect this number to increase substantially in 1998. "In the past few months, ADAP caseloads have been expanding by about 1,000 people per month on a nationwide basis," says Richard Jefferys, director of Project Access for the AIDS Treatment Data Network in New York. "This year, we believe that at least 35,000 ADAP clients will request support for PI therapy."

Increased ADAP Funding Won't Eliminate the Shortfall

Congress has responded to the HIV/AIDS medication crisis by boosting the fiscal 1998 ADAP budget more than $118 million or 71 percent to nearly $286 million. Will it be enough to provide PIs to all the low-income, HIV-infected people who need them? "Not likely," says Joseph Kelly, deputy director of the National Alliance of State and Territorial AIDS Directors (NASTAD). "The CDC recently estimated that there are 225,000 low-income, HIV-infected people without health insurance who do not qualify for Medicaid or other public assistance programs."

Kelly adds that ADAP, which served a total of 80,000 people in 1997, is reaching only about a third of this population. "The mission of NASTAD is to make sure that there are plenty of treatment options available to people with HIV who lack resources. We've got a long way to go to meet the medication needs of this group."

5 W+M
2/9/98
Attachment 4-3

CARE Act Support Services Take Back Seat to Medications

After three months on a waiting list, John B. was notified that the state ADAP program in the EMA city where he lives would begin paying for his protease inhibitors (PIs). The HIV-infected unemployed factory worker was overjoyed. His enthusiasm waned, however, when informed that the food, housing and other support services that would assist him when his unemployment benefits ran out were no longer available. His EMA community had allocated much of its CARE Act Title I funding for medications, leaving little to address the other needs of people living with HIV/AIDS.

Variations of this scenario are occurring nationwide as state and local communities confronted with dwindling ADAP resources scramble to meet the growing demand for PIs and other AIDS medications. In 1997, for example, states spent an estimated $59.9 million or nearly one-fourth of their Title II funding on AIDS medications, in addition to the $167 million provided through ADAP.

This strategy inadvertently created a big hole in the CARE Act safety net, which was designed to provide a broad spectrum of health and human services for HIV-infected people who are uninsured or underinsured. States and EMAs are eliminating some services altogether and, via revised income and medical criteria, are restricting access to others. (For more information, see *How Two States and One EMA Are Coping*.)

AIDS activists bristle at the notion that one type of CARE Act service — financial assistance for medications — should take precedence over all others. They say those receiving PI therapy need complex medical supervision including, as recommended by federal HIV/AIDS treatment guidelines, viral load tests every three months. At $100-$250 a test, viral load testing is consuming a growing share of Title I and Title II budgets.

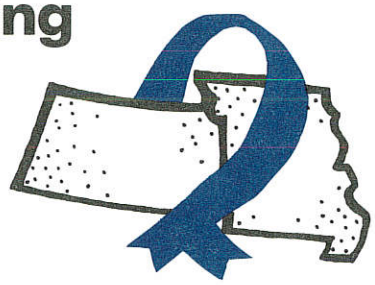
Other services funded under Title I of the CARE Act, such as housing, transportation and food, are being reduced or eliminated in some communities — much to the consternation of those who need them. Many CARE Act clients struggle with multiple problems, such as homelessness, substance abuse and single parenthood, in addition to HIV. They cannot maintain the difficult PI regimen — taking numerous pills at precisely scheduled times throughout the day — without the support services necessary to bring more stability to their lives. In addition, because PI therapy does not work for everybody, traditional CARE Act services for those dealing with late-stage AIDS, such as home health care, are still in demand.

"We need all CARE Act services," insists Kathy Cerra, at-large member of the Cities Advocating Emergency AIDS Relief (CAEAR) Coalition. Cerra previously served as co-chair of the Title I EMA planning council in metropolitan Kansas City. "I know some members of Congress have grown tired of the AIDS crisis. They think if they give us money for medications, then HIV will become a manageable disease, and we won't need much else."

Cerra's concerns are not without merit. "Although Congress expanded ADAP 71 percent for fiscal 1998, all other CARE Act programs got smaller increases than in the previous three years," says Javier Salazar, legislative representative for AIDS Action, which advocates for HIV/AIDS policy changes in the nation's capital. "With ADAP consuming so many resources, it's getting harder to justify to Congress additional increases in other AIDS-related programming."

How Two States and One EMA Are Coping

It looked like it was going to be a good New Year for a lot of HIV-infected residents in Kansas and Missouri. By Christmas, virtually all eligible clients who had requested financial support for protease inhibitors (PIs) under the AIDS Drug Assistance Program (ADAP) in either state were receiving the medications they needed.



Unfortunately, there are a few flaws in this idyllic holiday scene. First, many low-income people living with HIV are not *eligible* for PIs or other medications under the restrictive income criteria for ADAP in Missouri. Second, Kansas expects to run out of ADAP funds in January, two months before the end of the fiscal year. In addition, because so much CARE Act funding for support services has been allocated for medications, other essential health and human services are in short supply.

In Missouri, ADAP assistance is available only to HIV+ individuals whose incomes do not exceed 185 percent of the federal poverty level. That means that a single person earning more than $14,600 a year — or $19,630 for a mother with a child — would not qualify for ADAP and would have to pay the full cost (about $14,000 annually on average) of PI therapy. Missouri's conservative income criteria is simply a matter of economics, according to Mary Menges, bureau chief of HIV/AIDS care and prevention services for the Missouri Department of Health. Given the finite nature of its ADAP budget, the state wants to ensure that there will be enough money to continue PI therapy without interruption due to a funding shortfall — a situation that could cause an infected person to develop permanent resistance to all antiretroviral medications.

Kansas, by contrast, offers ADAP assistance to HIV-infected people whose incomes do not exceed 300 percent of the federal poverty guideline (up to $23,670 annually for a single person and $31,830 for a two-person family). State officials have projected that their ADAP fund will be depleted sometime in January. Kansas has already applied for an advance on its fiscal 1998 federal ADAP award in order to continue providing PIs

Continued on page 4

S WAYS 2/9/98

Attachment 4-4

Rich ADAP Formularies Are a Health Care Bargain for States

The Department of Health and Human Services recently rejected a proposal by AIDS advocates to expand Medicaid to HIV+ people whose disease has not yet progressed to AIDS. The reason: it's not cost-effective to supply expensive antiretroviral medications to thousands of low-income individuals living with HIV.

HHS's assessment is true, say AIDS researchers, *only* if states limit their cost analyses to a single program, such as Medicaid or ADAP. The equation changes, however, when states calculate the total cost to taxpayers of providing health care to those with HIV/AIDS. It turns out that offering infected people a full spectrum of AIDS-related medications — including protease inhibitors and drugs for opportunistic infections — is a health care bargain, saving large states like New York millions of dollars a year.

That's what the New York Health Department determined when it figured the state's HIV/AIDS-related health care costs in conjunction with a rich ADAP formulary. New York's budget projection model, which was developed by Glaxo Wellcome, uses CD4 counts of ADAP patients to predict disease progression and treatment needs under three different scenarios: 1) no drugs whatsoever are provided by ADAP; 2) no protease inhibitors are provided under the state's ADAP formulary; and 3) the ADAP formulary is comprehensive in that it includes virtually all the current medications approved for the treatment of HIV/AIDS and related conditions.

Under the model, New York's comprehensive formulary was by far the most cost effective. (New York first tested the model after-the-fact on its 1995 formulary to assure its efficacy.) Although annual ADAP costs were highest with a rich drug formulary ($41.9 million), total spending by the state for ADAP in addition to primary care, hospitalizations, and other health care was significantly less ($71.3 million) than under other scenarios.

The model's projected clinical costs and outcomes (which included a 100 point increase in CD4 counts under the rich formulary) were based on extensive clinical trial data by AIDS researchers P.M. Gulick and J. W. Mellors (New England Journal of Medicine, 1997, volume 33).

"The bottom line is that it's cost-effective to introduce protease inhibitor combination therapy early in the disease process, before patients begin developing opportunistic infections," explains Sissi Pham, principal pharmaco-economic research scientist for the U.S. Medical Affairs Division of Glaxo Wellcome. Pham says that opportunistic infections are expensive to treat (PCP: $8,600 a year, Cryptococcal meningitis: $18,000 and non-Hodgkin's lymphoma: $26,000) and most patients involved in long-term protease inhibitor therapy have, to date, avoided them.

AIDS advocates and researchers rejoice that the Glaxo Wellcome ADAP budget projection model was used to help persuade Congress to increase ADAP funding 71 percent in fiscal 1998. However, they are frustrated that a great many state and federal officials continue to look at HIV/AIDS costs on a program-by-program basis. "It scares people when they see ADAP costs soaring," says Jerry Tolsen, research scientist at Glaxo Wellcome. "They don't see the bigger picture, that total health care costs go down when you provide a comprehensive ADAP formulary."

Projected Annual Cost of Treating ADAP Patients in New York

	No Drugs	Limited Formulary	Rich Formulary
ADAP costs	0	$29.7 m	$41.9 m
Total cost to NY for all HIV/AIDS -related care for ADAP patients (includes ADAP costs)	$85.7 m	$79.5 m	$71.3 m

How Two States and One EMA Are Coping — Continued from 3

and other medications to its HIV-infected clients for the rest of the current fiscal year.

The Title I planning council in metropolitan Kansas City — an EMA encompassing both Kansas and Missouri communities — has attempted to fill in some of the gaps left by the two state ADAPs. It designated more than $900,000 in fiscal 1997 CARE Act funding for medications. This includes $600,000 or some 25 percent of its Title I annual allocation and most of its Title II allocations from Kansas and Missouri. EMA-funded medications are available to HIV+ people with incomes up to 300 percent of the federal poverty level.

The higher income guidelines are a boon to many employed HIV+ individuals who are well enough to work but don't have a health insurance policy that will pay for expensive HIV/AIDS medications. "If we can help people with moderate incomes start PI therapy early in the infection cycle, then they will likely be able to continue to work," says Judy Moore-Nichols, HIV/AIDS program manager for the Kansas City, Missouri Health Department, which administers Title I funding in the Kansas City area.

But Moore-Nichols admits the Kansas City EMA has paid a price — in the form of

Continued on page 6

S W+M
2/9/98
Attachment 4-5

Week of Prayer Helps Clergy Address HIV/AIDS Issues

Activities Begin March 1

Three years ago, *AIDS* was a term rarely mentioned in African-American churches in metropolitan Kansas City. Today, however, a growing number of local black ministers are beginning to confront HIV, a disease that affects African Americans more than any other racial or ethnic group.

This slow-but-steady shift in attitude can be attributed in large part to the Black Church Week of Prayer, an annual event designed to raise AIDS awareness among black clergy and their congregations.

A week-long series of prayer services, workshops and other events are planned for the third annual Black Church Week of Prayer, scheduled from March 1-7. Most of the events will address some aspect of this year's theme, *Our Community, Our Commitment, Our Faith.*

"We want people of faith to understand that HIV is not some kind of strange or loathsome condition," explains Reverend Eric Williams, co-chair of Black Church Week of Prayer and pastor of the Calvary Temple Baptist Church. "It is one of a host of problems that African Americans struggle with — one that black churches should address together as a community of faith."

One workshop sponsored by the Black Church Week of Prayer will focus on HIV prevention and treatment for African-American women. HIV presentations will be paired with discussions about breast cancer and other female-oriented medical conditions so participants will begin to view HIV education as part of their normal health care regimen. Another workshop will give black clergymen and women an opportunity to explore their reluctance to deal with AIDS issues within their churches.

BLACK CHURCH WEEK OF PRAYER For The Healing of AIDS
of GREATER KANSAS CITY

"We want people of faith to understand that HIV is not some kind of strange or loathsome condition. It is one of a host of problems that African Americans struggle with — one that black churches should address together as a community of faith."

Reverend Eric Williams, Co-chair of Black Church Week of Prayer and Pastor of the Calvary Temple Baptist Church.

A special event for HIV+ African Americans is planned. It will feature alternative therapies that can be used as an adjunct to traditional HIV therapy. There will be information about acupuncture, massage and other ways to relieve the side effects of antiretroviral medications as well as reduce the stress that could further erode the immune system of an infected individual.

The efforts of the Black Church Week of Prayer do not end on March 7. "We work with churches all year long, helping them to establish HIV ministries," Reverend Williams adds. To date, the Black Church Week of Prayer has assisted 20 area churches in setting up HIV prevention-education programs and/or creating support systems for people living with HIV/AIDS.

BLACK CHURCH WEEK OF PRAYER FOR THE HEALING OF AIDS

March 1-7, 1998

- **March 1** - *Kick Off Day*, 5:00-7:00pm, the Gem Theater, 18th & Vine, KCMO
- **March 2** - *Women's Day*, 4:30-8:30pm, Scottish Rite Temple, Paseo & Linwood Streets, KCMO
- **March 3** - *HIV+ Persons, PWAs & Caregivers*, 2:00-6:00pm, Calvary Temple Baptist Church, 29th & Holmes, KCMO
- **March 4** - *Prayer Meeting*, 7:00-9:00pm, St. Mark's Church, 1101 Euclid, KCMO
- **March 5** - *Clergy Workshop*, Registration 9:00-10:00am, Friendship Baptist Church, 3530 Chelsea Drive, KCMO
- **March 6** - *Youth Day*, 8:30am-1:30pm, St James United Methodist Church, 56th & Paseo Blvd, KCMO
- **March 7** - *Gospel Concert*, 7:00pm, Calvary Temple Baptist Church, 29th & Holmes, KCMO

For more information call the AIDS Council
816/751-5166

S W+M
2/9/98

Attachment 4-6

short TAKES

■ **Some AIDS researchers fear that the U.S. is on the verge of a second-wave HIV epidemic among young gay men.** Unlike their more risk-conscious peers in the late 1980s and early 1990s, a growing number of teen and young adult homosexuals engage in unprotected sex at least some of the time. This includes four out of 10 gay men who frequent gay bars in Baltimore, according to a recent study by the Johns Hopkins School of Hygiene and Public Health. Nearly one out of 10 gay bar patrons who participated in the study tested positive for HIV. Those responding to the survey said they were less concerned about becoming infected now that effective antiretroviral medications are available. Many held the false notion that protease inhibitors will cure HIV.

■ **Americans are less likely to negatively judge people with HIV/AIDS than they were a decade ago, according to an October CNN/Gallup Poll.** Only 15 percent of survey respondents indicated they would avoid a person who they suspected had AIDS, down 43 percent from 1987. Although four out of 10 still believe "it's people's own fault if they get AIDS," more than five out of 10 held that view in 1987. Thirty-one percent continue to see AIDS as a "punishment" for immoral behavior, compared to 43 percent 10 years ago. But even those who are critical of people with HIV/AIDS want the government to do more to relieve the AIDS crisis. More than half of those surveyed said the government isn't doing enough.

fewer support services — for its commitment to provide PI therapy to as many low-income, HIV-infected people as possible.

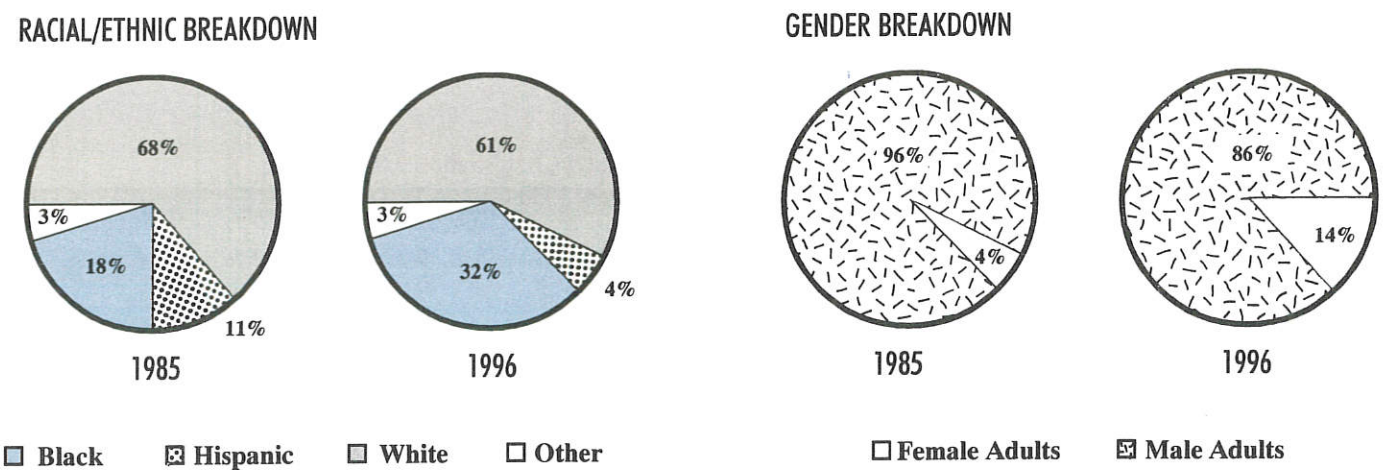
While primary care services have been maintained at optimal levels — in part because many EMA clients are served by area clinics funded by Title III CARE Act funds — numerous other support services have been curtailed. For example, most housing and transportation services are available only to people with AIDS. In fact, housing dollars are in such short supply that rental supplements are provided only to those with incomes at or below 150 percent of the federal poverty level. There are more than 100 eligible people on the waiting list.

Even with a substantial increase in ADAP for fiscal 1998, which begins in April, Kansas and Missouri communities may be fighting an uphill battle. As the federal recommendation about early PI intervention is more widely publicized, many CARE ACT clients who are not currently using PIs are expected to request the antiretroviral therapy. In addition, two out of three HIV-infected people nationwide qualify for ADAP but have not yet accessed the system, according to CDC estimates. A portion of this group will likely apply for medication assistance in 1998.

"We haven't been helping enough disenfranchised folks — the homeless, the indigent and the throwaways of society who don't know about CARE Act programs," says Dave Peters, executive director of the AIDS Project of the Ozarks and a member of Missouri's HIV/AIDS Care and Prevention Services Statewide Advisory Committee. Moore-Nichols agrees. She says that the Kansas City EMA is developing a marketing campaign because "now that there is an effective HIV medication, we have an obligation to reach out to those who may benefit from it."

HIV/AIDS Trends in Metropolitan Kansas City

Changes in new annual HIV/AIDS cases, 1985 to 1996



SOURCE: Kansas City, Missouri Health Department

S W+M
2/9/98

Attachment 4-7

WASHINGTON, D.C. WATCH

Before the 105th Congress adjourned for the year, it passed the fiscal 1998 appropriations bills (Labor/HHS and VA/HUD) that provide funding for AIDS-related programming. Thanks to the high-profile lobbying efforts of AIDS Action and other advocacy groups, almost every federal HIV/AIDS prevention and service program has been expanded.

Ryan White CARE

CARE Act programming for fiscal '98 received the largest boost, $1.15 billion, up nearly $154 million or more than 15 percent. A major portion of this increase was allocated for the Title II AIDS Drug Assistance Program ($285.5 million, up $118 million or 71 percent) which helps to supply protease inhibitors and other medications to low-income, HIV-infected individuals. CARE Act services channeled through eligible metropolitan areas (Title I) as well as through states (Title II) were increased about 3 percent each.

FISCAL YEAR 1998 APPROPRIATIONS FOR FEDERAL AIDS PROGRAMS

FEDERAL HIV/AIDS PROGRAM	FISCAL YEAR 1997 ACTUALS	FISCAL YEAR 1998 FINAL
HRSA- Ryan White CARE Act Total	$996.3 m	$1,150.2 m (+153.9 m) (15.4%)
Title I	$449.9 m	$464.8 m (+14.9 m) (3.3%)
Title II · Care Services	$250.0 m	$257.5 m (+7.5 m) (3%)
Title II · ADAP	$167.0 m	$285.5 m (+118.5 m) (71%)
Title IIIb	$69.6 m	$76.3 m (+6.7 m) (9.6%)
Title IV	$36.0 m	$41.0 m (+5.0 m) (13.9%)
Title V	$23.8 m	$25.1 m (+1.3 m) (5.5%)
CDC-Prevention	$616.8 m	$634.3 m (+17.5 m) (2.8%)
NIH-AIDS Research	$1,501.7 m	$1,608.0 m (+106.3 m) (7.1%)
HUD-HOPWA	$196.0 m	$204.0 m (+8.0 m) (3.9%)
SAMHSA	$1,360.1 m	$1,360.1 m (+0)

Source: AIDS Action

Prevention

HIV/AIDS education and prevention activities, which are administered by the CDC, were expanded by $17.5 million or nearly 3 percent in fiscal '98. Some in Congress believe that the need for prevention services is waning because, over the last two years, the number of new AIDS cases reported annually has declined somewhat. However, the incidence of HIV/AIDS continues to grow among women and minorities — groups that must be targeted for extensive prevention information.

Housing

Although the Housing Opportunities for People with AIDS (HOPWA) program garnered an $8 million or 4 percent increase, AIDS activists say that HOPWA continues to be underfunded. Thousands of infected people in need of housing assistance are on waiting lists, including more than 100 in metropolitan Kansas City.

Other HIV/AIDS Programs

AIDS research through the National Institutes of Health received a moderate increase in fiscal '98 ($1.6 billion, up $106 million or some 7 percent) after nearly doubling in fiscal '97. Although no AIDS-related program lost funding, a substance abuse program for HIV-infected people, operated by the Substance Abuse and Mental Health Services Administration (SAMHSA), was flat-funded at fiscal '97 levels.

Federal Funding for Needle Exchange Programs

For years, Congress has prohibited the use of federal funds for syringe exchange programs, which are designed to reduce HIV transmissions among injecting drug users. However, the fiscal '98 Labor/HHS appropriations legislation opens the door for federal support of syringe exchange initiatives. It allows HHS Secretary Donna Shalala to provide funds for syringe exchange programs if she determines that they prevent the spread of HIV without encouraging the use of illegal drugs. (The vast majority of research has shown this to be the case.) According to the legislation, Shalala cannot exercise this new authority until April 1, 1998.

Encourage HHS Secretary Shalala to lift the funding ban on syringe exchange programs as soon as possible. Contact her at

200 Independence Ave. S.W. #615F
Washington, D.C. 20201
Phone: (202) 690-7000
Fax: (202) 690-7203

S W+M
2/9/98

Attachment 4-8

CALENDAR

JANUARY • FEBRUARY

■ **January 13** - *Prospects For Controlling HIV Infection* with Dr. David Ho, 4:00pm in Spencer Auditorium, 4400 Wornall. For more information call Kansas City AIDS Research Consortium at **816/756-5116.**

■ **January 21** - *Kansas AIDS Networking Project.* Meets at the Kansas Historical Society, 9:00am-12:00 noon, Topeka KS. For more information call Kansas Dept of Health & Environment at **785/296-6036.**

■ **January 27** - *AIDS Council of Greater Kansas City Annual Meeting*, 5:30-7:00pm, Diastole 2501 Holmes, KCMO. For reservations call the AIDS Council office at **816/751-5166.**

■ **February 6-7** - *Rocky Mountain Regional Conference on HIV Disease*, Doubletree Hotel, Denver Colorado. For more information call Jodi Steward at **303/837-0166.**

■ **February 14** - *National Condom Day*

■ **February 18-20** - *A Gathering of Wisdom with Joycelyn Elders, MD,* at the Holiday Inn, Golden Gateway Hotel, San Francisco, CA. For more information call RDL Enterprises at **916/443-0218.**

■ **March 1-7** - *Black Church Week of Prayer For The Healing of AIDS.* For more information, see page 5 or call the AIDS Council, **816/751-5166.**

CATALYST
JAN·FEB 1998
THE AIDS COUNCIL OF GREATER KANSAS CITY
2801 WYANDOTTE · SUITE 167 · K. C., MO · 64108-3345

ADDRESS SERVICE REQUESTED

S W+DD
2/9/98
Attachment 4-9

• DOUGLA NTY AIDS PROJECT •

February 9, 1998

To: Senate Ways and Means Committee

From: Cynthia Wiklund, MSW Student Intern
Douglas County AIDS Project, Lawrence, KS

Re: Senate Bill 545

Chairman Kerr and members of the Ways and Means Committee:

My name is Cynthia Wiklund and I am a graduate student in the Masters of Social Welfare program at The University of Kansas. I am currently completing an internship at the Douglas County AIDS Project in Lawrence. DCAP is a not-for-profit, community-based organization that provides direct client services to individuals and families infected and affected by HIV and AIDS in the Douglas, Jefferson, and Franklin county communities in Kansas.

I am here today to provide some information regarding the 39 individuals living with HIV for whom the agency provided services for in 1997. Of these 39 individuals, 18 are currently enrolled in the Ryan White Title II Program, and 12 of these individuals rely on the AIDS Drug Assistance Program for access to their HIV medications. At this time, it is these 12 individuals who are most at risk of suffering significant setbacks in their health if their access to financial assistance in obtaining their necessary HIV medications is cut off or suspended for any length of time. The remaining 21 individuals, while not currently utilizing ADAP funds, could potentially be at risk in the future, should their current health or employment change in such a way that they would become eligible for Title II funds and need to access the financial assistance the ADAP program offers.

I would like to offer the following three case vignettes which represent three of our clients who currently utilize ADAP funds:

- Client A is a man who has tried his best to remain employed since his HIV diagnosis; however, due to his fluctuating health status, had only been able to maintain employment sporadically. This client began the new drug "cocktail" treatment (obtained with the use of ADAP funds) three months ago, and has reported a significant improvement in his health status. He is experiencing a marked decrease in fatigue and his most recent lab values clinically verify his improvement. This client is now planning to return to work on a permanent basis due to these improvements in his overall health attributed, in large, to the new medications.
- Client B is also a man with highly marketable work skills who has done well with the HIV medication regime. Over the past few months, he has gradually returned to the work force with no adverse affects on his health status. Due to the increase in his income, this client will probably not qualify for Title II funds in the future, although without the access to these medications initially, he would not have been as likely to experience the improvements in his health allowing him to return to work.
- Lastly, Client C is a woman who has been HIV+ since approximately 1990. She began taking HIV medications approximately one year ago and has returned to college this past fall. Thanks again to improved health the medications have afforded her, she is now developing the skills for the career that has long been her goal. Without access to the HIV medications, this goal may not have ever been within her reach.

Thank you.

S W+M
2/9/98
Attachment 5

United Way Center for Human Services
2518 Ridge Court, #244
Lawrence, KS 66046
913/843-0040 telephone
913/843-2669 fax