

## Ryan White CARE Act Reauthorization

The U.S. federal government spends more than \$21 billion on HIV/AIDS annually, yet up to 59 percent of Americans with HIV are not in regular care and more than a quarter of those who are infected do not know it.

The Ryan White CARE Act is the nation's largest HIV/AIDS specific support program (Total budget for fiscal year 2006 is \$2.065 billion). The authorization for the CARE Act expired a year ago.

President Bush has repeatedly called on Congress to reauthorize this program and Senators Enzi and Kennedy have devised a balanced compromise with their House counterparts to renew and update this program that so many Americans with HIV/AIDS rely upon.

Reauthorization, however, is being held up by a few who have placed parochial political interests above the goal of ensuring fair and equitable funding and access to treatment for all Americans living with HIV.

The New York delegation, for example, argues that updating formulas would devastate their state's treatment infrastructure. A closer look, however, reveals that the impact on New York, like other states with large urban areas, would not be so great:

- In 2006 the national average funding per AIDS case was \$1,613. New York's average was \$2,122 per case – nearly 33 percent more per case than the national average.

- Under the corrected funding formulas, the national average in 2007 would be \$1,793, and New York's would still be a significantly higher \$2,107 – just 5 percent less than the state currently receives.
- In 2000-2003, New York carried over an average of \$29 million a year in Title I and Title II funds. If New York can afford to carry a surplus of \$29 million in those years, how can it justify holding up life-saving legislation over a \$2.1 million per year funding adjustment?
- *The New York Times* reported that New York was paying for dog walking and candlelight dinners with AIDS funds while other areas of the country do not have sufficient funds to pay for medications for those living with HIV.

If the CARE Act is not reauthorized by October 1, a provision in the existing law signed by President Clinton in 2000 will revise funding formulas to require the inclusion of all patients in a jurisdiction living with HIV. Current law only counts those who have been diagnosed with AIDS, the end stage of HIV infection. As a result, states that do not have accurate or “mature” HIV reporting systems (California, Maryland, and Massachusetts) are likely to see dramatic reductions in federal funding.

This reduction will be offset, in part, by funds that are set aside and intended to stabilize decreases in funding (“hold harmless”) as well as fund AIDS drugs for patients in states with waiting lists for treatment. Without reauthorization occurring by October 1, the “hold harmless” will consume the entire set aside and eliminate funding for the much needed AIDS drug assistance supplemental.

The end result will be uncertain funding for states across the country and thousands of Americans living with HIV/AIDS without access to treatment.

Reauthorization is also necessary to ensure that CARE Act programs are updated to reflect the latest trends in the epidemic.

African Americans and Latinos account for a disproportionate share of new AIDS HIV/AIDS diagnoses. Blacks now represent a majority of new HIV/AIDS cases with African American women representing the fastest growing percentage of new HIV infections. Survival after an AIDS diagnosis is also lower among African-Americans than other racial/ethnic groups.

Likewise, the share of AIDS cases in the U.S. South has increased, rising from 40 percent of cases in 1996 to almost half (48 percent) of cases in 2004. When HIV data is included, a majority of Americans living with HIV/AIDS reside in Southern states. Yet current funding allocation does not represent these trends.

The CARE Act now treats these groups as a fraction of the worth of those living elsewhere. This is wrong. All Americans living with HIV should be treated equally and have access to life saving treatment.

Congress must, therefore, reauthorize the CARE Act by October 1 and in doing so, update the program to ensure access to treatment to all Americans living with HIV, promote early diagnosis, and provide more equitable funding that reflects the face of AIDS today.

# Additional Talking Points

## **Ensuring Access to Treatment**

Under the current CARE Act formulas, some areas of the country are receiving funding for AIDS patients who have been deceased for over a decade while other states are being short funded and as a result have patients with HIV dying on waiting lists for AIDS drugs.

Nearly 350 individuals are currently on waiting lists for the AIDS Drug Assistance Program (ADAP). A number of other states have or are expected to cap enrollment or reduce formularies for their ADAPs.

A recent Government Accountability Office (GAO) found that “ADAPs with waiting lists may not represent all eligible individuals who are not being served.”

In all, up to 59 percent of the more than one million people living with HIV/AIDS in the U.S. are not in regular care.

While some areas like New York City have received press attention for the lavished AIDS services provided such as free dog walking and AIDS housing in “glitzy” four-star hotels, patients in other areas of the country can not even access basic medical treatment.

**The reauthorization bill seeks to address this by prioritizing medical care and treatment over less essential services and programs.**

Increasing the amount that must be spent on primary medical care and medication will improve patients’ ability to access life saving treatment. This truly should be the top priority of the CARE Act. Other services should be secondary to providing life saving care to all those who are living with HIV/AIDS.

## **Promoting Early Diagnosis**

Knowledge of HIV status is essential for both prevention and treatment efforts.

Studies have found that the sooner treatment begins after infection, the more beneficial the outcome for the patient.

Studies have also found that when an infected individual becomes aware of their HIV status, the more likely they are to take precautions that might expose others to infection.

Yet approximately 24 to 27 percent of those living with HIV in the U.S. do not know that they are infected.

As many as 45 percent of persons testing positive for HIV received their first positive test result less than a year before AIDS was diagnosed. With an average of 10 years between HIV infection and an AIDS diagnosis, this suggests that people are living with HIV for many years before they are aware of their infection and may be unknowingly spreading the virus to others.

There are numerous social and legal barriers that have hindered efforts to diagnose those with HIV. Many at risk for HIV do not perceive or know that they are at risk and due to the stigma associated with HIV/AIDS many others are fearful to come forward to seek testing. Laws and regulations have also made the HIV antibody test perhaps the most regulated diagnostic tool in history. These regulations, requiring extensive pre- and post-test counseling including reasons not to take the test and explicit patient consent, have discouraged health care providers from offering tests and hindered efforts to confidentially notify partners of those who are infected that they are at risk and offered testing.

**The reauthorization bill provides \$30 million in grants to support and promote early diagnosis efforts.**

The new Early Diagnosis Grants will provide \$20 million to states with laws requiring routine HIV testing of pregnant women and universal testing of newborns and \$10 million to states that provide routine testing for clients at STD clinics and substance abuse treatment centers.

### **Providing More Equitable Funding**

The U.S. HIV/AIDS epidemic is primarily centered among minorities and in the South. Yet federal funds are still focused in large metropolitan areas in the Northeast and the West Coast.

Federal funding is twice the amount for an AIDS patient in San Francisco than it is for an AIDS patient in any city in the South.

Federal AIDS funding should no longer discriminate and all Americans living with HIV should hold the same value in terms of federal funding.

**The reauthorization bill provides more equitable funding while preserving funding for urban areas and protecting against dramatic shifts in funding for areas that were first hit by the epidemic.**

Some are suggesting that a cap should be imposed on the increase in funding a state can receive. The more appropriate policy would be to ensure that all eligible patients be treated as equals under the law.

The New York Times  
November 12, 1997, Wednesday, Late Edition - Final  
SECTION: Section A; Page 1; Column 2; National Desk

## New Challenge to Idea That 'AIDS Is Special'

By SHERYL GAY STOLBERG

Behind the swinging glass doors that welcome visitors to the Gay Men's Health Crisis is a world where H.I.V. is not just a deadly virus, but also a ticket to a host of unusual benefits.

At the center, the nation's oldest and largest AIDS social-service agency, almost everything is free: hot lunches, haircuts, art classes and even tickets to Broadway shows. Lawyers dispense advice free. Social workers guide patients through a Byzantine array of Government programs for people with H.I.V., and on Friday nights dinner is served by candlelight.

The philosophy underlying the niceties and necessities is "AIDS exceptionalism." The idea, in the words of Mark Robinson, executive director of the organization, is that "AIDS is special and it requires special status." That is a concept that has frequently been challenged by advocates for people with other diseases.

Now some advocates for people with AIDS are quietly questioning it themselves.

With death rates from the disease dropping for the first time in the history of the 16-year-old epidemic, the advocates suggest, it is time to re-examine the vast network of highly specialized support services for people with H.I.V. Some people are growing increasingly uncomfortable with the fact that the Government sets aside money for doctors' visits, shelter and drugs for people with AIDS but that it does not have comparable programs for other diseases.

"Why do people with AIDS get funding for primary medical care?" Martin Delaney, founder of Project Inform, a group in San Francisco, asked in an interview. "There are certainly other life-threatening diseases out there. Some of them kill a lot more people than AIDS does. So in one sense it is almost an advantage to be H.I.V. positive. It makes no sense."

Mr. Delaney, a prominent voice in AIDS affairs since the onset of the epidemic, is calling on advocates to band with people working on other diseases in demanding that programs for AIDS be replaced with a national health care system.

He complained that organizations like the Gay Men's Health Crisis had been "bought off" by the special status given to AIDS.

"We took our money and our jobs," Mr. Delaney wrote in the Project Inform newsletter in the summer, "and we dropped out of the national debate."

That criticism has not won many fans within "AIDS Inc.," as some call the cottage

industry of agencies that care for H.I.V. patients. But Mr. Delaney's article, "The Coming Sunset on AIDS Funding Programs," has set off an intense debate.

"I think Delaney knows that he is putting out a provocative, stimulating kind of discussion," said Jim Graham, executive director of the Whitman-Walker Clinic in Washington, a counterpart to Gay Men's Health Crisis. "This is the whole discussion about AIDS exceptionalism. I think AIDS is an exceptional situation. AIDS is caused by a virus. That infectious virus is loose in America. And when you have a virus, an infectious situation such as this, it takes an exceptional response."

Yet many people involved with AIDS say some change is in order. Many programs created in response to the epidemic were intended as stopgaps, to help the dying in the health emergency. Some of the money that pays for free lunches at Gay Men's Health Crisis, for instance, is from the Federal Emergency Management Agency, which usually works on natural disasters like hurricanes and earthquakes.

But it is becoming clear that the AIDS crisis is long term. New treatments appear to be turning the disease from a certain death sentence to a chronic manageable illness. Accepting the projection that the epidemic will last for at least another generation, advocates say, the Government and private agencies need to take a hard look at spending in the coming years.

"We are not going to die, at least not all of us, and at least not all so soon," said Bill Arnold, co-chairman of the ADAP Working Group, a coalition in Washington that is lobbying the Government to add money to its AIDS Drug Assistance Program. "A lot of us are saying that the AIDS network or AIDS Inc. or whatever you want to call it, this whole network that we have created in the last 15 years, needs to be reinvented. But reinvented as what?"

That question is provoking considerable anxiety among employees at the estimated 2,400 service agencies in the United States, several hundred of which are in New York City.

The agencies offer an array of services including sophisticated treatment advice and free dog walking. Although most are tiny, some have grown into huge institutions financed by Federal, state and local government dollars, as well as contributions.

Critics say the organizations cannot possibly re-examine themselves because they have become too dependent on the Government.

"They have all become co-opted by the very system that they were created to hold accountable," Larry Kramer, the playwright, said.

Mr. Kramer founded Gay Men's Health Crisis in 1981, but has long been critical of the group. "It's staffed with a lot of people who have jobs at stake," he said.

With 280 employees and 7,000 volunteers, the program is the biggest and busiest agency of its kind. For many with human immunodeficiency virus, the organization and its lending library, arts-and-crafts center and comfortably decorated "living room" offer a home away from home, a place where, as one participant said, "your H.I.V. status is a nonevent." For some, the hot lunches often provide the only nutritious meals the patients

get all day. For others, they are simply a source of community.

Craig Gibson, 31, of the Bronx, is one of 10,000 people a year who seek services there. Several days each week, Mr. Gibson goes to the living room to play cards after lunch.

"You come here, you see your friends," he said one afternoon. "Today they had a great chicken parmesan."

A walk through the lobby shows the power and success of AIDS philanthropy. A huge plaque in the entryway lists dozens of donors who have contributed \$10,000 or more, including three who have given more than \$1 million. Even so, 19 percent of the \$30 million annual budget comes from Government sources, Mr. Robinson said.

"We still need this extraordinary short-term help," he said.

But Mr. Robinson said he was aware that the financing might not last forever. Even as the organization expands, it is doing so with an eye toward eventually scaling back. It just spent \$12.5 million to renovate its new headquarters in a simple but expansive 12-story brick building on West 24th Street.

Mr. Robinson, a former accountant, said the building was designed so that any other business could easily move in. The lease is relatively short, 15 years.

The agency, he added, has realized that it cannot afford to be all things to all people. Until recently, Mr. Robinson said, "anybody with H.I.V. or AIDS could walk into our advocacy department, and virtually anything that was wrong with their life was addressed."

"If they were having problems with their landlord," he said, "we would deal with it. If they needed an air-conditioner, we would deal with it. Now we are really trying to focus on what is specifically related to AIDS."

To understand why Mr. Robinson and others say they believe AIDS deserves special status, a person has to go back to the response to AIDS in the days when it was known as the "gay cancer." The Government and the rest of society all but ignored the illness, forcing the people who were affected -- by and large homosexuals -- to fend for themselves.

"The original reaction," Mr. Arnold said, "was in response to: 'This is not our problem. We don't like you. Go away and die.' "

"By the time you have got 200,000 to 300,000 people dead," he said, "they all have friends. They all have relatives. That's a lot of people impacted. So now you have some critical mass."

That mass has translated into a political force -- and significant Federal money. In his budget proposal for 1998, President Clinton has asked Congress to allocate more than \$3.5 billion for AIDS programs, including \$1.5 billion for AIDS research at the National Institutes of Health and \$1.04 billion for the Ryan White Care Act, which provides medical care, counseling, prescription drugs and dental visits for people with H.I.V.

If Congress enacts the plan, AIDS spending would increase 4 percent over last year, and 70 percent over 1993, when Mr. Clinton took office.

In a paradox, some doctors say the array of services makes it harder to care for people whose behavior puts them at risk for AIDS, but who are not yet infected.

"We're trying to figure out how to provide services to H.I.V.-negative people to help them stay negative," said Dr. Michelle Roland, who treats indigent patients at San Francisco General Hospital. Many of Dr. Roland's patients are drug abusers, people at high risk.

"The truth is," she said, "we have a lot more access to resources for H.I.V.-positive people for drug treatment, education and housing."

While advocates for people with other diseases often lobby vociferously for more money for research, the notion of exceptionalism -- that a particular illness deserves special Government status -- is unique to AIDS, and it is generating a backlash.

For years, the American Heart Association has gone to Capitol Hill budget hearings with charts showing that more research money was spent per patient on AIDS than on heart disease. Advocates for people with Parkinson's disease have done the same. It will not be long, Mr. Delaney argues, before people with those and other diseases follow suit, demanding Ryan White-style programs for themselves.

Some authorities, including the president of the American Foundation for AIDS Research, Dr. Arthur Ammann, said Mr. Delaney was correct in pushing for universal health care. "We've got to form an alliance with these other diseases," Dr. Ammann said, "and say, None of us is going to get adequate health care the way the system is going."

But others call Mr. Delaney naive.

"It's interesting to muse about what he says," said Mr. Graham of the Whitman-Walker Clinic. "But it's both undesirable and impossible. So what's the point of talking about it?"

Naive or not, in challenging exceptionalism Mr. Delaney has clearly broken a taboo.

"We sort of question it among ourselves behind closed doors," said Mark Hannay, a member of the New York chapter of Act Up, the AIDS Coalition to Unleash Power. "Like, isn't this nice, but we're the only ones getting it."

<http://www.nynewsday.com/news/health/ny-nyhous054331659jul05,0,7828663.story?coll=ny-health-headlines>



## HIV/AIDS shelter costs challenged

BY ELLEN YAN  
STAFF WRITER

July 5, 2005

The [New York] city agency that secures temporary shelter for indigent people with HIV/AIDS shelled out \$2.2 million in questionable payments over 2 1/2 years, partly to rent rooms listed to people who had died, the city comptroller charged in an audit released yesterday.

The Human Resources Administration paid \$182,391 for rooms listed to 26 people up to two years after their deaths, with one housing provider getting 76 percent of the money, \$137,920, said the report from Comptroller William Thompson Jr.

Auditors said many of the problems stemmed from the agency's failure to review its own data and client files before making payments to housing providers. In the audit, Thompson's office looked at five housing facilities as well as payments and records made from July 2002 to December 2004.

Among the findings, auditors said, \$1 million went to housing providers for residents who did not sign registration logs; \$456,292 was paid for overnight stays on or after clients' last days of occupancy; \$417,463 in payments for people not in the agency's new database; \$118,185 in double billing; and a \$20,030 check to one vendor who submitted a \$2,030 bill, an overpayment the agency said it will correct.

HRA spokesman Bob McHugh said yesterday that agency heads had not seen the comptroller's final report.

"For whatever reason, they chose to release it on the Fourth of July, so we're not going to comment ... until we get a chance to review it," McHugh said.

In letters sent to the comptroller's office, HRA disagreed with many findings. In a June 15 letter, the agency said it's still waiting for Thompson's office to provide all the details so it can double-check the findings.

For example, officials replied in letters to the comptroller's office that at least three people were erroneously listed as dead in Social Security records.

In addition, the agency wrote, weekly registration logs are not final proof of whether housing was provided, because people with AIDS may have been too sick to sign.

The agency also accused Thompson's office of giving an "unbalanced" picture of housing conditions by concluding the 91 units checked were "generally in satisfactory condition" but then rating 25 of them as "unsafe and unsanitary."

The housing agency agreed with most of the audit's recommendations, including checking vendors' bills against client and Social Security records.

Daily HIV/AIDS Report

April 11, 2001

## **Across The Nation | New York City Agency Housing HIV-Positive Homeless People in Luxury Hotels, *New York Post* Reports**

New York City now spends as much as \$329 per person per night to house HIV-positive [homeless](#) people with AIDS in "glitzy" four-star hotels, the [New York Post](#) reports (*New York Post*, 4/11). The city's [Division of AIDS Services and Income Support](#) is required by a 1999 court order to provide housing for homeless HIV/AIDS patients on the day they apply for emergency housing (*Associated Press*, 4/11). DASIS finds shelter for about 200 homeless AIDS patients each day in locales ranging from "crack-infested brothels to four-star hotels." As the agency has "failed to find permanent housing" for some of their clients and has "ruined" relationships with less expensive hotels by failing to pay them in time, DASIS is "forced" to turn to four-star luxury hotels. Jennifer Flynn, director of the New York City AIDS Housing Network, estimated that the city spends about \$180,000 per week on hotel rooms, or more than \$9 million per year. "They have the money to house these people, and they're wasting it," she said, adding, "Putting them in these hotels shows that the city has no plan to provide these people with permanent housing" (*New York Post*, 4/11). The city's Human Resources Administration, which oversees DASIS, said that it turns to four-star hotels due to "limited availability" of less costly rooms, and HRA spokesperson Debra Sproles noted that funds spent on expensive hotel rooms indicates the "unworkability of the court order" (*Associated Press*, 4/11). Some DASIS clients report waiting up to 12 hours each day to receive hotel placements and facing "scorn" when entering the "swank" hotels in which they are placed (*New York Post*, 4/11).

### **Federal Oversight Appeal Dismissed**

In other DASIS news, the U.S. Court of Appeals for the Second Circuit yesterday dismissed the city's appeal of a September 2000 [court order](#) that placed the agency under federal oversight for three years, the [New York Times](#) reports. The three-judge panel said it "did not have jurisdiction" in the case, and sent it back to the Federal District Court. Brooklyn Federal Judge Sterling Johnson last year ruled that DASIS be placed under federal oversight because the agency "failed to provide adequate services for thousands of people with AIDS" and had "delayed or ended subsistence benefits like emergency housing, rent assistance, food stamps and [Medicaid](#)" for its clients. However, Johnson's court order did not specify "required action on the part of the city." The Court of Appeals determined that it lacked jurisdiction to overturn the ruling because the district court "had yet to determine" such requirements. Leonard Koerner, the city's chief assistant corporation counsel, said, "We will be able to appeal again once the case becomes final. The merits of the case shall be reviewed again by the circuit court at a later date" (Saulny, *New York Times*, 4/11).



## AIDS Medication Out Of Reach For Many



*By Eric Flack*

**(LOUISVILLE, September 24th, 2003, 7 p.m.)** -- Advocates for AIDS patients in Kentucky say people are dying because they can't afford their medication. And they say the state hasn't set aside enough money to help. The state admits the number of people who need medication but can't get it is getting longer.

The House of Ruth in Louisville helps people below the poverty line fight an expensive illness. AIDS treatment costs more than \$9,000 a year. It's expensive for Kim Smith, and she has "insurance and a job. And a doctor would take care to make sure I had the best there was available. And when you don't have any means to start with, it seems like quite a big hill to climb."

Al was diagnosed with full-blown AIDS eight months ago. At the time, he thought his diagnosis was a death sentence. "I was thinking there was no hope for me."

But now Al has hope. For now, his medication is working -- drugs paid for in part by the University of Louisville. Still, with \$700 a year in co-pays and no job, Al simply says he simply doesn't "have the money."

A program called the Kentucky AIDS Drug Assistance Program, or KADAP, pays for AIDS medication for the uninsured.

Rhiannon was one of the first people participate in the KADAP Program. Rhiannon is one of the lucky ones, and knows it. "There's too many people out there with HIV and AIDS who need the medications," he said. "They need them now. They don't need to wait."

But al is waiting. And he isn't alone. Right now, 169 people in Kentuckiana are on the KADAP waiting list. By December, that number is expected to grow to 200. Already this year, five people have died waiting for medication.

KADAP gets more than \$4 million a year from the federal government. The state only puts in \$90,000 -- that's enough to pay for medication for nine people a year. But not enough for Al.

"It's hard for me to go to sleep at night," Al says, "because I'm so scared I might close my eyes and not open 'em back. That's the hardest part."

KADAP already stretches its dollars as far as it can. The amount it spends on each patient is one of the lowest in the nation. The coordinator of the KADAP says they plan to ask for more money when budget negotiations start later this year. Whether they get it remains to be seen in these tight budget times. And Kentucky isn't the only state with a problem. Fifteen other states have waiting lists, too.

*Online Reporter:* [Eric Flack](#)

*Online Producer:* [Michael Dever](#)

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**From:** Natane Singleton  
**Sent:** Tuesday, September 12, 2006 3:40 PM  
**To:** Laura Hanen  
**Cc:** Murray Penner  
**Subject:** Latest ADAP waiting list numbers  
**Importance:** High

Hi Laura,

Here are the updated ADAP waiting list numbers:

**Total: 342**

Alaska: 10 (all receiving meds through the end of September under the PAI)  
Kentucky: 108 (78 of these are on the PAI but will go onto KADAP in October)  
Montana: 21  
South Carolina: 179 (as of 9/6)  
West Virginia: 24 (as of this week)

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[http://www.nastad.org/Docs/highlight/200696\\_NASTAD%20ADAP%20Watch%20Aug%2006%20FINAL.pdf](http://www.nastad.org/Docs/highlight/200696_NASTAD%20ADAP%20Watch%20Aug%2006%20FINAL.pdf)



**ADAPs with Waiting Lists**  
(310 individuals, as of July 27, 2006)

**Arkansas:** 4 on waiting list  
**Kentucky:** 153 on waiting list  
**Montana:** 20 on waiting list  
**South Carolina:** 94 on waiting list  
**West Virginia:** 39 on waiting list

**ADAPs with Other Cost-containment Strategies (instituted since April 1, 2006)**

**Alabama:** Capped enrollment, will begin waiting list  
**Indiana:** Capped enrollment, will begin waiting list  
**Oklahoma:** Annual per capita expenditure limit  
**South Carolina:** Reduced formulary

*\*Eight ADAPs have capped enrollment for Fuzeon access and seven states do not include the drug on their formularies (43 ADAPs reporting); Two states have capped enrollment for Aptivus access and four states do not include the drug on their formularies (43 ADAPs reporting).*

**ADAPs Anticipating New/Additional Cost-containment Measures (before March 31, 2007\*)^**

**Georgia**  
**Louisiana**  
**Michigan**  
**Puerto Rico**  
**Rhode Island**  
**U.S. Virgin Islands**

*\* March 31, 2007 is the end of ADAP FY 2006. ADAP fiscal years begin April 1 and end March 31.  
^One additional state reported anticipating the need to implement new/additional cost containment measures but did not wish to be named.*