

# THE RYAN WHITE CARE ACT AMENDMENTS OF 2000

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## HEARING BEFORE THE SUBCOMMITTEE ON HEALTH AND ENVIRONMENT OF THE COMMITTEE ON COMMERCE HOUSE OF REPRESENTATIVES ONE HUNDRED SIXTH CONGRESS SECOND SESSION

ON

**H.R. 4807**

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## THE RYAN WHITE CARE ACT AMENDMENTS OF 2000

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TUESDAY, JULY 11, 2000

HOUSE OF REPRESENTATIVES,  
COMMITTEE ON COMMERCE,  
SUBCOMMITTEE ON HEALTH AND ENVIRONMENT,  
*Washington, DC.*

The committee met, pursuant to notice, at 10:07 a.m. in room 2123, Rayburn House Office Building, Hon. Michael Bilirakis (chairman) presiding.

Members present: Representatives Bilirakis, Deal, Burr, Coburn, Cubin, Bryant, Brown, Waxman, Green, Strickland, DeGette, Barrett, Capps, Towns, and Eshoo.

Staff present: Marc Wheat, majority counsel; Brent DelMonte, majority counsel; Kristi Gillis, legislative clerk; and John Ford, minority counsel.

Mr. BILIRAKIS. Good morning. This hearing will come to order.

This morning the subcommittee is holding a hearing on H.R. 4807, the Ryan White CARE Act Amendments of 2000. This bipartisan legislation was introduced by two members of this subcommittee, Congressman Tom Coburn and Congressman Henry Waxman.

I really want to take this opportunity to sincerely commend them both for their hard work on this important issue. Henry is not here at this moment, but I have extended that to him, previously.

I was pleased to be an original co-sponsor of the bill, which demonstrates what can be accomplished when parties and differences are set aside.

The Ryan White Emergency Comprehensive Aides Resources Emergency, CARE, Act was enacted in 1990. During the 104th Congress, this subcommittee approved bipartisan legislation to reauthorize the act.

The Ryan White CARE Act provides critical funding for health and social services to the estimated 1 million Americans living with HIV and AIDS. The Reauthorization Bill before us will ensure that these patients continue to receive the care and medications they need to enhance and prolong their lives.

H.R. 4807 recognizes that women and minorities increasingly comprise a larger percentage of new cases of HIV in the United States. This demographic shift has not been addressed under existing law, since funds are currently targeted toward areas with high numbers of AIDS patients.

The current formula does not accurately reflect the number of individuals who are infected with HIV, but have not contracted

AIDS. As a result, Federal resources are not going to the areas hardest hit by the disease today.

H.R. 4807 will begin to shift funding toward communities with a large population of HIV positive individuals. By targeting resources to the front line of the epidemic, we will be able to reduce transmission rates, and ensure the necessary infrastructure is in place to provide care to HIV positive individuals as soon as possible. This change will allow the Federal Government to be proactive instead of reactive in the fight against HIV and AIDS.

This shift will only occur, however, when reliable data on HIV prevalence is available. The bill will also include a hold harmless provision to ensure that no metropolitan area will suffer a drastic reduction in CARE Act funds.

H.R. 4807 also increases the focus on prevention. States with effective partner notification and HIV surveillance programs will be eligible for additional Federal funds. Partner notification programs have been proven particularly effective in finding individuals from traditionally under-served communities, and getting them into care.

This emphasis on prevention services is part of our comprehensive effort under the legislation to eliminate barriers for access to care.

I would like to thank all of our witnesses for taking the time to join us. I am sure that their knowledge and insight will prove valuable as we discuss this important legislation.

It is always a pleasure to welcome a Floridian before the subcommittee. Today, we will hear from Mr. Thomas Liberti, Chief of the Bureau of HIV/AIDS for the Florida Department of Health.

Florida's population is racially and ethnically diverse. This diversity has complicated effective disease prevention efforts. As Mr. Liberti will explain, minority populations in Florida have been disproportionately affected by HIV and AIDS.

I look forward, as I know we all do, to learning more about the State's efforts to address this serious problem, and how the Federal Government can help.

I am also particularly pleased to welcome, on behalf of all of us, Jeanne White, today. Since her son, Ryan's, tragic death over 10 years ago, she has served as an eloquent spokesperson and tireless crusader for individuals stricken with HIV and AIDS. With your help, Jeanne, we can pass legislation that would make Ryan proud.

The Chair now yields to Mr. Brown, the Ranking Member.

Mr. BROWN. Thank you, Mr. Chairman. I would like to thank Administrator Fox and our other distinguished witnesses, including Joe Davy, from the Columbus, Ohio, AIDS Task Force, and Jeanne White. Thank you for joining us, today.

I would like to commend Mr. Coburn and Mr. Waxman, as well as their staff members, Roland Foster and Paul Kim, for their exceptional work on the Ryan White CARE Act Amendments of 2000.

The Ryan White CARE Act has been and continues to be the Nation's most effective weapon against HIV/AIDS. The U.S. has been well served by the act in two critical areas: one, it combats the illness, itself; and second, it combats the fear of prejudice and alienation that HIV/AIDS has engendered in this country.

The act was created in the memory of Ryan White, the young Kokomo, Indiana teenager, who became a hero in the fight against HIV/AIDS. All he wanted was something most kids take for granted; the right to attend school. Ryan was a hemophiliac, and contracted HIV through a bad blood transfusion. His goal was to change the misconceptions surrounding AIDS.

While fighting to get his education, he in fact served as an educator for the millions of Americans who tried to stand in his way. Ryan died at age 18, in April 1990.

Now, 10 years later, it is clear the Ryan White CARE Act has made a tremendous difference in the lives of people living with HIV/AIDS. I know that because much of the Congressional District I represent in Northeast Ohio is included in Ohio's only Title I eligible metropolitan area.

Title I funds have provided health care and support services, and medications that have literally brought people back to life. Whether they live in the more rural areas of my district, like Medina County, or in the more urban O'Leary or Lorraine, the Ryan White CARE Act is there to help with medical care, dental services, medications, alcohol and drug treatment, mental health services, and nutrition.

It is appropriate for the House Health and Environment Subcommittee to be considering the reauthorization of the Ryan White CARE Act at the same time that thousands of miles away, scientists, activists, and people living with HIV/AIDS are meeting in Durban, South Africa, as part of the Thirteenth International AIDS Conference.

AIDS is set to kill more people worldwide than World War I, World War II, the Korean War, and Vietnam War, combined. Those individuals committed to fighting AIDS on a global scale face the same kinds of obstacles Ryan White faced two decades ago: ignorance, fear, apathy, and the urgent need for more resources.

Ryan White was on this earth only for 18 years, but in that time, he taught Americans that we need to fight AIDS; not fear it, not ignore it, not use it to perpetuate harmful prejudices. His lessons live on in the Ryan White CARE Act. Let us keep his lessons alive and reauthorize this bill.

Thank you, Mr. Chairman.

Mr. BILIRAKIS. And I thank the gentleman for his eloquent statement.

I now yield to the gentleman, the co-writer, if you will, of the legislation, Dr. Coburn.

Mr. COBURN. Thank you, Mr. Chairman. I appreciate you having this hearing today.

I want to take this time to thank Mr. Waxman and Paul Kim and Karen Nelson of their staff. Our staffs worked hard to make sure that we came up with a bill that addresses the needs that are out there. Over the past year, we have worked with almost every interest group in this area, as has Mr. Waxman, to try to address the needs.

Besides reauthorizing the important parts of this act, we are changing direction in the House-passed bill for a very important reason. Those with HIV are too often not figured in, in the components for care. No. 2, this is a disease that is preventable. It is pre-

ventable. It need not go further. The act will be changed to emphasize prevention, as it should be.

The best and most efficient use of our dollars in this country for treating HIV/AIDS is to prevent the next person from getting it. So the act will have an emphasis on prevention.

It also will change the manner in which we fund HIV treatment, by including those infected with HIV in the calculations for grants.

We all know that tremendous strides have been made in preventing the progress from HIV infection to full-blown AIDS. We have 300,000 to 400,000 people in this country who have HIV today, and know it, and do not have AIDS. We have another 300,000 to 400,000 people in this country that have HIV, that do not know it.

That is a tremendous number of people that we need to be helping; let alone the other 10 million people that are exposed, at this time in this country, through behaviors that put them at risk for this. So the emphasis has been moved from where the epidemic is, which is in HIV infection, and not necessarily full-blown AIDS.

So we do not drop any of our attention to AIDS, but we increase our attention and directed purpose toward those with HIV, and preventing the next person from getting it.

The other thing that is addressed in this is our battle against perinatal HIV infection. As most of you know, great strides have been made. We have been very successful in lessening perinatal transmission.

But we have not gone far enough. As New York State's experience shows, we can do much better in the country. It is the position of the American Medical Association that perinatal testing ought to take place; that newborn testing ought to take place, if the status of the mother is unknown.

We now know that with that information, we can eliminate a large portion of HIV infection in neonates, and we ought to be about doing that.

Then finally, this bill addresses those that have not been served appropriately; especially minorities, especially women, especially rural areas, that have not had access to equal treatment.

HIV does not care who you are. It does not care where you live. It does not care about your sexual orientation, and neither should we. We should make sure that everybody who has this disease has full and equal access to treatment. I feel confident that we are going to accomplish that with this bill.

Then, finally, this bill assures accountability of Federal dollars. As we have seen from the GAO audit, there are some significant problems with the large amounts of money that have been misspent or misused in this fight.

When people in Oklahoma can not get ADAT money, and yet people are stealing millions of dollars from Ryan White funds, I think that the Congress has to address that. I believe that we have, effectively, in this bill.

With that, I yield back to the chairman, in the hope that we can move to a fast markup on this, and to the full committee.

Mr. BILIRAKIS. I thank the gentleman.

Ms. Eshoo, for an opening statement.



Ms. ESHOO. Thank you, Mr. Chairman, for having this hearing, and good morning to you, and to the witnesses that have joined us today. I want to recognize and thank Congressmen Waxman and Coburn for their work on the bill, as well as the work of their staffs.

The Ryan White programs are vitally important to people living with HIV and AIDS. Reauthorization will ensure that lifesaving and life enhancing medical and social services will continue to be available to people fighting this disease.

Reliability and stability are really the goals of the legislation, yet there is an important section of the bill that runs contradictory to these principles, the hold harmless provision.

Under existing law, an eligible metropolitan area, known as EMAs, receiving Title I funds, can lose no more than 5 percent of its funding over a 5-year period. This hold harmless provision was specifically designed to prevent the rapid de-stabilization of existing systems of care, when changes in the Title I formula were adopted by Congress in 1996.

H.R. 4807 changes this dramatically, allowing an EMA to lose 25 percent of its funding, over the same time period. The result will be a rapid decline among systems of care, and reduced access to critical AIDS services.

The negative impact will be disproportionately felt in the Bay area. My Congressional District is part of the Bay area. The Bay area continues to be among the hardest hit by the HIV epidemic, and our epidemic is growing.

According to the CDC, San Francisco has the third highest number of AIDS cases among metropolitan areas. Last week, the San Francisco Department of Public Health reported that the new HIV infections in the Bay area nearly doubled in 1999.

These statistics reinforce what we have known since the CARE Act was enacted in 1990. Bay area communities have an unusually high number of AIDS cases, relative to their populations. Yet, the current formula does not account for this increased public health burden.

While the original CARE Act based part of the Title I formula grant on the rate of AIDS cases per 100,000 people, the density factor was removed when the act was reauthorized in 1996. Knowing the potentially devastating impact that removal of the density factor could have on San Francisco and other cities with a large number of AIDS cases, relative to the overall population, Congress included the 5 percent hold harmless specifically to minimize the negative impact of this change.

The current funding formula also fails to reflect those living with HIV. In the Bay area, there are a significant number of people with HIV, who have not progressed to an AIDS diagnosis in part, due to their ability to access CARE Act services. As a result, San Francisco and other EMAs are penalized for keeping people healthy under the existing formula.

We still do not recognize density or living HIV cases in the Title I formula; two factors which have resulted in significant funding cuts for the Bay area. Yet, H.R. 4807 takes away the safety net. A 25 percent hold harmless is effectively a harm clause now.

I think that the Senate has it right. By doubling the hold harmless reduction to 10 percent, they have continued an aggressive phase-out of the hold harmless, without pulling the rug out from under any given EMA.

I look forward to working with the bill's sponsors, both in the House and the Senate, to fashion a responsible hold harmless provision that will not leave the Bay area without its safety net.

Mr. Chairman, I would like unanimous consent to submit for the record an article that appeared in the San Francisco Chronicle on Friday, June 30, that is entitled, "San Francisco HIV Rate Surges; Alarming Incidence of New Infections Raise Fears of Scourge to Come."

Mr. BILIRAKIS. Without objection, that will be the case.  
[The information referred to follows:]

[Friday, June 30, 2000—San Francisco Chronicle]

#### S.F. HIV RATE SURGES

#### ALARMING INCIDENCE OF NEW INFECTIONS RAISES FEARS OF SCOURGE TO COME

Sabin Russell, Chronicle Staff Writer

**San Francisco**—San Francisco's long-feared and often predicted new wave of infection is here.

After years of stability—wrought by strong prevention programs, a safer-sex ethic and powerful drugs—city health experts now estimate that the number of new infections by the virus that causes AIDS nearly doubled, to 900, in the past year.

"This is a harbinger of what is going to happen all over the country," warned Tom Coates, director of the University of California at San Francisco AIDS Research Institute. "What happens in the HIV epidemic usually happens here first."

The estimate is based on a dozen indicators monitored by city health authorities. The newest and most worrisome data come from a string of city clinics that perform anonymous HIV testing. The centers serve a higher-risk clientele than in the general population, so they serve as an early warning system.

#### EPIDEMIOLOGISTS WORRIED

From 1997 to 1999, the percentage of HIV positive cases turning up at these centers nearly tripled, to 3.7 percent from 1.3 percent. The numbers may seem small, but they are frightening to epidemiologists, who note that infection rates can grow like money with compound interest.

"We are very concerned, and we are very worried," said San Francisco Department of Public Health epidemiologist Dr. Willi McFarland. "These are sub-Saharan African levels of transmission."

The city epidemiologist has spent time in Zimbabwe researching AIDS. One study in that country found a 2.5 percent annual infection rate among factory workers. In Zimbabwe today, UNAIDS estimates that 1 in 4 adults is HIV positive.

As world attention shifts to the catastrophic spread of AIDS in Africa, troubling signs of a rekindled epidemic are turning up in this American gay mecca, where it all seemed to have started nearly 20 years ago.

During the early 1980s, as many as half of the city's homosexual men were infected with the AIDS virus. Since 1981, more than 18,000 San Francisco residents have died of AIDS.

"The rise that we see at the anonymous test sites is only one piece of the picture," said McFarland. "We have 11 different indicators, and they are all pointing in the wrong direction."

Among the troubling trends:

- Rates of rectal gonorrhea, while far below levels in the 1980s, grew from 20 per 100,000 in 1994 to 45 per 100,000 in 1999.
- The proportion of gay men reporting that they always use a condom fell from 70 percent in 1994 to 54 percent in 1999.
- The proportion of gay men having unprotected anal sex with more than one partner grew from 23 percent in 1994 to 43 percent in 1999.

San Francisco Department of Public Health director Dr. Mitchell Katz said that McFarland's data are the first in the country to link increased incidence of HIV in-

fection to the well-recognized warning signals that had been tracked for the past five years.

#### LATEST TESTING EQUIPMENT

"Until this report, there were no data to say there are more infections," he said. "This is the first report of its kind in the country."

The data have additional scientific credibility because they are based on the use of new testing technology that allows scientists to separate new HIV infections from well-established ones. Using stored samples, the study found a 2 percent infection rate at clinics in 1996; a low of 1.3 percent in 1997, then the disturbing increase: 2.6 percent in 1998, 3.7 percent in 1999.

The reasons for the shift are many and complex. One factor is that with the use of powerful antiviral drugs that have slashed death rates, there are simply more people in San Francisco living with AIDS. "The citywide pool of potential infection is wider than it has ever been," said McFarland.

#### PATIENTS TAKE "DRUG HOLIDAYS"

Another factor may be the weariness some AIDS patients have with the lifelong regime of taking the drugs, which are unpleasant, inconvenient and toxic. Patients are taking "drug holidays" by choice, as part of clinical trials and by necessity. But when the drugs are not taken, evidence shows that the virus comes back, and with that, presumably, a greater ability to infect someone else.

Data also clearly show that the safer-sex ethic—condom use and a switch to oral instead of anal sex in the gay community—has been losing favor. Widely credited with halting the spread of HIV in San Francisco in the mid-1980s, safer sex practices are mocked by a skeptical younger generation and are openly flouted in the condom-free practice known as "barebacking."

"There is a responsibility issue here," said UC San Francisco's Coates, a gay man living with HIV. "The solution needs to come from within the community, and especially from within the community of HIV-infected people. It is up to us, the HIV-infected, to take charge of this issue as we have taken charge of our disease, and let the infection stop with us."

#### LETTING DOWN GUARD

AIDS prevention educators said the changing portrait of the epidemic has caused many gay men to let down their guard. "We don't have the visual reminders of what it can be like to have HIV," said Steven Gibson, program director for the Stop AIDS project. "We don't see the wasting syndrome. When was the last time you saw someone with KS lesions in the Castro?" Kaposi's sarcoma lesions were among the first opportunistic infections seen in gay men during the early years of the epidemic.

City AIDS surveillance experts recently convened a meeting to sift through the various reports from monitoring stations. Because California does not report the names of those who test positive for HIV—a step public health experts here fear would steer people away from testing and treatment—the city relies on a system of "consensus" forecasts to determine the HIV infection rate.

Throughout the 1990s, that rate is believed to have held steady at about 500 new infections a year. The estimate for 2000 has been revised upward to between 800 and 900, 575 of them gay men.

The worst year for new infections was 1982, when an estimated 6,000 were infected before the disease had a known cause. By 1984, San Francisco's gay community achieved an astonishing change in sexual behavior, and the infection rate was cut to 1,000 a year.

Given the drumbeat of studies suggesting that the prevention messages of the past are losing their power, experts said the discovery of a resurgence in infections is more sad than surprising.

"We may have squandered an opportunity to extinguish this epidemic," said McFarland.

Mr. BILIRAKIS. I might add, at this point, that the opening statements of all members of the subcommittee will be made a part of the record.

Ms. ESHOO. Thank you, Mr. Chairman.

Mr. BILIRAKIS. I thank the gentlelady.

Mr. Waxman, the other co-writer of the bill.

Mr. WAXMAN. Thank you very much, Mr. Chairman.

I am pleased that the subcommittee is moving quickly in its consideration of the Coburn/Waxman Bill, H.R. 4807, the Ryan White CARE Act Amendments of 2000. I want to thank you, Mr. Chairman, and Mr. Coburn, and our staffs: Roland Foster for Mr. Coburn, and Mr. Kim, on our side, and all the community organizations that participated in developing this legislation.

People with HIV/AIDS depend on Ryan White programs to stay healthy and to stay alive. Those programs must be reauthorized and should be refined to better combat the epidemic. That is why this legislation is so important, and why it must be enacted into law.

As the original author of the Ryan White Act, I know that bridging our differences is the only way we can defeat the AIDS epidemic. The legislation reflects many compromises. It is not perfect. It is not how either Dr. Coburn or I would have written it, left to our own devices. We both made significant concessions on issues of great importance.

But we cooperated out of our common commitment to fighting the epidemic and to reauthorizing Ryan White this year. Today, I am pleased that our bipartisan consensus bill promises a stronger, more decisive response to the epidemic than is possible today.

We will hear from witnesses about the terrible threat HIV/AIDS poses to our communities of color, to women, and to adolescents. We will hear that the epidemic is reaching into every community and every State in America.

Our bill responds to these changes in the epidemic. Services and care will be focused more than ever on reaching HIV positive individuals who are not in care, eliminating disparities in services, and access in helping historically under-served communities.

The legislation also begins to shift Ryan White funding and services toward the HIV infected population, not just individuals with AIDS. This is an important transition, and it will occur when reliable data on HIV prevalence is available.

The legislation makes other important reforms. It authorizes new funding. It enhances program quality and accountability. It calls for greater coordination of HIV care and HIV prevention efforts.

These are the reasons that most of the members of the committee are co-sponsors. It is the reason that I hope this support will lead to the speedy consideration of the bill and make passage this year possible. The Senate has already passed its bill by unanimous consent. So now it is up to us.

We cannot delay passage of this legislation. Today, as we speak, the world's experts are meeting the Durban, South Africa, to find new ways to fight an epidemic which has killed 18 million people, orphaned millions of children, and devastated entire countries.

The virus never rests, and nor should we, until this legislation is enacted into law, and this terrible disease is eradicated from the face of the earth.

Thank you, Mr. Chairman.

Mr. BILIRAKIS. I thank the gentleman.

I recognize Ms. Cubin, for an opening statement.

Ms. CUBIN. Thank you, Mr. Chairman.

Over the course of the last 10 years, we have seen the face of HIV and AIDS change dramatically, both in terms of its ability to

resist our drug fighting measures and our ability to sustain human life.

In a relatively short period of time, we have managed to make great strides in the fight against AIDS; progress that perhaps was inconceivable, 10 years ago.

This is naturally very encouraging to all of us. We can attribute much of this success to the Ryan White CARE Act, and to the many groups and individuals, who have fought tirelessly for this cause, many of whom are here with us today.

Thanks to powerful drugs and powerful drug therapies like the cocktail, people with HIV and AIDS are now living longer. While this is good news, and we all agree with that, I fear that many in this country now see AIDS as a chronic disease; one that has effectively been contained. I hope we are not all foolish enough to believe that.

Africa, as has been stated, is a prime example. Last December, I traveled through six different countries in sub-Saharan Africa, and I saw first-hand how unmerciful this disease is, and how uncontrollably it is spreading over there.

One in four people in that country, in that continent, or in that area, anyway, will die from the disease. Citizens there can not afford these expensive drugs, and they also lack the education, and have cultural obstacles to overcome, as well, in learning how to deal with this disease.

So let us not forget the toll that AIDS has taken, both in this country, and across the globe. We can not afford to become complacent in how we view this disease. That is why it is so vital that we reauthorize the Ryan White CARE Act, and more importantly, that we continue to improve upon it.

Ms. CUBIN. Thank you, Mr. Chairman, and I yield the balance of my time to Mr. Coburn.

Mr. COBURN. Thank you. Mr. Chairman, I would just ask unanimous consent to enter into the record an article from July 6, from the Bay Area Reporter, which lists exactly the raw data on the number of new HIV infection cases, and the fact that the "900" number is not an official Department of Health number.

Mr. BILIRAKIS. Without objection, that will be the case.  
[The information referred to follows:]

[Tuesday, June 6, 2000—Bay Area Reporter]

#### DPH BUNGLES ON HIV INFECTION RATE PROJECTIONS

by Terry Beswick

Sensational headlines circled the globe last Friday, June 30.

"S.F. HIV Rate Surges; alarming incidence of new infections raises fears of scourge to come," exclaimed the San Francisco Chronicle.

"New HIV infections soar in San Francisco," declared the Reuters new service.

"The percentage of new HIV cases in The City almost tripled from 1997 to 1999," said the Examiner.

Epidemiology oftentimes seems to be more of an art form than a science, at least in this town. And when it comes to the human immunodeficiency virus, San Francisco can seem like ground zero in the art of going out on a limb with disease forecasting.

San Francisco health officials were working overtime feeding juicy quotes and leaking unpublished data to the media last week—timed in advance of media frenzy surrounding next week's International AIDS Conference in Durban, South Africa, and also in the midst of heated negotiations in Washington, D.C. where Congress

is poised to cut Ryan White CARE Act funding to San Francisco due to a dropped AIDS caseload.

The crux of the stories was that DPH had reviewed a dozen or so indicators of the HIV infection rate in the city's gay community—in particular looking at the number of men who took the HIV antibody test at anonymous test sites—and found that the rate of new infections had doubled, or even tripled, in the last few years.

DPH officials were quoted saying that the estimated number of new infections among gay and bisexual men in San Francisco had gone up from 500 to almost 900.

Now, the same officials are singing a different tune.

"The 900 number is not an official DPH number... The comparison to sub-Saharan Africa is unfortunate," Dr. Willi McFarland, an epidemiologist with DPH told the Bay Area Reporter, referring to a quote he gave to the Chronicle: "These are sub-Saharan African levels of transmission."

While all the media reports quoted local officials stating that a chief factor feeding the higher infection rate was the fact that people with AIDS are living longer, creating a large pool of infected people, who in turn are infecting others, McFarland and DPH director Mitch Katz were later both instead emphasizing other factors, including the size of the gay population itself.

"The reason why the [900] number of new infections is a less reliable data point is that it's very sensitive to estimates in the size of the population," Katz told the B.A.R. "And while I have not yet reviewed the documentation that supports the 900 new infections a year, what I do know is that part of the increase from 500 is due to a better estimate in the size of the gay male population which increases its size, and also it may be that the community itself is growing in size. Obviously the more gay men or the more people at risk in general that you have, the higher the number of new infections."

No vote was taken at a closed May 24 meeting of AIDS prevention experts in San Francisco organized by DPH and the Center for AIDS Prevention Studies of the University of California at San Francisco. The meeting was convened in preparation for a "community consensus" meeting to be held this fall.

The stated purpose of the meeting was to consider revising the estimated number of new HIV infections taking place in San Francisco each year, based on data collected from a variety of sources.

It is no secret among prevention experts in San Francisco that there has been an increase in new infections in the gay and bisexual community, and a number of factors are feeding into this, chiefly "barebacking," or unprotected anal sex, behavior likely compounded by a concurrent epidemic of "party drugs" including crystal methamphetamine in the gay community. Prevention experts also point to a perception that new combination antiviral therapies have made the disease less threatening.

Using the new detuned ELISA HIV antibody test, which helps researchers determine whether an HIV infection has occurred before or after 129 days prior to the drawing of the sample of blood, researchers applied a complicated formula to come up with their estimates of the number of new infections that were leaked to the media sources and led to last week's headlines.

In an unreferenced abstract, among thousands to be published in conjunction with the Durban conference next week, McFarland reported a 2.1 percent infection rate at anonymous test sites in 1996; a low of 1.3 percent in 1997; 2.3 percent in 1998; 3.4 percent in 1999.

None of the media reports provided the raw numbers used to come up with these annualized percentages.

In 1996, McFarland told the B.A.R., of 3,505 gay and bisexual men taking the test, there were 25 recent infections.

In 1997, of 3,114 gay and bisexual men, 14 were recently infected.

In 1998—and here's the big jump leading to all the headlines—of 3,291 taking the test, 30 were recently infected.

In 1999, there was an unexplained drop in the number of gay and bisexual men taking the test at anonymous test sites, but according to McFarland, there were 1,995 who took the test, and of these, 26 had been infected within the last 129 days.

Yet Jim Dille, executive director of the UCSF AIDS Health Project, which operates the anonymous test sites in San Francisco under contract with DPH, noted about 9,000 people took the HIV tests in 1999. Of those, 127 tested positive, Dille said, though some of these may have been older infections, as the detuned ELISA test was not used.

At press time, DPH researchers had failed to explain why their numbers are apparently a subset of the total number taking the test at anonymous test sites.

"It's unfortunate that it got out before we were able to say as a group that this is our best estimate of the number of new infections," said Steven Tierney, director of HIV prevention at DPH. "I do think that the number has clearly gone up."

"Obviously we feel very strongly that there is evidence that there is increased HIV incidence in San Francisco which parallels the reports of increased unsafe sex behavior which we've made previously," agreed Katz.

Some of DPH's usual critics were quick to jump on the apparently sloppy, incomplete data leaked from DPH to the major media outlets last week.

"Instead of telling the public how many HIV tests have been administered in San Francisco and the consequent number of positive, negative and indeterminate results, UCSF and the DPH have concocted an elaborate mathematical method using numerous 'indicators' and employing novel detuned ELISA tests unapproved by the Food and Drug Administration to concoct HIV increases on paper," said David Pasquarelli of ACT UP/San Francisco.

"These increases are not real and the study's methods, indicators, and testing technology have never before been employed for this purpose nor verified by researchers unaffiliated with the AIDS industry," he added.

Mr. BILIRAKIS. I now recognize Ms. Capps for an opening statement.

Ms. CAPPs. Mr. Chairman, I commend you for holding this important hearing this morning, as we seek to reauthorize the Ryan White CARE Act.

Of course, today's topic is one of the most important public health issues facing our Nation. The Centers For Disease Control and Prevention estimates nearly 1 million Americans are living with HIV and AIDS.

While deaths from AIDS have declined in recent years, new infections have remained steady at 40,000 per year. Recent data suggests the infection rate is increasing again among traditional groups, but also especially among groups that have not heretofore registered much infection, and the dramatic drop that we saw for a time in the rate of deaths from AIDS has slowed down. All of these are matters of concern.

Clearly, the time is right for Congress to reauthorize the Ryan White CARE Act. I really appreciate the speediness with which this bill was crafted.

The CARE Act, of course, as has been mentioned, was passed in 1990, after the death of Ryan White, the young Indiana activist, who fought for an end to discrimination against people with HIV and AIDS. It is hard to believe that was 10 years ago.

It was reauthorized once in 1996, with overwhelming bipartisan support. The Senate, earlier this month as we know, unanimously passed legislation reauthorizing the CARE Act. Now it is time for the House to act.

I am a co-sponsor of H.R. 4807, crafted by my colleagues, Henry Waxman and Tom Coburn. I do have some concerns about the bill, but I support it for these reasons. It builds on the Senate-passed version by adding improvements to Ryan White programs, focusing on eliminating disparities, assisting historically under-served communities, and bringing those individuals with HIV/AIDS who are not receiving treatment into systems of care and support.

It also enhances public participation, and ensures that planning councils conduct their business meetings consistent with the Sunshine Policies of the Federal Advisory Committee Act. H.R. 4807 requires administrative simplification and increases funding overall in the Ryan White programs.

Finally, the bill begins to shift Ryan White funding and services, as we have heard, toward the HIV-infected population, and not just individuals with AIDS. This is an important transition, and an ex-

ample of how a funding stream needs to keep pace with changing demographics, a model which I believe you give to the wider health community.

Mr. Chairman, just yesterday, I heard from Jane Breckward, from Santa Barbara Health Care Services, and this is in my district. I have worked with her for many years. She works, on a daily basis, with members of the community who benefit greatly from Ryan White funding.

She spoke in especially strong support of Title II and Title III funding. Title II funding allows for food services for people in the community, living with HIV and AIDS; programs such as Meals on Wheels and food banks. It also provides for housing, counseling, help with emergency housing, first month rent, utilities, transportation; basic expenses that can determine if someone will be able to afford a place to live.

Title III funds are used for early intervention, helping those who have been diagnosed navigate the options available to them during this most terrifying time in their lives. These funds can help with medical care, education, dental care. They also help those diagnosed understand their insurance options.

In Jane's words, Ryan White funding is really about local control. This program requires that we do a needs assessment every year, so that we have a very targeted, specific idea of how the population we serve is changing, and how the funding is being utilized.

I believe that Ryan White is the Federal Government at its best, really, referring to local expertise, but providing that needed helping hand with targeted Federal funding.

So, Mr. Chairman, although not perfect, as has been mentioned, even by the co-authors, I support this legislation, and hope that the subcommittee will schedule a speedy markup, so that we can move it to the floor for a vote.

Thank you and I yield back the balance of my time.

Mr. BILIRAKIS. I thank the gentlelady.

Mr. Deal, for an opening statement.

Mr. DEAL. Thank you, Mr. Chairman.

Certainly, the issue of AIDS continues to be a plague on mankind; not only in this country, but across the globe. This past week, I met with a constituent of mine who had lost three family members. They are victims of a portion of the AIDS epidemic that has not been adequately addressed by Congress.

The mother was given tainted blood back in the 1980's. As a result of that and the fact that she was never informed of this, she and two of her minor children died of AIDS, as a result of that.

So there are many facets to this issue of AIDS and the problems associated with it. I will expect to be introducing other legislation very soon that will address those innocent victims who were never informed that they were given tainted blood back in the 1980's, in order to try to compensate them, in part, for some of the problems that have been associated with this.

But I thank you for holding the hearing on this facet of the AIDS problem today. I yield back.

Mr. BILIRAKIS. I thank the gentleman.

Mr. Green, for an opening statement.



Mr. GREEN. Thank you, Mr. Chairman, for calling the hearing today. I want to thank both Representative Waxman and Representative Coburn for their work on this important issue. As a strong supporter of the Ryan White CARE Act, I hope that we will reauthorize this program this summer.

As you know, Texas has the fourth highest number of AIDS cases in the United States, after New York, California, and Florida. In the Houston metropolitan area, it is estimated through 1998, there were 7,580 persons living with AIDS; cumulative cases through 1997 were 16,955.

The epidemic is changing dramatically in the Houston area. According to a needs assessment conducted last year, well over 80 percent of the persons living with AIDS are male. From 1992 to 1997, the number of newly diagnosed cases among females increased 94 percent, while the number of males decreased 23 percent. However, in 1997, there were over three times more men who progressed to an AIDS diagnosis than women.

Newly diagnosed AIDS cases in the Anglo community have decreased. African Americans have surpassed Anglos in the number of newly diagnosed AIDS cases each year, and data suggests growing needs within the African American community.

Heterosexuals represented between 14 and 16 percent of the cases in 1998, which is an increase of about 20 percent since 1994. A majority, 55 percent, are female; and a majority of those females are African American.

The Ryan White CARE Act addresses the urgent concerns of my constituents and helps bridge the gaps so that this epidemic can be slowed and ultimately stopped.

Since its enactment in 1990, the CARE Act has directly benefited hundreds of thousands of individual clients who have HIV. Over the years, the program has helped build an infrastructure that enables many people with HIV to assess a comprehensive continuum of care.

In recent years, the development of new treatments has resulted in reduction in the AIDS death rate. This increased longevity among people with HIV has contributed to an increased demand for the HIV care infrastructure.

In my district, Ryan White providers have experienced from 30 to 40 percent increases in the number of new patients. This increase is understandable, given the success of new treatments, when coupled with support services.

If the United States is to continue to meet the challenges represented by this complex epidemic, it is essential that we support innovative and flexible solutions to solve our Nation's AIDS' problem.

In closing, I hope to also co-sponsor a bill when the impact on the Houston area is available, especially from GAO projections. The Ryan White CARE Act, itself, was created in this spirit, and is an essential component in our Nation's fight against HIV and AIDS. Hopefully, it will be reauthorized immediately.

Thank you, Mr. Chairman. I yield back my time.

Mr. BILIRAKIS. I thank the gentleman.

Mr. Burr, for an opening statement.

Mr. BURR. Thank you, Mr. Chairman. I will be very brief.

As an original co-sponsor of this bill, I want to applaud the work of Dr. Coburn and Mr. Waxman, in working out the differences, with the real belief that we can move forward and pass this bill as quickly as we possibly can.

I yield back the balance of my time.

Mr. BILIRAKIS. I thank the gentleman. That certainly is our intent.

Mr. Towns, for an opening statement.

Mr. TOWNS. Thank you very much, Mr. Chairman.

Let me also commend my colleagues, Congressman Waxman and Congressman Coburn, for this outstanding job that they have done.

However, as I look and I see in terms of some of the problems that we are having with the formula, and also the hold harmless provision, I really feel that you might have an opportunity here to fight for some additional funds.

There is a surplus that we talk about, from time to time. I think that if we have a surplus, I do not know of a better place to use it than here. We are talking about life and death. We are talking about people that are dying.

We have many people that can not get the therapies that are available. They can not afford it. In some instances, there is no access.

When you look at all of this, and we think about the fact that yes, it is changing, and we know that, I do not feel that we are actually doing the kind of things that we need to do in order to make certain that we are doing the best job.

I want to applaud my colleagues for their creative thinking. I think they have done a great job in this area. But I do believe that this is the time and the opportunity for us to fight for additional dollars, because the surplus is out there. I can not even call it a surplus until we put more money in programs like this.

So, Mr. Chairman, I want you to know that I stand ready to fight for additional funds, along with this legislation. I think that if we do that, then with the hold harmless provision, the people will not be so frightened by it, because what we are talking about here is targeting resources.

Even though the problem is great, and even if we targeted resources, we are still leaving a lot of people out. I do not think we should leave anybody out.

So, Mr. Chairman, let me yield back. I would like to ask for permission to put my entire statement in the record.

Mr. BILIRAKIS. Without objection, that will be the case.

[The prepared statement of Hon. Edolphus Towns follows:]

PREPARED STATEMENT OF HON. EDOLPHUS TOWNS, A REPRESENTATIVE IN CONGRESS  
FROM THE STATE OF NEW YORK

Chairman Bilirakis and Ranking Member Brown, and my fellow colleagues, today's hearing is of the utmost importance to many in America. When most of us first learned of Ryan White HIV/AIDS was a very different disease than we know it to be today. Years ago when individuals were diagnosed with HIV infection it was an automatic death sentence. People once diagnosed marched on a straight course from being positive, to developing full blown AIDS, then dying. Today, with the development of new treatments such as combination therapy and better understanding of the disease, people are living longer, fuller lives and are not moving into full blown AIDS as readily. These are the wonderful developments that are happening, but there are still some very troubling problems that we must deal with.

Let me illustrate by telling you what the HIV epidemic in New York State looks like. Approximately 141,000 AIDS cases have been reported and approximately 56,000 New Yorkers are living with AIDS—almost 19 percent of the national total. **There are 8,200 living AIDS cases in Brooklyn alone.** Of those living with AIDS three quarters of them are minorities, and 25% are women. This is just the beginning of the picture of HIV disease in New York. **The estimate of the number of people living with HIV, beyond those with AIDS is 75,000-115,000.** These numbers are truly frightening to those of us who have been continuously working hard to slowdown and stop this epidemic.

This five-year reauthorization period allows us to take a look at where we are in the epidemic and make **vital**, but **careful** changes to the Ryan White Care Act. I want to acknowledge the work that my colleagues Congressmen Waxman and Coburn have done on this bill. But I have a few concerns that I want to make sure are fully discussed about this important piece of legislation. There has been ample discussion, sometimes not always civil, about the “hold harmless” provision in title one of the bill. The provision is meant to do just what it says and help areas be held harmless should there be a shift in funding so that patients who need these vital services can continue to be cared for.

Concerns have been expressed to me about targetting provisions meant to decrease funding to particular localities. I think we all need more money, but the hold harmless provision is there to help us all. Admittedly New York City has been assisted by this provision in the past. As our cases of living AIDS decrease and we do an even better job of keeping people alive with HIV without them moving into full blown AIDS we could possibly need the hold harmless provision. I think we should take another look and develop one that more closely mirrors the Senate version. None of us wants to be in a position of drastically decreasing funding for any locality.

\$1.6 billion were appropriated for FY 2000 for the Ryan White Program. We should be talking about raising all the EMAs to the per patient level of San Francisco, not redistributing \$8 million dollars between 51 EMAs.

Let's move cautiously with some of the changes we are intending for the better which may give us unintended consequences.

I look forward to some enlightening testimony from our invited witnesses.

Thank You.

Mr. BILIRAKIS. Ms. DeGette, for an opening statement.

Ms. DEGETTE. Thank you, Mr. Chairman.

I want to add my congratulations for having this hearing. I apologize that I will be running in and out, because I have another hearing going on at the same time.

I look at this reauthorization as both good and bad news. The good news is, of course, thanks to improvement in the care and introduction of the new drug therapies, there has been a dramatic decline in AIDS death rates over the last few years.

Also, due to prevention efforts and, again, the drug therapies, the number of pediatric AIDS cases resulting from mother to child transmission fell by 78 percent between 1994 and 1999.

However, as we all know, the success of these drugs has led people to a sense of complacency, particularly among our Nation's youth. Some believe that the epidemic has peaked, and so that makes it harder than ever to reinforce the message of prevention. According to the Centers for Disease Control, there are 40,000 new infections each year in the U.S., and half of those cases are among young adults and adolescents.

I hope to hear today what efforts we will be taking to address, as Jeanne White, who is Ryan White's mother, said, “. . . the threat HIV poses to the future of our young people.” In addition to pursuing a more focused strategy on the Nation's youth, I also would hope that the witnesses today would address the issue of maternal and child health.

I have noted the inclusion of language in this bill that targets funding to States that have imposed mandatory HIV testing of all

newborn infants, or have required testing of all newborn infants under which the attending obstetrician for the birth does not know the HIV status of the mother or the infant.

I think that this mandatory testing may be essential in some States. However, in States like Colorado, my own State, we have been part of the successful national trend, through prevention and voluntary testing, to dramatically reduce the transmission of HIV from pregnant mothers to infants.

Last year, there was not a single child born in Colorado that had HIV. So as a result, and having come out of the Colorado legislature, I can say I think it is highly unlikely that a legislature like Colorado's would ever pass legislation to require mandatory testing of all new infants.

Yet, by not doing so, under this legislation, Colorado, because of its great success, would be ineligible to apply for 75 percent of the set-aside funding in this legislation for prevention efforts.

I know a lot of people do not expect me, as a fairly liberal Democrat, to be such a Federalist. But I really question whether it is the best use of our resources to require all States to have mandatory HIV testing, when maybe it is not appropriate in some States like my own State, where it might be more appropriate in some other States.

Often, at the Federal level, we pass policies that have an unintended consequence. In the CHIP program, for example, we have separated pregnant women from infants, as only children are eligible for the program. This may be the first time that pregnant women have been separated in such a manner, and it makes little public policy sense particularly when, as a Nation, we need to be concerned about other issues.

So I would like to ask the witnesses today to talk about whether we should provide additional resources to all States, without preference, to implement outreach and education to at-risk pregnant women about the need to know their HIV status, to provide safe and confidential testing, and then provide them with comprehensive and accessible perinatal care to address the issue of perinatal transmission of HIV. That is what Eugene Jackson, who is going to testify today, says.

I would like to know whether Federal policy should be changed to allow pregnant women to receive coverage under the CHIP program, so they can have access to care that can further reduce mother to infant HIV transmission, a prevention measure, and other important health care issues like infant mortality.

I have other issues, as well, Mr. Chairman, but in the interests of time, I would just like to again say thank you for holding this hearing. I know there are a lot of important issues that we are going to discuss. I yield back the balance of my time.

Mr. BILIRAKIS. I thank the gentlelady.

[Additional statement submitted for the record follows:]

PREPARED STATEMENT OF HON. TOM BLILEY, CHAIRMAN, COMMITTEE ON COMMERCE

Mr. Chairman, thank you for having this hearing today. I would also like to salute Dr. Coburn and Mr. Waxman for their work.

The Ryan White CARE Act should address the health care necessities of all Americans living with HIV/AIDS equally, without prejudice to their race, sex, or place

of diagnosis. But, some Americans living with HIV/AIDS are treated more equally than others.

Clearly, the funding allocation of the Ryan White CARE Act needs to get a dose of common sense. Our public health system needs to be brought up to date in light of the latest scientific understanding of the epidemic.

But in the year 2000, advances in HIV treatment have slowed the progression of HIV disease for infected persons on treatment and contributed to a decline in AIDS incidence. These advances in treatment, as well as factors like the rapid spread of HIV among populations not well served by AIDS prevention efforts, have rendered AIDS surveillance data significantly less valuable in identifying trends in the incidence of HIV infection or the impact of the epidemic on the health-care system.

I note that both the Commonwealth of Virginia and the State of Michigan began mandatory confidential reporting of HIV back in 1989. According to Loretta Davis-Satterla, the Director of the Division of HIV/AIDS-STD with the Michigan Department of Community Health who testified before the Subcommittee on Health and Environment on May 11, 2000, "Confidential HIV reporting has greatly enhanced Michigan's ability to rapidly and effectively respond to the dynamics of this epidemic... In contrast to AIDS case surveillance, HIV case surveillance provides data to better characterize populations in which HIV infection has been newly diagnosed, including persons with evidence of recent HIV infection. Compared with persons living with AIDS, those reported living with HIV infection in Michigan are more likely to be women and African Americans."

It is imperative that the Ryan White CARE Act be reauthorized to provide the incentives to move public health in the right direction so that the HIV/AIDS epidemic can be tracked more accurately, and appropriate funding and information about this disease be better directed.

Mr. Chairman, I thank you again and I look forward to the testimony this morning.

Mr. BILIRAKIS. I believe that completes all the opening statements, so we will call on Dr. Fox to come forward at this point. Claude Earl Fox, M.D., M.P.H., is Administrator of the Health Resources and Services Administration.

Dr. Fox, your written statement, as per usual, is a part of the record. We will turn the clock, since you are representing the administration, to 10 minutes. Do the best that you can in that regard. We appreciate your coming forward, sir. Please proceed.

**STATEMENT OF CLAUDE EARL FOX, ADMINISTRATOR,  
HEALTH RESOURCES AND SERVICES ADMINISTRATION, AC-  
COMPANIED BY JOSEPH O'NEILL, ASSOCIATE ADMINIS-  
TRATOR, BUREAU OF HIV/AIDS, HEALTH RESOURCES AND  
SERVICES ADMINISTRATION**

Mr. FOX. Thank you, Mr. Chairman. If it is permissible with the Chair, I would like to ask Dr. Joe O'Neill, who is head of the HIV/AIDS Bureau, to join me at the table.

Mr. BILIRAKIS. By all means, without objection, that will be the case.

Mr. FOX. I want to thank both Congressmen Coburn and Waxman for putting this bill together, and the committee, for this hearing. The CARE Act certainly literally and figuratively has been a lifesaver for millions of people in this country with HIV and with AIDS.

As you have already heard, the epidemic is changing over time. We are seeing an increased number of minorities, an increased number of women, an increased number of youth, and an increased number of uninsured, as have the treatments, that have changed drastically, even since the last passage of this act.

The administration is, as I said, very appreciative of this bill. There are a number of areas in the bill that we think go a long way toward enhancing the care to people with AIDS.

I would like to run through quickly some of those areas. I will keep my comments brief, because I know the committee wants to leave time for questions.

The first is that we are very supportive of the use of epidemiological data and the collection and use of the sero-prevalence data in determining how we appropriate funds, as well as how services are provided.

We agree with the drafters of this bill that it certainly gives us a much more current reflection of where the epidemic is headed. We think, again, it is very appropriate to use, in a variety of areas, looking at unmet needs, allocation of funds, et cetera.

We appreciate the emphasis on the early intervention activities. We would very much like, as this bill suggests, to be able to target early intervention activities, both in Title I and Title II testing, counseling, and referral, like we do in Title III, presently.

On the new supplemental Title II awards, again, we are very supportive of these. We do have some concerns about how they are constructed, but we are supportive of the concept. I, personally, come from a very rural State, and I understand the issues that are of concern to the committee here.

On the new Title III Capacity Grant Program, we know that as the epidemic moves into minority communities more than it has in the past and into under-served communities, we have to look at ways for getting services where they are not there now. We think the Capacity Grants will help do that.

The issue around partner notification, we are supportive of, to provide additional resources for the Centers For Disease Control, in making that available to States. I was the State Health Commissioner in one of the first States to implement partner notification.

We are supportive of the emphasis on quality assurance and outcomes and, again, agree with the committee that we need to do more in this area. We need to look at process. We need to look at outcomes, as well. I also compliment the committee on proposing additional resources to make that available.

The expanded authority for making sure that we translate science to practice through our AIDS education training centers and with providers, again, we think is very appropriate.

The issues of accountability have been raised. The GAO has looked at fraud and abuse in this program and has, for the most part, given the program a clean bill of health. There have been some areas where there have been problems, but they said, overall, we had adequate controls. We do support the audit requirements that are in this bill. I think they help to assure accountability.

The relationship that this bill establishes between support services and medical services, we think, is very appropriate and very essential. We look on this as medical services being the hub and the support services being the spoke. Again, we think that it will improve access to care. Then, finally, the increased resources to CDC for both surveillance and for evaluation, we think is very appropriate.

There are some areas of concern on the part of the administration. I would like to run through these quickly, as well.

The first is the use of Ryan White funds in the area of community prevention, broad-based prevention. Let me hasten to say, we are very supportive about prevention and very supportive of coordination between prevention and care.

However, we would like to make sure that whatever bill passes Congress that the prevention issues are tied, at least as far as Ryan White grants are concerned, to the provision of primary care.

The expertise in my agency is in care. It is not in surveillance and prevention. We have a number of things that we are doing right now with CDC that I would be glad to elucidate to this committee. But, again, we support the issue of prevention. I think we would like to see, at least as far as Ryan White is concerned, that it be tied to primary care.

The second area of concern is the requirement for mandatory testing of newborns. The administration has a very high priority on the prevention of mother to child transmission. We think this is something, obviously, that needs to receive a great deal of attention. But we agree with the OIM that testing should be universal and routine, but not mandatory.

We are supportive of grants to States to increase prevention activities to reduce transmission, but we think funding should not be dependent on States having to enact mandatory testing laws.

The next area that we have a concern about is the administrative requirements around the competitive Title II supplemental grants. We, again, agree in concept around the supplemental grants.

Having, again, spent the majority of my career at the State and local level, we feel that there probably is another way to get this done that would be less administratively burdensome to the States, allow us to use some of the existing information that States provide in their Title II applications, and accomplish the ability to get money out there, but in a way that is administratively least burdensome.

Then the final area of concern is around the FTE issue. Let me say, to begin with, that HRSA has placed an extremely high priority on additional FTEs for this program. We only have about 175 FTEs running a \$1.6 billion program. We think we are pretty administratively lean in this area.

However, the requirement to mandate a 20 percent increase in FTEs, particularly when there is not a guarantee for increased funding, we have some concern about.

We have placed, for the Agency, a priority in the AIDS area for any new FTEs that we are able to get funding for, from Congress, for the HIV/AIDS Bureau. I have been very public about this.

We also, during the last year, have allocated some existing FTEs from our current programs into the HIV/AIDS program. So I think we have made good on trying to make this a priority.

But we are very concerned that this really removes the discretion on the part of the Agency, and mandates an increase in the level of funding that we think there may or may not be funding there to enact. If that is the case, then we will have to take further FTEs from some of our other programs. So we have concerns about that.

Let me say in closing that, again, we think that in general this bill goes a long way to improve the care for people with AIDS, and the appropriate allocation and utilization of Ryan White funding. Again, we appreciate your having us, and to have the opportunity to discuss this bill.

[The prepared statement of Claud Earl Fox follows:]

PREPARED STATEMENT OF HON. CLAUDE EARL FOX, ADMINISTRATOR, HEALTH RESOURCES AND SERVICES ADMINISTRATION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

#### INTRODUCTION

Good morning, Chairman Bilirakis and Congressman Brown and distinguished members of the Committee, thank you for inviting me to discuss H.R. 4807—"the Ryan White CARE Act Amendments". It is my pleasure to be here today. As you know, the Ryan White CARE Act has played an important role since its enactment in 1990 in providing health care to hundreds of thousands of individuals living with HIV/AIDS in the United States.

I also want to thank you, Chairman Bilirakis, for convening this hearing today on this important piece of legislation, and I want to express our gratitude to Congressmen Coburn and Waxman and others for their leadership on this very important bill.

The Ryan White CARE Act is more important now than ever. The HIV/AIDS epidemic is much more complex in 2000 than it was in 1990. The volume of cases has increased and the affected population has changed. We estimate that between 800,000 and 900,000 Americans are now living with HIV/AIDS. Of these cases, about a third of the individuals have been diagnosed and are in care; another third have been diagnosed but may not be receiving ongoing care for their HIV disease; and the final third have not been diagnosed and, therefore, are not in care.

We must continue to make available quality primary health care and services needed to adhere to difficult treatment regimens if we are to continue our progress against this relentless disease. While our prevention efforts are geared towards reducing new infections, those living with the disease must be able to access care and services that have proven to be life-saving and cost-effective. To ensure this, the reauthorization of the Ryan White CARE Act is one of the Administration's top legislative priorities. The Administration is very committed to carrying on the tradition of care and treatment of individuals with HIV/AIDS through the continuation of this program. We look forward to working with your subcommittee as the bill moves through the House.

This morning, I would like to offer you an overview of the HIV/AIDS epidemic in the United States, and highlight the importance of the CARE Act in providing treatment and services to individuals living with HIV/AIDS.

#### OVERVIEW OF EPIDEMIC

The HIV/AIDS epidemic has taken a heavy toll in the United States since it was first identified in 1981. Over 733,000 Americans have been reported to have AIDS, and more than 430,000 men, women and children have lost their lives to the disease. The total number of Americans with HIV infection is not available; however, that number is expected to be greater than the current number of individuals diagnosed with AIDS. Though it began as a disease of gay white males, African-Americans and Hispanics now have AIDS infection rates several times higher than that of whites.

In 1998, white Americans were about 72% of the total U.S. population, but represented just 34% of newly reported AIDS cases. African Americans—almost 13% of the U.S. population in 1998—were 45% of new AIDS cases that year. New AIDS cases among Hispanics, who were just over 11% of the population in 1998, accounted for 20% of the U.S. total that year.

Women represented 23% of all new AIDS cases in 1998; 60% of these newly infected women were African American, 20% Hispanic. Two of every three women living with HIV are believed to be mothers of at least one minor child. These women are, on average, poorer than HIV-positive men and are more likely to be unemployed and more poorly educated than their male counterparts.

Youth are increasingly at-risk for HIV infection. About a quarter of all people now living with HIV were infected as teenagers. As many as half of all new HIV infections occur in people under the age of 25, and a quarter of these new infections occur in youth under age 22.



## ADMINISTRATION COMMENTS ON HR 4807

The Administration supports the efforts made in developing legislation that addresses the many complex issues in delivering services to low-income, uninsured, and underinsured persons with HIV/AIDS. We believe that many provisions in the bill improve upon the existing Ryan White CARE Act and offer expanded opportunities to develop new ways of ensuring access to life-saving, quality HIV health care services. The bill authorizes communities to reduce the number of new infections and improve the health and well-being of all Americans impacted by this disease, regardless of race, gender, income, geographic location, and availability of health insurance coverage. Many of the changes in the bill address concerns raised by the House minority caucuses.

Overall, the House bill refines the focus of the Ryan White CARE Act by:

- improving access to care for persons who know their status but are not in care;
- improving the quality of health and ancillary services delivered by Ryan White providers; and
- increasing accountability of federal funds.

The Administration supports efforts in H.R. 4807 to improve access to HIV care services. The legislation establishes an important precedent in the use of epidemiological data and evaluation studies to improve the understanding of HIV's impact in local communities. It also allows grantees to assess the demands for services for persons not in the care system and establishes comprehensive planning strategies to address their complex medical and social service needs. H.R. 4807 also recognizes the importance of early intervention services—such as testing, counseling, and referrals—as a means to identify, educate, and provide services to persons currently outside of the health care system.

Through the establishment of new Title II supplemental awards and a new Title III capacity grant program, H.R. 4807 authorizes federal resources in rural and historically underserved communities in an effort to resolve inequities in the capacity and infrastructure of critical HIV-related services. Furthermore, a new partner notification program provides additional resources to public health agencies currently conducting partner notification programs. These efforts, building on the current CARE Act, will significantly improve access to important health services for low-income, underinsured, and uninsured persons with HIV.

Quality improvement activities help ensure access to appropriate health care services. Ryan White providers should also assess the effectiveness of their programs in delivering care to all persons with HIV. This bill provides direction in establishing quality programs and allows additional resources to be used to meet this challenge. In addition, the bill expands the authority of the program to develop and implement new medical consultation activities to ensure timely and appropriate dissemination of HIV clinical practice standards.

The Administration has been active in making sure grantees receive ample training and technical assistance to improve their ability to account for federal funds. The Administration supports the audit requirements included in H.R. 4807. Additionally, the bill establishes an appropriate relationship between social and health services to give all clients adequate access to the benefits of medical care. It authorizes funds for the Centers of Disease Control and Prevention (CDC) to work with State health departments in establishing surveillance and evaluation systems to monitor program goals. Overall, these provisions make effective use of federal, state, and local investments for providing essential HIV services in the most cost-effective and appropriate manner.

While the Administration supports the provisions I just discussed, we have concerns with the following key issues:

- the use of Ryan White funds for community-based prevention programs;
- State grants for newborn testing and mandatory testing laws; and
- extensive additional administrative requirements.

The proposed expansion of Ryan White CARE Act funds to include broad community-based prevention activities duplicates existing programs and may comprise existing prevention efforts. Activities such as case finding, surveillance, social marketing campaigns, and partner notification programs—have been funded and administered by the CDC. Among Federal agencies, the CDC has the greatest knowledge of the administrative and fiscal requirements needed to manage community-based prevention activities. HRSA's HIV/AIDS Bureau, which administers the Ryan White CARE Act, has neither the expertise nor the administrative capacity to oversee the appropriate use of prevention activities in communities. Allowing CARE Act funds in Titles I and II to support community-based prevention planning and resource allocation would realign the CARE Act's fundamental purpose. This realignment could result in an increasingly disorganized prevention system, with few checks and bal-

ances to ensure compliance with established guidelines, procedures, or monitoring activities. It may also redirect resources away from valuable Ryan White Care and treatment activities.

The Administration sets a high priority on activities that reduce the transmission of HIV from mother to child. Since publication of the ACTG 076 findings in 1994, a concerted national effort has brought the benefits of HIV testing and appropriate treatment to as many women and children as possible. As reported to the CDC, the numbers of pediatric AIDS cases peaked in 1992 at 947 cases. By 1998, the number had declined by over 70% to just 228 cases.

Last year the National Academy of Sciences/Institute of Medicine (IOM) released its study on preventing perinatal transmission in the United States. One of the study's recommendations urged the adoption of a national policy of universal HIV testing. As part of this policy, the IOM supported HIV screening as "routine with notification" and the right of refusal; the education of prenatal care providers; improved provider practices; performance measures and contract language to ensure available health services; improving coordination of care with HIV providers; and increasing utilization of prenatal services. The IOM, however, did not support mandatory testing laws. Instead, they warned that:

"The logic of this approach is unclear; newborn testing may confer benefits for HIV-infected newborns, but cannot prevent perinatal transmission. If the national goal is to prevent HIV transmission from mothers to children, the federal government should support, not undermine, prenatal testing and other State-based prevention efforts. The Ryan White CARE Act Amendments of 1996, paradoxically, could have the opposite effect."

The Administration supports continued funding for Section 2625 to provide grants to States for State-based prevention efforts directed at reducing transmission and to providing health services to those who are infected. But funding should not be dependent on a State's enactment of "mandatory testing" laws or as a condition of the Ryan White grant award. This most important issue must be met with sound policy and a long-term commitment.

The inclusion of staffing requirements is prescriptive. Funding and staffing levels for program management activities are appropriately set through the Executive Branch budget formulation and Congressional appropriation processes. The Administration does not support the use of Congressional statute to supplant this decision-making process.

Other requirements included in H.R. 4807 create an unprecedented administrative burden. Although the Administration supports the concept of establishing supplemental grant programs within the existing Title II base and ADAP programs, administrative requirements in the legislation establish a separate and burdensome process for HRSA's HIV/AIDS Bureau and for State health department officials. State agencies currently submit extensive information for annual awards. The Administration supports a streamlined process that allows for the allocation of resources based on standardized measures and a minimal application process based on currently available State data.

Once again, we welcome the opportunity to work with you as H.R. 4807 moves forward. I thank you for holding this hearing, and I am happy to answer any questions.

Mr. BILIRAKIS. Thank you very much, Doctor.

By the way, certainly I would not ask you personally to stay after your testimony, but I think it would be great if your office had a representative here, to pay attention to the other panelists.

Mr. FOX. I plan to stay for the full hearing, Mr. Chairman.

Mr. BILIRAKIS. We find that that is usually very helpful.

Sir, your testimony singled out increased resources for partner notification as an important prevention tool for the program. I would ask you how important of a tool is it to identify at-risk individuals, and get them into prevention and care programs?

Mr. FOX. Well, we use this tool in other areas, and it has worked. The State I was State Health Commissioner of, the State of Alabama, has had partner notification in place. Actually, we started sero-prevalence reporting in, I think, 1987.

They are currently, I think, finding about two partner contacts per HIV case that is reported. I talked to the State epidemiologist

there, yesterday, in fact. I think they feel it is quite effective, and is helpful in trying to reduce instances of AIDS.

Mr. BILIRAKIS. Well, thank you for that, because I am sure that we all agree that the best care is prevention; is it not?

Mr. FOX. Right.

Mr. BILIRAKIS. To address the challenge of insufficient value being derived from AIDS data alone, the CDC and the Council of State and Territorial Epidemiologists, CSTE, have recommended that all States and territories include name surveillance for HIV infection as an extension of their AIDS surveillance activities.

On May 11 of this year, Surgeon General Satcher testified before this subcommittee that he agreed with CDC and CSTE.

Do you agree with the Surgeon General, CDC, and CSTE?

Mr. FOX. Yes, sir, the Department supports the sero-prevalence reporting. We think, again, it gives us a better idea of where the epidemic is going.

I would say, however, that we would need to have appropriate confidentiality provisions. In fact, in Alabama, when we implemented the sero-prevalence reporting, we actually deferred it for a year, until we could get a bill passed through the State legislature that gave us some additional confidentiality protection around that reporting. But, in general, yes, we are supportive of that.

Mr. BILIRAKIS. Are you suggesting that in the process of supporting it that you feel that there should be either additional legislation or some sort of language included in this legislation?

Mr. FOX. I think that States should look at what their own State laws provides. There may be some model legislation around confidentiality that States could look at and consider.

I suspect there is some variability around the levels of confidentiality protection around this information. I think, as any public health surveillance system, the long-term quality really depends on the ability to protect the confidentiality of the clients involved.

Mr. BILIRAKIS. Well, I certainly would agree. I know we all would agree with that.

Well, I would like to invite you to coordinate with this committee, in terms of any suggested legislation additions or revisions.

That is very significant, because if we all agree that name surveillance for HIV infection should be an extension of the AIDS surveillance activities then we ought to be working toward that end, altogether.

Mr. FOX. We look forward to working with you, Mr. Chairman.

I do think the CDC recommendation, or at least I know what was discussion in the Department, did allow a provision for States that wanted to have a unique identifier, to do so.

There are some States, I think, that are providing their sero-prevalence data in that fashion, although certainly, some States will do it one way, and some are doing another.

Mr. BILIRAKIS. All right, I would yield to Mr. Brown at this time.

Mr. BROWN. Thank you.

Dr. Fox, you stated in your testimony that you had some concern that community prevention was not sufficiently tied into primary care. Could you elaborate on that, and suggest what kinds of changes you would like to see us make?

Mr. FOX. Well, I think some of the changes in this bill will increase the prevention efforts. One, the ability for us in Titles I and II to do testing, counseling, or referral, will help improve our prevention efforts.

We also want to link, and there are some provisions in this bill that allow Ryan White grantees to link with a number of other outside providers like emergency rooms, primary care clinics, both HRSA grantees and otherwise, for referral into the program.

But I think my main concern is that HRSA's general emphasis for the Department is in access to care. CDC's emphasis is in surveillance and prevention.

What we would like to see is the ability to expand the provisions of Ryan White to include those activities around prevention, testing, and counseling, that help tie and bring people into care, and will hopefully help prevent some cases, as well.

But the primary emphasis on the part of Ryan White has been care. I think we want to make sure that the emphasis continues to be care, primarily, in the four Titles of Ryan White.

On CDC's activities and expertise in prevention and surveillance, again, we worked with them. We have a number of examples that we are working with them on both looking at development of data instruments, technical assistance, evaluation, joint planning.

But I think that the primary activities around prevention probably should be funded through CDC, and the primary activities around care should be funded through HRSA, although there is some local overlap.

We are just speaking to make sure that the continued emphasis of this act is care, with some expansion around prevention, mainly with it tied to the issues of primary care and access to primary care for people with AIDS.

Mr. BROWN. Thank you. I have one last question. We will hear later from a witness concerning the case of fraud in Puerto Rico. Should we be concerned about a wide-spread or systemic problem in care programs?

Mr. FOX. Absolutely not. There were a number of unfortunate incidents. The GAO has looked at them. They can comment for themselves. But the GAO report that has been provided to Congress basically said there is no wide-spread fraud and abuse within the Ryan White program.

The Inspector General, within the last couple of years, has looked at specifically the Title I and Title II programs. In those reports, they did state that they felt that there were adequate controls in place. So we do not feel there is widespread fraud and abuse.

Having said that, I do not think it is in anybody's interest to not have appropriate accountability and controls within this program. So we are very supportive of the audit provisions in this bill.

Mr. BROWN. Thank you, Mr. Chairman.

Mr. BILIRAKIS. Dr. Coburn, to inquire.

Mr. COBURN. Welcome, Dr. Fox.

Mr. FOX. Thank you.

Mr. COBURN. And Dr. O'Neill, it is good to see you both.

You know, I am somewhat perplexed, Dr. Fox. Is prevention not the best care we can give these folks?

Mr. FOX. Mr. Coburn, this is a somewhat grey area.

Mr. COBURN. It is not grey to me. Obviously, it is grey to you, but it is not grey to me.

Mr. FOX. I am not implying that prevention is grey. I am talking about the issue that I am trying to raise with this committee around prevention, and the issue in the Ryan White Act.

As I said earlier, we are very supportive of prevention. We think that for prevention there needs to be a significant emphasis on the part of the administration and the Congress. The Ryan White CARE Act, however, has been primarily about care.

Mr. COBURN. I understand that. My question to you is, the people who are treating people with HIV, who have their confidence, can impact prevention more than anybody else in this country.

To say that we have a concern about spending prevention dollars as we interface with people that are infected, and I am not talking about behaviors that are truly under the CDC's prerogatives; I am talking about where people are interfacing care, that is where we make the impact, in terms of behavior change, condom use, and the other things.

I am extremely concerned that you are concerned that we should not be having a strong emphasis on prevention, as we interact to help those people.

Mr. FOX. Mr. Coburn, we support and agree with you on having a strong emphasis on prevention. I think the thing we want to ensure is that the prevention activities are tied to the issues of care. We think there are a lot of opportunities, whether somebody is HIV positive or negative, and hopefully, if they are negative, to intervene and prevent them from becoming positive, in the course of all the things we do around the Titles of Ryan White.

Mr. COBURN. But the other side of that, if somebody is positive, to make sure they do not give it to somebody else. That is called prevention.

Mr. FOX. Exactly, and we are in agreement.

Mr. COBURN. Okay, the other question I have, you know, there is a lot of controversy on this grant process for funding for perinatal transmission.

New York State has debunked all the negatives that everybody was screaming about, when they said we should not do the Baby AIDS that we did. In fact, they passed what we tried to pass in 1996. They have seen a marked, marked reduction. As a matter of fact, that is where the majority of perinatal decrease has come, from the State of New York.

If I read your testimony correctly, it is the Clinton Administration's position that New York should not have access to somewhere between \$2 million to \$4 million a year, in terms of perinatal transmission funds under our grant program.

You know, they have been successful. I would like to introduce for the record, if I might, with unanimous consent, a report from the State Department of Health in the State of New York, where there has been no decrease in people accessing perinatal care. There has been no decrease in those coming forward to care, because they have mandatory testing, if the mother's status is not known.

The point is, we had one of the members of our committee who said Colorado had not had one perinatal. They do not know, be-

cause they do not test. They have no knowledge of how many babies were born in Colorado with HIV. They know the ones they tested were not. But they do not know the ones that were not tested were not.

The point is, there is no reason, with what we know today, for babies, we can prevent all transmission to babies, through somebody who delivers in a facility. I mean, the drug therapies are there. So I guess the question is, why would you not want a State, which has done the most to reduce perinatal transmission, not to get an extra \$2 million to \$4 million through this program?

Mr. FOX. Mr. Coburn, without speaking specifically to the money going to New York State, let me just say that I think we would like to see this issue addressed with the least amount of Governmental intervention possible, to get the job done.

We believe that routine universal testing will do that. The IOM has recommended that. The two societies that provide the primary care for mothers and children, AAP, the American Academy of Pediatrics, and the American College of Obstetrics and Gynecology, have recommended it. We agree with that.

We also believe that there are a couple of other examples where universal routine screening, in a de facto sense, results in virtually everybody being screened. One is the issue of newborn screening.

I think, for the most part, a number of States have different programs. But we have the ability, in some States, to opt out of that; parents do. We believe that, for the most part, 99.999 percent of infants get screened.

We believe that if this administration, this Congress, this country, moves toward routine universal screening for HIV, and it indeed becomes routine, which we believe it can, that with informed decent, that people have the ability to opt out, that the practical effect will be very few will. Again, we think that we can accomplish that with probably less Governmental intervention than a mandatory bill.

Mr. COBURN. I would remind you, Dr. Fox, this is not mandatory. This is optional for the States. It just says, if you are going to do what is best for babies, then we are going to help you do it. If you are going to stop all perinatal transmission, we want to help you do that, and it is optional.

Mr. FOX. Excuse me, my understanding, Mr. Coburn, is if you tie the funding, at some point, to whether or not a State has a provision, it is like the highway funds. I mean, States are going to have to do that to get the money.

I think, again, we feel that there should be informed consent. It should be routine. It should be universal. But we also agree with the IOM report, that it should be mandatory.

Mr. BILIRAKIS. I would suggest that it may be a good idea to maybe have a quick second round with Dr. Fox, because I know this is a very complex issue.

But without objection, the letter that Dr. Coburn referred to of February 3, from the State of New York to him, will be made a part of the record.

[The information referred to follows:]



# STATE OF NEW YORK DEPARTMENT OF HEALTH

Corning Tower The Governor Nelson A. Rockefeller Empire State Plaza Albany, New York 12237

Antonia C. Novello, M.D., M.P.H.  
Commissioner

Dennis P. Whalen  
Executive Deputy Commissioner

February 3, 2000

Hon. Tom A. Coburn, M.D.  
Member of the Congress  
U.S. House of Representatives  
429 Cannon House Office Building  
Washington, DC 20515

Dear Dr. Coburn:

I have been asked to reply to your letter of December 20, 1999, to Commissioner Novello on prevention of perinatal HIV transmission. The perinatal HIV prevention program at the New York State Department of Health is a comprehensive program that seeks to address many of the steps in the chain of events leading to an HIV-infected child, as identified by the Institute of Medicine in their 1998 report, "Reducing the Odds" (Figure I, enclosed).

An important initial prevention step in this chain of events is to ensure that all pregnant women are enrolled in prenatal care in the first trimester and ideally, have received pre-conception care. Significant program resources, including new funding from the Centers for Disease Control and Prevention (CDC) for outreach to high risk women, are directed to this purpose in New York State. In 1997, 10.6% of all women (according to birth certificate data) and about 10% of HIV positive women in New York State (based on chart reviews) received no prenatal care.

The second step in preventing perinatal transmission is to ensure that all women in prenatal care receive HIV counseling and testing according to the U.S. Public Health Service guidelines. In New York State, regulations adopted in 1996 (10 NYCRR sections 98.2(c), 405.21(c), 751.5(a)) require all regulated prenatal care providers (hospitals, clinics, HMO providers) to provide HIV counseling with a clinical recommendation to test, to all prenatal care patients. Such counseling and recommended testing is the standard of medical care in New York State, even for physicians not practicing in regulated settings. The Commissioner has sent a letter to this effect to all prenatal care physicians in the State. The letter was co-signed by the State Medical Society and the State chapters of professional organizations in pediatrics, obstetrics and family practice. The Department also monitors prenatal HIV counseling and testing rates at all regulated health care providers through review of a sample of prenatal care medical records. These data are fed back to providers and technical assistance is provided to improve delivery of these services.

For women who test HIV positive or are known to be HIV positive during pregnancy, the State has developed a network of specialty providers for perinatal HIV medical care. These providers ensure that each HIV positive pregnant woman has a full evaluation for combination

antiretroviral therapy depending on her own health status, prescribe zidovudine (ZDV) according to the PACTG 076 regimen for prevention of perinatal transmission, and make referrals for housing, adherence counseling and other supportive services that these women may need to adhere to therapy. New York Medicaid and the State's AIDS Drug Assistance Program (ADAP) provide reimbursement for pharmaceuticals for women in need so that all women have access to preventive therapy. The Department, with the help of a panel of expert clinicians, publishes detailed clinical treatment guidelines for antiretroviral therapy and prevention of perinatal transmission, and also funds a network of clinical education providers across the state to train clinicians caring for HIV positive patients.

In the area of newborn HIV testing, Public Health Law (PHL) 2500-f, signed into law by Governor Pataki in 1996, created an exception for newborn HIV testing to the informed consent requirements for HIV counseling and testing in the HIV Confidentiality Law, PHL Article 27-F. It also directed the Commissioner to develop a comprehensive program for the testing of newborns for HIV. This program is further defined in State regulations (10 NYCRR Subpart 69-1) and has gone through two phases. During the first phase, beginning on February 1, 1997, the Department's Newborn Screening Laboratory began HIV testing of all newborn filter paper specimens submitted for metabolic screening without removing patient identifiers and returning those test results to the birth hospital for transmittal to the pediatrician of record. Prior to that time, blinded HIV newborn testing had been done for epidemiological purposes since the late 1980's, and mothers had been encouraged to receive a copy of their newborn's HIV test result since May 1996 (over 90% of mothers consented to receive their newborn's HIV test result in that program).

Universal newborn HIV testing has resulted in the identification of all HIV-exposed births. HIV test results from the newborn testing lab are often not available until two weeks after birth. These results are not timely enough to permit administration of ZDV therapy to prevent HIV transmission, but can be used to counsel women to stop breastfeeding which may prevent some cases of transmission. Newborn testing has allowed hospital and health department staff to ensure that over 98% of HIV positive mothers are aware of their HIV status and have their newborns referred for early diagnosis and care of HIV infection. In less than 2% of cases have women not been located to receive newborn HIV test results and have their HIV-exposed newborns tested for HIV infection. The Department is in the process of reviewing all pediatric medical records up to 6 months of age for HIV-exposed infants born starting in 1997 to determine the quality of HIV care they are receiving and to document the perinatal HIV transmission rate.

The second phase of the newborn HIV testing program began on August 1, 1999. It added regulatory amendments to Subpart 69-1 to require expedited HIV testing in the hospital delivery setting in cases where an HIV test result from prenatal care is not available. This addition to the newborn testing program was undertaken because of evidence that perinatal HIV transmission may be reduced by initiating ZDV therapy during labor or soon after delivery, even if ZDV was not taken during prenatal care (NEJM 1998;339:1409-1414). Hospitals now screen all women admitted for delivery for HIV test results from prenatal care. If a prenatal HIV test result is not available, the hospital must provide the woman with HIV counseling and expedited testing if she consents. If the mother does not consent to HIV testing of herself, the hospital



must perform expedited testing on her newborn immediately after birth under the authority of the comprehensive newborn HIV testing law. Expedited tests must be available as soon as possible, but in no case longer than 48 hours. Provisional data from the initial months of the program show that 32 HIV positive women/newborns were identified for the first time by expedited testing at delivery, permitting early initiation of ZDV in most cases; 12 additional positive cases could have been identified if all hospitals had fully implemented the program, and 17 false positive HIV results occurred. False positive preliminary HIV tests occur because Western blot confirmation of preliminary positive results cannot always be obtained in the 48 hour time period. The Department has encouraged the Food and Drug Administration (FDA) to approve additional rapid HIV tests in the near future to alleviate this problem. A significant benefit of the expedited testing program is that delivery hospitals are now working more closely with their prenatal care providers to ensure that HIV counseling and testing is done at the appropriate time during prenatal care and that the test results make it to the delivery hospital.

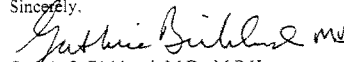
Rates of participation in prenatal care in New York State are monitored by review of birth certificate data. These rates have been increasing gradually over recent years. Currently about 80-85% of women delivering report first or second trimester prenatal care and about 10.6% of women report no or unknown prenatal care. There has been no detectable change in prenatal participation trends through 1997 that might be related to the newborn testing program. Anecdotally, we have not heard of problems in this regard. The analysis is currently being updated through 1998. Prenatal care for HIV positive women is also being examined through review of prenatal charts. Limited numbers of women whose HIV status was identified by newborn testing are being interviewed to see what the impact of newborn testing has been.

Ultimately, the goals of the perinatal HIV prevention program in New York are to reduce perinatal HIV transmission to the lowest possible level through: ensuring access to prenatal care for all pregnant women; ensuring counseling and testing of all women in prenatal care; ensuring that all HIV positive pregnant women are offered and adhere to ZDV therapy and are evaluated themselves for combination therapy and other care needs; ensuring that HIV test information is transferred in a timely way to the anticipated birth hospital; and, conducting expedited testing in the delivery setting for all women/newborns for whom prenatal HIV test results are not available.

Newborn testing will continue to be conducted at the Department's Newborn Screening Laboratory to ensure that all HIV positive newborns are identified and referred for care. The newborn testing data also provide valuable, timely information to monitor the epidemiology of perinatal HIV and prevention efforts.

Thank you for your interest in our program. Please let me know if I can provide any further information.

Sincerely,

  
Guthrie S. Birkhead, M.D., M.P.H.  
Director, AIDS Institute

Enclosure

SUMMARY

**Reducing the Odds**  
**Preventing Perinatal Transmission of**  
**HIV in the United States**

Michael A. Stoto, Donna A. Almario, and  
Marie C. McCormick, *Editors*

Committee on Perinatal Transmission of HIV

Division of Health Promotion and Disease Prevention

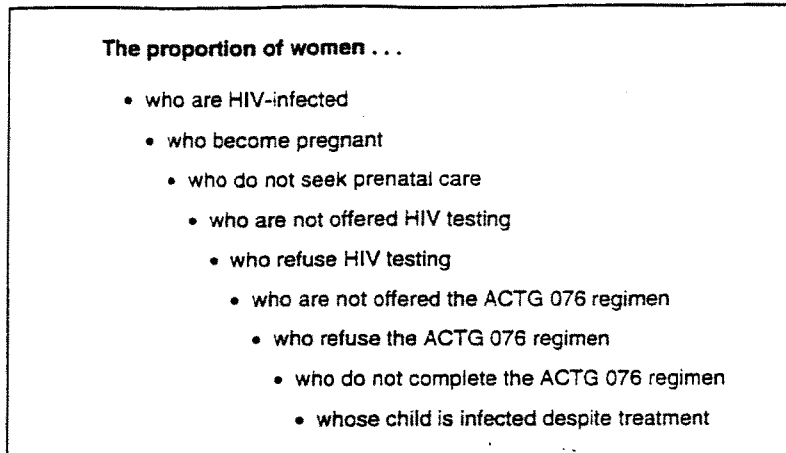
INSTITUTE OF MEDICINE

Board on Children, Youth, and Families

Commission on Behavioral and Social Sciences and Education

NATIONAL RESEARCH COUNCIL  
INSTITUTE OF MEDICINE

NATIONAL ACADEMY PRESS  
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**FIGURE 1** The chain of events leading to an HIV-infected child.

alpha-fetoprotein), and other conditions (blood type and diabetes). Newborn children are routinely tested for errors of inborn metabolism and other problems. Although most of these outcomes are rare, a positive test result triggers interventions that benefit both mother and child, and these efforts have been responsible for substantial improvements in health and well-being.

As these screening programs have been implemented over the years, a substantial body of experience has been gained. In practice, when screening is conducted in contexts of gender inequality, racial discrimination, sexual taboos, and poverty, these conditions shape the attitudes and beliefs of health system and public health decision makers as well as patients, including those who have lost confidence that the health care system will treat them fairly. Thus, if screening programs are poorly conceived, organized, or implemented, they may lead to interventions of questionable merit and enhance the vulnerability of groups and individuals. Through the experience with public health screening programs, a series of characteristics of well-organized public health screening programs has evolved (Wilson and Jungner, 1968).

The committee's summary of the relevant characteristics is as follows:

1. The goals of the screening program should be clearly specified and shown to be achievable.
2. The natural history of the condition should be adequately understood, and treatment or intervention for those found positive widely accepted by the scientific and medical communities, with evidence that early intervention improves health outcomes.

Mr. BILIRAKIS. Ms. Eshoo, to inquire.

Ms. ESHOO. Thank you, Mr. Chairman, and thank you, Dr. Fox. How does it feel to have your surname in the news, every day, with a President with that same surname?

You probably noticed that in my opening statement, I asked unanimous consent, and it was granted, that the San Francisco Chronicle article be made part of the record.

That article outlines that after years of declining or stable levels, the number of new HIV infections almost doubled between 1998 and 1999.

Over the weekend, at the International Aids Conference in Durbin, South Africa, Helene Gail of the CDC expressed her profound disappointment that this upswing in HIV infection in the United States could be a nationwide trend.

I have a couple of questions to pose to you about that, and then a second question. First, does this not suggest that communities like those in the Bay area will be facing more challenges in caring for people with HIV disease during the next 5 years, rather than fewer challenges; and does a loss of up to 25 percent of care funds make sense, given this trend?

My second question is, over the last 5 years, we have witnessed a dramatic drop in AIDS deaths, while this news is tempered with the estimated 40,000 new infections each year, and the growing number of people living with HIV and AIDS. Based on your viewpoint, do you believe that any metropolitan area or State has sufficient resources to meet the needs of the growing number of people living with HIV and AIDS?

So could you address here your answer to my questions?

Mr. FOX. Thank you. I am in a terrible position, because my mother told me never to get in the middle of family squabbles.

Ms. ESHOO. Well, with all due respect, I do not think that this should be diminished as a family squabble.

Mr. FOX. No.

Ms. ESHOO. We are having a hearing on legislation that contains provisions that the State of California, which is the Nation's State, suffers significant cuts. Then it is accelerated in the area that I point to.

Mr. FOX. We have supported, and continue to support, the issue of looking at the formula. One, let me say that we support having a hold harmless. The administration has not taken a position on the amount of hold harmless. Again, we have not said whether it is 2 percent, 10 percent, or 25 percent. So I think on that issue, we do not have a position on what the amount of the hold harmless should be.

We do believe that communities should be protected from huge funding shifts. I would agree with you on that.

The whole issue of the epidemic, where the epidemic is going, and the new AIDS cases, I think one of the issues that I would like to raise is, we have not, in this country, done a good job of figuring out how to do behavioral modification.

I think we have done an excellent job in education. But we do not know how to modify behavior. I think this is one of the dilemmas with the whole epidemic.

The second is that we have, as you know, continual new waves of people becoming sexually active. I think the education process is one that as people grow into adulthood, we have new waves of generations that we have to educate.

I do not think we know how to do this very well. I think, again, we are supportive of appropriate prevention services. We are supportive of trying to do everything we can to reduce the number of people who become HIV positive.

But, again, I think that the issue of the funding, and how that plays out within the cities, the States, the communities, other than taking a position that we support hold harmless clauses and we do not want to see huge disruptions in funding, we have taken no position beyond that.

Ms. ESHOO. Well, if you do not want to see huge disruption, relative to funding, then a 25 percent cut, I think, would fall into that category of a huge disruption.

That is why I said in my opening statement that I think that the Senate has it right. Because it does not do the harm that a 25 percent hold harmless would do.

Is there anything else that you want to add about the upswing, in terms of cases?

Mr. FOX. I think, again, this whole epidemic is changing. I think the issue of whether it is HIV fatigue; whether it is the fact that we have people, because of the new treatments, and because of the improved therapies, thinking that they are somehow immune to contracting HIV; but I think it is probably a combination of all of those.

Ms. ESHOO. All right, thank you, Mr. Chairman. I yield back.

Mr. BILIRAKIS. I thank the gentlelady.

Mr. Bryant, to inquire.

Mr. BRYANT. Thank you, Mr. Chairman.

I want to be as quick as I can here. I have three questions, Dr. Fox, that I will ask you. I would ask, if you would, get copies of these questions, and answer these in writing, and submit these as a late filed exhibit to your testimony today.

The first one is, as you know, women and minorities are represented in higher proportions in HIV cases reported, than in AIDS case reports. Do you believe that changing the Ryan White CARE Act funding formulas to take into account HIV cases, rather than just AIDS cases, would be a more effective way to better target funding and address some of the health disparities that exist for minorities?

No. 2, what are the challenges of HIV care in rural America, and what is your administration doing to expand services to rural areas?

No. 3, in the GAO testimony, they indicate that "the distribution of discretionary grants has generally mirrored the pattern of the formula grants." I want to know, how can that be, if the discretionary grants reviewed and awarded by your administration are on merit and degree of need?

The last question I would like to ask you, and I would like a short answer, if I could, in your testimony, you indicate, and I agree with Dr. Coburn, about the prevention aspects of this. But you indicate that the CARE Act funds, by allowing these funds to

provide early intervention and prevention services, that would re-direct resources away from the valuable Ryan White care and treatment activities.

Yet, last month, your administration used funds from this Ryan White CARE Act to pay for over 100 individuals to fly to the Virgin Islands for a meeting.

Another example, the San Francisco AIDS Foundation has over \$5 million in salaries alone, last year. This year, it has spent some \$55,000 in an unsuccessful effort to defeat a ballot initiative, which had absolutely nothing to do with HIV and AIDS.

Do you view such expenses as this trip to the Virgin Islands and this ballot initiative as appropriate use of these very valuable funds?

Mr. FOX. Mr. Bryant, I do not have enough information on the ballot initiative to comment on it. We obviously do not support money being spent for that.

The meeting that you allude to in the Virgin Islands was a meeting of 150 Ryan White providers. These were physicians. As you know, the Virgin Islands and Puerto Rico have three of the six highest AIDS incidents areas in this country. We rotate the meetings that we provide for the providers.

This meeting was held in the summer. It was held at a time when the hotel rates were about comparable to hotel rates within the U.S.

We also used it as a mechanism to raise visibility for the AIDS issue in Puerto Rico and the Virgin Islands. If the Virgin Islands were a State, it would have a higher Medicaid match than Mississippi. The amount of poverty and the incidents of disease there is tremendous.

So, again, this was not 100 to 150 bureaucrats. This was a group of physicians who were there, learning about AIDS therapies. There were visits to the clinics there in the Virgin Islands. Again, we think that with those types of meetings, we try to rotate those meetings in high incidents areas.

Mr. BRYANT. Let me cut you off here, because I want to yield some time. But very quickly, you might want to expand on your answer on that question, too, if you feel like you need to. Also, if you could reference the salaries in the San Francisco office, being at \$5 million last year.

At this point, I yield the balance of my time to Dr. Coburn.

Mr. COBURN. Dr. Fox, I think the San Francisco AIDS Foundation really does a pretty good job. I am not out to get them in the hold harmless.

You know, we have seen an almost 14 percent to 15 percent annual increase in HIV funds, through the Ryan White CARE Act. Mr. Porter, who chairs the Appropriations Committee, is dedicated to make sure that we are funding an increased amount, and then we have done supplemental money on ADENT.

I guess the thing is, even under our hold harmless, the San Francisco AIDS Foundation will probably not see an actual dollar decline. Plus, they have a reserve, right now, of \$7 million in the bank.

So do you think it is a legitimate concern that the hold harmless, as we have outlined, is too aggressive? In your opinion, is it too much?

Mr. FOX. Mr. Coburn, if I were to comment on that, it would be strictly my personal opinion.

Mr. COBURN. Well, I would like to have your personal opinion.

Mr. FOX. I would rather not give it.

Because I am here representing the administration. I am not here representing myself.

Mr. COBURN. Well, let me ask you another question. If we could have the posters put up. I think this will show it for everybody.

Mr. BILIRAKIS. The time has expired. Now we are going to have a second round.

Mr. COBURN. All right, then I will withdraw that. We will just leave the posters up.

Mr. BILIRAKIS. Thank you.

Mr. Waxman, to inquire.

Mr. WAXMAN. Thank you, Mr. Chairman.

Mr. Fox, we are pleased to have you here today.

I do want to correct the record. The bill does not mandate testing of newborns. It does provide funding for those States that do chose to mandate those tests. It gives them some priority over some of the funds.

We tried, in this legislation, to build on HRSA's efforts by focusing the CARE Act on eliminating disparities in services and access, and on helping historically under-served communities. Would you say the bill is successful on this score?

Mr. FOX. Yes, sir, very much so, and we think this will give us the ability to better target the resources.

Mr. WAXMAN. I know we have a broad agreement with you on virtually the entire bill, but I want to discuss the remaining concerns that you have raised.

First, I share your concern with duplicating prevention and surveillance activities between CDC's programs and Ryan White. For example, at one point, there was a proposal to authorize surveillance activities through Titles I and II. But we decided against creating competing funding streams for precisely the reasons you have mentioned.

In fact, the intent of the House bill is two-fold: to fund outreach activities, consistent with early intervention services, and to promote greater coordination of HIV prevention and treatment services at the local, State, and Federal levels.

I know you strongly support these policies. I think it is very important that we make clear that this is the intent of the House bill. Would your staff be willing to join us in clarifying through report language the policies underlying the House provision?

Mr. FOX. Absolutely, Congressman.

Mr. WAXMAN. I also appreciate your concerns about the Title II supplement. I know it will be difficult for HRSA to administer these programs efficiently. But as we will hear today, the States and the community groups feel strongly that awarding the supplemental grants, based on "severe need" is a very important goal.

We want you to be able to use as much existing data as possible in this process, but also push forward the process of developing

standard, quantitative criteria. We asked you to do this in 1996, and we want you to try again. It is very important, and it would create a more equitable grant program. Can we count on your agency to help us accomplish these goals?

Mr. FOX. Mr. Congressman, we will work with you on this in any way we can.

Let me just state that we are administratively extremely thin in the AIDS Bureau. We have a small number of FTEs for the amount of work that we are doing. On the planning grants, we have 60 new planning grants, based on last year, working with the CDC.

We support the issue of supplemental grants. I think we want to do it, though, in the least administratively burdensome way possible, both for us and for the States. But we look forward to working with this committee and the House on that.

Mr. WAXMAN. You expressed concern about the perinatal HIV program. I share your beliefs that voluntary outreach counseling and testing of pregnant mothers does more to prevent perinatal transmission than mandatory newborn testing.

But the provision expands funding for the existing Perinatal HIV Grant Program from an existing \$10 million to \$15 million. There is a set-aside for mandatory newborn testing States. But unexpended set-aside funds are also rolled over, back into this \$15 million. Most importantly, all of the \$30 million can be used for voluntary outreach counseling and testing of pregnant mothers.

Given that and the support of the Title IV community groups, would you not agree that this provision goes a long way toward providing additional resources for voluntary counseling, testing, and outreach of pregnant mothers?

Mr. FOX. Yes, sir, we would agree.

Mr. WAXMAN. We will hear later today from a witness concerning the case of fraud in Puerto Rico. You have already indicated that we have these kinds of situations. But do you think we ought to be concerned about widespread or a systemic problem in the CARE Act programs?

Mr. FOX. Mr. Waxman, the GAO has looked at it and said there is not a widespread problem. We, again, agree with the provisions in this bill. We want to do everything that we can do within reason to make sure that these funds are well spent. But we do not believe that it is a widespread problem.

Mr. WAXMAN. You have had the opportunity to review the House and the Senate bills. We take a different approach to the new Title II supplement, making it broadly available, instead of limiting it to a small number of cities.

Is it not possible that States will want to use the funds in rural areas or towns, which are too small to qualify, under the Senate's definition of emerging communities?

Mr. FOX. Well, I think, actually, that is one of our concerns about the competitive process of the Title II supplemental awards, that some of the largest cities, who have the ability to put together a really shiny grant application, are going to be able to do that. If it is competitive, they may still end up with a big chunk of the money.

If the intent here is to get those funds out to rural communities, to under-served communities, those are often the communities that



have the least ability to put together a competitive award. We just think there are some other ways to get at it.

We support getting the money out there. There are a lot of communities in need. But I think we have concerns that a competitive process may actually keep us more where we are than where this committee wants to go.

Mr. WAXMAN. Thank you very much.

Thank you, Mr. Chairman.

Mr. BILIRAKIS. I thank the gentleman.

Ms. Capps, to inquire.

Ms. CAPPS. Thank you, Mr. Chairman.

I want to thank you, Dr. Fox, for your cooperation, your testimony, and for the impressive work that HRSA has done, working with this subcommittee in developing a bill.

This is my first opportunity, being in Congress, to be a part of a hearing on AIDS in this subcommittee. I spent a lot of years as a public health nurse in my community. I am very aware, when the Ryan White Act was first enacted, from the community's perspective. I would like to use my time to explore two areas and learn from you.

One is on the relationship between two Governmental agencies, in the area of prevention, if you would just get into the nuances of that a little bit more.

Your agency knows a lot about AIDS transmission and, of course, is part of the prevention activity. Yet, the responsibility of prevention belongs to CDC, as their mandate. But you do, certainly, cooperate in that area.

That is part of the ever-changing picture. It is challenging for me to get a grasp on how this population and the demographics have moved around in this brief 10 year period of Ryan White.

Then the second part is equally challenging, with the different disease entities, in terms of life lengthening, life span, and how that care gets translated into what kind of support does the AIDS patient need in our community, and to remind you of the compliment that Ryan White received from my local people, about it being a local partnership.

They feel immensely thankful that they can be part of the process of deciding where the dollars will go. So, again, it is a congratulations, but also a seeking to learn from you.

Mr. FOX. Thanks. As you alluded earlier, this is a local program. Two-thirds of the funding decisions are made locally, in Ryan White.

Let me just say quickly, and Dr. O'Neill may want to elaborate, we have a number of interactions with CDC. Since I have been HRSA Administrator, we have worked hard to try to make sure we had appropriate interface with both that agency and with the prevention services.

The first is, we have a number of activities that we have been working jointly on, looking at development of surveillance and data instruments across the two agencies. We are working on the joint evaluation projects. We are working on some joint best practices models, looking at the interface between prevention and services, and how to better do that.

Then, finally, we have been working on issues of locally how to get the services; in other words, how to have the two planning counsels work together and plan together in a way that brings together prevention and care.

Finally, we have an ongoing series of routine calls between our staff and CDC's staff, to talk about issues that we are working on. Dr. O'Neill may want to elaborate further, but we do have a lot of activities going on with CDC. We are going to continue to try to improve that, but in all areas, data, technical assistance, evaluation, local planning. We are working jointly with them.

Ms. CAPPS. Thank you. I guess in light of all of this, too, I will await to hear from your friend. With all the effort that has gone on in the last 10 years, it is really important that we stay on top of this now. We are concerned about our communities becoming complacent, and certain populations relaxing in their behaviors. That is, to me, a real challenge and a real message that I hear today, in the questions to you.

Mr. FOX. Let me just say, again, we want this to be a CARE Act with a strong prevention component, linked to what we do around AIDS.

Mr. O'NEILL. I would just add that we are really treading in an area that this linkage between prevention and care is not one that I think there is any clear-cut, right answer to, at this point.

By that, I mean that from the point of view of a practicing physician, I absolutely agree with Dr. Coburn in that very effective prevention occurs and can occur in that one-on-one clinical setting. We very much feel that that is actually an area that HRSA has great expertise in.

When you think about what we do, most everything of what we do is about supporting one-on-one interventions between provider and patient. We are very committed and very interested in continuing to expand the ability in doing prevention in that area.

I think way on the other end, it is very clear that we do not do population-based, broad surveillance and large programs. But there is this area in the middle that I think, quite frankly, we are all trying to grapple with, as health professionals and as legislators, and everyone to try to figure out what is the optimal way, both to accomplish this, and what is the optimal structure between the different agencies that are going to do the best and most efficient job of accomplishing this goal.

These are areas where people of, I think, very good will, could have some disagreement. But the overall point is, I think, very clear, that we have got to do a better job in prevention, and that there is a tremendous area in this one-on-one clinician to patient setting, as you know, as a public health nurse, that you can really accomplish a tremendous amount, that you are not going to get with broad-based efforts.

Ms. CAPPS. I appreciate that, and I yield back.

Mr. BILIRAKIS. Thank you.

Ms. DeGette.

Ms. DEGETTE. Thank you, Mr. Chairman.

First of all, Dr. Fox, thank you for coming out to my district to see the Fitzsimmons Campus. I know they were very excited to have you there.

As a pediatrician, I think you have got a unique perspective on prevention strategies for youth. As you know, in my opening statement, I talked a little bit about the sense of complacency among our Nation's youth about the threat of HIV and AIDS.

I am wondering if you can talk briefly about what additional steps you think that we can take, as we talk about the future of the CARE Act.

Mr. FOX. Well, let me say first, we serve youth through all of the Titles of Ryan White, currently. We have a specific emphasis in Title IV on youth. We have just funded five new projects, trying to look at ways to get youth into care. We have some activities, a reach project with NIH, that we are working on, as well.

As I said, I think the bill to expand testing, counseling, and referral in Titles I and II will offer some opportunities to intervene with youth, as well as with others.

Then, finally, we have had some internal discussion. As you may or may not be aware, the Agency administers one of the Abstinence Programs within the Department. We have had some internal discussions about ways to link perhaps some of what we are doing in Ryan White with what we are doing in some of our abstinence sites. Obviously, if we are discussing abstinence with kids, we ought to be talking about the risk of HIV/AIDS.

So I think there are some opportunities there that we can take advantage of, with other grantees that we have. I think those are the things that we currently can do. Obviously, this is a huge area. You know the number of 50 percent of the new infections are among individuals under age 25. So this is a huge area of concern for us.

Ms. DEGETTE. Thank you, and let me follow up on another area that I am concerned about. That is the role of Medicaid in the CHIP programs, in providing increased access for people with HIV/AIDS.

I am wondering if you can talk about whether you think that role can be expanded, such as expanding coverage to pregnant women in CHIP, just as we have in Medicaid?

Mr. FOX. Yes, the administration is very supportive of looking for ways to work with States on ways to try to expand and get into family coverage, and to broaden the coverage. Certainly, we want to cover all the kids. But I think we are interested in going beyond that, in any way we can. So there are some things that are evolving within the Department right now that hopefully will impact that.

The second thing is, I would like to use this opportunity to say that one of the issues around ADAP in the Title II Ryan White funding, and one of the reasons that we have problems with significant waiting lists, limitations on medications, and others within the States, is the Medicaid policy.

In some States, it is very, very restrictive around services to people with AIDS. When that happens, it throws more demand on the ADAP Program.

So one of the things that we have not been able to mandate, because obviously, Medicaid is a State program, is to try to jawbone and encourage States to really look at what they are doing with their Medicaid programs, and to not limit the prescriptions to try

to maximize services to people with AIDS. Then we can use Ryan White, the ADAP funds, for those people that do not have Medicaid.

Ms. DEGETTE. Right.

Mr. FOX. So it is an important issue. It dramatically impacts the waiting list and the provision of services through the Ryan White CARE Act.

Ms. DEGETTE. Just to follow-up, it would seem to me that you really need that continuum of care for pregnant women. So if you are going to cover them, if they are eligible for Medicaid, similarly, if their child who is born may be covered by CHIP, it might be more effective to cover that pregnant woman under CHIP, as well.

Mr. FOX. Exactly, and let me tell you one other thing that we are exploring. That is the issue of trying to look at the interface, at the State and community level, between Ryan White funding, between Medicaid, and between Medicare.

Ms. DEGETTE. Good.

Mr. FOX. I think our goal ought to be to develop as seamless a system as possible, at the community level, for people with AIDS with the least amount of eligibility requirements. That is something where, again, I think that we have a lot of work to do in the Federal Government.

Ms. DEGETTE. Let me just interrupt for 1 second and say, do not forget CHIP in that equation, because what we are trying to do with that program is cover more and more kids who are slightly above the Medicaid eligibility limit. Part of the problem we have had in implementing that program is that it does not interface well with the existing issues.

Mr. FOX. Exactly, and there are huge opportunities under CHIP, as I am sure you are aware, to expand coverage for mental health services, for adolescents, and other types of services that are generally lacking for other parts of the population.

I think the ability to intervene there, in both HIV issues as well as other issues, is tremendous. Some States are taking advantage of it, and others are not.

Let me just mention one other thing that Joe just reminded me of. We have just put together the first text ever on the guide to clinical care for women with AIDS. We think this is going to be a resource to States, to communities, to grantees, in issues around maternal and child health in the issue of AIDS.

There has not been a textbook like this done. We are going to be publishing it in Spanish. Again, it is just one example of some things we are trying to do to help communities deal with this issue.

Ms. DEGETTE. Thank you.

Thank you, Mr. Chairman.

Mr. BILIRAKIS. Mr. Towns, to inquire.

Mr. TOWNS. Thank you, Mr. Chairman.

Let me begin by saying, are you pleased with these planning councils?

Was this asked before I arrived?

Mr. FOX. No, no.

Mr. TOWNS. Okay.

Mr. FOX. You know, I think that the planning councils fulfill a very important function with local input into how services are pro-

vided. What this bill and what this committee is going to do in the next iteration of Ryan White, we think, will continue to improve what the planning councils do.

The planning councils will be asked in this bill to tie the provision of care to the issue of unmet need. I think that we are very supportive in trying to define who is not being served in the community. We think that the planning council recommendations around care should be based on what the needs are in that community, and they are going to vary in every community.

We think that, again, there should be an emphasis on finding who is not in care, trying to get them in care, and then providing that ray of support services to keep them in care.

So I think that we feel the planning councils have fulfilled an important function. We support the provisions in this act that we think will empower planning councils to do an even better job in the appropriate allocation of resources within the communities.

Mr. TOWNS. How does this bill that we are discussing today address the concerns of the Congressional Black Caucus? As you know, they were concerned about access. They were concerned about community organizations. They were concerned about continuity.

To be specific, you know, one of the things that we saw with programs and we saw with funding is that you would sometimes spend a great deal of money, setting up a kitchen that would provide nutrition for clients, patients.

Then the next cycle around, they would not be funded. But in the meantime, you would put all this modern equipment in there to provide food services, and now they are not even funded. This becomes a waste of money, in the sense of the word. Because if they are not funded, and therefore the program does not operate. What happens to the equipment? It is just there.

So how does this address some of the concerns that the Congressional Black Caucus had?

Mr. FOX. Mr. Towns, I think it does address some of those concerns. The first is, I think the use of HIV prevalence data is going to push the services in the CARE Act more toward services to minorities. It is going to push the services more toward services to women. I think it is going to help us better target resources to where the epidemic actually is now.

The second thing is, this bill provides for a series of capacity grants that we can not currently do, that are going to allow us to be able to go into a minority community and work with the minority group, who perhaps wants to provide services, but does not have the capacity to do that now.

We can help them set up systems. We can go in and help them add another site to provide dental services in an African American community.

We do not have that capacity to do that in all the Titles of Ryan White. We think that this bill is going to give us the ability to do that. We are going to be better able to target funds.

Then, finally, the provisions that think around looking at quality and looking at outcomes is something that we are very supportive of, to make sure that every dollar we spent helps improve care in some way.

Then, finally, there is the issue of tying, making sure that all of the services that are provided in your community are tied to enhancing somebody's care, and making sure that they get in care, stay in care, or get better.

This bill, again, supports that. We think it will help very much to make sure that resources are more appropriately targeted and will follow the epidemic.

Mr. TOWNS. Let me close by saying this. I have two more questions, but if I do it this way, maybe I can get it without asking those two other questions. Is there anything more that we should do? I am talking about this committee.

Mr. FOX. I do not know that I have a suggestion to say that the majority of the provisions of this bill, we are very supportive of. We think this bill really does reflect what we need to do with next iteration of Ryan White. We look forward to working with the committee on the provisions of this bill.

But I think, for the most part, this bill moves in very appropriate directions, as far as what we ought to be doing to make sure that these dollars are well spent.

Mr. TOWNS. Mr. Chairman, let me just indicate that I plan to send two questions in. I would hope that I could get an answer for them in writing.

Mr. BILIRAKIS. Oh, yes, without objection, that is always the case with our witnesses, anyhow.

Mr. TOWNS. Then let me yield back.

Mr. BILIRAKIS. I thank you.

Well, we are going to go into a very brief second round.

Let me ask you, Dr. Fox, your opening paragraph said the epidemic is changing. Ms. Eshoo and others have emphasized that. Ms. Eshoo has referred to the additional challenges that we are faced with now, because the epidemic is changing. Why is the epidemic changing?

Mr. FOX. Well, the epidemic is changing for a lot of reasons, Mr. Chairman. I think one is we have pattern of substance abuse in this country, that is providing for infection, in many instances, through heterosexual sex, that has taken the epidemic to the realm of women. We have, again, minority communities, for a variety of reasons that do not have access to care. So there are a number of reasons why the epidemic is changing.

But I think that we certainly feel that the CARE Act, and I think the GAO supports this, is providing funding to the populations that reflect where the epidemic is going.

Forty-five percent, I think, of all new infections are in African Americans. Twenty percent are in Hispanics. About two-thirds of all the care provided in the CARE Act, overall, is to minorities. We do a good job of that.

Mr. BILIRAKIS. All right, but I think that is the point. I mean, I have co-sponsored the CARE Act and am highly supportive of it. We all are. It is going to do an awful lot of good. So we are not talking either/or here.

But, you know, I have the feeling, based on your testimony, that we are not emphasizing enough the prevention. Forgive me, Ms. White, but I think she would rather have Ryan here with her now, rather than being here testifying for the Ryan White CARE Act. So

the Ryan White CARE Act is very helpful to Ms. White, and that is what it was intended to do.

You know, my personal opinion, honestly, is that we are not emphasizing prevention adequately.

Mr. FOX. Mr. Chairman, I think Dr. O'Neill may be able to elucidate it a little bit better than I did. But let me just say that we are strongly supportive of a CARE Act that has a strong emphasis on prevention.

But this is a CARE Act, and we want to keep the primary function on care, with a strong link to prevention, and to provide prevention. As Joe said, it is an issue that, again, we want there not to be any new AIDS cases.

Mr. BILIRAKIS. Yes.

Mr. FOX. But I think we want to make sure that we continue to provide the care and the resources to people that have AIDS, as we do that, and we have to do both.

But all we are saying is, our primary emphasis and our primary expertise within HRSA is care. We are not the experts in surveillance and data. We need to make sure that prevention is part of what we do, but this act is about care.

Mr. BILIRAKIS. Of course.

Mr. FOX. And, again, I do not think we are disagreeing. I am having difficulty clarifying my point.

Mr. BILIRAKIS. All right, I am going to yield the balance of my time to Dr. Coburn.

Mr. COBURN. Well, I want to go back to my charts there, for a minute. This information was supplied by GAO. It depends on which side of the Bay you are on, whether or not you get adequately funded. Because you can look at San Jose and you can look at Oakland, and then you can look at San Francisco.

What I would like for you to do is defend for me the funding for San Francisco at twice the rate of everybody else in this country per AIDS case. I would like for you to defend the administration's position that that is an adequate representation of what we ought to be doing.

Mr. FOX. Mr. Coburn, again, we agree that there is a need to look at the distribution of the funds. We do not take issue with that. There are a lot of inequities that exist within this country around how AIDS funding is provided.

But I want to say that when the GAO makes their report later, that there are even more issues beyond those elucidated in the GAO report. It includes the issue of local support. It includes the issue of Medicaid funding. It includes the issue of where we are putting our Title III grants. It is very complex.

I think, without trying to defend or take up any particular allocation here, we agree that it needs to be looked at, and we want to work with this Congress to do that. But we do not have a specific position on how the funding ought to be changed.

Mr. COBURN. Except the supplemental funds mirror that, in distribution, in every case. So the supplemental funds will be inordinately high in those areas that are inordinately high.

I guess the answer is, you can not defend that. Nobody really can defend it. The fact is that Ryan White funds have been going up, on an average, of 29 percent. The first year, in terms of hold harm-

less, is 2.5 percent, or 2.4 percent. This year, I believe, we have increased it 14 percent. So a net effect is, San Francisco will still see a net increase in dollars.

So, you know, what we need to do is to make sure that the black teenager in my district, who is HIV positive, has access to just as much, in terms of treatment, care, and longitudinal insight, as somebody living in the middle of San Francisco.

Mr. FOX. But that is what we are trying to do.

Mr. BILIRAKIS. The gentleman's 5 minutes is yielded to him now, as per the suggestion of Mr. Brown.

Mr. COBURN. Okay.

Mr. BILIRAKIS. So please continue for another 5 minutes.

Mr. FOX. We would agree with you, Mr. Coburn. I think we feel like you should not be disadvantaged by where you live, as to what kind of care you get. We agree with that.

Mr. COBURN. I want to just enter a couple of other things in the record. One is, I agree with the GAO. There is not tons of fraud in this.

I also want to compliment your agency. We have worked with them, and they have been fantastic, cooperative, giving us good insight, not afraid to tell us where we are wrong, and doing so in a manner that allows us to come to a conclusion. I think HRSA is one of the reasons we were able to work with such a good agreement with Mr. Waxman. I want to compliment your people for that.

But I would like unanimous consent to put this in, because this is just in Dallas. There were hundreds of thousands of dollars that one clinic wasted, that did not go to treat inner city blacks for HIV.

Mr. BILIRAKIS. Would the gentleman identify that?

Mr. COBURN. This is an article from the Dallas Morning News, dated June 16, 2000.

Mr. BILIRAKIS. Without objection, that will be made a part of the record.

[The article follows:]

## **FBI looks at AIDS clinic's spending**

### **'98 audit targeted use of U.S. funds**

06/16/2000

By Todd Bensman / The Dallas Morning News

The FBI is investigating findings in a Dallas County audit that a nonprofit South Dallas AIDS clinic misspent hundreds of thousands of federal dollars intended to benefit poor blacks, the region's hardest-hit victims of the disease.

The 1998 audit, which forms the backbone of an FBI investigation of the former Margaret K. Wright Clinic, has not been released publicly. However, four sources familiar with the audit said it found that the clinic rang up

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\$60,000 on psychic hotline calls and spent additional public funds on Neiman Marcus shopping trips and home appliances.

They said most of the expenses in question were billed to federal "Ryan White" grants administered to the clinic through the Dallas County Health and Human Services Department. Congress established that funding after a boy named Ryan White died of complications from the disease in 1990.

The FBI also is investigating allegations that the clinic bought expensive AIDS drugs that remain unaccounted for and applied federal funds toward treatment of patients who might not have existed, the sources said.

FBI spokeswoman Lori Bailey declined to comment on the investigation.

In addition to the FBI inquiry, the Texas State Board of Pharmacy is investigating allegations in the audit that the clinic mishandled prescription medications, board investigator Harrington Wallace said. He declined to discuss details of the investigation.

#### **Director's resignation**

Mythe Kirven, who founded the clinic in 1994, resigned as executive director in late 1998 when the audit findings were made known to the Dallas County Commissioners Court and the county Health and Human Services Department, which oversee distribution of federal grant money.

Ms. Kirven did not return telephone messages left with relatives who live near the clinic at 1906 Peabody Ave.

The clinic was renamed the South Dallas Health Clinic in November 1998. In a deal approved by county commissioners, the renamed clinic has been managed by Friendship West Baptist Church in Oak Cliff through its nonprofit arm, F.W. Empowerment Inc.

Robert Blake, who took over as clinic executive director last month, said that problems found in the audit are being cleaned up and that he plans to hire an outside auditor to implement permanent fiscal safeguards.

"You've got to keep track of people's money," he said. "That's critical. The first priority is to resolve former issues that were here, and second, to dispel negativity, then move into ... providing services."

County Commissioner John Wiley Price said the panel has increased efforts to monitor the clinic's spending of grant money.

"We're making sure we don't have the kind of slippage we had," he said.

The South Dallas Health Clinic regularly serves 200 to 400 AIDS and HIV patients with a \$1.5 million annual budget and is staffed by three volunteer doctors. Nearly all of the clinic's budget comes from federal Ryan White grants, records show.

Clinic officials say the center is the only AIDS treatment facility in North Texas aimed at poor blacks. Statistics indicate that blacks made up a far greater percentage of total AIDS cases than any other group in Dallas County in 1999. Parkland Memorial Hospital operates two clinics that also serve southern Dallas.

#### **Almost closed**

The South Dallas clinic was in danger of closing in October 1998 after county auditors questioned how administrators had handled the center's public money. The county responded by temporarily cutting off federal grant funding.

County health department Director Betty Culbreath-Lister stepped in and worked with several county nurses and others to keep the center open while she sought a new sponsor. She found one in the Friendship West Baptist Church, where she attended and was a board member for F.W. Empowerment. She said she has since left the board to avoid any conflict of interest.

Ms. Culbreath-Lister defended her office's oversight of the clinic, saying the county auditor's office was to blame for not finding the alleged problems sooner.

"They should have done a better job than to let someone spend a bunch of money on some bull," she said.

County Auditor Virginia Porter refused to discuss Ms. Culbreath-Lister's assertion. Ms. Porter also declined to provide the audit or discuss its contents, saying its initial findings had been forwarded to Dallas County District Attorney Bill Hill for possible criminal prosecution.

In a letter to *The Dallas Morning News* denying an open records request for 25 boxes of audit documents, Mr. Hill's office said the FBI had taken over the investigation.

It's not clear who is being targeted by the investigation or whether the inquiry extends beyond the 1998 audit findings.

However, county audit documents obtained by *The News* indicate officials continued to have trouble accounting for federal money through 1999.

A report from Ms. Porter dated Feb. 21 criticized bookkeeping at the clinic and said patient case files lacked proper documentation. The report also said security of drugs stored at the clinic was insufficient and officials failed to conduct proper background screening of employees.

### **Unpaid bills**

County officials also said that the clinic was unable to pay its pharmacy bills for months at a time last year because the county denied reimbursement for poorly documented treatment.

Sylvia Moreno, director of HIV/AIDS services for Parkland Memorial Hospital, said some patients have stopped going to the South Dallas Health Clinic because they didn't believe they were getting proper care.

"This clinic has been very troublesome for years," she said.

Ladonna McHenry, who said she started going to the clinic in 1995, switched to Parkland last month.

"Every time you go up there, they have a new front desk lady and new nurses," Ms. McHenry said.

Vicky Norton, who succeeded Ms. Kirven as clinic director and held the post until the F.W. Empowerment board requested her resignation in January, declined comment, citing a nondisclosure agreement with her former bosses at F.W. Empowerment. She did say she knew of no problems at the clinic during her watch.

Ms. Norton was succeeded as director by William Brewer, who ran the clinic until May.

Ricky Hill, vice president of F.W. Empowerment's board of directors, said the clinic has reformed its operation, largely through help from the church. He said the church has opened its own coffers to clinic operations and hired better staff members, including accountants.

County documents say more than half of the clinic's 25 staff members resigned or were terminated last year.

"We had our growing pains and learned our lesson well," he said.

### **Peer support**

Some other AIDS service providers in Dallas agree that the clinic has made positive changes.

Don Sneed, executive director of the nonprofit Renaissance III group that caters to black patients, told county officials last September that his group does "not recommend their facility."

Mr. Sneed said recently that he has softened his position and has "seen some remarkable improvements over the last few months."

Ricky Hill said more patients are coming to the clinic and that he expects new grants soon. He added that the clinic plans to expand services, using F.W. Empowerment money.

"We're flying," he said.

## **Clinic's history**

06/16/2000

- 1994 – Activist Mythe Kirven establishes the Margaret K. White Clinic, also known as South Dallas Health Access, offering low-cost care to AIDS and HIV patients. The clinic is named after her grandmother.
- 1997 – A routine Dallas County audit turns up questionable spending, and a broader audit is ordered.
- 1998 – Audit results are forwarded to Dallas County District Attorney Bill Hill. The county temporarily halts federal funding, and Ms. Kirven resigns as executive director. Friendship West Baptist Church, through its nonprofit arm F.W. Empowerment, takes over management of the clinic in November. Vicky Norton, who worked under Ms. Kirven, is named executive director.
- 1999 – The district attorney's office forwards the investigation to the FBI.

- 2000 – A report from Dallas County Auditor Virginia Porter criticizes bookkeeping at the clinic and says patient case files lacked proper documentation. In January, Ms. Norton resigns at the request of the F.W. Empowerment board. William Brewer serves as executive director until May, when Robert Blake is named to the post.

*SOURCE: Dallas Morning News*

Mr. COBURN. We talked about the IOM recommendations. I have them here. What has the administration done to implement these recommendations?

Mr. FOX. Mr. Coburn, the Ryan White CARE Act, as you know, particularly through Title III, has had a fairly significant involvement in looking at perinatal transmission. There has been a lot of effort toward trying to make sure that women are both identified and started on appropriate therapy. We have had a lot of activities in that area.

Mr. COBURN. But since this report has come out, what have been the steps that the administration has taken, since they came out and said that we ought to have universal testing, with an opt-out for all pregnant females?

Mr. FOX. I am going to defer that to Dr. O'Neill, because I think he can better answer that.

Mr. O'NEILL. There are a number of things. One I would call particular attention to is even actually in anticipation of the direction the report is going.

We instituted a specific program within our AIDS education training centers, and actually worked out a contract or an agreement between the AIDS Bureau, and the Bureau of Primary Care, at the community health centers. We did very aggressive training across the Nation, to all of our health centers, non-Ryan White or Ryan White, around this issue.

We have obviously done a lot of work, particularly through our Title IV program, and I think you are going to be hearing more about that from Dorothy Mann, when she speaks. But we take it very seriously. We, again, would want to work with you all on any additional ideas that would be helpful.

Mr. COBURN. I would like to ask an additional question. From the experience of New York and their testing program, do you believe that the data now shows that the claims that women will not seek perinatal care, if in fact they are asked to be tested, are untrue?

Mr. O'NEILL. I, embarrassingly, am not familiar enough with the New York data to give you an exact answer.

Mr. COBURN. Well, we have actually had an increase in the number of women seeking perinatal care, since that was passed. So, in fact, the claim against us doing that nationally, and against New York doing it, the actual opposite of that has been the effect. We should all recognize that. A woman cares for her child. If they have something that is going to hurt their child, they want to know about it.

You know, part of the politicization of the AIDS virus has hurt us deeply in this country, in handling it properly. The last thing

I would like to see, before I leave Congress, is for us to treat this like the disease it is.

Dr. O'Neill has been great to work with. He recognizes all these issues. I can not be complimentary enough of his service to us in helping to put this bill together.

But, you know, we have to look at what we are taught, as physicians, and know that we can be caring and we can be compassionate, but we have to recognize the truths of science, in terms of this disease. The reason prevention is such an important part of this bill, trying to move back toward that, is because that is the best care.

I have to say, I know Dr. O'Neill agrees with that, in terms of his interface with his patients. I know that he does that. But I would beg HRSA to not let one opportunity go past, that does not allow an interface and an emphasis on prevention. I believe history is going to judge us very, very poorly, when it comes to this epidemic in this country.

I will relate to you, I met with 27 African AIDS directors, less than a year ago. I believe that one of the reasons that Africa is in the trouble that it is today is because they followed our policies, initially. Consequently, they have an uncontrolled epidemic over there.

So just in closing, my question for you, I would just beg you that as you administer these funds, now and in the future, that you recognize the important nature, and the other personal accountability nature, that if you have this disease, you obviously have a responsibility not to ever give it to anybody, in any way.

So where we hear the data of what is happening in San Francisco now, we all know what is happening. I mean, the news reports are there. The interviews are there, and the public health data. We know why there is a rise, because people are ignoring prevention, and are having exposed contact.

It is okay to talk about that. That is what is really going on, and that is why it is rising, again. Because it is now being seen as a chronic disease, rather than a life-threatening disease. I just think that the emphasis has to be there.

I am sorry I went on so long. I would yield back.

Mr. BILIRAKIS. Mr. Brown.

Mr. BROWN. Mr. Chairman, I yield my 5 minutes to the gentlelady from California, Ms. Eshoo.

Ms. ESHOO. I thank the gentleman.

Mr. BILIRAKIS. I would suggest that maybe the gentlelady take your 5 minutes and her 5 minutes.

Mr. BROWN. If she needs mine and hers, she can do so.

Ms. ESHOO. I appreciate that very much.

There are several things that have been cast out here that I really think need to be corrected. First of all, we have charts up there, which I am glad that one of the staff people gave me a copy of, because I think it is an eye test that we would all fail.

But let me just get into some of these funding issues that Dr. Coburn has suggested are totally unfair, by this bar graph down at the bottom.

When Dr. Coburn talks about San Francisco funding, he is talking about the Bay area funding, No. 1. He stated a little while ago

something about the San Francisco AIDS Foundation. Let the record show that the majority of the funds of the San Francisco AIDS Foundation are private funds. I think everyone on the committee should appreciate that.

Now I have here a graph that demonstrates the flat funding. This is actually the case today; not what is up there, but what is the case today. This flat funding demonstrates over the last 5 years that the Bay area and San Francisco's actual dollars have shrunk.

So this is a debate between those who argue for per capita funding. But they fail to acknowledge that Title I funding in San Francisco, over the last 5 years, since fiscal year 1996, has essentially remained flat, while Title I funding in the rest of the Nation has increased nearly 50 percent.

Now the formula that has been placed in the House bill, which is very different than the Senate, does not recognize that services will be de-stabilized. If there was anything in this story of Ryan White funding, it was to stabilize funding, thereby stabilizing care. That is one of the pillars that holds the act up. What the House bill does is to de-stabilize that.

I agree with something that the gentleman said—that no geographic area should be de-stabilized or be penalized. But that is essentially where it is with the Bay area, today.

So I think that we do a real disservice, in terms of this entire debate, to somehow suggest that the Bay area gets more funding. They do not.

Now what the Senate recognizes, in their language, is that they double the hold harmless clause. I think that that is a very important aspect for us to appreciate here because, again, they recognized what de-stabilization can do. So they gradually, over a period of time, bring the funding down.

Now in the State of California, there is overall a \$3.5 million loss to the State. What the House language does is a \$4.5 million loss, on top of that, to the Bay area.

That is why I raised my voice in opposition to this. I think it is very important for the record to show that this per capita analysis of the CARE Act funding is really misleading, very misleading. Because as I said, from 1996 through the year 2000, Title I funding in San Francisco has gone down.

Now I do not know if there is any other member that wants to lean in on this. But again, those who argue for per capita funding are failing to acknowledge what the actual funding has been, over the last 5 years.

Again, the Ryan White care funds and the act were all about not leaving any area in a harmful way. The de-stabilization of funds is going to directly affect the care of people, the services for individuals, and the continuum of care, as we heard Dr. Fox testify to.

I might add that the Bay area and San Francisco have been a beacon of light across our Nation of how to bring together services that other areas would model themselves after. We are very, very proud of that. We have not only been the hardest hit, but we have also offered, I think, a real model and example for the rest of the country, of how to care for people.

Mr. TOWNS. Would the gentlelady yield?

Ms. ESHOO. I would be happy to.

Mr. TOWNS. It is interesting when you look at this chart, the kind of things that you see. What I see, you know, when I heard your comments, it seemed to me that we are arguing in the wrong direction.

I think we should be arguing that every EMA be brought up to San Francisco. I mean, I think that is what we should be arguing.

I am having difficulty with this. If we are serious about what we are doing, why do we not make that argument? We are still talking about a surplus. It seems to me that that is the kind of way that we should go.

Even if you take the \$8 million that we are talking about from San Francisco, and use you spread it across the 31 EMAs, what are you really doing?

I mean, I think, Mr. Chairman, that we should seize this moment, and take advantage of this opportunity. Let us deal with this issue, once and for all, because I think that this opportunity is here. Let us take advantage of it now. I think that we know the services are needed, all over this country, and we need to provide them.

I yield back.

Ms. ESHOO. I thank the gentleman. I think that he has made an eloquent statement about some of the innards of the language of the bill. Instead of expanding on what we know needs to be done, we are delving into one EMA, and disrupting the dollars, and hurting the services there.

I really do not understand why this is being done. Some people are grinning, like they have a corner on the market of why this is being done.

Mr. Waxman's work in this area is legend, across the country. I think that this is a real unfairness. I will keep speaking to it.

I do believe that the Senate has the right language on this, because they recognize that if, in fact, you continue to extract funds, that you are going to de-stabilize. That is not what Ryan White is about. To do this, I think, is really causing harm.

In the medical profession, there is a saying that says, "First do no harm." This hold harmless clause is being turned on its head. I think it is unfortunate that somehow this language has made its way into the House bill.

This is all part of the record here. I do not know what the full committee is going to do with this in the authorization. I know that I will keep raising my voice on it.

So I am going to yield back the balance of the time that was given to me. I thank my colleague, the Ranking Member, and I thank the chairman, as well.

Mr. COBURN [presiding]. I thank the gentlelady.

There are a couple of things that need to be noted, if I might add. No. 1, there is no limitation on funding in this authorization, whatsoever. So if we can appropriate it, we certainly could do it, Mr. Towns.

Mr. TOWNS. Would the gentleman yield?

Mr. COBURN. I would be happy to yield.

Mr. TOWNS. Will you join me in that effort and fight for it?

Mr. COBURN. Absolutely.

Mr. TOWNS. Thank you.



Mr. COBURN. Second, I would like unanimous consent to enter into the record what was entered into the record when we had this discussion 5 years ago, the testimony of Mr. Shepherd Smith, who is with Americans for a Sound HIV Policy. We had the same thing there.

The agreement was that when we did Ryan White 5 years ago, we all agreed that we were going to come to this point. To act like we are not going to do that now, to me, is somewhat disingenuous.

Ms. ESHOO. Would the gentleman yield?

Mr. COBURN. Let me finish.

Ms. ESHOO. Would you just clarify that, when you said 5 years ago we knew we would come to this point; what does that mean? You were not here 5 year ago. I was. Maybe you could just clarify that.

Mr. COBURN. I was here 5 years ago, as well. In the Ryan White CARE Act, we had an agreement. If you will read the Ryan White CARE Act, and I will be happy to pull that out for you and let you see it, we were moving in this direction then. We agreed that we were going to move in this direction.

Ms. ESHOO. On what; on the hold harmless?

Mr. COBURN. The second point I would make is that the GAO's testimony, on page nine and also on page two, shows that we are talking about EMAs, not the Bay area. There are three EMAs in the Bay area. We are talking about one of them that is markedly disproportionate to the other.

The other point that I would make, and then we will move on to the next panel, if the gentlelady would like or if the other members would like to have time, is the fact that there will be probably no cut in dollars for any EMA, especially on the rate at which we have increased the funding.

So although we are talking about a hold harmless, and it is 2.5 percent in the first year, the likelihood, based on what we have appropriated this year, is that the San Francisco EMA will receive no decrease in funding.

With that, I would close my comments. Mr. Green is recognized for 5 minutes.

Mr. GREEN. Thank you, Mr. Speaker. Again, I apologize, because our other committee is going on, plus there are bills on the House floor, and I could not be here.

Dr. Fox, one of my concerns is, I represent a district that my only problem with Ryan White in the last four terms, and it was really a local problem when we found out, was the services not being provided to the growth populations.

One of my concerns is the increasing number of HIV positive or AIDS victims in my district who are women, who also are Hispanic women. Do you think the Coburn and Waxman bill can address the need for serving these higher growth in populations, along with African American woman?

Mr. FOX. Mr. Green, I think the ability to use HIV prevalence data will allow us to better target the resources. It will put us more appropriately and more accurately where the epidemic is going.

The other thing we have done is, we have actually used the Title III planning grants, and we have 60 new planning grants out there now, to help target those resources to the minority communities

where the epidemic is happening. We have primarily targeted the Title III grants, the early intervention grants, to non-EMA areas. So the answer is yes, we think this bill will help us more appropriately target resources.

Mr. GREEN. I know that in the Houston area, we are expanding with our EMA, where some of the growth is in East Texas or the rural area. There is an effort to expand in that area.

I have one last question. One of the concerns that I was announcing was more and more mothers with young children, who are infected with the disease. Are the existing programs, including housing and family counseling issues, adequate for that; and what can be done to ensure that the needs of the families are met, also, for these women and the families?

Mr. FOX. One of the things that we support in this bill that is currently in there is the ability to expand the activities of Ryan White to work with referral points like emergency rooms, where a lot of people go for care, and obviously to family planning clinics.

I know that because we also over see the TITLE X family planning budget, there have been increased appropriations there to help counsel women coming in for contraceptive services, around the issue of AIDS and STDs. So I think there are, again, some things in this bill that will help us get out a little bit further into the community and, hopefully, both do some prevention and some referral for care.

Mr. GREEN. Thank you, Mr. Chairman. I yield back my time.

Mr. COBURN. I thank the gentleman.

Mr. Barrett.

Mr. BARRETT. Thank you, Mr. Chairman. I appreciate the fact that we are holding this hearing. I certainly am proud to be a co-sponsor of this legislation. I think that it can improve on a law that I consider to be a very good law.

Obviously, as Mr. Towns and Ms. Eshoo and Mr. Coburn have indicated, one of the priorities that we have is providing the resources necessary. So my hope is that we do not allow this to die over a funding squabble. Dr. Fox, I do not know if you have any comments, in response to the funding issue that was raised here.

Mr. FOX. Well, obviously, it is a complex and controversial issue. I think the Department has recommended that we look to the IOM to do a study and assist this.

As I have said earlier, there are a lot of factors. The GAO will elucidate some of those. But there are other factors where the Title III grants are going, and what is happening with Medicaid, that impact on the resources within a community.

We have recommended that IOM give a thorough study to this. We have not recommended any particular approach to change, but do understand that there are a lot of concerns and inequities. We think this is one way to go about it, to try to get a set of recommendations that we could bring back to Congress, and then move forward from there.

Mr. BARRETT. In the GAO report, on page nine, it does show that San Francisco has taken, it looks like, about a \$500 hit, and the other EMAs have taken between a \$100 and \$200 hit. Is that consistent with what you are planning?

Mr. FOX. We do not take issue with any of the accuracy of the GAO report. I think there are additional factors that impact on resources in the communities that are perhaps not in there. But we do not take issue with what they have in that report.

Mr. BARRETT. Thank you. Again, I think for those of us who do not come from areas that receive a great deal of funding, it is important that whatever changes we make do not have a negative impact on us.

Again, I do not think anybody likes to fight over money in an area like this. So for those of us who would see any changes to this bill as a negative impact on our areas, it is something that we would obviously have some concerns with.

So I would yield back the balance of my time.

Mr. COBURN. Thank you.

The gentleman from Ohio is recognized for 5 minutes.

Mr. STRICKLAND. I have no questions, Mr. Chairman, but I am looking forward to hearing our later witnesses. Thank you.

Mr. COBURN. I would like to thank Dr. Fox and Dr. O'Neill for being here, and their work, and your testimony, and your patience.

Again, as the chairman of this committee, Mr. Bilirakis, has suggested, I think it is very important that some of your staff is here for the rest of the testimony, so that that input can be considered by you.

Mr. FOX. Mr. Coburn, we are going to all stay here, including myself. So we will be here throughout the balance of the hearing.

Mr. COBURN. We will break for these sets of votes. Then we will come back right after the last vote.

[Whereupon, at 12:07 p.m., the committee recessed for a vote, to reconvene at 12:47 p.m., the same day.]

Mr. BILIRAKIS. Our thanks to this second panel, not only for the knowledge that you are going to impart to us, but also for your patience in waiting as long as you have. Actually, it is not as long as usually the second panel has to wait around here.

Well, the second panel consists of Ms. Janet Heinrich, Associate Director of the U.S. General Accounting Office, accompanied by Mr. Jerry Fastrup, Assistant Director; Ms. Jeanne White, National Spokesperson for the AIDS Action; Mr. Tom Liberti, Chief, Bureau of HIV/AIDS, Florida Department of Health, Dr. Guthrie S. Birkhead, Director, AIDS Institute, New York State Department of Health; Mr. Joe Davy, Policy Advocate, Columbus AIDS Task Force; Ms. Dorothy Mann, Board Member, AIDS Alliance for children, Youth & Families, out of Philadelphia; Mr. Jose R. Colon, Coordinator, Pacientes de SIDA Pro Politica Sana, from San Juan, Puerto Rico; and Mr. Eugene Jackson, Deputy Executive Director for Policy, National Association of People with AIDS.

Again, ladies and gentlemen, thank you for being here. Your written statement is a part of the record. I will turn this timer on for 5 minutes. Hopefully you can stay around that period of time. We will not cut you off if there is a point that you are trying to make. We will start off with Ms. Heinrich.

**STATEMENTS OF JANET HEINRICH, ASSOCIATE DIRECTOR; ACCOMPANIED BY JERRY FASTRUP, ASSISTANT DIRECTOR, U.S. GENERAL ACCOUNTING OFFICE; JEANNE WHITE, NATIONAL SPOKESPERSON, AIDS ACTION; THOMAS M. LIBERTI, CHIEF, BUREAU OF HIV/AIDS, FLORIDA DEPARTMENT OF HEALTH; GUTHRIE S. BIRKHEAD, DIRECTOR, AIDS INSTITUTE, NEW YORK STATE DEPARTMENT OF HEALTH; JOSEPH DAVY, POLICY ADVOCATE, COLUMBUS AIDS TASK FORCE; DOROTHY MANN, BOARD MEMBER, AIDS ALLIANCE FOR CHILDREN, YOUTH & FAMILIES; JOSE F. COLON, COORDINATOR, PACIENTES DE SIDA PRO POLITICA SANA; AND EUGENE JACKSON, DEPUTY EXECUTIVE DIRECTOR FOR POLICY, NATIONAL ASSOCIATION OF PEOPLE WITH AIDS**

Ms. HEINRICH. I am pleased to be here today, as you discuss ways to improve the distribution of Ryan White Act funds to States and localities. The program faces new challenges as the epidemic of HIV changes and new treatments extend the life expectancy of infected persons.

At the request of the subcommittee, I will focus on three issues: the potential for distributing funds on the basis of counts of persons with HIV infection, rather than on counts of only persons diagnosed with AIDS; the differences in per capita funding for States within an eligible metropolitan area, which receive grants under both Title I and Title II of the act, as opposed to States which receive only Title II grants; and the current effect of the hold harmless provision, adopted in the 1996 reauthorization.

Seventy percent of Ryan White funds are distributed by formulas under Titles I and II of the act. Title I has provided \$527 million in assistance in fiscal 2000 to a consortia of local service providers in eligible metropolitan areas.

Title II provides funding for State agencies. In fiscal year 2000, \$528 million was distributed for the AIDS Drug Assistance Program, and \$266 million to provide health and support services. Almost all Title II funding growth has resulted from increases in the Drug Assistance Program.

With the current rate of new infections remaining at approximately 40,000 cases per year, with AIDS deaths declining, and continuing progress and treatments for people who are HIV positive, resulting in delayed development of AIDS, it would be reasonable to distribute funds on the basis of the total number of persons living with HIV infection.

We know that there are differences among the States in their policies related to HIV reporting. CDC officials indicate that they expect all States to be reporting newly diagnosed HIV cases by 2003, and that an additional one to 2 years, or one to 3 years may be needed to get information on previously diagnosed HIV cases, entered into these new surveillance systems.

The potential for incomplete reporting of older cases, at least initially, was clear when we compared the experience of States that had been reporting HIV cases, for different lengths of time. States with long reporting histories had many more HIV cases, compared with the number of AIDS cases, than did newly reporting States.

In chart one, which we have here on the left, this is illustrated by comparing Texas and Colorado. Texas just began reporting HIV

cases in 1999, but Colorado has been reporting since 1985. Reported HIV cases in Texas are about one-eighth the number of AIDS cases. In Colorado, the number of reported HIV cases exceeded reported AIDS cases by a factor of two to one.

It seems prudent to delay any switch from using AIDS cases to HIV cases in the grant formulas, until we can be assured that the data is reasonably complete.

Regarding the second issue that you asked us to address, States with eligible metropolitan areas receive considerably more funding, per case, than States without. The current formulas result in AIDS cases in designated metropolitan areas essentially being counted once in distributing Title I funding to a metropolitan area, and counted a second time, in distributing Title II funding to the States.

The magnitude of the resulting funding differences is illustrated in this next chart. In fiscal year 2000, States that have no metropolitan area have received approximately \$3,340 per case. States with less than 50 percent of their cases within a metropolitan area have received \$3,600. States with more than 75 percent of their cases within a metropolitan area have received nearly 50 percent greater funding than States with no metropolitan area, or about \$4,955 per case.

Finally, I would like to discuss the hold harmless provision, added to Title I in the 1995 reauthorization. Before then, funding was distributed among the eligible metropolitan areas on the basis of the cumulative count of diagnosed AIDS cases. Many of the people diagnosed with the disease in the 1980's had died, yet were still counted in the formula.

The reauthorization changed this practice, shifting funding away from metropolitan areas with high proportions of deceased cases, and toward those with higher proportions of newly diagnosed cases. Under the transition rules adopted at the time, these metropolitan areas that would otherwise have lost funding were guaranteed a gradual decrease.

Four metropolitan areas benefited from the hold harmless provision: Houston, Jersey City, New York, and San Francisco. But by 1999, San Francisco was the only metropolitan area that continued to benefit.

In chart three, you can see that San Francisco receives 80 percent more Title I funding than other metropolitan areas: approximately \$2,360 per case, compared to \$1,290, in fiscal year 2000. The benefit that San Francisco derives from this hold harmless provision has declined somewhat, but continues to be sizable.

In conclusion, as the HIV epidemic continues to evolve, it becomes increasingly important that Federal resources match the distribution of persons who suffer from this dreaded disease. When data on all living HIV positive cases becomes available in the next few years, their inclusion in funding formulas would improve the ability of the Ryan White Act to effectively deliver funding for services to those in need.

As we recommended in the past, improvements could also be achieved with this reauthorization, if double counting of metropolitan area cases was phased out.

This concludes my statement, Mr. Chairman. I would be happy to answer any questions that you or members may have. We also are prepared to provide you additional information that you may need, as you continue your deliberations.

[The prepared statement of Janet Heinrich follows:]

PREPARED STATEMENT OF JANET HEINRICH, ASSOCIATE DIRECTOR, HEALTH FINANCING AND PUBLIC HEALTH ISSUES, HEALTH, EDUCATION, AND HUMAN SERVICES, UNITED STATES GENERAL ACCOUNTING OFFICE

Mr. Chairman and Members of the Subcommittee: I am pleased to be here today as you discuss ways to distribute Ryan White CARE Act funds to states and localities. As you know, the program is facing new challenges as the epidemic of the human immunodeficiency virus (HIV) changes and spreads to new segments of the American population. At the same time, new medicines and treatments have lengthened the life expectancy of infected persons. This, in turn, emphasizes the need to insure that program funding reflects the changing pattern of the epidemic.

In fiscal year 2000, Ryan White grants have provided nearly \$1.6 billion in federal funding to assist state and local service providers in delivering health care and support services to individuals and families affected by HIV infection. Title I of the Act provides assistance to metropolitan areas most affected by the disease and Title II primarily provides funding for state agencies responsible for persons not served under Title I and for funding drug therapies. Although the Ryan White program serves individuals with HIV, funds are distributed on the basis of the number of individuals whose disease has progressed to acquired immunodeficiency syndrome (AIDS).

At the request of the Subcommittee, I will focus on three issues:

- the potential for distributing funds on the basis of counts of persons with HIV infection in each geographic area rather than on counts of only persons whose disease has progressed to AIDS;
- the differences in funds for states with an eligible metropolitan area (EMA), which receive grants under both title I and title II of the Act, and states without an EMA, which receive only title II grants;<sup>1</sup> and
- the current effect of the hold-harmless provision adopted in the 1996 reauthorization, when the method of counting living AIDS cases replaced the practice of counting cumulative AIDS cases.

To address these issues, we have analyzed data from the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) in the Department of Health and Human Services (HHS) and have developed computer models to calculate how funding would change under alternative formula scenarios.

In brief, we found that only about 60 percent of the states include HIV cases that have not progressed to AIDS in their reports to CDC. To ensure that the formulas provide an equitable distribution, all states would need to report HIV cases. CDC officials told us that they expect all states to be reporting new HIV cases by 2003 and that an additional 1 to 3 years may be needed to allow cases that existed before then to be entered into their reporting systems. However, the states' ability to completely identify past cases is not known.

We also found substantial differences in funding between states with an EMA and those without one. For example, in fiscal year 2000 states that had no eligible EMA received on average of \$3,340 per person suffering from AIDS. In contrast, the states with more than 75 percent of their AIDS cases in an EMA received nearly 50 percent more, averaging \$4,954 per AIDS case. States such as California and New York with more than 90 percent of their cases in EMAs received \$5,240 per case or almost 60 percent more than states without an EMA. GAO has in the past recommended changes to the Ryan White Funding Formulas that would result in more comparable funding across states.

Finally, a hold-harmless provision was included in the 1996 reauthorization to help with the transition of the EMAs that would receive less by using living AIDS rather than cumulative AIDS cases, which included both living and deceased cases. The transition has been very gradual and has had the effect of providing some EMAs with more funding on a per-person-with-AIDS basis than other similarly situated EMAs. Currently, only one EMA, San Francisco, continues to benefit from the

<sup>1</sup> Eligible metropolitan areas are urban areas with at least 500,000 population and at least 2,000 living AIDS cases reported in the past five years.

hold-harmless provision, and it received substantially more aid than other similarly situated EMAs. For example, San Francisco received more than 80 percent greater title I funding per person with AIDS than other EMAs. Oakland, across the bay from San Francisco, and all other EMAs received \$1,289 per person in fiscal year 2000 title I funding compared with San Francisco's \$2,359 per person. San Francisco continues to benefit from the holdharmless provision because a large proportion of its cumulative AIDS cases were deceased under the formula used before fiscal year 1996 and because there have been smaller increases in new AIDS cases compared with other EMAs. GAO has in the past recommended changes to the Ryan White funding formulas that would enhance comparable funding across states.

#### BACKGROUND

Since the first cases were identified in 1981, more than 700,000 persons in the United States have been diagnosed with AIDS. Recent developments in medical and pharmacological therapies have improved the survival of persons with AIDS and have slowed the progression from HIV to AIDS. At the end of 1999, an estimated 300,000 persons were living with AIDS. It is also estimated that an additional 500,000 to 600,000 people are infected with HIV that has not progressed to AIDS. The composition of the AIDS population has also changed over time, with minorities and women representing a larger portion of all cases.

Federal efforts to provide health and support services involve a wide variety of programs and activities. In addition to Ryan White grants, federal funding is provided through CDC, the Department of Housing and Urban Development, Medicare, Medicaid, Social Security Disability Insurance, and the Supplemental Security Income program, among others.

Seventy percent of Ryan White funds are distributed by formula under titles I and H of the act, while titles III and IV provide discretionary grants for a variety of support services. Title I has provided \$527 million in assistance in fiscal year 2000 to consortia of local service providers in EMAs. To be eligible, a metropolitan area must have a population of at least 500,000 and must have had a cumulative total of more than 2,000 reported AIDS cases in the past 5 years. There were 16 EMAs when the program began in 1991, and the number has grown to 51 today.

Title I funding has increased at an average annual rate of 24 percent since 1991. (See fig. 1.) Half of these funds is distributed by formula on the basis of estimated living AIDS cases in each EMA. HRSA distributes the remainder of title I funds among EMAs on a discretionary basis in response to proposals EMAs submit. Historically, the distribution of discretionary grants has generally mirrored the pattern of the formula grants.

Title II provides funding for state agencies. In fiscal year 2000, 96 percent of funds was distributed by formula, \$528 million for the AIDS Drug Assistance Program (ADAPS) and \$266 million to provide health and support services to persons not living in an EMA and for other activities. Title II funds have grown at an average annual rate of 29 percent.

Almost all this growth has resulted from increased funding in the ADAPS program. (See fig. 2.)

In our previous report on the CARE Act funding formulas, we had recommended to the Congress that the funding formulas be modified so that

- comparable medical services funding be made available regardless of where people with AIDS live and
- an indicator be added to the formulas that reflect relative differences across states and EMAs in the cost of serving people with AIDS.<sup>2</sup>

As I will discuss in more detail, these recommendations continue to be applicable today.

#### STATE HIV REPORTING IS IMPROVING BUT IS STILL INCOMPLETE

Because the Ryan White program serves persons who have been diagnosed with HIV that has not progressed to AIDS as well as those for whom it has, it would be reasonable to distribute funds on the basis of the total number persons living with HIV. However, while all states report AIDS cases, many do not report the number of persons with HIV that has not progressed to AIDS. Therefore, for purposes of distributing formula funds equitably, the total number of AIDS cases continues to be the best available indicator of need.

CDC indicates that 21 states, with 58 percent of all AIDS cases, do not report HIV cases, report only some cases, or are awaiting CDC approval of their reporting sys-

<sup>2</sup>*Ryan White CARE Act OF 1990: Opportunities to Enhance Funding Equity* (GAO/HEHS-96-26, Nov. 13, 1996).

tems. Most notable among these are New York and California which together have 31 percent of all AIDS cases. New York's legislature recently authorized HIV reporting to CDC but has not yet begun implementation, and California has yet to authorize HIV reporting. Table 1 lists the states with CDC-approved reporting systems and those not yet approved.

Table 1: States and Their HIV Reporting Status

CDC-approved	Not approved
Alabama, Alaska, Arizona, Arkansas, Colorado, Florida, Idaho, Indiana, Iowa, Kansas, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Texas, Utah, Virgin Islands, Virginia, West Virginia, Wisconsin, Wyoming.	California, Connecticut, Delaware, District of Columbia, Georgia, Guam, Hawaii, Illinois, Kentucky, Maine, Maryland, Massachusetts, Montana, New Hampshire, New York, Oregon, Pennsylvania, Puerto Rico, Rhode Island, Vermont, Washington

CDC officials told us that they expect all states to be reporting newly diagnosed HIV cases by 2003 and that an additional 1 to 3 years may be needed to get all HIV cases entered into a new reporting system. The potential for lags in reporting the older cases was clear when we compared the experience of states that had been reporting HIV cases for different lengths of time. States with long reporting histories had many more HIV cases compared with their number of AIDS cases than did newly reporting states. This is illustrated by comparing Texas and Colorado. Texas just began reporting HIV cases in 1999 but Colorado has been reporting since 1985. Reported HIV cases in Texas are about one-eighth the number of AIDS cases. In Colorado, with a much longer reporting history, the number of reported HIV cases exceeds reported AIDS cases by a factor of about 2 to 1. (See fig. 3.) The extent to which states can identify preexisting cases once they begin HIV reporting is not known. Some of the discrepancy, illustrated by the Colorado and Texas comparison, could be reduced as Texas identifies more preexisting cases. States that begin reporting more recently may continue for some time into the future to have a larger proportion of previously diagnosed but not reported cases.

The cost of serving persons who have HIV disease can vary substantially, depending on the stage of their disease. Persons whose disease has progressed to AIDS often require more expensive drug therapies and more intensive care. If HIV data were integrated into the funding formulas, greater weight could be assigned to persons whose need for therapy are in the more expensive stages of the disease. Doing so would better ensure that the distribution of funds is commensurate with the cost of care. Information on such cost differences and how to estimate the number of persons in different stages of the disease would need to be addressed before this type of adjustment could be incorporated.

#### STATES WITH NO EMA ARE DISADVANTAGED UNDER THE CURRENT FORMULA STRUCTURE

Whether states have an EMA or not, they have the same service delivery responsibilities: to provide health care and support services to persons who have HIV disease. However, states with EMAs receive more funding per case because EMA/AIDS cases are counted once in distributing title I funding and counted a second time in distributing title II funding. States without an EMA receive no funding under the title I distribution, and, thus, when total Ryan White resources are considered, some states receive considerably less than others per case. The magnitude of these funding differences is illustrated in figure 4. In fiscal year 2000, states that have no EMA have received approximately \$3,340 per case. States with less than 50 percent of their cases within an EMA have received \$3,600 per case. States with more than 75 percent of their cases within an EMA have received nearly 50 percent greater funding than states with no EMA, or \$4,954 per case.

A comparison of Colorado and Indiana provides a clear example of these funding disparities because both states have roughly 2,300 living AIDS cases. Colorado has an EMA because most of its cases are concentrated in the Denver metropolitan area. Indiana's cases are more dispersed. As a consequence, Indiana does not have an EMA and receives no title I funding. The effect is that Indiana receives \$3.3 million less to help it serve the same number of cases as Colorado.

#### THE HOLD-HARMLESS PROVISION CURRENTLY BENEFITS A SINGLE EMA

Finally, I would like to discuss the hold-harmless provision added to title I in the 1996 reauthorization. Before the 1996 reauthorization, funding was distributed



among EMAs on the basis of the cumulative count of diagnosed AIDS cases. By 1996, many persons diagnosed with the disease in the 1980s had died, yet they were still counted for purposes of distributing funding to EMAs. The areas of the country with the longest experience with the disease had the most deceased cases and benefited the most from using cumulative case counts in the formula.

The 1996 Ryan White reauthorization changed this practice by replacing cumulative case counts with estimates of living AIDS cases. The effect of the change was to shift funding away from EMAs with high proportions of deceased cases and toward those with higher proportions of newly diagnosed cases.

Because these shifts would have been quite large, a hold-harmless provision was added so that the EMAs that were affected would gradually make a transition to an allocation based on living AIDS cases. Under the transition rules adopted at that time, EMAs that would otherwise have lost funding were guaranteed to receive in fiscal year 1996 the same funding they received in 1995, 99 percent in 1997, 98 percent in 1998, 96.5 percent in 1999, and 95 percent in 2000.

HRSA records show that four EMAs benefited from the hold-harmless provision in 1996: Houston, Jersey City, New York, and San Francisco. By 1999, San Francisco was the only EMA that continued to benefit from the provision for two reasons. First, it had benefited the most from using cumulative rather than live cases before fiscal year 1996 and second, it has had smaller increases in newly reported cases than other EMAs. It received 80 percent more title I funding than other EMAs: \$2,360 per case compared with \$1,290 in fiscal year 2000 (see fig. 5).

The high grant that San Francisco derives from the hold-harmless provision has declined somewhat but continues to be sizable. Figure 6 shows that in fiscal year 1996 San Francisco's title I grant was more than twice the grant of other EMAs. In fiscal year 2000, it has been reduced to roughly 80 percent.

As I noted earlier, roughly half of title I funding is distributed by formula, and half is distributed on a discretionary basis. Discretionary funding is awarded on the basis of the quality of proposals submitted to HRSA. The discretionary grants awarded to San Francisco appear to reflect the hold-harmless provision as well as those in need. For example, for fiscal year 2000 San Francisco's discretionary award per AIDS case was roughly twice as large as the average for the other EMAs.

In conclusion, Mr. Chairman, the HIV-AIDS epidemic continues to evolve and the location of the disease continues to change as well. As a consequence, it becomes increasingly important that federal resources match the distribution of persons who suffer from this dread disease. When data on all living HIV cases become available in the next few years, their inclusion in funding formulas will improve the ability of the Ryan White CARE Act to effectively deliver funding to persons in need. However, improvements in matching funding to persons in need of health and support services could also be achieved with this reauthorization if, as we have recommend, the double counting of EMA AIDS cases was phased out. We would be happy to work with subcommittee staff to achieve this.

Mr. Chairman, that concludes my prepared statement. I would be happy to answer any questions that you or other members of the Subcommittee may have.

#### GAO CONTACTS AND ACKNOWLEDGMENTS

For future contacts regarding this testimony, please call William J. Scanlon at (202) 512-7118 or Jerry Fastrup at (202) 512-7211. Greg Dybalski and Michael Williams also made important contributions to this statement.

Figure 1: Title I Funding, Fiscal Years 1991-2000

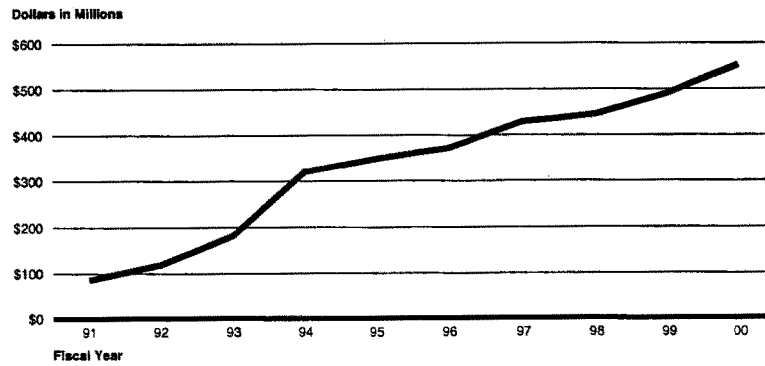


Figure 2: Title II Funding, Fiscal Years 1991-2000

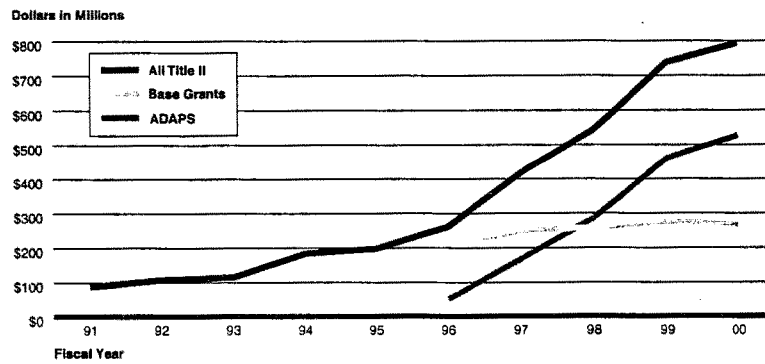


Figure 3: HIV Reporting Not Comparable Across States

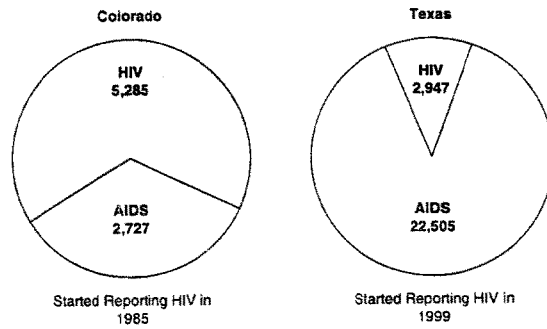


Figure 4: States With No EMA Receive Less Funding

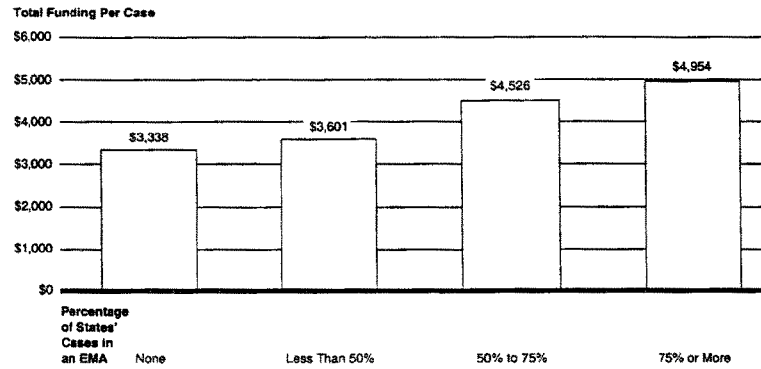


Figure 5: San Francisco Receives Substantially More Funding Than Other EMAs

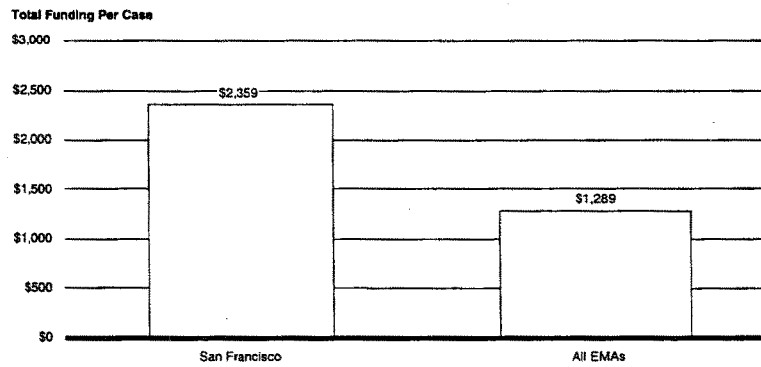
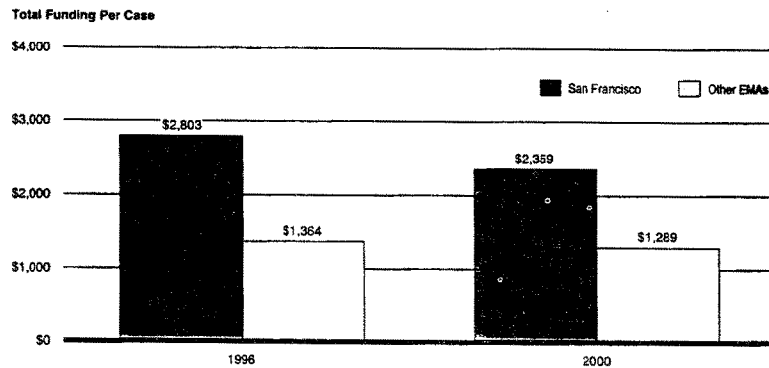


Figure 6: San Francisco's Funding Advantage Has Declined Modestly, fiscal Years 1996-2000



Mr. BILIRAKIS. Thank you very much, Ms. Heinrich.  
 Now the very courage Jeanne White, the National Spokesperson for AIDS Action. Jeanne, please proceed.

#### STATEMENT OF JEANNE WHITE

Ms. WHITE. Well, thank you, Chairman Bilirakis and Dr. Coburn and members, for this privilege to testify before this distinguished committee.

My name is Jeanne White. I am the mother of two children, my daughter Andrea and my late son, Ryan, after whom the Ryan White CARE Act is named. I come here today, first as a parent, and second as a spokesperson for AIDS Action Council, the national voice on AIDS.

Two weeks ago, I had the honor to meet with Chairman Bilirakis, Dr. Coburn, Representative Waxman, Representative Burr, Representative Cox, and Representative Greenwood. The kindness and concern that each member expressed reassured me that Ryan's legacy has not been forgotten.

Accompanying me on my visits last week were three people, who participate in AIDS action's Pedro Samora Fellowship Program. Rachael French is attending Duquesne University in Pittsburgh. Margarita Castafiel will be attending the School of Public Health at UCLA. Edward Hu will be attending Boston University's Medical School.

Ryan would be as proud of these future leaders as I am for their devotion to this cause. These young people are part of the generation who will lead the charge against this ongoing epidemic. For this next generation, it is essential that we reauthorize the Ryan White CARE Act.

I have dedicated myself to traveling the country and continuing the work that Ryan began. What I have seen in these travels is that the face of AIDS is changing. AIDS is the leading cause of death among African Americans between the ages of 25 to 44, and the second leading cause of death among Latinos in the same age group.

The numbers are overwhelming, but the faces are real. When I see these faces, I am reminded that I am a mother; a mother who lost her son to AIDS, and so many of our own sons and daughters have died from AIDS.

Ryan would want us to help those who are alive today. He would want us to provide the treatments that are now available through the CARE Act. Ryan helped me and so many others understand that we must do everything we can to help each and every person who has HIV and AIDS.

Ryan was a mover and he was a shaker, believe me. He was the first national voice on AIDS. He was strong, but he was still a boy. He was my boy.

As a mother, I just wanted to reach out and make everything better. I tried, but as his health deteriorated, it became clear that a mother's voice and a mother's love would not save him from this disease.

In 1984, the doctors told me Ryan had only 3 months to live. He lived for five and-a-half years with AIDS. Believe me, I am very grateful for every moment of the 18 years I spent with my son.

Ryan did not choose to lead a public life. But he wanted people to understand the disease. Let me quote from Ryan's testimony before President Bush's Commission on AIDS.

"Because of the lack of understanding on AIDS, discrimination, fear, panic, and lies surrounded me. I was labeled a troublemaker, my mom, an unfit mother, and I was not welcome anywhere. People would get up and leave so they would not have to sit anywhere near me. Even at church, people would not shake my hand."

Thank God, things are changing. But even in this bright era of hope, it seems like the darkest days are still among us. Unfortunately, the new faces of AIDS still feel pain, fear, and discrimination. I witnessed firsthand the ravages of this disease. I know the terrible toll HIV and AIDS has taken on moms, dads, brothers, sisters, grandmas and grandpas, aunts and uncles, and loved ones.

The year 1990 was a very difficult year for my family. As my son fought for his life, across the Nation, families like mine were hoping against hope for a miracle to end this dreadful disease.

When Ryan died, all my hopes of Ryan beating the odds, finding a cure, and praying for miracles were gone. I was very reluctant to continue my son's advocacy, because I felt like people wanted to hear Ryan, and not me. But I had a powerful support team that was not going to let me be silent.

I then thought of something Ryan had said that gave me the strength to come to Capitol Hill. He said, "Mom, I am not afraid of dying. I know I am going to a better place. It is how you live your life that counts."

Well, as you know, I came to Washington in 1990, and worked with Congressional leaders from both parties to continue Ryan's legacy, and pass the original CARE Act. I am so proud and honored that Congress named this bill after my son, Ryan.

While this legislation could never replace my son or the emptiness that I still feel today, I am happy that a program named after my son has benefited thousands of men and women and children and families living with HIV and AIDS.

The CARE Act makes real Ryan's dream of compassion for people living with this disease. It provides care, drugs, and services to those who face the same struggles as my late son, Ryan. Ryan never understood those who wanted to deny care to people with AIDS. Now the CARE Act ensures that more people have access to care and services.

This disease affects all kinds of people: black, white, brown, young, old, rich, poor, Republican, and Democrat. We must make sure that this program stays strong, so that people living with HIV and AIDS can live as long as possible.

As a mother dedicated to seeing that our sons and daughters with HIV are taken care of, I urge you to reauthorize the Ryan White CARE Act. It is what Ryan would also want us to do.

Thanks.

[The prepared statement of Jeanne White follows:]

PREPARED STATEMENT OF JEANNE WHITE, NATIONAL SPOKESPERSON, AIDS ACTION

Thank you Chairman Bilirakis, ranking member Representative Brown, Dr. Coburn, Representative Waxman and members of the committee for the privilege to testify before this distinguished committee. My name is Jeanne White, and I am the mother of two children, my daughter Andrea and my late son Ryan, after whom the

Ryan White CARE Act is named. I come here today as a spokesperson for AIDS Action Council, the national voice on AIDS, and as a parent.

Two weeks ago I had the honor to meet with Chairman Bilirakis, Dr. Coburn, Representative Waxman, Representative Cox, Representative Greenwood, and Representative Burr. The kindness and concern that each member expressed reassured me that Ryan's legacy has not been forgotten.

Accompanying me on my visits last week were three young people who participate in AIDS Action's Pedro Zamora fellowship program. Rachael French is attending Duquesne University in Pittsburgh, Margarita Castaneda will be attending the School of Public Health at UCLA and Edward Hu will be attending Boston University's Medical School. Ryan would be as proud of these future leaders as I am for their devotion to this cause. These young people are part of a generation who will lead the charge against this ongoing epidemic. For this next generation it is essential that we reauthorize the CARE Act.

I come here as a mother, just a mom from Cicero, Indiana, deep in America's heartland, who has witnessed first-hand the ravages of this disease and the fear and pain it has levied against individuals and communities. As you know, the demographics of HIV are changing and it is more important than ever that we provide the services that these communities need. On behalf of men, women, children and families living with HIV/AIDS from East and West, North and South, I ask you to reauthorize the Ryan White CARE Act.

I remember walking the halls of Congress during the passage of the original CARE Act. Back then, I never would have imagined that this legislation would help so many people like my son, giving them the strength to live another day. I also never would have imagined how the need for this invaluable program would grow. That is why we must reauthorize the CARE Act. We must "go for it", as Ryan would often say to me as he and I were fighting our battle against HIV.

In August 1990, just four months after Ryan's death, the United States Congress passed the CARE Act to provide services and treatment for the thousands of Americans living with HIV disease. While this legislation could never replace my Ryan or the emptiness I still feel today from that loss, I am happy that a program named after my son has benefited hundreds of thousands of men, women and children living with HIV disease.

Since its enactment in 1990 and its reauthorization in 1996, the CARE Act has helped deliver medical and social services that give many people something they never had before in the course of HIV disease: access to comprehensive and compassionate care. The CARE Act is largely responsible for people with HIV/AIDS living longer, more productive lives and has given communities all over this country the ability to design care and treatment services tailored to their own needs. The Act has cast a wide safety net that helps people with HIV disease live life to the fullest.

Best of all, the Ryan White care system and the programs that enrich it continue to teach us all about what works in the care and treatment of our nation's most vulnerable citizens. It is truly a model of care that can be adapted to meet the needs of the hundreds of thousands of individuals living with other serious and life-threatening diseases.

Members of the committee, the CARE Act is as strong as my son Ryan was. That's good, because we need the CARE Act now more than ever. We've come a long way since Ryan's death, but we still have so far to go. More people than ever are living with HIV disease and need the care and support the CARE Act provides.

Thankfully, in recent years the development of new therapies has resulted in a dramatic reduction of the AIDS death rate. If Ryan had lived just a few more years he, too, might have benefited from these same treatments. But with these new hope-giving and life-extending therapies has come an added pressure on the hundreds of health service providers who care for individuals living with HIV disease. Many of these providers have experienced a dramatic increase in the number of new patients. The remarkable fact that people with AIDS are living longer has contributed to an increased demand on the HIV/AIDS care safety net.

This intricate, vital care system, built to ensure comprehensive health care and services for people with AIDS who had nowhere else to turn, is struggling to keep pace with new and ongoing demands.

The challenge of serving every individual with HIV disease who has nowhere else to turn is understandable. Given the success of the new treatments when coupled with the critical support services that make success a reality, the CARE Act brings us closer to the goal of ensuring a standard of care set out by the Public Health Service treatment guidelines for HIV and opportunistic infections. This is a call for early and aggressive treatment.

The number of individuals in need of the CARE Act bears out the urgency for swift reauthorization. In 1990, when the CARE Act was passed, there were 155,619

AIDS cases. In 1996, during its reauthorization there were 481,234 cases. And, in 1999, at the turn of the century, America has recorded 733,374 cases of AIDS.

Mr. Chairman and members of the committee, ever since Ryan's death, I have dedicated myself to traveling the country and continuing the work of AIDS awareness that Ryan began. What I have seen is that the face of AIDS is changing.

For example, in 1998, tens of thousands of people received primary care and support services under the CARE Act. Sixty percent of those were people of color. Indeed, AIDS is the leading cause of death among African Americans between the ages of 25-44 and the second leading cause of death among Latinos in the same age group. People of color make up 55% of all reported AIDS cases, 82% of all children with AIDS, 50% of all cases reported among men, and 77% of all cases among women.

Indeed, more women than ever in the U.S. have AIDS, and the rate is increasing. In just over 10 years, the proportion of all AIDS cases reported among adult and adolescent women more than tripled, from 7% in 1985 to 23% in 1998, according to the Centers for Disease Control and Prevention.

I want to pay particular attention to the threat that HIV poses to the future of our young people, the very same young people who staff your offices and help you to write and pass legislation. In much the same way that the young people on your staffs make Capitol Hill run, Ryan was my very own mover and shaker, serving as a trailblazing national voice on HIV issues, speaking for his generation.

Ryan's generation listened to him. A 1997 Wall Street Journal survey found that young Americans—people aged 18 to 29—identify AIDS as the defining event for their generation. Yet sadly, a majority of young people believe that AIDS is over. As a mother dedicated to seeing that no more of our sons or daughters are lost to HIV, I find it heartbreaking to think that there are 40,000 new infections every year in the U.S.—half of which are among young people, as reported by the Centers for Disease Control and Prevention (CDC).

In fact, I am pleased to report that preventing HIV infection is one of AIDS Action Council's top priorities. It is far less expensive to prevent someone from becoming infected in the first place than to care for that person once they are infected. Our nation must increase spending on HIV prevention programs at the Centers for Disease Control and Prevention. As you may know, the CDC has an ambitious goal to reduce the cumulative number of new HIV infections in half by the year 2004. Congress should support the prevention efforts underway at the CDC and also reauthorize the CARE Act. I don't know what people would do without the CARE Act. Individuals and families need the CARE Act, and providers need it to continue treating people affected by HIV disease.

Each thread in the CARE Act's safety net is inter-woven in such a way so that the specific needs of individuals living with HIV disease are met. The Ryan White CARE Act is there to ensure that our nation can continue to meet service needs and successfully support access to life saving therapies.

The CARE Act is based on the recognition that medications alone are not enough to successfully fight AIDS. The structure of the CARE Act has worked effectively to: dramatically improve the quality of life for people living with HIV disease and their families; reduce the use of costly inpatient care; and increase access to care for underserved populations, including people of color. This coordinated and comprehensive approach makes the CARE Act a cost-effective and efficient investment—one that must be continued.

I want to thank the Congress for recognizing that the nation needed a great leap of scale in order to care for individuals living with HIV/AIDS and putting in place this efficient statute. The CARE Act continues to show that its strength is deep and its success is wide. From the very beginning, the framers of the Act agreed that for the legislation to adjust to HIV, its structure had to be as resilient as the virus itself. To fortify its structure, the Act has at its core four pillars of strength.

First, the Act gives cities and states autonomy to decide how best to care for their citizens. Thanks to local decision-making, public health officials, community-based organizations, and individuals living with HIV/AIDS have been allowed to come together to tailor the delivery of services to best meet their needs. Local control has resulted in cooperative efforts from various levels of government to develop dynamic and effective strategies in response to the AIDS epidemic.

Second, individuals who receive care through the CARE Act can access a comprehensive range of services designed to maximize the availability and effectiveness of life-saving therapies. The spectrum of medical and supportive services included in the CARE Act is vital to providing better access to quality care.

Third, the CARE Act is a foundation for fostering better collaboration between local, state, and federal agencies in order to improve access to care for people living with HIV.

Fourth, the CARE Act's flexibility has provided incentives to develop innovative approaches to treating HIV disease while improving access to care.

Thanks to the enduring foundation of the CARE Act, providers in every state of the nation, and in every community, are delivering care and treatment and recording success. Your constituents are weaving the threads that make up the HIV/AIDS safety net. This foundation has been tested. Time and time again, it's been proven strong. However, on the tenth anniversary of the CARE Act, we must prepare for a new century.

I believe that we can build upon the greatness of the Ryan White CARE Act. We must look forward, modernize the Act and ensure that it can meet the demands and challenges facing the HIV/AIDS communities.

One of my greatest challenges was to make sure that Ryan was allowed to attend school and get his education. During that battle, I learned a few lessons about the importance of tolerance, the power of information and the value of persistence. In the 10 years since the CARE Act was passed, we've learned important lessons about how best to care for people with HIV disease. Well, practice makes perfect; the Act can only get better through our well-informed improvements.

One important lesson we've learned in treating individuals with HIV disease is that no two people or two communities are the same. This means that the CARE Act must continue to respond to these differences.

First for example, we should make sure that smaller communities experiencing the impact of the HIV epidemic also have the necessary resources for care and treatment. This includes the ability to make sound decisions through local control and greater equity in funding distributions. The experts—service organizations, community-based organizations and individuals infected and affected by the disease must be involved in defining what the needs are and how best to meet them, always with accountability built in.

Equally important, we must recognize that just because HIV has touched an ever-growing number of lives in smaller communities, this does not in any way lessen the force with which HIV continues to strike our largest cities. That's why as we prepare the Act for the 21st century, any changes we make to the Act must not compromise existing infrastructures and/or service delivery systems in metropolitan areas.

Second, much in the same way that HIV has become a part of communities large and small in every region of the country, it has become a part of every culture and population in our nation. HIV is a mirror for our nation's diversity. We must do all that we can to ensure that these populations receive appropriate care with all due speed.

We've come a long way since the beginning of the epidemic in terms of what we know about HIV and how to treat it. And, yet, some of the misunderstanding and discrimination that Ryan fought so hard against still persists today.

That is why access to care and services for underserved communities must remain a priority across all titles at the same time that we continue to plan for emerging needs. Towards this end, incentives and technical assistance should be extended to ensure that CARE Act programs are ready to meet the needs of targeted populations.

Third, just as we must provide incentives to community-based health providers to treat underserved populations, we must do more to encourage localities to contribute more funding to HIV care and treatment. At the point when science is bringing us the hope of new and vastly improved treatment options, it is unacceptable that there are individuals in need of HIV-related medications, despite the presence of the AIDS Drug Assistance Program. We must reward states and cities that invest resources in response to the needs of their communities and stimulate greater participation from more reluctant local and state governments.

Fourth, the CARE Act has also taught us that the continuum of care under the statute includes dental care and training of both dental residents and medical professionals in the treatment of individuals with HIV. Now, we must build upon the success of the Dental Reimbursement Program and expand it to allow programs in non-university settings the opportunity to participate, and we should prioritize funding to those programs with strong linkages to community-based programs.

Fifth, as the CARE Act enters its second decade, we must find better ways of documenting the quality care it provides and use this information to fine tune its programs. Currently the HIV/AIDS Bureau (HAB) at the Health Resources and Services Administration (HRSA) is doing just that. The HAB needs the resources to generate needed data collection and dissemination, analysis and evaluation so that we can pinpoint the most effective use of CARE Act funding. We should enhance the accountability built into the Act, so that better planning for resource distribution can be done.



If the United States is to continue to meet the challenges presented by this complex epidemic, it is essential that we support innovative and flexible solutions to solve our nation's AIDS epidemic. As the epidemic continues to grow and expand into more disenfranchised communities, the need for CARE Act services has become even more critical to the health and well being of individuals who have to deal with multiple barriers to accessing health care.

The Ryan White CARE Act, itself, was created in this spirit. This important piece of legislation is scheduled to expire on September 30, 2000. It is an essential component in our nation's fight against HIV and AIDS and must be reauthorized.

I am grateful for Congress' continued bipartisan support of the Ryan White CARE Act over the past decade. The result of these efforts is that thousands of people living with HIV/AIDS have been able to lead productive lives because of the care, treatment and services provided by the CARE Act. Throughout the United States, the CARE Act continues to make a tremendous difference in the lives of people living with HIV disease.

The success of this legislation is a lasting tribute to my son, and it comforts me to know that so many people are being helped through the services and treatments provided in Ryan's name. I am thankful to have shared 18 precious years with my son and I am thankful that Ryan's legacy lives on through the CARE Act. In 2000, we must reauthorize the Ryan White CARE Act to help those living with HIV/AIDS. It is what Ryan would want us to do.

Mr. Chairman and members of the committee, thank you once again for the opportunity to testify today and I welcome any questions that you might have.

Mr. BILIRAKIS. Thank you very much, Jeanne.

Mr. Tom Liberti, again, welcome, from very hot Florida to hot Washington.

#### **STATEMENT OF THOMAS M. LIBERTI**

Mr. LIBERTI. Thank you, Mr. Chairman.

Good afternoon Mr. Chairman and distinguished members of the House Subcommittee on Health and Environment. My name is Tom Liberti. I am the Chief of the Florida Department of Health, Bureau of HIV/AIDS.

The Bureau administers all of the HIV/AIDS prevention programs in Florida, including early intervention, patient care, and surveillance in our State.

I am pleased to have the opportunity to speak to you today regarding HIV/AIDS in Florida, and also the importance of the Ryan White CARE Act in helping us provide comprehensive and compassionate services to persons living with HIV and AIDS, and the Coburn-Waxman reauthorization legislation.

I would like to take this personal opportunity, on behalf of the citizens of Florida, to thank each of you, and especially Mr. Chairman, for your leadership in addressing HIV and AIDS prevention and care.

Mr. Chairman, Florida has been hit very hard by the AIDS epidemic. HIV infections have penetrated nearly every metropolitan and rural community in our State. Although Florida has only 5.5 percent of the U.S. population, we have approximately 10.5 percent of the 725,000 AIDS cases reported in the United States through 1999.

As mentioned, minority populations in Florida, and particularly blacks, have been disproportionately affected by HIV and AIDS. The numbers of AIDS cases and HIV cases and their ranks have been increasing at an alarming rate.

Of the 78,000 reported AIDS cases, 46 percent are black, 39 percent are white, and 15 percent are Hispanics. Males account for 78

percent of the cases, and females account for 22 percent. I have included a full report with my comments.

How important is the Ryan White CARE Act? The Ryan White CARE Act has made an enormous difference in the lives of Florida's men, women, and children who are infected and affected with HIV/AIDS. For many living with AIDS in Florida, these services are their only source of care and treatment.

In 2000, \$16 million of Florida's \$84 million will be allocated to 14 HIV consortia throughout the State for basic support services and primary care.

Florida has worked hard to provide a continuum of care for all residents infected with HIV and to provide equal access to the standard of HIV care. We are also committed to avoiding duplication or overlap of services and obtaining services and products of the highest quality at the lowest possible cost. Through the coordination of CARE Act grantees, State and local partnerships have been established at every level.

Florida's AIDS Drug Assistance Program has experienced tremendous growth, thanks to the Congress, over the last few years, and we expect to serve over 12,000 HIV infected individuals through ADAP during the upcoming fiscal year.

For 2000, the Florida ADAP is being funded with a combination of Ryan White Title II and State general revenue funds, for a total of \$70 million.

At this time, the program provides 54 drugs on the formulary. This, of course, includes access to all antiretrovirals, all protease inhibitors, and all of the major drugs to fight opportunistic infections and many others.

The Ryan White CARE Act is responsible for the expansion of this critical program and the subsequent decline in HIV-related deaths in Florida. In 1995, there were 4,336 people who died of AIDS in Florida. I am happy to say, in 1998, there were only 1,547; but we can do better.

Florida strongly supports the Ryan White reauthorization. The approaches articulated in the Ryan White reauthorization bill reflect many of the new dynamics of the HIV epidemic. The number of people living with HIV disease is growing, and the diversity of the epidemic is broadening. This bill will give States the flexibility to tailor their response to the unique needs of the changing epidemic.

We strongly support the transition which will promote more effective targeting and distribution of care resources. Confidential name reporting of HIV infection was implemented in Florida in July, 1997. Florida's confidential HIV infection reporting system has identified 16,754 newly reported HIV cases through May of 2000.

HIV infection reporting has clearly shown a significant increase in HIV infection in Florida's minority communities. While blacks comprise 13 percent of Florida's population, they account for 60 percent of the most recently reported HIV cases.

As a result of this alarming trend, numerous minority initiatives have been implemented, including the most recently launching of a statewide media campaign and the creation of a minority HIV/AIDS Task Force, to name a few.

Very quickly, we also support the use of Title II funding for early intervention activities, including activities that assist in case finding and linkages to care, that will strengthen Florida's efforts to fight the spread of this disease.

Through early intervention activities, including innovative counseling and testing, such as the use of oral fluid testing, we will be able to identify more individuals who are HIV infected and unaware of their status.

We support counseling, and the provisions for partner counseling and referral activities are effective interventions for reaching individuals who are at high risk for HIV infection and unaware of their risk.

Mr. BILIRAKIS. Please summarize, Tom.

Mr. LIBERTI. Since the Ryan White CARE Act was passed in the early 1990's, the CARE Act has served as the most important program for HIV/AIDS care and treatment in our State.

We would like to thank you once again for the opportunity to provide testimony on the impact of HIV/AIDS in Florida, and to commend the members of this committee for their hard work, support, and leadership in this critical area.

I am available for questions and comments, as you work on this legislation.

[The prepared statement of Thomas M. Liberti follows:]

PREPARED STATEMENT OF THOMAS M. LIBERTI, CHIEF, BUREAU OF HIV/AIDS,  
FLORIDA DEPARTMENT OF HEALTH

Good Morning, Mr. Chairman and distinguished Members of the House Subcommittee on Health and Environment. My name is Tom Liberti. I am Chief of the Florida Department of Health Bureau of HIV/AIDS. The Bureau of HIV/AIDS administers all HIV/AIDS prevention, early intervention, patient care and surveillance activities in the state. I am pleased to have the opportunity to speak to you today regarding HIV/AIDS in Florida, the importance of the Ryan White CARE Act in helping us provide comprehensive and compassionate services to persons living with HIV/AIDS and the Coburn-Waxman reauthorization legislation, HR 4807. I would also like to take this opportunity, on behalf of the citizens of Florida, to thank each of you for your leadership in addressing HIV/AIDS prevention and patient care.

I would like to begin my testimony by providing a brief overview of the HIV epidemic in our state and the enormous impact of the Ryan White CARE Act in our state. I then have six major points I would like to cover in support of the Ryan White Reauthorization.

OVERVIEW OF THE EPIDEMIC IN FLORIDA

Florida has been hit very hard by the AIDS epidemic. HIV infections have penetrated nearly every metropolitan and rural community in our state. Although Florida has only 5.5 percent of the U.S. population, we have 10.2 percent of the 724,656 cumulative AIDS cases reported in the U.S. through 1999. Florida's population of more than 15 million people is racially and ethnically diverse: 73 percent are white, 13 percent are black, 12 percent are Hispanic and 1 percent are Asian/Pacific Islander and less than 1 percent are American Indian. Minority populations in Florida, particularly blacks, have been disproportionately affected by HIV/AIDS, and the numbers of HIV/AIDS cases in their ranks have been increasing at an alarming rate. Of the 78,000 reported AIDS cases, 46 percent are among blacks, 39 percent are whites and 15 percent are Hispanics. Males account for 78 percent of the reported AIDS cases and females account for 22 percent. In the attachment, you will see additional information regarding HIV/AIDS demographics in Florida.

THE IMPORTANCE OF THE RYAN WHITE CARE ACT

The Ryan White CARE Act has made an enormous difference in the lives of Florida's men, women and children who are infected and affected with HIV/AIDS. The Ryan White CARE Act has enabled us to make a broad range of health care and support services available through community systems of care to increasing num-

bers of people with HIV/AIDS. For many living with HIV/AIDS, these systems are their only source of care and treatment.

In 2000, \$16,568,647 of Florida's \$84 million Ryan White Title II award will be allocated to 14 HIV consortia throughout the state. These consortia provide basic, primary patient care and support services to eligible persons living with HIV disease in their respective areas.

Florida has worked hard to provide a continuum of care for all residents infected with HIV and to provide equal access to the standard of HIV care. We have taken a leadership role in promoting the coordination of Title I (patient care funding to cities), Title II (patient care funding to states), Title III (funding for early intervention service and planning), Title IV (funding for pediatric and family programs) and Part F programs (Special Projects of National Significance, dental reimbursement and AIDS Education and Training Centers). The state is committed to coordinating and planning programs that ensure that all persons living with HIV disease in Florida have access to basic care and support needs. We are also committed to avoiding duplication or overlap of services and obtaining services and products of the highest quality at the lowest possible cost. Through the coordination of CARE Act grantees, state and local partnerships have been established at every level.

Florida's AIDS Drug Assistance Program (ADAP) has experienced tremendous growth over the last few years, and we expect to serve over 12,000 HIV infected individuals through ADAP during 2000-2001. For the year 2000, the Florida ADAP is being funded with a combination of Ryan White Title II and state general revenue for a total of \$70,000,000. At this time, the program provides 54 drugs on the formulary. This includes access to all antiretrovirals, all protease inhibitors, most major drugs to fight or prevent opportunistic infections, hepatitis A and B vaccines, blood modifiers, drugs for neuropathy, drugs for wasting, drugs for lipid-lowering and diabetes and drugs to lessen the side-effects of HAART therapy. This program is available in all of Florida's 67 counties through the Department of Health. The Ryan White CARE Act is responsible for the expansion of this critical program and the subsequent decline in HIV-related deaths in Florida. HIV/AIDS deaths peaked in 1995 with 4336 deaths and declined to 1547 in 1998.

Another significant impact of Ryan White Title II is the AIDS Insurance Continuation Program. In the year 2000, we will fund the AIDS Insurance Continuation Program with Ryan White Title II funds and general revenue funds for a total of \$4,593,016. This project, administered by the Health Council of South Florida in Miami, has been an overwhelming success with enrollment having grown from approximately 100 clients in 1993/94 to approximately 1500 at present. This program is a tremendous success because it allows individuals with AIDS to continue to receive their private health care while avoiding the tremendous public expense associated with health care received under Medicaid or other publicly funded programs.

#### SUPPORT OF THE RYAN WHITE REAUTHORIZATION

Florida strongly supports the Ryan White Reauthorization. The approaches articulated in the Ryan White Reauthorization reflect many of the new dynamics of the HIV epidemic. The number of people living with HIV disease is growing and the diversity of the epidemic is broadening. This bill will give states the flexibility to tailor their response to the unique needs of the changing epidemic. As you consider the CARE Act Reauthorization, I would like to highlight the following six major areas of support that are part of HR 4807:

- Transitioning to the use of HIV cases as the basis for funding allocations**—We strongly support this transition which will promote more effective targeting and distribution of CARE resources. Confidential name reporting of HIV infection was implemented in Florida in July 1997. Florida's confidential HIV infection reporting system has identified 16,754 newly diagnosed HIV cases through May 2000, including 158 pediatric cases. The current estimated number of persons infected in Florida is 65,000-100,000. We estimate that 65 percent of those know their status and 35 percent do not. HIV infection reporting plays a vital role in our ability to target HIV prevention and early intervention efforts. HIV infection reporting has allowed the state to be "in front of the epidemic." This enables us to get those infected with HIV into care earlier, so they can live longer, healthier lives. HIV infection reporting has clearly shown a significant increase in HIV infection in Florida's minority communities. While blacks comprise 13 percent of Florida's population, they account for 60 percent of the HIV cases. As a result of this alarming trend, numerous minority initiatives have been implemented, including the launching of a statewide media campaign, the creation of the Minority HIV/AIDS Task Force, the passage of legislation to improve racial and ethnic health outcomes, and the hosting of

state and national minority leaders at an interagency health symposium and a number of leadership conferences. We also work very closely with minority, community-based organizations to implement culturally sensitive HIV prevention and treatment programs and with clergy and their congregations to mobilize risk-reduction education and supportive attitudes from within the community.

- **The use of CARE Act Title II funding for early intervention activities—**The use of CARE Act Title II funding for early intervention activities, including activities that assist in case finding and linkages to care, will strengthen Florida's efforts to fight the spread of the terrible disease. Through early intervention activities, including innovative counseling and testing, such as the use of oral fluid testing, we will be able to identify more individuals who are HIV infected and unaware of their status. Getting these individuals into early care and treatment is vital to successful HIV treatment. In addition, access and the availability of health care services represent key opportunities to prevent further HIV transmission.
- **The voluntary expansion of partner counseling and referral activities—**Partner counseling and referral activities are effective interventions for reaching individuals who are at high risk of HIV infection and are unaware of their risk. From January to December of 1999, 6,258 positive HIV tests were reported in Florida. Of this number, 2,801 tests were assigned for notification of test results. Of these, 1,442 requested the partner counseling and referral services provided by the Department of Health. This intervention identified 2,784 partners and at-risk persons. From this number, 187 were identified with a new positive HIV antibody test.
- **Streamlining the administration of the CARE Act—**We strongly support the provision which requires the Secretary of HHS to consult with states and Eligible Metropolitan Areas (EMAs) to develop a plan for simplifying the application process for Title I and Title II. Presently, the annual CARE Act application process is overly burdensome for state and local health departments, Title I planning councils and the federal agency that administers Ryan White. The enormous amount of time that these entities devote to the administrative requirements of a yearly application process direct fiscal and human resources away from the provision of services that are the focus of the CARE Act.
- **Grants for activities to reduce perinatal transmission—**We strongly support the authorization of additional funds to further reduce perinatal transmission. We recommend, however, a separate authorization for these grants and not taking money from increases in Title II funds, base or ADAP. This provision gives states the flexibility to devise programs appropriate to their jurisdictions. In Florida, we have seen a dramatic reduction in pediatric HIV/AIDS cases over the last few years. Since 1992, we have experienced an overall 82 percent reduction in reported pediatric AIDS cases. In May of 1999, an important success for Florida was reported in the Centers for Disease Control and Prevention *Morbidity and Mortality Weekly Report*. Data from this report indicated that Florida had one of the highest percentages of pregnant women who could recall being tested for HIV. Another important milestone in our efforts to make a difference in the lives of Florida's women and children was the passage in the Florida Legislature of the Targeted Outreach to Pregnant Women Act (TOPWA). This legislation provides funds for local prevention and outreach projects for women who are pregnant and at risk of delivering an HIV or substance exposed newborn. These extremely successful projects are coordinated through local health departments with community-based providers.
- **New competitive component of Title II—**HR 4807 adds a supplemental component to Title II which will support grants to states that have one or more eligible communities. Eligible communities are non-EMA areas that demonstrate severe need. We strongly support this new competitive component for Title II. It allows states that need additional resources to address critical service shortages in rural and underserved areas.

Since the Ryan White CARE Act was passed in the early 90s, the CARE Act has served as the most important program for HIV/AIDS care and treatment in our state. We would like to thank you once again for the opportunity to provide testimony on the impact of HIV/AIDS in Florida and to commend the members of this committee for their hard work, support and leadership on this critical issue. I am available for questions and comments as you work on this legislation.

Mr. BILIRAKIS. Thank you very much, sir.  
Dr. Birkhead, please proceed.

# STATEMENT OF GUTHRIE S. BIRKHEAD

Mr. BIRKHEAD. Thank you, Mr. Chairman and members of the subcommittee.

My name is Guthrie Birkhead. I am the Director of the AIDS Institute at the New York State Department of Health. The AIDS Institute administers the Ryan White CARE Act Title II funds that go to New York State.

I am pleased to have the opportunity to speak to you today about the importance of the Ryan White CARE Act, which is essential in helping us provide comprehensive services to persons with HIV/AIDS in New York.

The HIV epidemic has heavily impacted New York State. Approximately 141,000 AIDS cases have been reported in New York, and approximately 56,000 New Yorkers are living with AIDS. That is about 19 percent of the national total.

Persons with AIDS in New York differ from those in many parts of the country in that 75 percent are members of minority groups. Women make up 26 percent of cases; more than in other areas. Injection drug use is the most common risk factor reported in 40 percent of cases.

Persons diagnosed with AIDS are just the tip of the HIV iceberg. It is estimated that the number of persons living with HIV in New York, beyond the 56,000 with AIDS, is about 75,000 to 115,000. We will have a better idea of the number of persons with HIV infections in New York, as we implement HIV reporting over the next one to 2 years.

New York began its response to the HIV epidemic with the creation of the AIDS institute in 1983, ADAP in 1987, and by 1991, the State had a well developed system of HIV care, supported by Medicare and State grant dollars.

When Federal Ryan White funding became available, the CARE Act funds were used, along with increased in State funding, to augment the existing ADAP Program, extend primary care services to the uninsured through our ADAP Plus Program, to fund community-based case management and supportive services, and to establish regional Ryan White care networks, which are local groups in 16 geographic areas that help determine local priorities.

CARE Act funding is an essential source in New York to support our continuum of services, and has had a tremendous impact on the health and quality of life for New Yorkers.

CARE Act funds make available the new therapies to uninsured persons through our ADAP Program, which is a traditional pharmaceutical program, and our ADAP Plus Program, which provides ambulatory insurance to persons without insurance.

These programs are supported by a combination of State and Ryan White Title II funds, with a significant contribution of Title I funding from the Title I EMAs. This illustrates what can be accomplished in partnership with funding from all sources, State and Federal, to provide state-of-the-art care.

More than 53,000 persons living with HIV/AIDS have enrolled in New York's ADAP since its inception. More than 20,000 were enrolled in 1999. The program recently has experienced explosive growth due to the new therapies. The monthly utilization has increased 137 percent, up to 10,900 served last month. Monthly ex-

penditures have increased 450 percent in the last 5 years, up to \$12 million per month.

However, ADAP has been very successful in assuring access to therapies. In the first quarter of the year 2000, 80 percent of our ADAP recipients were using three or more antiretroviral drugs in combination, while another 11 percent were taking two drug combinations. We have seen no significant differences in the rates of access by race, gender, income or risk factor.

Without, however, the increases in Federal ADAP supplemental funds, New York would not be able to offer access to this standard of care.

Combination therapies are not the only thing that allow persons to live longer and healthier. They allow people to reduce their risk of transmission to others.

But treatment is not just a matter of writing a prescription and paying the pharmacy bill, and the CARE Act has been instrumental in maximizing the potential for these new drugs to extend and improve life by supporting programs and quality assurance, case management, and in very important treatment adherence and education, which allow people to stay on schedule with their medications.

CARE Act funding also enables us to make HIV services accessible to those most difficult to reach, high risk populations not linked to the health care system, which include substance users, communities of color, the homeless, women and children, youth, and particularly youth on the street and gay youth, and persons with multiple diagnoses [HIV, mental illness, and substance use].

For example, we have located HIV services and settings where affected populations already receive services like substance abuse treatment settings, and agencies serving communities of color, and have brought the services to the client via mobile vans and home visits.

CARE Act funded programs in conjunction with Medicaid and State funds have resulted in improved access to care, reduced hospital costs, and reduced morbidity and mortality. Hospital utilization in the last 3 years fell 30 percent. The average length of stay fell 45 percent. HIV/AIDS death fell 77 percent in New York.

Reauthorization of the CARE Act is critical to our efforts to provide quality care for persons with HIV/AIDS, and the following are our recommendations for the reauthorized CARE Act. First, we thank Congress for maintaining the existing title structure of the CARE Act.

Second, we support the House bill provision that will eventually change base Title I and II funding formulas from AIDS cases to one based on HIV cases. It will take States like New York a couple of years, after embarking on HIV reporting, to get our systems fully operational in providing quality data.

An essential component of the formula is the hold harmless provision. The current House version, leading up to 25 percent reductions by the fifth year, we do not support. We do support the hold harmless provisions in the Senate bill, which call for reductions of no more than 2 percent per year, as there have been in the past.

Third, we do support the House provision that adds supplemental components to Title II, if the increase in Title II base funds

is at least \$20 million over fiscal year 2000. This supplemental component will support competitive grants to States that have communities with severe need.

The Senate bill's provision, which relates to a supplemental component, creates Title I-like awards. We believe that the House bill would more effectively address the priority unmet needs for all non-Title I areas.

We do support grants for counseling, testing, and treatment of pregnant women and infants in New York. As has been indicated, our newborn testing program has provided valuable information to track perinatal HIV transmission, and to assist in getting HIV exposed infants and newborns into care.

HIV testing in the newborn or delivery setting may permit treatment to prevent perinatal transmission for women not tested during prenatal care. We understand that this funding will not be at the expense of other Title II programs.

I have just a couple more recommendations. Because the number of persons living with HIV continues to increase because of treatment, we do recommend expanded authorized funding levels for all Titles. We recommend further that the reauthorized CARE Act allow ADAP supplemental funds to be used specifically for medical monitoring, laboratory testing, and medication adherence support, all of which are key components of HIV treatment, as well as for HIV health insurance continuation.

Finally, getting people tested for HIV and into care as quickly as possible is important for successful HIV treatment. Therefore, we support the House bill provision related to the use of the CARE Act funds for intervention services and early intervention, which allows use of Title I and II funds to support services in a variety of settings.

We thank the House for its vision in this area. We would suggest, however, that some language has been eliminated from previous versions of the bill which allowed these early intervention funds to be used in a variety of community-based settings, and not just medical settings.

Often, providers best able to reach under-served minority populations are community-based organizations that might not meet the current definition established in the bill. We encourage the restoration of language that would enable all funded entities to carry out these early intervention services.

I hope my remarks have illustrated the critical importance of the Ryan White CARE Act in New York. I look forward to your questions. Thank you.

[The prepared statement of Guthrie S. Birkhead follows:]

PREPARED STATEMENT OF GUTHRIE S. BIRKHEAD, DIRECTOR, AIDS INSTITUTE, NEW YORK STATE DEPARTMENT OF HEALTH

Good morning. My name is Guthrie Birkhead. I am the Director of the AIDS Institute at the New York State Department of Health. The AIDS Institute administers the Ryan White CARE Act Title II funds that go to New York State. I am pleased to have the opportunity to speak to you regarding HIV/AIDS in New York State and the importance of the Ryan White CARE Act in helping us provide comprehensive services to persons with HIV/AIDS in New York.

Let me begin by telling you a little about the HIV epidemic in New York State. Approximately 141,000 AIDS cases have been reported in New York State and approximately 56,000 New Yorkers are living with AIDS—about 19 percent of the na-



tional total. The epidemiology of AIDS in New York is different from many other areas of the country. Of those living with AIDS, at least three quarters are members of minority groups: 43 percent are Black, 32 percent are Hispanic, 23 percent are White, and about 2% are Asian American, Pacific Islander or Native American. Women make up 26% compared to 74% for men. Injection drug use is the most common risk factor reported in 40% of cases. Persons diagnosed with AIDS are just the tip of the iceberg of HIV infection. It is estimated that the number of persons living with HIV, beyond the 56,000 with AIDS in New York State, is 75,000-115,000. We will have a better idea of the number of persons with HIV, and the number of new HIV infections each year, as HIV reporting is implemented in New York over the next 1-2 years.

In discussing the impact of the Ryan White CARE Act on New York State, it must be noted that New York began to organize its response to the HIV/AIDS epidemic with the creation of the AIDS Institute within the State Health Department in 1983. By 1991, the State had built a system of HIV care that included ambulatory care, hospital care, home care, nursing home care, and case management supported by Medicaid and State grant dollars; a range of supportive services paid for by State and federal grant funds; and the AIDS Drug Assistance Program, or ADAP, which began in 1987. When federal Ryan White funding became available in 1991, New York State's system of community-based health care and services was already well developed; Ryan White funds were used, along with increases in State and CDC resources, to expand and augment this system. Specifically, Ryan White resources were used to:

- Augment existing initiatives, most notably the ADAP and home care programs for the uninsured;
- Extend primary care services to the uninsured;
- Fund new community-based case management and supportive services programs; and
- Establish Ryan White HIV care networks throughout the State. The care networks are local groups of providers in 16 geographic areas who work with the State health department to determine local program priorities and funding allocations.

As the number of people with HIV and AIDS in New York has increased over the years, so has the funding available through the CARE Act. New York State receives about \$285 million for HIV/AIDS services through all titles and sections of the Ryan White CARE Act. Ryan White funding is an essential source of support for New York's continuum of HIV services and has had a tremendous impact on the health and quality of life for New Yorkers affected by HIV/AIDS.

A primary impact of the Ryan White CARE Act in New York is to make available existing and emerging HIV/AIDS therapies to uninsured persons who are above the level of Medicaid eligibility. In New York State, the ADAP model has been expanded and is now known as the "HIV Uninsured Care Programs." These programs play a vital role in New York State's health care system for people living with HIV/AIDS.

The program has three components:

- ADAP, the traditional program that assures access to drugs for uninsured and underinsured New Yorkers with HIV/AIDS;
- ADAP Plus, a program which provides access to ADAP enrollees to primary care services and laboratory tests for HIV disease management; and
- The Home Care Program, which provides more intensive medical services needed to maintain uninsured and underinsured people in their homes and avoid costly hospitalization or nursing home care.

Through these programs, providers are reimbursed on a fee-for-service basis for the delivery of HIV services and medications. The approaches are client-centered and seek to empower individuals with no or inadequate insurance to access needed services. The programs are primarily supported by federal funds under Ryan White Title II along with an appropriation of state funds. In addition, the Department of Health has formed unique partnerships with the Title I Eligible Metropolitan Areas (EMAs) in New York, which predominately support the ADAP Plus ambulatory insurance program, to jointly support the programs. Thus, the HIV Uninsured Care Programs are an example of what can be accomplished by blending funding from all sources, State and Federal, to ensure state-of-the-art care for HIV-positive persons.

The introduction of combination antiretroviral therapies for HIV in 1995 has had a dramatic effect in reducing progression of HIV to AIDS and AIDS deaths. As a result, New York's ADAP program has experienced explosive growth in the number of individuals accessing care and in expenditures during the past three years. More than 53,000 people living with HIV/AIDS have enrolled in ADAP since its inception;

more than 20,000 were enrolled in 1999. To illustrate the growth of the program, let me give you some figures on monthly utilization. In January 1996, approximately 4,600 people were served. In June 2000, 10,900 were served—an increase of about 137 percent in a little over three years. More dramatic is the increase in monthly expenditures. Expenditures for the month of January 1996 were \$2.2 million. By June 2000, monthly expenditures were \$12.1 million—an increase of 450 percent. This is due to the expense of the combination HIV therapies, which may run \$12,000 to \$15,000 per person per year. The ADAP Plus ambulatory insurance program has also seen a doubling of utilization and annual expenditures for medical care and laboratory services.

Through ADAP, New York has been able to assure that all of the populations affected by HIV have equal access to the standard of HIV care—specifically combination therapy. In the first quarter of 2000, 80 percent of ADAP participants were using three or more antiretroviral drugs in combination, while another 11 percent were taking two-drug combinations. Our ongoing analysis shows no significant differences in the rates of access to antiretrovirals by gender, race/ethnicity, income, or HIV risk factor. If not for the availability of Ryan White funds for ADAP—and the increases in ADAP supplemental funds available under the CARE Act—New York would not be able to offer access to the standard of HIV care to all of its residents affected by HIV.

The combination therapies not only allow persons with HIV to live longer and healthier, allowing many to be able to return to the work force, they also reduce the risk of HIV transmission to others. However, treatment for HIV is not simply a matter of writing a prescription and paying the pharmacy bill. Quality health care, case management, treatment education and adherence support programs are necessary to allow people to stay on schedule with their medication. The Ryan White CARE Act has been instrumental in maximizing the potential of these new drugs to extend and improve life through a comprehensive system of care and support services. Successful adherence to HIV medications is particularly critical because HIV develops resistance to the combination therapies very quickly if medication doses are missed or delayed. Resistant strains could limit the effectiveness of HIV drug therapies in the future. Ryan White CARE Act funding is now being used in New York to help persons with HIV stay on schedule with their medications and improve the effectiveness of the therapies.

Another significant impact of the Ryan White CARE Act on New York State is our ability to effectively meet a challenge which has existed in our State since the beginning of the epidemic—that is, the challenge of making HIV services accessible to those populations who are not linked to the health care system and are most difficult to reach and at highest risk: substance users; communities of color; the homeless; women and children; youth, particularly youth on the street and young gay men; and persons with multiple diagnoses (HIV, mental illness and substance use). New York has integrated funds from State and Federal sources to design population-based program models that offer a comprehensive package of services to all affected populations throughout the State. For example, we have located HIV services in settings where affected populations already receive services, like substance abuse treatment settings and agencies serving communities of color; we have co-located HIV services with support services that facilitate access to care; and we have brought the services to the client, via mobile vans and via home visits.

In designing initiatives and determining the relative priority for program models, we have worked closely with the Ryan White Title II networks which have been established throughout the state, with our Title I EMAs and their planning councils, and with the private, not-for-profit, and academic communities. All initiatives are planned and prioritized with the participation of infected persons and health and human services providers on the front lines. This is another significant effect of the Ryan White CARE Act—it has fostered the establishment of local and state partnerships at many levels, contributing to our success in ensuring access to a continuum of HIV care services for persons in all parts of the state and at all stages of the disease.

These programs, put into place with a combination of Ryan White CARE Act funds in conjunction with Medicaid and state grant funds, have resulted in improved access to care, reduced hospital costs, and reduced morbidity and mortality from AIDS. Expensive hospital utilization has been reduced, with drastic decreases in hospital discharges and lengths of stay. Hospital discharge data show a reduction in HIV/AIDS hospitalizations from 65,000 in 1995 to less than 45,000 in 1998—a decrease of more than 30 percent. The average HIV/AIDS hospital length of stay was 18.9 days in 1990 and 10.2 days in 1998—a reduction of more than 45 percent. In 1990, 50 percent of stays were ten days or less, and in 1998, 75 percent were ten days or less.

In addition, the availability of combination antiretroviral therapy and a full continuum of HIV services in New York State has resulted in a dramatic reduction in HIV-related mortality. Between 1994 and 1995, there was a one percent reduction in all deaths from HIV/AIDS. Between 1995 and 1999, there has been a decline in HIV/AIDS deaths of more than 77 percent. And effective therapy will prevent the development of antiretroviral resistance and reduce HIV transmission to others.

Reauthorization of the Ryan White CARE Act is critical to our efforts in New York to provide quality health care for persons with HIV/AIDS. I would like to discuss the proposed Ryan White bills and our recommendations for the reauthorization of the CARE Act that will enhance our ability to serve persons with HIV/AIDS.

(1) First, we thank Congress for maintaining the existing Title structure of the CARE Act, with ADAP supplemental funds as a component of Title II funding to states. Changing the structure of the Act could have resulted in harmful disruptions in services.

(2) Second, we support the House bill provision that revises the Title I and base Title II funding formula from one based on AIDS cases to one based on HIV cases toward the end of the reauthorization period. While it will take states like New York who are just now embarking on HIV reporting some time to get their systems fully operational and producing quality data, we believe that continuing to base the allocation of funds on AIDS cases could be detrimental to states that have been successful in making treatments available to persons with HIV, as fewer of them progress to AIDS. An essential component of the formula, though, is the hold harmless provision. The CARE Act should establish hold harmless provisions for Title I and Title II that will avert drastic reductions in awards and disruptions in services. The House bill's hold harmless provisions could lead to a 25% reduction in awards to states and cities in the fifth year of the reauthorization period. We support the hold harmless provisions in the Senate bill, which call for reductions of no more than two percent per year.

(3) Third, we support the House provision that adds a supplemental component to Title II if the increase in Title II base funds is at least \$20 million over the FY 2000 amount. This supplemental component of Title II will support competitive grants to states that have communities with severe need. The Senate bill's provision related to a supplemental component of Title II does not include competitive awards. Rather, it creates more "Title I-like" awards. We believe the House bill would be more effective in addressing priority unmet needs in all non-Title I areas.

(4) We support grants for counseling & testing and treatment of pregnant women and infants. In New York State, our newborn testing program has provided valuable information to track perinatal HIV transmission and to assist in getting HIV-exposed newborns into health care. HIV testing in the newborn setting may permit treatment to prevent perinatal transmission for women not tested during prenatal care. We understand that this funding will not be at the expense of other Title II programs.

(5) Because the number of people living with HIV continues to increase we recommend expanded authorized funding levels for all Titles of the Act.

(6) We recommend further that the reauthorized CARE Act allow ADAP supplemental funds to be used specifically for medical monitoring, laboratory testing, and medications adherence support—all of which are key components of HIV treatment—as well as for health insurance continuation. The House bill allows for the use of ADAP funds for continuation of health insurance, but does not address medical monitoring, lab testing and adherence support.

(7) Getting people tested for HIV and into care as quickly as possible is important for successful HIV treatment. Therefore, we support the House bill provision related to the use of CARE Act funding for early intervention services, which allows for the use of Title I and Title II funds to support early intervention services in a variety of settings. In addition, the House bill allows for the use of funds for outreach for purposes of identifying individuals with HIV who are not receiving services. We thank the House for its vision in this area. However, we question the elimination of the provision allowing for early intervention activities in any entity receiving Title II funds. Previous versions of the House bill included this important language, but it was removed from the bill that was finally introduced. Often, the providers best able to reach underserved, minority populations are community-based organizations that might not meet the definitions established in the legislation. We strongly encourage the restoration of the language that will enable all funded entities to carry out early intervention activities.

(8) The House bill requires that we allocate an "appropriate" amount of funds to support identifying individuals not utilizing services and encouraging them to do so. Do not mandate in legislation that we allocate a specific portion of our Title II grant

for certain types of activities. It is essential that we have flexibility in administering our Title II programs to ensure that local needs are addressed.

(9) Previous versions of the House bill allowed for the use of Title II funds for surveillance activities. We supported this provision. The bill that was introduced, however, eliminates this provision. We support the use of Title II funds for surveillance, perhaps with a cap and language requiring that funds supplement rather than supplant existing funding for such activities.

(10) The House bill calls for additional participatory planning processes with regard to the Title II application. We do not support this provision. Existing requirements related to participatory planning are more than sufficient. For example, we are required to conduct public hearings on our application, we are required to involve all titles and consumers in the statewide coordinated statement of need, our Title II consortia participate in planning, and we are required to coordinate activities with other programs and agencies.

(11) Do not require in statute that we conduct planning and priority setting based on the needs of individuals not in care. This information cannot be routinely gathered short of a major research program, which probably would not be cost effective.

(12) We do not support a legislative mandate that support services must be related to health care. Both the House and Senate bills require support services to facilitate, sustain or enhance health care. Some support services enhance quality of life, and some affected populations, like women and children, require support services that might not be directly linked to care, such as permanency planning and legal services that assist families affected by HIV.

(13) We support the House language calling for preferences related to Title III awards supported by newly appropriated funds. The House language allows for preference to be given to underserved or rural areas, while the Senate language allows for preference for rural areas only.

I hope my remarks have illustrated the critical importance of the Ryan White CARE Act to New York State, and that you will consider our recommendations for a reauthorized CARE Act. I would be happy to discuss these issues further with you or your staff.

Thank you for the opportunity to speak to you today.

Mr. BILIRAKIS. Thank you very much, Doctor.

I might add that as promised, Drs. Fox and O'Neill have stayed in the audience, and are listening to all this testimony. We really appreciate that very much.

Mr. Davy, please proceed.

#### STATEMENT OF JOSEPH DAVY

Mr. DAVY. Thank you, Chairman Bilirakis, Representative Brown, and members of the committee, for the opportunity to testify before you today.

Ladies and gentlemen, our clients are still dying of AIDS, though not in the numbers they were just a few short years ago. Because our clients are living longer lives, their need for services has increased tremendously. The cost of medications is out of reach for all but the wealthiest of individuals.

Case loads of our case managers have increased approximately 10 percent in each of the last 3 years. The complexity of our clients' needs has changed dramatically.

Today, you have heard about the changing face of AIDS in America. I am here to tell you that it is not a changing face of AIDS, but an expanding face of AIDS.

At Columbus AIDS Task Force, over 35 percent of our clients are African American and Hispanic. Yet, those two populations account for only about 18 percent of the total population in Central Ohio. It is also true in Ohio that 55 percent of new infections are still a result of male to male transmission.

The success of the Ryan White CARE Act is credited, in large part, to the local control inherent in the operation of the CARE Act.

I would like to thank the Members of Congress for producing legislation that works very well for addressing the needs of our clients.

I appreciate that Representative Coburn and Waxman, and their respective staffs, have worked very diligently over the past several weeks to put together a bill which continues to address these needs.

I was particularly encouraged to see in the final drafts of the bill the Representatives' recognition of the success of the CARE Act. Many of the provisions in both the House and Senate versions of reauthorization will improve and strengthen the CARE Act.

By far the most relevant provision affecting Ohio and other communities around the country with large epidemics is the Title II Supplemental Grant Program. This important provision would recognize communities which do not qualify for Title I funding, yet have a severe need to address the burgeoning epidemic.

Second, the hold harmless provisions in the Coburn-Waxman bill are an ingenious mechanism to achieve equitable distribution of CARE Act funds without jeopardizing communities' existing service delivery systems.

You will recall that in the last reauthorization, hold harmless was meant to be a stop gap for communities that would be affected by the change in formula definition. It was never intended to be a permanent part of the CARE Act.

The provision recognizes that Ryan White funding should be based on need, but that it takes time to plan for pending funding decreases through changes in service delivery. I believe the hold harmless provision in the Coburn-Waxman bill does just that.

Third, the Columbus AIDS Task Force, for several years, has worked under an outcome-based measurement model for all the services we provide. We know that to provide the programs and services we offer, it takes competent, professional staff to manage and administer those programs.

We are concerned about any provisions in reauthorization that would impair our ability to attract employees with the experience and background to provide our clients with the best service we can.

Fourth, as many of our clients are returning to the work force, we find that many of them are finding employment in the field of AIDS service delivery. Provisions in the Coburn-Waxman bill seek to exclude these individuals from Title I planning councils.

Recognizing the role that affected and infected individuals play in AIDS service organizations, as staff members, board members, and volunteers, we are concerned about provisions which would eliminate this valuable insight from planning councils.

Finally, provisions in the Coburn-Waxman bill add incentives for States to move to mandatory testing laws for the reduction of perinatal transmissions of HIV. We are encouraged by the bipartisan agreement reached by Representatives Coburn and Waxman.

While we at Columbus AIDS Task Force certainly encourage the development of programs that will reduce all transmission, we are concerned about using tight dollars for mandatory testing programs for perinatal transmissions.

Ladies and gentlemen of the committee, again, I thank you for the opportunity to provide testimony on this important piece of legislation.

I would also again like to thank you for your continued support of the Ryan White CARE Act. You have truly made a difference in the lives of my friends and clients.

Finally, I urge you to the swift reauthorization of the Ryan White CARE Act. Thank you.

[The prepared statement of Joseph Davy follows:]

PREPARED STATEMENT OF JOSEPH DAVY, POLICY ADVOCATE, COLUMBUS AIDS TASK FORCE

Thank you Chairman Bilirakis, Representative Brown, and members of the committee for the opportunity to testify before you today. My name is Joe Davy and I am the Policy Advocate for Columbus AIDS Task Force in Columbus, Ohio.

In 1989, I watched someone very close to me go through a long illness. At the time, John's family and friends did not know he had AIDS because of the stigma that went along with AIDS back then. He was in and out of the hospital several times that year with various bouts of pneumonia, anemia, and lesions. Although several of us suspected he might have AIDS, it was never confirmed. He died several months after his 21st birthday.

On October 1, 1994, months before his 40th birthday, I watched my best friend die of AIDS after battling the disease for nearly 10 years. Dennis was one of those people whom everyone loved. He was vibrant, intelligent, and an inspiration to all who knew him. At his memorial service, his father, who had struggled with Dennis' sexual orientation and illness, talked about Dennis' coming out to him. Dennis had been living in San Francisco for several years and was coming home for a visit. He had told his father that he had something very important to discuss with him. Dennis' father suspected Dennis was gay and that he probably had AIDS so he tried to prepare himself for the conversation. When Dennis and his father sat down to talk, Dennis began the conversation, "Dad, I have something to tell you that I have been hiding from you." His father braced himself. Dennis confessed, "I drive a Yugo!"

In these past 12 years, we have watched too many people die of AIDS. Some have faced it alone like John, others have laughed at it bravely like Dennis. While all of those who have faced this disease have had to deal with it in their own way, there is one sad truth. They all needlessly died too young.

Unfortunately, John and Dennis died before the treatments that are available today are prolonging people's lives. We have all heard and seen the amazing effects of the new cocktail therapies on our clients' lives. Many of the clients at the Columbus AIDS Task Force are returning to the work force after being told three or four years ago that they only had weeks, or in some cases, days to live. While these stories are incredible and hopeful, they only tell one side of the story.

Our clients are still dying of AIDS, though not in the numbers they were a few short years ago. Because our clients are living longer lives, their need for services has increased tremendously. The cost of the medications is out of reach for all but the wealthiest of individuals. Case loads of our case managers have increased approximately 10% each year the last 3 years. In addition to the increased size of our case loads, the complexity of our client's needs has changed dramatically.

You have probably heard about the changing face of AIDS in America. I am here to tell you today that it is not a changing face of AIDS, but an expanding face of AIDS. At the Columbus AIDS Task Force, over 35% of our clients are African American and Hispanic. Yet those two populations account for only about 18% of the total population in central Ohio. It is true that AIDS is affecting the minority populations in catastrophic proportions. But, it is also true that in Ohio, 55% of new infections are still a result of male to male transmission. So the epidemic is not changing from one population to another but is expanding across several populations.

It is not unusual for our social workers to get calls from newly released prisoners. Often, these men and women may have heard one of our educators speaking at a pre-release program or have seen our information on the prison computers. When they are released from prison several weeks later, they will call us from the bus station with ten dollars in one pocket and a prescription in the other. Often, they have no family or other means of support and are looking to us to provide them with housing, help with paying for their medications, assistance with directions on how to properly take their medications, and identifying other social services they may need and be eligible for.

Many of our clients are coming from homeless shelters as well. Often, these clients come with issues of addiction and alcoholism, mental health, domestic abuse, and others. Our case managers find that these individuals' HIV/AIDS status is often

third or fourth on the list of the things they need to deal with. Getting the client stabilized in housing and substance use or mental health services is of the utmost concern before we can even deal with complicated HIV drug regimens.

I point out all these things because they all highlight the importance of the Ryan White CARE Act in the lives of people living with HIV/AIDS. Because of the Ryan White CARE Act, our clients are able to be on life prolonging medications they could not otherwise afford. People with HIV/AIDS are able to maintain stable housing, work through mental health and substance use issues, and have the resources available to remain independent, and, in some cases, return to the work force. AIDS Service Organizations like the Columbus AIDS Task Force are able to hire case managers and social workers to provide these valuable and much needed services to people living with HIV/AIDS.

Through Title III of the Ryan White CARE Act, the Columbus AIDS Task Force has been able over the past two years to increase access to primary health care services for our clients in Southeastern Ohio, a largely rural area with an increasing AIDS epidemic. Without the funds from the CARE Act, people living with HIV/AIDS in these rural communities would have to drive to Columbus for their health care and other services. For some, that could mean a 200 mile round trip just to see a doctor. These individuals cannot afford overnight stays and that kind of trip on a person with a weakened immune system can be exhausting. With Ryan White, we are able to provide training for service providers in the rural communities to ensure those providers are current on HIV treatment issues. This enables our clients in rural communities to access services closer to home from trained, competent providers.

Ladies and gentlemen, the success of the Ryan White CARE Act is credited in large part to the local control inherent in the operation of the CARE Act. I would like to thank the members of Congress for producing a piece of legislation that works very well for addressing the needs of our clients. I know that Representatives Coburn and Waxman and their respective staffs have worked very diligently over the past several weeks to put together a bill which continues to address those needs. I was particularly encouraged to see in the final drafts of the bill the Representatives' recognition of the success of the CARE Act. Many of the provisions in both the House and Senate versions of Reauthorization will improve and strengthen the CARE Act but these provisions do not serve to overhaul the Act.

In that regard, I would like to point to some provisions of Reauthorization that will have the greatest impact on HIV infected individuals and the organizations which provide HIV/AIDS services.

By far, the most relevant provision affecting Ohio and other communities around the country with large epidemics is the Title II Supplemental Grant Program. This important provision would recognize communities which do not qualify for Title I funding yet have a severe need to address the burgeoning epidemic. Funds generated by this provision will be used to provide care and treatment services in cities and states where the AIDS epidemic is overwhelming service delivery systems.

Second, the Hold Harmless provisions in the Coburn-Waxman bill are an ingenious mechanism to achieve equitable distribution of CARE Act funds without jeopardizing communities' existing service delivery systems. You will recall that in the last reauthorization, Hold Harmless was meant to be a stop gap for communities that would be affected by the change in formula definition. It was never intended to be a permanent part of the CARE Act. The provision recognizes that Ryan White funding should be based on need, but that it takes time to plan for pending funding decreases through changes in service delivery. I believe the Hold Harmless provision in the Coburn-Waxman bill does just that.

Third, Columbus AIDS Task Force, like many AIDS Service Organizations, for several years has worked under an outcome-based measurement model for all the services we provide. We are proud of the fact that our client needs assessment surveys continue to return glowing reports on the services we provide. We also know, however, that to provide the programs and services we offer, it takes competent, professional staff to manage and administer those programs. We are proud that we are able to maintain our administrative and fundraising costs to under 15% of our budget, which is less than or equal to other not-for-profit organizations of similar size. We are concerned about any provisions in Reauthorization that would impair our ability to attract employees with the experience and background to provide our clients with the best service we can. We strongly believe in accountability and continue to hold ourselves to a higher standard than that required by our funders but provisions which seek to limit or expose administrators' salaries seem punitive and intrusive.

Fourth, as many of our clients are returning to the workforce, we find that many of them are finding employment in the field of AIDS service delivery. Provisions in

the Coburn-Waxman bill seek to exclude these individuals from Title I Planning Councils. Recognizing the role that affected and infected individuals play in AIDS Service Organizations, as staff members, board members, and volunteers, we are concerned about a provision which would eliminate this valuable insight from the Planning Councils.

Finally, provisions in the Coburn-Waxman bill add incentives for states to move to mandatory testing laws for the reduction of perinatal transmissions of HIV. We are encouraged by the bipartisan agreement reached by Representatives Coburn and Waxman. According to the CDC's HIV/AIDS Surveillance Report, during the time period from 1992-1998, perinatal transmission of HIV has decreased over 75%. While we at Columbus AIDS Task Force certainly encourage the development of programs that will further reduce perinatal transmission, we are concerned about using tight dollars for mandatory testing programs. Pregnant women should be counseled about the benefits and responsibilities of testing and potential treatments if they are found to be HIV-positive. Women should then be allowed to make the choice of whether to be tested after they have been counseled. I know we share the same goals to reduce perinatal transmission.

Ladies and Gentlemen of the committee, again I thank you for the opportunity to provide testimony on this important piece of legislation. I would also again like to thank you for your continued support of the Ryan White CARE Act. You have truly made a difference in the lives of my friends and clients. And, finally, I urge you to the swift reauthorization of the Ryan White CARE Act. I would be happy to answer any questions you may have at this time.

Mr. BILIRAKIS. Thank you very much, sir.

Ms. Mann.

#### STATEMENT OF DOROTHY MANN

Ms. MANN. Good afternoon, Mr. Chairman and members of the subcommittee. I am the Executive Director of the Family Planning Council, serving Philadelphia and the four surrounding counties.

The Council provides STD, HIV, and family planning services to over 107,000 clients, annually. My organization is the lead agency of a community network known as the Circle of Care, which provides prevention, comprehensive health, and support services to HIV positive children, youth, women, and their families.

This program is principally funded through Title IV of the Ryan White CARE Act, and receives additional support from Titles I and II.

I am here today representing AIDS Alliance for Children, Youth, and Families. AIDS Alliance is a national organization that addresses the needs of children, youth, and families, who are living with, affected by, or at risk for HIV and AIDS.

With the Thirteenth International Conference on AIDS currently taking place in Durban, South Africa, the Nation hardest hit by the AIDS pandemic, our awareness of the global AIDS crisis has never been greater.

Yet, here in the United States, it has almost become acceptable that 40,000 people are newly infected with HIV each year.

Today, I will focus my remarks on the critical importance of incorporating prevention messages into care, because unless we change how we approach this epidemic, another 40,000 people will be infected with HIV next year, as well.

Young people are particularly hard hit by HIV. People under 25 account for at least half of the 40,000 new HIV infections in the United States.

So it is abundantly clear that with 40,000 new HIV cases a year, for the next 5 years at least, the number of people needing services



under the Ryan White CARE Act will continue to increase, as will the cost and complexity of the services they require.

I would like to take a moment to commend H.R. 4807's emphasis on making HIV prevention an integral component of care for HIV positive people.

The Ryan White CARE Act is not a substitute for the HIV prevention programs, based on CDC. But the CARE Act has a critical role to play in helping to stem the spread of this disease.

Titles I and II have been explicitly described and allowed to do case finding as a new responsibility in the House bill. I commend you for this.

It goes without saying that HIV is spread from an infected person to an uninfected person. But we have focused HIV prevention almost exclusively on uninfected people, and we have largely ignored those who are already infected.

Let me be clear. I am not advocating laws or policies that criminalize or stigmatize HIV positive people, or their behavior. I am talking about interventions that help HIV positive people reduce their risk behaviors and protect their partners from infection.

Among the Titles of the CARE Act, Title IV has had the most emphasis on integrating HIV care and prevention. At my Title IV project in Philadelphia, for example, reproductive health specialists, funded by Title X of the Public Health Service Act, see HIV positive women in care, to provide contraceptives, screening and treatment for STDs, and counseling regarding HIV and STD prevention. This kind of integration and integrated approach should be replicated throughout CARE Act programs.

As you know, one of the true success stories in this epidemic has been the effort to reduce the number of children who are born with HIV. H.R. 4807 includes many new provisions to help in this battle; three, to be exact.

First, it will authorize an additional \$20 million for States' activities related to reducing perinatal HIV transmission. There is no mandatory anything in this bill. These funds are available to all States; those that provide mandatory HIV testing for newborns whose mother's status is unknown, and other States, with significant perinatal HIV transmission rates.

Second, an IOM study will be commissioned to conduct an analysis of State efforts to make recommendations to States on future steps to reduce perinatal transmission.

Third, the Secretary is directed to expand and coordinate efforts at NIH and FDA to develop rapid HIV tests. Accurate and affordable rapid HIV tests would help diagnose pregnant women whose HIV status is not known at the time they are in labor.

AIDS Alliance is supportive of these efforts to ensure that the reauthorized CARE Act helps States and communities to build on the success in reducing perinatal transmission. Science has given us the tools. States must be encouraged to use them.

Finally, reversing the Nation's complacency about AIDS is a daunting task; 40,000 new infections, over 100 per day, is intolerable.

Do we really have a war on AIDS in this country? If we had 40,000 American casualties in a war, would we find that acceptable? I think not.

The time has come for us to muster the vision, resources, and courage to give Americans infected with HIV the best care our country can provide, and to truly end the spread of this epidemic. Thank you.

[The prepared statement of Dorothy Mann follows:]

PREPARED STATEMENT OF DOROTHY MANN, EXECUTIVE DIRECTOR, FAMILY PLANNING COUNCIL, ON BEHALF OF AIDS ALLIANCE FOR CHILDREN, YOUTH & FAMILIES

Mr. Chairman and members of the subcommittee, good afternoon. My name is Dorothy Mann, and I am Executive Director of the Family Planning Council serving Philadelphia and the four surrounding counties. The Family Planning Council provides STD, HIV, and family planning services to over 107,000 clients annually. It is also my honor to belong to the HIV Community Planning Group in Philadelphia and the CDC's HIV/STD Prevention Advisory Committee.

My organization is the lead agency of a community network, known as the Circle of Care, which provides comprehensive health and support services to HIV-positive children, youth, women, and their families. This program is principally funded through Title IV of the Ryan White CARE Act, and receives additional support from Titles I and II of the CARE Act and private sources.

I am here today representing AIDS Alliance for Children, Youth & Families, formerly known as AIDS Policy Center. AIDS Alliance is a national organization that addresses the needs of children, youth and families who are living with, affected by, or at risk for HIV and AIDS. Among our members are organizations and individuals that provide or receive services under Title IV of the Ryan White CARE Act. Our board of directors is comprised of people living with HIV and their family members, as well as HIV service providers, researchers, and policy experts.

I want to begin by thanking the members of this committee for your ongoing support of the Ryan White CARE Act and for your work to reauthorize the Act. I cannot emphasize enough the importance of reauthorizing the Ryan White CARE Act this year. Every day throughout this nation, the CARE Act is saving the lives of children, young people, and adults with HIV. By renewing this program, you will also help to renew our nation's commitment to people living with HIV.

With the 13th International Conference on AIDS currently taking place in Durban South Africa, the nation hardest hit by the AIDS pandemic, our awareness of the global AIDS crisis has never been greater. While it is clear that the rates of transmission are highest in Sub-Saharan Africa, one message that has been lost here at home. Here in the United States it has almost become acceptable that 40,000 people are newly infected with HIV each year. Today, I will focus my remarks on the critical importance of incorporating prevention messages into care because unless we change how we approach this epidemic, another 40,000 people will be infected with HIV next year, too.

My remarks also focus on why HIV-positive children, youth, women and their families still need the Ryan White CARE Act, and how the CARE Act can be strengthened for the future.

*HIV/AIDS: A Continuing Crisis*

The HIV/AIDS epidemic continues to have a devastating impact on children, youth, women and their families in the United States. As someone who has been working in this field since the early days of the epidemic, I can tell you that the need for the CARE Act has never been greater.

As you know, one of the true success stories in this epidemic has been the effort to reduce the number of children who are born with HIV. From 1994 to 1999, the number of pediatric AIDS cases resulting from mother-to-child HIV transmission fell by 78%. This remarkable decrease is the result of efforts to diagnose HIV-positive pregnant women and provide treatment to them and their newborns.

However, the number of women and youth who are infected with HIV in this country continues unabated. Between 120,000 and 160,000 women are living with HIV in the United States, and the proportion of new AIDS cases attributed to women tripled from 7% in 1985 to 23% in 1999.

Young people are particularly hard hit by HIV. People under age 25 account for at least half of the 40,000 new HIV infections in the U.S. each year, and those under age 22 account for one-quarter of new infections.

Unfortunately, new data released just this week at the International AIDS Conference in South Africa has confirmed that these dramatic declines have leveled off, partly because the new treatments stop working for many patients over time. Research also shows that many people, including women and youth, are continuing to

engage in behaviors that put them at risk for HIV. So, it is abundantly clear that, for the next five years at least, the number of people needing services under the Ryan White CARE Act will continue to increase, as will the cost and complexity of the services they require.

Some people have wrongly concluded that, as fewer children are born with HIV infection, fewer resources are needed for pediatric and maternal HIV/AIDS services. In fact, as the death rate among children with AIDS goes down, more children than ever before are living with HIV and AIDS and are in need of comprehensive services. Members of the subcommittee, in our excitement over the declining rate of new HIV infections among children, we must not abandon those children who are already living with the disease. In addition, it will be a challenge to continue to reduce perinatal transmission as the number of HIV-infected women of childbearing age keeps rising. More resources are required to provide HIV-positive pregnant women with prenatal care, HIV counseling and testing, and access to treatment to improve their health and reduce perinatal HIV transmission.

#### *Proposed Emphasis on HIV Prevention and Care*

Before taking time to discuss some background information and the specific provisions of H.R. 4807 related to women, children, youth and families, I would like to take a moment to commend its emphasis on making HIV prevention an integral component of care for HIV-positive people. The Ryan White CARE Act is not a substitute for the HIV prevention programs based at CDC. But the CARE Act does have an important role to play in helping to stem the spread of this disease.

It goes without saying that HIV is spread from an infected person to an uninfected person. But we have focused HIV prevention efforts almost exclusively on uninfected people, and we have largely ignored those who are already infected.

I am a member of the HIV prevention planning group in Philadelphia. In the 1999 prevention plan that we developed and CDC approved, HIV-positive individuals are not designated as a priority population. In fact, out of every *hundred dollars* that is spent on HIV prevention in Philadelphia, only *two dollars and eighty-four cents* is directed specifically towards HIV-positive people.

Ignoring the prevention needs of HIV-positive individuals has led to serious consequences. There is mounting evidence that as people with HIV are living longer and more active lives, they are more likely to engage in unprotected sex. I understand that the San Francisco Department of Public Health recently determined that, in that city, you are most likely to have gonorrhea if you are an HIV-positive man who has sex with men, if you are on combination therapy for HIV, and if you have a high CD4 count. If these HIV-positive men are getting gonorrhea, that means they are having unprotected sex that can also result in HIV transmission.

Let me be clear: I am not advocating laws or policies that criminalize or stigmatize HIV positive people or their behavior. I am talking about interventions that help HIV-positive people reduce their risk behaviors and protect their partners from infection.

What can be done about this problem? We must work to break down the walls between HIV prevention and care programs. One way to accomplish this goal is for CARE Act-funded programs to bring appropriate prevention interventions into the care setting, in coordination with programs funded by CDC and SAMHSA.

Among the titles of the CARE Act, Title IV has had the most emphasis on integrating HIV care and prevention. At my Title IV project in Philadelphia, for example, reproductive health specialists see every HIV-positive woman in care to provide contraceptives, screening and treatment for STDs and counseling regarding HIV and STD prevention. This kind of integrated approach should be replicated throughout the CARE Act programs.

CARE Act programs must also contribute to efforts to increase the number of HIV-positive people who know their HIV status. It is estimated that between one-third and one-half of HIV-positive people do not know that they are infected. We need to expand outreach to high risk individuals so that they can be offered HIV testing and linked to comprehensive care that includes HIV prevention.

#### *Ryan White Title IV: A Success Story*

Clearly, the HIV/AIDS epidemic continues to have a terrible impact on children, youth, women and their families in communities all across America, including my own. But with your support, the Ryan White CARE Act has equipped local communities to face this crisis. And Title IV of the CARE Act has helped to lead the way.

Title IV provides grants to public and private nonprofit organizations to develop and sustain comprehensive, coordinated systems of HIV care and services for low-income children, youth, women and families. As a competitive grant program, Title

IV targets federal funds directly to communities in greatest need and to providers that are well qualified to meet the unique needs of these populations.

The comprehensive HIV services provided by Title IV includes medical care, social services such as case management, and access to clinical research programs. These services are provided through a model known as “family-centered care,” which means that care and services are built around the needs of whole families affected by HIV.

Title IV currently funds 58 grantees in 26 states, the District of Columbia and Puerto Rico, and these grantees provide or arrange for direct HIV services at several hundred clinical sites. These grantees are enrolling—and retaining—extremely vulnerable populations in care. In 1998, over 37,000 children, youth, women, and their family members received ongoing services through Title IV. The number of people in need of Title IV services continues to grow each year. From 1996 to 1998 alone, client enrollment in Title IV programs increased by 23%.

**Title IV and Perinatal Transmission.** Title IV has played a major role in helping to reduce the rate of perinatal HIV transmission in the United States. Title IV projects reduce perinatal transmission by providing outreach, counseling, and testing to high-risk women and health care to pregnant women and their children. The recent Institute of Medicine report on efforts to reduce perinatal HIV transmission identified the key role that Title IV projects have played in this effort. The report also recommended that the existing infrastructure for providing perinatal HIV prevention and treatment should be strengthened by building on the Title IV service network.

**Title IV and Youth.** Title IV projects are also at the forefront of the national effort to engage and retain HIV-positive young people in comprehensive care. Since 1995, the number of teens and young adults served by Title IV has more than doubled. Title IV projects have been particularly successful at reaching young women of color, one of the fastest-growing HIV risk groups in the nation. In 1998, the Title IV Adolescent Initiative was established to increase the number of HIV-positive youth receiving primary medical care and support services in a youth-sensitive environment. This initiative currently provides funding to five model youth programs.

In addition, the Title IV program has collaborated with NIH to establish the REACH project, a research program that is studying the medical, psychosocial, and behavioral aspects of HIV in adolescents. With approximately 350 teens enrolled at 15 sites across the country, the REACH project is the source of much of what is known about HIV disease in adolescents.

**People of color.** Title IV continues to lead the CARE Act in reaching people of color. In 1998, 82% of all Title IV clients were people of color, reflecting a continued increase in the number and proportion of clients who are African American or Latino. From 1997 to 1998 alone, the number of African American clients served by Title IV increased by 16%, and the number of Latino clients increased by 20%.

#### *Proposed Changes to Title IV*

Let me now turn to some of the specific provisions of H.R. 4807, a bill to reauthorize the CARE Act that was recently introduced by Dr. Coburn along with 22 cosponsors in the House. The bill proposes several important modifications to Title IV, all of which are supported by AIDS Alliance. Most notably, the bill will strengthen the unique mandate of Title IV to facilitate client access to HIV-related clinical trials and other research. Not only will the bill help to promote collaboration between Title IV grantees and NIH-funded AIDS research projects, but it also will preserve the right of patients to choose whether or not to enroll in research protocols.

The bill will also ensure that the Title IV program continues and expands its efforts to engage and retain HIV-positive youth in care. However, since Title IV accounts for just 3% of CARE Act funding, and young people make up at least half of all new HIV infections, Title IV cannot accomplish this task alone. That is why AIDS Alliance enthusiastically supports a modest, but important, provision in H.R. 4807 that will require Title I and II grantees to demonstrate that they are allocating an appropriate share of funds towards youth services.

#### *Proposed Changes Related to Perinatal Transmission*

H.R. 4807 also includes three new provisions related to reducing perinatal HIV transmission. First, it will authorize an additional \$20 million for state activities related to reducing perinatal HIV transmission, such as outreach and linkage to care for HIV-positive pregnant women.

Second, an IOM study will be commissioned to conduct an analysis of state efforts to reduce perinatal HIV transmission, and to make recommendations to states on future steps to further reduce perinatal transmission.

Third, the Secretary will be directed to expand and coordinate efforts at the NIH and FDA to develop rapid HIV tests. Accurate and affordable rapid HIV tests would have many potentially important uses, one of which would be to help diagnose pregnant women whose HIV status is not known at the time of labor.

AIDS Alliance is supportive of these efforts to ensure that the reauthorized CARE Act helps states and communities to build on the success in reducing perinatal transmission.

In closing, I would like to urge you once again to reauthorize the Ryan White CARE Act this year. Communities across the nation, including my own, are seeing an increase, not a decrease, in the number of people who need HIV care, treatment and support services from the CARE Act. This program is the cornerstone of our nation's response to AIDS, and it must continue.

Let me leave you with a final thought. Reversing the nation's growing complacency about AIDS is a daunting task. But we must do more—much more—than simply prevent an escalation in the HIV infection rate of 40,000 new cases each year. Forty thousand infections, over 100 per day, is intolerable. Do we really have a war on AIDS in this country? If we had 40,000 American casualties in a war, would we find that acceptable? I hardly think so. The time has come for us to muster the energy, resources and courage to truly end the spread of this terrible epidemic.

Thank you for your time. I would be happy to answer any questions you may have.

Mr. BILIRAKIS. Thank you so much, Ms. Mann.  
Mr. Colon.

#### STATEMENT OF JOSE F. COLON

Mr. COLON. Buenos tardes, Chairman Bilirakis, Congressman Coburn, Congressman Waxman, and members of the committee. "Saludos" means greetings in Spanish, but it is also related to the word "salud," which means health.

My name is Jose Fernando Colon. I live in San Juan, the capital of Puerto Rico. I am part of a group called "Pacientes de SIDA pro Politica Sana." I live with HIV.

I am here today hopeful of receiving bipartisan support within the scope of your power as legislators and policymakers on the serious repercussions over the lives of AIDS patients, that the criminal embezzlement and fraudulent use of Federal funds earmarked for services not rendered has had over those affected HIV/AIDS in Puerto Rico, and in the continental USA, as well.

Since March 11, 1999, "Pacientes de SIDA pro Politica Sana" has been working as an HIV organization in reaction to the fraud committed at the San Juan AIDS Institute by its former directors and administrators.

Our goal and first priority is to empower HIV/AIDS patients, loved ones and/or significant others to make sure that the information revealed during the Federal judicial proceedings in the case of USA versus Kouri, Sotomayor, Borel; and also, USA versus Luis E. Cubon and Jorge Garib should serve as an international soundboard so that something similar is never repeated.

\$2.2 million was embezzled for personal and political use, as was reflected by the plea of guilt of five of the accused, and the convictions of Kouri, Sotomayor, Borel, Dubon, and Garib.

Most of these persons were prominent lawyers, accountants, and sad to say, doctors. Revealed during the testimony of the case were horrifying facts such as the box full of over \$100,000 in cash that was delivered to a former Vice President of the House of Representatives to finance a political campaign.

Credit cards with per year expenditures of approximately \$19,000 and \$20,000 used in restaurants and happy occasions were

used by the administrator and a so-called doctor Kouri, who masterminded the whole fraud.

Money intended for patients was used to pay for maids, luxury cards, cocktail parties, trips, and a \$47,000 press conference. What were they giving out, Mont Blanc, Cartier, or Tiffany pens? A van destined to carry patients to and from medical facilities was painted over and used in a political campaign.

I personally know a grandfather, who joined us in our demonstrations, that not only lost his daughter, but his granddaughter, as well, while all of this was happening.

I also know a grandmother that went through the same loss. She cries every time she calls me, and repeats over and over again that nobody helped them.

One day, I was with Aramis, my companion that passed away. I remember that at the hospital, a bill that cost us \$53,000, which we were able to pay only because of beneficence, a Dr. Jorge Garib, an infectologist, came in, opened the curtain in the room, and asked my partner's name. When he said who he was, he simply told him, cold as ice, "Do you know that you have a pneumonia that kills?"

His mother and I looked at each other perplexed, and saw the pain and outrage on my partner's face. Aramis could have had more years of life, quality life, if this had not happened.

Today, this morning, today, the same doctor is being sentenced in San Juan, because he was part of the party.

But it is sad to say that it was through a Puerto Rican woman's accusation that all of this justice has been done. Where were the authorities? What were they doing? How much suffering would have been spared if audits and reports had been done by the Federal authorities that disbursed the funds? Where was HRSA?

Among those who accepted guilt is former Senator and former Head of the Health Commission of the Senate, Dr. Edgardo Rosario Burgos.

Top elected officials have been implicated in the mishandling of the funds by various witnesses presented by the U.S. Government, one of which was even wired by the FBI to document the convicts' statements to this effect.

Some of the politicians mentioned during the trial have been Mr. Hector Luis Acevedo, former Mayor of San Juan; Jose Granados Navedo, a former Vice President of the House of Representatives; and our present Governor, Dr. Pedro Rossello.

With me, and as part of my written testimony, I have a copy of a letter written in 1993 to the Secretary of Health, Donna Shalala, telling her that all of this was happening, and nothing happened. In our quest for truth, we asked Mr. David Walker, Comptroller General of the General Accounting Office, to conduct an audit, so that the public is reassured of the appropriate use of funds.

We also again asked Honorable Donna Shalala for an explanation of why, between the years 1988 and 1994, there were no audits or reports made to the Federal Government. This was stated in testimony in court, by Mr. Lawrence R. Pool, an official from HRSA, that said, "There are no indications that such reports were ever prepared."

I want to quote the words said to me in a conference call by Mr. Douglas Morgan, another official from HRSA, that "Some mistakes had been committed." When I asked what mistakes and by whom, I got only silence as an answer.

This is continually happening, not only in Puerto Rico, I assure you, but in other parts of the United States. In Puerto Rico, we are having many problems, including a health reform that we do not know if it is going to work and how is it going to affect AIDS patients.

We have the constant bombarding of Vieques, where 51 HIV/AIDS patients live. I do not know how they can do it, because it is difficult living outside of Vieques. So can you imagine having AIDS there?

In that context, we welcome all your efforts to guarantee the proper tools through this act, the Ryan White CARE Act, H.R. 4807, to provide clear tools of accountability. These are tools that will help those patients like me to be part of the planning councils, to become voices; not just people that receive salaries. Some of these salaries are absolutely immoral.

We want to clearly state that whatever investigations or audits that are done in the accountability measures that you take, they should never, never go against the good faith of the organizations of people that have really worked.

Fund cutting is not the issue here. Our dilemma is the proper use and accountability of funds. To do this, we need your help.

AIDS does not discriminate. I have seen the situation with San Francisco, and the discussion between Ms. Eshoo and Mr. Coburn, in regards to the funds in San Francisco, and this and that. That sounds to me like a lot of bureaucratic talk.

What we really need is to get down to business and listen to the patients. Get those tools for accountability, and think about people like my brother that died, my cousin that died, my friend, my companion.

This is not easy for me. My T-cells must be going really down, right now. But I have to do what I have to do, to make you see the reality that we have gone through. It is a grotesque reality.

We have to get this message clear to those people that still do not believe that HIV and AIDS can touch them. That is prevention.

Dr. Coburn, I agree with you. We do have to have prevention. We have to have prevention, but we have to have accountability on those funds, so that these thieves are stopped, no matter how high the position.

Please listen to my voice. It is the voice of a lot of people. I represent a lot of people that are out there. They are, as I am, clinging ferociously to life.

Thank you very much.

[The prepared statement of Jose F. Colon follows:]

PREPARED STATEMENT OF JOSE F. COLON, COORDINATOR, PACIENTES DE SIDA PRO POLITICA SANA

Dear Sirs and Madams: "Saludos" to all committee members. The word "saludos" translates to greetings, but it also is related to the word "salud," which means health. My name is Jose Fernando Colon and I live in San Juan, capital of the Commonwealth of Puerto Rico, co-founder of the organization "Pacientes de SIDA pro Pol tica Sana." I live with HIV.

I am here today hopeful of receiving bipartisan support, within the scope of your power as legislators and policy makers, on the serious repercussions over the lives of AIDS patients that the criminal embezzlement and fraudulent use of federal funds earmarked for services not rendered, has had over those affected by HIV/AIDS in Puerto Rico and in the continental US as well. I can mention cases in Orlando, Dallas and Los Angeles.

Since March 11, 1999, "Pacientes de SIDA pro Política Sana, Inc.," (Aids Patients for Sane Policies), has been working as an HIV/AIDS patients organization in reaction to the fraud committed at the San Juan AIDS Institute by its former directors and administrators.

Our goal and first priority is to empower HIV/AIDS patients, loved ones and/or significant others to make sure that the information revealed during the federal judicial proceedings in the case USA vs. Kouri, Sotomayor, Borel, and also USA vs. Luis E. Dubon and Jorge Garib, (Case # 97-091, JAF), should serve as an international soundboard so that something similar is never repeated.

\$2.2 millions were embezzled for personal and political use, as was reflected by the plea of guilt of five of the accused and the convictions of Kouri, Sotomayor, Borel, Dubon and Garib. Most of these persons were prominent lawyers, accountants, and sad to say, doctors. Revealed during the testimony of the case horrifying facts such as box full of over \$100,000.00 in cash was delivered to a former vice-president of the House of Representatives to finance a political campaign. Credit cards with per year expenditures of approximately \$19,000 in one credit card and more than \$20,000 in another for restaurants and happy occasions were used by the administrator of the Institute and a so called doctor who masterminded the whole fraud.

Money intended to patients has been used to pay for maids, luxury cars, cocktail parties, trips, thrills and a \$47,000.00 press conference. What were they giving out Mount Blanc, Cartier or Tiffany pens?

A van, destined to carry AIDS patients to and from medical facilities, was painted over and used in a political campaign. I personally know a grandfather, who joined us in our demonstrations, that not only lost his daughter but his granddaughter while all of this was happening. I also know a grandmother that went through the same loss. She cries every time she calls me and repeats over and over again that nobody helped them.

One day I was with my partner Aramis, who passed away nine years ago. I remember a day when at the hospital, (a bill that cost \$53,000.00, which we were able to pay only because of beneficence), Dr. Jorge Garib, an infectologist, opened the curtain in the room, asked my partner's name, and when he said it was he, he simply told him, cold as ice: "do you know that you have a pneumonia that kills?" His mother, and I looked at each other perplexed and saw the pain and outrage in my partner's face. Aramis could have had more years of quality of life. These years were denied to him. Today, in this precise moment that infectologist is being sentenced in a courtroom in San Juan. He was part of the party. I have waited nine long years for this day, and I am thrilled to be able to be here to let you know. But it is sad to say that it was through a Puerto Rican woman's accusation that all of this justice has been done. Where were the authorities? What were they doing? How much suffering would have been spared if audits and reports had been done by the federal authorities that disbursed the funds?

The case San Juan Aids Institute case was conducted at Hon. Judge José A. Fuste's courtroom at the Federal Courthouse, District of Puerto Rico. The US District Attorney's Office for Puerto Rico, directed by Hon. Guillermo Gill, received full support from Hon. Janet Reno, US Attorney General, who stated that the case should continue no matter who is implicated.

Amongst those who accepted guilt is former Senator and former head of the Health Commission of the Senate, Dr. Edgardo Rosario Burgos.

Top elected officials have been implicated in the mishandling of the funds by various witnesses presented by the US Government, one of which was even wired by the FBI to document the convict's statements to this effect. Some of the politicians mentioned during the trial have been Mr. Hector Luis Acevedo, former Mayor of San Juan, Jose Granados Navedo, a former member and former vice-president of the House of Representatives, who had to resign to his post due to the pressure created by the scandal, and finally Dr. Pedro Rossello, our current Governor.

With me and as part of my written testimony I have a copy of a letter written in 1993 to Secretary of Health Donna Shalala by former Representative David Noriega asking her to investigate. Noriega had to push an investigation in the House of Representatives because Shalala's letter simply answered that they look into it. However no results or actions were taken.



In our quest for truth, we asked Mr. David Walker, Comptroller General of the General Accounting Office, to conduct an audit so that the public is reassured of the appropriate use of funds.

We also asked Hon. Donna Shalala, Secretary of Health and Human Services, for an explanation of why auditors did not detect this fraud before. Funds were disbursed for various years, (1988-1994), without the proper protocols and financial reports, as testified by Mr. Lawrence R. Poole, an official from the Department of Health and Human Services, and reported by the press:—"there are no indications that such reports were ever prepared."

I want to quote the words said to me in a conference call with Mr. Douglas Morgan an official from HRSA, when I asked him what had happened. He told me that "some mistakes had been committed," and when I asked what mistakes and by whom, I only received silence as an answer. Why so much silence from the people that are responsible of following up the destination of funds and their proper use?.

Since the ending of the second part of the case we have encountered the fact that at least three more organizations in Puerto Rico are being investigated by a Grand Jury. The Health Secretary of the Commonwealth of Puerto Rico, Mrs. Carmen Feliciano, was called to stand no more than three weeks ago in regards to the ongoing investigation of an organization called "Oasis de Amor." Besides, PRConcra, an organization that serves the gay community, and "Fundacion Ayudanos a Vivir," an organization which closed, and used to give services to infants, are also being investigated. All of this in the midst of a health reform that still has a lot of matters to be polished, and raises questions about its implementation.

Besides as you must know we have a problem with the island municipality of Vieques where fifty one HIV/AIDS patients have to live under a bombardment that for over sixty years has destroyed the island's ecology and environment. This destruction has been so strong that Vieques has one of the highest cancer rates in all Puerto Rico. Imagine having AIDS there.

We welcome all your efforts to guarantee the proper tools for a sane accountability of federal funds, (Ryan White Funds, HR #4807), provided for the treatment of HIV/AIDS. I thank Congressmen Coburn and Waxman for including some accountability measures in the House of Representative's version of the act. We support random federal audits of HIV/AIDS service providers, increased patient participation in the planning process, particularly those that who are real clients and not just employees of groups receiving Ryan White funds. We also applaud increased training for new Ryan White Council members, and sunshine laws guaranteeing planning meetings under public scrutiny.

We want to clearly state that in no way should these investigations jeopardize the excellent work that other good faith organizations and their members have done in the past in regards to patients' health care and services. Fund cutting is not the issue here, our dilemma is the proper use and accountability of funds.

We are determined to follow the AIDS Institute case, and any other similar cases, to its final consequence. We will work as watchdogs of HIV/AIDS funds and services. Tools of accountability will help our effort. We believe that some loose ends are still in the air and that all those that are guilty should pay for their crimes, no matter how high their rank, position, political affiliation was, or is. To do this we need your help.

Because AIDS does not discriminate by political affiliation we must insist in bipartisan action to protect the lives of all. Not doing so will open the gates to the continuation of the devastation, pain and sorrow caused by HIV/AIDS.

I live everyday with the virus. The person that represents my hope and joy does also. Nine years ago I lost my companion Aramis, after seventeen years of companionship. I have lost my brother Eddie and my cousin Michael, besides a number so high of friends that it is difficult for me to count them. It is not easy for me to be here. My T-Cells must be dropping by the second. But I have to do what I have to do to push for remedies to the sad and grotesque reality that I, and many others, have lived.

The Ryan White Care Act is a light of hope for all of us. United we must fight to stop and delete forever the disease of HIV/AIDS. We claim to all those concerned to be as human as they can be in this effort, so the impact of our message reaches the hearts and minds of thousands that still ignorantly believe that HIV/AIDS has nothing to do with them.

We ask you to pass this bill assuring us that there will be greater efforts towards accountability of funds and human resources; and please, let us work together to stop nepotism.

HIV/AIDS should not be an industry. I pray for the day that many people will have to look for other jobs because the fight against HIV/AIDS will be over. Tragically some people do not see it this way. People must sacrifice to fight this disease

and stop receiving salaries so high that they have become immoral. Only through giving from the heart we are going to win this battle. Please listen to my voice. It represents the voice of many like me who cling ferociously to life. Thank you very much for letting me speak.

Mr. BILIRAKIS. Thank you so much, Mr. Colon.  
Mr. Jackson.

#### STATEMENT OF EUGENE JACKSON

Mr. JACKSON. Mr. Chairman and members of the Subcommittee on Health and Environment, good afternoon.

My name is Eugene Jackson. I am, since yesterday, the Deputy Executive Director for Policy and Community Development at the National Association of People with AIDS [NAPWA]. Prior to joining NAPWA, I served as the Executive Director of Project Connect, an AIDS service organization in Jackson, Mississippi.

First and foremost, Mr. Chairman, I am a person living with HIV since 1985. I am here to tell you that the Ryan White CARE Act works. From a personal and professional perspective, I can tell you that programs supported by the CARE Act funds are saving lives. CARE Act programs have been instrumental in building the capacity of communities all across this Nation to respond to the HIV epidemic.

I am a CARE Act success. In January 1998, I spent 46 days in the hospital, starting off with a sinus infection, and resulting in end-stage renal disease secondary to an HIV infection. My hospital bill was more than \$85,000 alone, not including physician fees and other services.

Even though prior to my admission I was a practicing attorney, I could not get health insurance, because I was HIV positive.

On discharge, my outpatient prescription bill was more than \$1,500 per month. Thanks to Title II of the CARE Act, I was able to receive my medications through the AIDS Drug Assistance Program [ADAP].

Notwithstanding the fact that I was considered medically disabled in 1996 and qualified for disability, my Medicare insurance did not go into effect until December 1998. Nevertheless, Medicare does not provide prescription drug coverage.

Thanks to ADAP under Title II of the CARE Act, I was provided my most expensive medications. Because of the assistance I received under the CARE Act, I am now working full-time in the private sector with private health insurance and a prescription drug plan.

Title II of the CARE Act helped me when I needed it most, and allowed me to once again become a productive member of my community while living with HIV disease.

As you continue your work to reauthorizing the Ryan White CARE Act, NAPWA commends you in striving to adopt the act to demographics shifts in the epidemic, particularly in addressing the needs of historically under-served and vulnerable populations.

NAPWA provides a national voice for all people living with HIV. Our mission is to advocate on behalf of all people living with HIV, in order to end the pandemic and the human suffering caused by HIV and AIDS.

From this perspective, I applaud the efforts to distribute additional resources across the country. Coming from rural Mississippi, I know first-hand the challenges of living with HIV and providing services in under-resourced communities.

While we may not have the large number of cases as large urban areas, people living with HIV in rural and under-served areas have no fewer service needs. In fact, persons in Mississippi depend on the services provided by the CARE Act more so than several other States, as our State legislature has only appropriated \$750,000 for HIV and AIDS. Some States provide no funding for HIV care and services.

In other heavily impacted parts of the country, the HIV community has spent the past 10 years building a Ryan White care infrastructure. I urge you to ensure that this delicate infrastructure is protected in any shifts of funding across jurisdictions.

It is critical that we protect the care infrastructure in those communities that shouldered the burden of the first wave of the epidemic, and continue to serve large numbers of people living with HIV.

Balancing the need to redistribute resources and the desire to protect the HIV care infrastructure, as it exists all across the country, requires careful consideration.

In H.R. 4807, we appreciate the establishment of Quality Management Programs, and women, infants, children, and youth set-asides. But we are concerned about the provision which creates a new grant program for States that currently have laws that require all newborn infants in the State be tested for HIV, or that require that a newborn be tested for HIV, if the attending obstetrician for the birth does not know the HIV status of the infant's mother.

Mr. BILIRAKIS. Please summarize, Mr. Jackson.

Mr. JACKSON. We urge you, instead, to provide additional resources to all States, without preference, to implement aggressive outreach and education to at-risk women that need to know their HIV status, provide safe and confidential testing, and then provide them with comprehensive and accessible prenatal care to address the issues of prenatal transmission of HIV.

If they choose, States can implement mandatory testing laws, but Congress should not provide those States preferential treatment.

Nevertheless, we believe that the interest of people living with HIV, who depend on services provided by the CARE Act, would best be served with the following modifications.

Include language under Title II to make planning councils mandatory. It is important to the continued success of the CARE Act that communities access the needs and set funding priorities.

Mr. BILIRAKIS. Please summarize. I want you to get your point across. Possibly you may not be able to explain in too much detail.

Mr. JACKSON. In closing, I thank the committee for the opportunity to provide a perspective from people living with HIV, who depend on life-saving medical and supportive services made possible by the CARE Act.

NAPWA and the HIV community look forward to working with you to reauthorize the CARE Act. I welcome any questions that you may have.

[The prepared statement of Eugene Jackson follows:]

PREPARED STATEMENT OF EUGENE JACKSON, JR., DEPUTY EXECUTIVE DIRECTOR FOR  
POLICY, NATIONAL ASSOCIATION OF PEOPLE WITH AIDS

Mr. Chairman, and Members of the Subcommittee on Health and Environment, Good morning. My name is Eugene Jackson, Jr. and I am the Deputy Executive Director for Policy at the National Association of People with AIDS (NAPWA). Prior to joining NAPWA, I served as the Executive Director of Project Connect AIDS Service Organization in Jackson, Mississippi.

First and foremost though Mr. Chairman, I am also a person living with HIV since 1985. I am here to tell you that the Ryan White CARE Act works. From a personal and professional perspective, I can tell you that programs supported by the CARE Act funds are saving lives. CARE Act programs have also been instrumental in building the capacity of communities all across this nation to respond to the HIV epidemic.

*Successes*

I am a CARE Act success. In January of 1998, I spent forty-six days in the hospital resulting in end-stage renal disease secondary to an HIV infection. My hospital bill was more than \$85,000 dollars alone, not including physician fees and other services. Even though prior to my admission I was a practicing attorney, I could not get health insurance because I was HIV positive. On discharge my outpatient prescription bill was more than \$1500 per month. Thanks to Title II of the CARE Act, I was able to receive my HIV medication through the AIDS Drug Assistance Program (ADAP). Notwithstanding the fact that I was considered medically disabled in 1996 and qualified for disability, my Medicare insurance did not go into effect until December 1, 1998. Nevertheless, Medicare does not provide prescription drug coverage. Thanks to ADAP under Title II of the CARE act I was provided my most expensive medications. Because of the assistance I received under the CARE Act, I am working full-time in the private sector with private health insurance and a prescription drug plan. Title II of the CARE Act helped me when I needed it most, and allowed me to once again become a productive member of my community, while living with HIV disease.

As you continue your work to reauthorizing the Ryan White CARE Act, NAPWA commends you in striving to adapt the Act to demographics shifts in the epidemic, particularly in addressing the needs of historically underserved and vulnerable populations. NAPWA provides a national voice for all people living with HIV. Our mission is to advocate on behalf of all people living with HIV in order to end the pandemic and the human suffering caused by HIV and AIDS.

From this perspective, I applaud efforts to distribute additional resources across the country. Coming from rural Mississippi, I know first-hand the challenges of living with HIV and providing HIV services in under-resourced communities. While we may not have the large numbers of HIV cases as large urban areas, people living with HIV in rural and underserved areas have no fewer service needs. In fact persons in Mississippi depend on the services provided by the CARE Act more than several other states, as our state legislature has only appropriated \$750,000 for HIV/AIDS. Some states provide no funding for HIV care and services.

In other heavily impacted parts of the country, the HIV community has spent the past ten years building a Ryan White care infrastructure. I urge you to ensure that this delicate infrastructure is protected in any shifts of funding across jurisdictions. It is critical that we protect the HIV care infrastructure in those communities that shouldered the burden of the first wave of the epidemic and that continue to serve large numbers of people living with HIV. Balancing the need to redistribute resources and the desire to protect the HIV care infrastructure, as it exists all across the country requires careful consideration. In H.R. 4807 we appreciate the establishment of Quality Management Programs, and Women, Infants and Children and Youth Set-Asides, but we are concerned about the provision which creates a new grant program for states that currently have laws that require that all newborn infants in the state be tested for HIV or that require that a newborn be tested for HIV if the attending obstetrician for the birth does not know the HIV status of the mother of the infant. We urge you to instead, provide additional resources to all states, without preference, to implement aggressive outreach and education to at risk pregnant women about the need to know their HIV status, provide safe and confidential testing, and then provide them with comprehensive and accessible prenatal care to address the issues of prenatal transmission of HIV. States, if they choose to, can implement mandatory testing laws, but Congress should not provide those states preferential treatment for funding.

As we analyze H.R. 4807, we also appreciate the supplemental grant program for certain states with severe needs, allowing states to use funds for therapeutics by

purchasing or maintaining health insurance or plans that cover a full range of therapeutics; the increases in the minimum Title II base award to \$500,000 for states with 90 or more living cases of AIDS and to \$200,000 for states with fewer than 90 living cases of AIDS; and requiring states to seek comments and conduct public hearings as part of the developing a comprehensive plan.

Nonetheless, we believe that the interest of people living with HIV who depend on services provided by the CARE Act would be best served with the following modifications. 1. Include language under Title II to make planning councils mandatory. It is very important to the continued success of the CARE Act that communities assess the needs and set funding priorities. 2. Eliminate the infant testing provision. HIV testing should be offered to pregnant women so that appropriate HIV therapy can be implemented early.

In closing, I thank the Committee for this opportunity to provide a perspective from people living with HIV who depend on the life-saving medical and supportive services made possible by the Ryan White CARE Act. NAPWA and the HIV community look forward to working with you to reauthorize the CARE Act, and I welcome any questions that you may have.

Mr. BILIRAKIS. Thank you very much, Mr. Jackson, and thanks to all of you.

Ms. White, you, of course, have expressed your strong support for the Ryan White Act, and your pride in the fact that it is named after Ryan. You say in your testimony, "It is far less expensive to prevent someone from becoming infected in the first place, than to care for that person, once they are infected."

So I would ask you, you have been at this, unfortunately, for quite a long period of time. It is fortunate for a lot of people, but unfortunate for you. Do you have any recommendations on efforts that most effectively prevent the transmission of HIV/AIDS?

Ms. WHITE. I think definitely by encouraging at-risk people, at-risk youth to get tested. I think people who are sexually active, I think they definitely need to be encouraged, through promotional ads, or whatever, to get testing.

I think by knowing your status, I think that is the most likely way of preventing the disease. I mean, I really think that is No. 1.

Mr. BILIRAKIS. Well, I plead ignorance here. Do you feel that after all of these years, where we have been living with the scourge of AIDS and what not, that there are people out there, at-risk people, who are not aware?

Ms. WHITE. Oh, yes, especially our youth; I mean, they think they are invincible. I have seen the new statistics, that some youth are waiting. That is some youth. I think we must understand that is some youth. I think there will always be sexually active youth.

I think family plays a big role in that, too. I would like to think that everybody had parents as good as maybe I did, but that is not the case, and moral values.

But also at the same time, I think youth are youth. They are the most likely to experiment with sex, drugs, and sexuality. I think we, as parents, have to be on the lookout for that.

But I think we, as a Nation, have to look out for everybody's needs. I think that is looking out for our youth. If you are going to be sexually active, then encourage them to get tested.

Mr. BILIRAKIS. Mr. Liberti, this is sort of a follow-up to Ms. White's comments. Since Florida has enacted HIV partner notification in reporting, have you seen a reluctance of those at risk of HIV to getting tested or treated?

Mr. LIBERTI. Mr. Chairman, the short answer is no. We have implemented HIV partner notification or at least publicly funded patients in 1987, and had 10 years of experience under our belt, when we passed HIV reporting, by name, in 1997. So we offered our partner notification services to as many reported cases as we could.

For the patients who have volunteered their partners, and we have referred their contacts in, just last year, we found over 180 new partners in the State of Florida that would not have known their HIV status, if it was not for reaching out and letting them know. They are quite appreciative of this interaction.

Mr. BILIRAKIS. So you have not really found any large degree of reluctance?

Mr. LIBERTI. No, it is a voluntary program. If the public health worker or the community worker does their job well with the patient and motivates them, the partner notification is done, either by public health intervention or by the client.

That has worked out with the individual client. No one is mandated or forced to give up names. That just does not work.

Mr. BILIRAKIS. Thank you. Now in terms of the improvements made to Florida's programs, now that you have expanded reporting to include those diagnosed with HIV, rather than just AIDS, your testimony on page 7, your written testimony indicates, and again I quote, "HIV infection reporting has clearly shown a significant increase in HIV infection in Florida's minority communities."

So I guess I would ask you, logically, what was Florida able to do, once it had that new data?

Mr. LIBERTI. Let me tell a quick story, because I think this is very powerful.

We knew that there was a serious problem in the African American community. As soon as we got our first data from HIV infection reporting, we went to the Black Caucus in our State. They saw the numbers of how severe HIV was penetrating the black community.

I have told this story before. The conversation with our black leaders lasted about 10 minutes. They said, "What can we do?" They went directly into action. They passed a law that formed an HIV minority task force. They immediately appropriated \$750,000 in our budget for an African American media campaign that was launched this year.

So someone might say, well, they knew that it was a problem before that. It does not really matter. The point was that that was the defining moment when our African American leaders took action, and we are pretty proud of them.

Mr. BILIRAKIS. Thanks so much, Mr. Liberti. Again, thank you for all your great work in this regard.

Mr. Brown, since you just arrived.

Mr. BROWN. I apologize for not hearing the panel. I had a couple of amendments on the House floor. Thank you all for coming.

Mr. Davy, I would like to ask you a question. Having looked at your testimony, you said in your written testimony that the epidemic is not a changing face of AIDS, but an expanding face of AIDS. Tell us what you mean by that, sort of Ohio-specific, but nationally, also.

Mr. DAVY. Chairman Bilirakis and Representative Brown, what I mean by that is, the epidemic has not gone from the gay community to the African American community or communities of women. It is still very prevalent in the gay communities. It is expanding in African American communities. It is expanding in communities of women.

The male to male transmission in Ohio is still 55 percent of the epidemic of new HIV infections. In Columbus, it is over 60 percent of new infections.

So what I mean by that is that my concern is that we think we might have solved it in one community, and now it has changed to another community. But that is not the case. It has just expanded to new communities.

Mr. BROWN. Okay, I thank the chairman. I have no further questions.

Mr. BILIRAKIS. Dr. Coburn.

Mr. COBURN. I want to clarify something that Mr. Davy said. I want to make sure you understand the intention on the planning councils is not to preclude anybody who is working in an HIV field from being on a planning council.

But the intention is to make sure that patients who are not inside the Beltway, inside the group, people who are actually being treated, have a voice on that panel. There is nothing in this bill that will limit anybody else from being on that planning council.

But we do say, one third of those seats ought to be patients receiving treatment. That is so that we have the feedback that is necessary so that we will not have the problems that we had in Puerto Rico.

So there is no intention to exclude anybody who is now working in the AIDS service industry, who was a beneficiary of Ryan White care funds, from being on the council.

We are just saying that one third of those have to be reserved for patients being treated. So the feedback communication loop is there. I hope you understand that that is our intent.

Mr. DAVY. Chairman Bilirakis and Representative Coburn, I appreciate that. My concern really revolves around making sure that the people that are on the planning councils are the ones that have the best information they can.

Oftentimes, what we are finding today is, many of our patients are coming to work at our AIDS service organizations. There appeared to be a conflict of interest clause in the bill that would preclude some of those individuals from serving on the planning councils. We just wanted to be sure that is not the case.

Mr. COBURN. That is not our intention, whatsoever.

I want to go to Mr. Liberti, for a minute. It seems to me that your partner notification programs, based on what you just said, have been effective.

Mr. LIBERTI. Well, I think we have believed in some core public health values for quite some time. It took us 5 years, for instance, to pass HIV infection reporting in our State. We had a healthy debate. We knew we were going to be the largest State in the country, at that time. New York has just come on board.

When we advocated for HIV partner notification, we felt that it was going to accomplish a couple of things that we were not accom-

plishing; that there were too many people that were being tested in public sites, including jails, for instance, that were not even finding out their HIV status. This would allow the names to be given to public health, so we could follow those people.

We felt there were too many people that were finding their HIV status, and not being linked to service. Let me clarify, because I think there is confusion around the country on this issue.

When I say "linked" I mean linked in a very patient-specific, timely fashion; not a general referral made to go see a doctor.

Mr. COBURN. I think that is very important that you make that point. Those of us who have worked in the public health field understand how notification works, and the confidentiality surrounding it.

Mr. LIBERTI. Right.

Mr. COBURN. You know, other than an attempted case by a worker to expose HIV names in Florida, there has not been a significant leak of confidential data in this country. Because the public health community, as well as the physician and provider community, understands this issue and works hard for it.

When you have a partner notification that would require you to go across State lines; in other words, you have a contact that needs to be contacted, how do you handle that?

Mr. LIBERTI. The present system that we have in place now is that the AIDS Program in our State works very closely with the Sexually Transmitted Disease Program. Those are the staff that are adequately trained to do partnership notification.

If the contact or suspect, using STD terms, is within our State, even across county lines, we have an inner State system of transmitting that information.

Mr. COBURN. I am asking you specifically about out of State.

Mr. LIBERTI. Right, out of State is usually done by reciprocal information. If the State we are going to has HIV reporting and a partner notification program, then the information is transmitted. They carry out the same follow-up.

Mr. COBURN. What if they do not have HIV reporting or partner notification?

Mr. LIBERTI. I believe the case is closed, and there is nothing we can do.

Mr. COBURN. So, in essence, if somebody has HIV, and they are in a different State, and that State does not have reporting or partner notification, it is just tough. They have been exposed, and they have no knowledge that they have an exposure. We do not have a way to allow them to know that they have an exposure. Is that correct?

Mr. LIBERTI. That is correct, under the understanding that I have right now.

Mr. COBURN. Dr. Birkhead, thank you for being here. We appreciate all the great work that you all are doing.

Five years ago, we passed the Baby AIDS Bill here, that was not enacted. I mean, it was enacted, but not funded. Your Governor supported that. You also passed a similar Baby AIDS Bill in New York. Can you tell us, have there been untoward consequences; or do you deem that a success? Where are the problems?



Mr. BIRKHEAD. I think it has been successful in a number of areas. We did institute mandatory newborn testing of the specimens that come to the State lab for metabolic screening, back in 1997. Those results were then returned to the mother and the pediatrician, a couple of weeks after birth.

In that initial phase of the program, I think the benefits were one, that mom and baby knew about the exposure status, as soon as possible. Mom could stop breast feeding.

Second, the newborn could then be tested by PCR to determine infection status. That is very critical, to begin heart therapy as soon as possible in a newborn who is infected perinatally. Third, the mom then became aware of her status, and could seek care for herself.

I think we recognize that we could be doing better. So last summer, we implemented a program of moving that mandatory testing into the hospital delivery setting, either with consent of the mom or testing of the newborn, through the mandatory program.

The hope there was that we could begin treatment, even during delivery or immediately post-partum, to prevent some actual cases of transmission.

So I think with the current program, we could do better if we had better rapid tests. That is an issue that we can talk about. But I think we are currently identifying all positive births in New York, and the benefits are those that I have indicated.

There was concern expressed that women might not seek prenatal care or avoid prenatal care. We have not seen evidence of that, either through looking at our birth certificate process, to look at when prenatal care began, or through reviewing charts of positive moms. We have not seen any change.

A lot of our efforts are now focused on women who have no prenatal care. Ideally, you would like to get them tested in prenatal care, and not even wait until the delivery setting.

Mr. COBURN. We would like to get them into prenatal care.

Mr. BIRKHEAD. Absolutely, and I think we still have about 10 percent of our women with HIV, who do not get any prenatal care. That in-hospital testing then serves as a safety net to catch them. But we would ultimately like to get them into prenatal care, and we have a number of outreach programs to try and do that.

Mr. BILIRAKIS. Thank you. We will come back to you, Tom, if you would like.

Ms. Eshoo, to inquire.

Ms. ESHOO. Thank you, Mr. Chairman, and thank you to all of the witnesses at the table for your important and good work; and to Mrs. White, thank you for your advocacy that has made a difference in our Nation.

You have certainly paid, as an individual. I do not think any parent should ever have to see the day when they bury their own child. But what you have done and the dignity with which you have done it, you have benefited everyone in this Nation. So thank you to you. I pay tribute to you.

Dr. Birkhead, thank you for your good work. I wanted to point out, committee members may not have heard it or read it, but on page nine of your written testimony, you say that the act should

establish hold harmless provisions for Title I and II, that will avert drastic reductions and awards, and disruptions in services.

The House bill hold harmless provisions could lead to a 25 percent reduction in awards to States and cities in the fifth year of the reauthorization period. You say, "We support the hold harmless provisions in the Senate bill, which call for reductions of no more than 2 percent, per year."

Obviously, this is a leading question. But in your judgment, tell us why you included that. I still maintain that the basis of the Ryan White Act is to bring stabilizing factors into each community, whether it is Mississippi, or to a major urban center, or any other place in our country. Do you quickly want to comment on that?

Mr. BIRKHEAD. I think our concern just was that whenever funding is pulled, it is very disruptive.

We have had a good experience over the last 5 years with continuing increases. If that were to continue the next 5 years, as we all hope, I think that that would be great, and perhaps the point is then moot.

But I think we are very concerned in the out-years of this new reauthorized act, that if funding was not being increased in places like New York, and particularly New York City, that would be disruptive.

Ms. ESHOO. Thank you. I think that there is either an overtone or an undertone here maintaining that this is strictly a San Francisco issue. You are from New York State. So I think that your testimony is something that has a great deal of weight to it. For the record, I want to say to members that Dr. Coburn referenced testimony of W. Shepherd Smith of April 5, 1995. I have a copy of that testimony that was given before this subcommittee. No place in the testimony is there an agreement by anyone that there would be a 25 percent reduction.

I also want to add to the record that in part of that testimony, he stated that they were the only AIDS organization which openly opposed the Ryan White reauthorization in the form that it was put forward, in the previous year. That would be 1994.

I would like to go to Janet Heinrich, from the GAO. Has GAO done an analysis of the hold harmless provision, and what the 25 percent cut-back would be, what it would mean?

Ms. HEINRICH. We have not done an analysis of what the 25 percent cut would mean. What we did is provide information on some of the historical perspectives of the Title I funding, and looked to see how it was playing out in 1999.

Ms. ESHOO. Let me ask you this. In looking at the November, 1996 GAO report, and the one that the committee has today, why was the density factor removed in the most current report?

Ms. HEINRICH. I am going to ask Jerry Fastrup to answer that.

Mr. FASTRUP. The density factor was included in the Title I formula, and was removed in the 1995 reauthorization. Our analysis of that density factor, at that time, was that it had some very substantial problems with it. The most important one being that it did not take into account differences in the size of the area.

So with that density factor, a city in Connecticut, a small city and a large city, would wind up getting the same funding, even

though one may have twice the case load as the other. There were some serious problems there.

Ms. ESHOO. Well, let me just interrupt for a moment, because I do not want to have all the time taken with this, as much as I would like to pursue it. Maybe we can get you to place some of it in writing, as other members are asking for questions to be answered in text, rather than verbally, today.

AIDS cases have gone down in San Francisco, in large part, because there are fewer HIV positive individuals that are progressing to an AIDS diagnosis. I think that is thanks to the quality of access to care, the kind of care that is rendered through the care services.

Is San Francisco being penalized for keeping people healthy? Also, if there are smaller increases in newly reported AIDS cases, as in the case in San Francisco, why continue to rely on the hold harmless provision?

Mr. FASTRUP. I am not sure I understand.

Ms. ESHOO. Take the first question, first.

Mr. FASTRUP. Give it to me one more time, please.

Ms. ESHOO. Well, AIDS cases have gone down in San Francisco. They have gone down, in large part, because there are fewer HIV positive individuals that are actually progressing to the full AIDS diagnosis. So there is not only good access to care, but there is also quality of care in the services.

Now I think that it could be said, that the area is being penalized for keeping people healthy.

Did you examine any of this in your ultimate analysis, or did you just play with numbers? I mean, they are human beings. Everyone at this table, even the gentleman from Puerto Rico was crying out and saying that there is a human face to all of this. There were people left out because someone ripped off public dollars. Did you do an analysis of that?

Mr. FASTRUP. The answer is, if AIDS cases are being kept alive, they are continuing to be counted as live cases. They are continuing to be reflected in the formula, and areas are getting funding, based on the number of live cases that they have.

So areas that are successful in keeping people alive will continue to receive funding, under these formulas.

Ms. ESHOO. But not if they live longer than 10 years. Did you take that into your analysis, or was there just a cutoff point here? Was it just very tidy, in terms of some GAO numbers?

Mr. FASTRUP. No.

Mr. BILIRAKIS. Without objection, the gentlelady has gone better than 2 minutes over her time, but I would grant her an additional 2 minutes.

Ms. ESHOO. Thank you.

Mr. FASTRUP. When the program was reauthorized in 1995, all there were, were 10 years of history there. I think it would be advisable to reexamine whether or not that time needs to be lengthened to 11 or 12 or 13 years. If people are living longer, that should be reflected.

Ms. ESHOO. Well, they are living longer. They are part of the care and the services. So I think that there is, if I might suggest, a hole in the report, not taking that into consideration.

Mr. Chairman, thank you for the additional time. I appreciate it very much.

Mr. BILIRAKIS. The other gentleman from Ohio.

Mr. STRICKLAND. Thank you, Mr. Chairman.

Mr. Davy, you described the challenges of providing care in rural Ohio, and that is what I represent. You support the new Title II supplemental grants, which were created in this bill. These funds are meant to help States which can demonstrate severe need in their efforts to fight HIV/AIDS.

The House bill makes these funds available in under-served areas, whether they are rural or urban. The Senate bill restricts these funds to a more narrow class of emerging communities. Do you believe the House bill is more desirable?

Mr. DAVY. Chairman Bilirakis, Representative Strickland, the Senate bill also has a provision which gives preferential treatment to rural communities under Title III, which I believe offsets the effect somewhat, of the supplemental Title II grant being specifically addressed to. I believe, there were 35, 36, 37 cities that were specifically named in that bill. So they are kind of different in the way that they get at the issue.

Rural communities are obviously a large problem in access to care. Anything that we can do in the CARE Act to strengthen access to care in rural communities is certainly a good thing.

Mr. STRICKLAND. Okay, thank you for that answer.

You also described that there is an increasing number of clients coming to you, who have been in prison, or are now living in homeless shelters, many of whom have substance abuse and, in some cases, severe mental health problems.

The Coburn-Waxman bill calls on cities and States to promote the coordination of Ryan White services with substance abuse programs. It also asks the Secretary to develop a plan for improving the delivery of Ryan White services to prisoners.

Having worked as a psychologist with mentally ill folks, and having been in a prison environment, and having served on the board of an open shelter, each of these areas of concern have particular interest to me.

Do you think that we need to be doing more to make sure that services are extended to those who are the most vulnerable in our society? I am talking about prisoners and homeless folks.

I would like to ask you and any other panel members that would like to respond, once individuals who may be living in open shelters or homeless shelters, or once people who are incarcerated in our prisons and jails are identified as being HIV positive, are the medications that are very, very costly, are these medications being extended to these individuals; or are they being somehow treated perhaps differently than other persons who may exist within our society?

Mr. DAVY. Chairman Bilirakis, Representative Strickland, you know, in our community in Central Ohio, many of the prisons still do not acknowledge that there is an HIV/AIDS problem in the prisons, let alone that there might be drug use or sex going on that could transmit those.

Mr. STRICKLAND. Can I interrupt you, just for a moment? Having worked in the prison for over 8 years, I can tell you, HIV exists

within our prison system, and sex occurs within our prisons. You can continue, please.

Mr. DAVY. I agree, and we know that.

We, on the Columbus AIDS Task Force, work very extensively with other substance abuse providers, mental health providers, to try to do good collaborations to maximize the use of our Ryan White funds.

What we have found over the history of this epidemic, and the reason that this infrastructure of AIDS has developed, is because nobody else wanted to deal with people with AIDS.

If someone showed up at the door with a mental health issue or a drug abuse issue, a homeless issue, and AIDS, AIDS was probably fourth or fifth on the list of things that that person needed to deal with. But they showed up at our door, because nobody else would serve that individual.

That has changed somewhat, but it is still not fixed. So, often-times, we are left with having case managers having to deal with all of these issues, and trying to work with as many other groups as we can.

Mr. STRICKLAND. I would like, if possible, a response from our friend from Florida, in regard to my question.

Mr. LIBERTI. Mr. Strickland, I think you are hitting on one of the challenges and one of the most complex problems that we are dealing with right now.

To add on to Mr. Davy, that expanding face of AIDS, we have 3,200 HIV patients in the Florida prison system. I can guarantee you, we did not have that number, 10 years ago.

All the challenges of delivering HIV care, and all the release policies, and where is the money for the drugs is a major issue. That is a very large population to deal with, that the Department of Health and Department of Corrections are working on.

The jails also have an increase of known HIV positives. One of the challenges that we deal with, as directors, every day, as you know, is that we can not use ADAP money. We can not use Ryan White Title II money for the drugs for patients in prisons or jails.

So we have to come up with very creative financing and very creative relationships with our Department of Corrections and local jails. It is starting to be a much bigger issue than it was a few years ago, because people are in and out of the local jails. The last thing you want to do is not have them have their medications.

So you have really hit on a very big issue that we are dealing with, at the local level.

Mr. STRICKLAND. Thank you, Mr. Chairman.

Mr. BILIRAKIS. I thank the gentleman.

Mr. Towns, do you have any questions? Please proceed.

Mr. TOWNS. Mr. Chairman, you know, I was trying to let you move on. But I really have to ask a few questions.

Dr. Birkhead, you have heard discussion this morning around this bill. Do you really feel that this goes far enough, the bill itself, in terms of trying to do the kinds of things that we trying to do in New York?

Mr. BIRKHEAD. I think most of the provisions are good for New York. There is always the question of funding levels. You made the comment earlier about that.

I think, you know, as ADAP expands, as people live longer with HIV, we will need more funding for the drug portion of ADAP. But it is really the appropriation levels that you are talking about there. I think in the current House bill, most of the provisions, we think, are good ones, and will help New York.

Mr. TOWNS. Are there any other comments on that, from anyone, in terms of the structure of the bill that we have been talking about this morning?

[No response.]

Mr. TOWNS. All right, thank you very much, Mr. Chairman. I do not want to go too far.

Mr. BILIRAKIS. Please continue. I did not mean to cut you off.

Mr. TOWNS. No, that is fine, because when you are out on the floor and dealing with legislation, you do miss out on a lot. I did not want to go into things that might have already been said. But I just did not want to pass up the opportunity to at least ask Dr. Birkhead that particular question. Thank you.

Mr. BROWN. Mr. Chairman?

Mr. BILIRAKIS. Yes.

Mr. BROWN. I would ask unanimous consent to enter into the record testimony that was submitted by Mr. Waxman, who is on the floor.

Mr. BILIRAKIS. Yes, and without objection, that will be the case, of course.

It is just unfortunate that Henry could not get back, because the work that he and Dr. Coburn that did on this, along with their staffs, Karen and so many others, is just extraordinary. I know we are all very grateful.

Without objection, the Chair yields an additional 3 minutes and, hopefully, that will finish us up, to Dr. Coburn.

Mr. COBURN. Thank you. I would direct everybody to page 51 of the GAO report. I think, for my friend from California, this will answer some questions for her.

Actually, in the data that was released, just in the last few weeks, about increased HIV infection in San Francisco, if you look at this new formula, actually San Francisco is going to gain, because we are going to do it on the basis of HIV infection.

If you look at the bottom of page 51, what you see is that in Washington, DC, 60 percent of the people, or 58.7 percent, are HIV positive, but do not have AIDS. But they are not being counted to adequately talk about the funding levels for them. Whereas, in San Francisco, 48 percent of the cases were AIDS versus 52 percent HIV.

So what we are trying to do is to include them both, and to totally reflect it. In fact, this alarming trend that we are seeing in San Francisco, in terms of new HIV trends, they will be protected, because more of the money is going that way. So I think it is real important.

I want to ask one other question of GAO. Please cut the legs out from under this, if I am wrong on this. But it really is still fair to say that San Francisco is receiving funding on the basis of people who have long ago died from AIDS. Is that correct?

Mr. FASTRUP. That is true.

Mr. COBURN. So if an epidemic is new in a community, and let us take any community, and let us say they had exactly the same number of people today, alive with either HIV or AIDS, the proportion of funding would be drastically different under Title I.

Mr. FASTRUP. That is correct.

Mr. COBURN. That is my only point. Look, I do not want San Francisco to receive one penny less. But I do want people who are not getting adequate treatment today, to be able to get it.

Mr. Towns is exactly right. We are going to float this boat up. We have 29 percent each year. Nothing has increased in this Government in the last 6 years like the Ryan White Act has, nothing, and that is going to continue.

But as we do that, we ought to make sure it is a fair distribution. That is what we are trying to address. We are not trying to undermine California or San Francisco, and that is not my intention. But it is a fair distribution of funds.

Ms. Mann, first of all, I want to thank you for all your work. You are a very dear friend of mine. I have made trips into her facilities, and learned a lot, and she has taught me a lot.

I appreciate your comments on prevention. You were not here, unfortunately, when HRSA testified.

Ms. MANN. Oh, I was, sir.

Mr. COBURN. Oh, were you? I did not see you. I am sorry. You are so petite.

But I am concerned that this grey area that Dr. O'Neill talked about, you really do not find very grey. In fact, half of our HIV infections are coming from people who know they have HIV.

So would you comment a little bit more, since you are right in the middle of this, on incorporating prevention into our CARE Act, so that we can at least take half of those, and limit the spread of this disease?

Ms. MANN. Yes, Dr. Coburn, I am really not all that small.

There are a couple of things that I hope we can clarify about this. I also sit on the CDC's STD/HIV Advisory Committee. So I am very aware and comfortable with the role of CDC and what it does in the area of HIV prevention and surveillance, and all the other kinds of things that they are so intimately involved in.

I really do not see a problem or conflict here, for two reasons. One, Title IV, since its inception, has been involved in prevention services, as part of the Ryan White CARE Act.

Now we do this in very specific ways. It is not massive counseling and testing programs that are funded in our community by CDC. These are very focused, case finding efforts, in order to find people with this disease, particularly, and our focus is on women, who are HIV infected, and getting them into our care system, that is funded by Title IV.

It is very specific and very clear and very directed, and is not, in any sense, a conflict. But prevention is more than counseling and testing. I think that sometimes we make that mistake.

What I think is also important here is that within the service, and I think Dr. O'Neill stated it very well, within people who have this disease, and I think you stated it earlier, what we have failed to do effectively is talk to them about prevention.

It is a very simple paradigm. You do not get this disease from a toilet seat or anything else. You get infected from an infected person, having unprotected sex, or sharing needles, with an infected person doing this with uninfected person. That is the only way you get it.

Most of CDC's efforts have been focused on the uninfected populations, and that is very commendable. What we have not done well enough in care is focus on behavior change and preventing transmission from people who already have this disease.

We know that behaviors do change, as soon as people learn their status. But how do we get prevention messages better integrated into care, where care providers are talking to their patients, their case managers, and their clinicians are talking to them about prevention?

It seems to me that this is not a particularly grey area. Care has an enormous responsibility. As I said in my testimony, 40,000 new cases of HIV is not acceptable in this country. It is down from 100,000 and 150,000, and that is good. But we have a long way to go.

So from my perspective, any place, anywhere, anyhow we can talk about prevention, in the community, in the clinic, we ought to be doing it.

Mr. BILIRAKIS. Would the gentleman yield?

Mr. COBURN. I would be happy to yield.

Mr. BILIRAKIS. You also said in your testimony that 40,000 new cases of HIV annually, has almost become acceptable here in the United States. Very briefly, what do you mean by that?

Ms. MANN. It is not considered a crisis here any longer. I mean, you are now seeing on the news, day after day after day, the concerns about this epidemic in the Third World, in Africa and in other places. When is the last time you saw anybody talk about 40,000 new cases of HIV, in terms of the public's consciousness?

I took a cab from my house to the train station to get here. I asked the cab driver, "Do you have any idea how many people get HIV in this country every year?" He said, "Oh, I do not know, a couple of thousand, a few hundred, whatever." I said, "How would 40,000 strike you?" He said, "No, that can not be right."

What I am saying is that the general population, your constituents, do not realize that every year, 40,000 people get this disease in this country. We have no public consciousness. It is not a crisis, and it should be.

Mr. COBURN. Mr. Chairman, I just have one other question for Mr. Liberti.

Mr. BILIRAKIS. Very quickly.

Mr. COBURN. Do you have data on people who know their HIV status, and then go back to high risk behavior with that HIV status in Florida?

Mr. LIBERTI. We really do not have data on that. We know that people who are HIV infected, those folks usually have several problems: mental health problems, housing problems, a cadre of drug problems. I do not think the drug problem has been stated loudly enough.

Mr. COBURN. But I am particularly interested, since you have partner notification, and you are identifying where the contacts are



coming from. You do not have any data looking back at the failure of education, for those that are infected, that go out and continue to infect? You do not see a recidivism rate in any areas at all, that you can trace from your data backwards?

Mr. LIBERTI. We do, but I can not really produce those numbers for you today.

Mr. COBURN. Okay.

Mr. LIBERTI. I could respond in writing.

Mr. COBURN. I would love to have that from you, if you have that.

Thank you, Mr. Chairman.

Mr. BILIRAKIS. And, really, we are asking all of you to be available, in terms of additional questions in writing that will be furnished to you.

Ms. Eshoo has mentioned that she will have some and others have. Hopefully, you will respond to those as soon as you can, so that we can have them in a timely fashion.

I want to express my appreciation on behalf of all of us to all of you. It has been a very lengthy hearing, but I think a very constructive one. We have learned a lot from you.

Thank you.

[Whereupon, at 2:24 p.m., the subcommittee was adjourned.]

[Additional material submitted for the record follows:]

PREPARED STATEMENT OF CHARLES L. HENRY, DIRECTOR, LOS ANGELES COUNTY  
OFFICE OF AIDS PROGRAMS AND POLICY

Mr. Chairman, and members of the subcommittee, I want to thank you for the opportunity to testify in favor of House Resolution 4807, amendments to and reauthorization of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.

My name is Charles Henry and I am the Director of the Office of AIDS Programs and Policy for the Los Angeles County Department of Health Services. On behalf of the tens of thousands affected by the AIDS epidemic in Los Angeles County and across the country, I urge you to reauthorize the CARE Act without delay. Reauthorization is vital to the maintenance of the critical health services safety net for persons with HIV disease and their families. I also urge you to enact measures to ensure that CARE Act resources are distributed equitably across the country and that increases in appropriations match or exceed the annual growth in AIDS cases.

Recognizing the unique significance of the CARE Act, the importance of its reauthorization and the ethical imperative to correct long standing historical inequities, the Los Angeles County Board of Supervisors became in April, 1999 the first entity in the country to advocate for the reauthorization of the CARE Act.

In 1981, two gay men in their thirties exhibited symptoms of a rare form of pneumonia to physicians in Los Angeles. These two men had what we now call AIDS, and were the first cases of disease diagnosed. Nineteen years later, these two cases of AIDS have become more than forty-one thousand AIDS cases in Los Angeles County alone, with more than twenty-five thousand deaths and nearly sixteen thousand living with AIDS today.

In those early days of the AIDS epidemic, Los Angeles, like many communities across America, grappled with the devastating effects of AIDS. For the first decade of the epidemic, it nearly overwhelmed communities and public health systems across America without prompting a coordinated, comprehensive response. Epicenters like New York, San Francisco, Miami, and Los Angeles were especially hard-hit and witnessed many AIDS deaths.

In 1991, Congress authorized the CARE Act, a lifeline to the creation of systems of care for people with HIV. The CARE Act offered the promise of ongoing responsiveness to communities most impacted by AIDS, and support for the delivery of vital health and health-related services.

The epidemic continued to rage, expand and shift over the next five years, calling Congress to reauthorize the CARE Act in 1996. The number of jurisdictions eligible for Title I funds increased from sixteen to forty-nine. Dramatic increases in AIDS

cases among communities of color foreshadowed the deepening crisis we see today here and abroad.

Among the amendments enacted were modifications of the formula used to allocate Title I funds. The number of cumulative AIDS diagnoses, regardless of mortality, was replaced with an estimate of living AIDS cases. The legislation constructed the estimate of living AIDS cases by counting only those individuals diagnosed with an AIDS-defining condition within the previous ten years. Cases diagnosed each year are then adjusted to estimate mortality, with a greater weight associated with recently diagnosed cases than with cases diagnosed earlier (the “ten-year weighted band”).

Although laudable in its intent, this practice has not fulfilled its intended purpose. Other amendments (notably the implementation of a “hold harmless” provision in the formula portion of the Title I award) and other factors (including a shift in CARE Act resources to increase support of Title II and state ADAP programs) has resulted, in significant funding disparities in Title I, the portion of the CARE Act directed to the epicenters of the epidemic.

Title I funds are not sufficient to meet the needs of all people with HIV/AIDS in all Title I jurisdictions. The insufficiency of resources requires careful consideration and difficult decisions to ensure that the burden of unmet need is distributed fairly. The burden of unmet need continues to escalate with the increasing numbers of people with HIV who do not have an AIDS diagnosis, the increased complexity of care and the absence of health care infrastructure in those communities in which the epidemic continues to expand.

The “hold harmless” provision maintains widely disparate per capita funding, ranging from a low of approximately \$1,800 per case to a high of more than \$4,000 per case. Even when adjusted for variable costs of providing care, one jurisdiction continues to receive roughly twice as much funding per living AIDS case as any other jurisdiction in the country.

As Congress did in 1991 and again in 1996, it must make every effort to ensure that the changes in the epidemic and the changes in the needs of people with HIV guide the changes to the CARE Act.

Achieving per case equity can be accomplished by an increase in appropriations to Title I of the CARE Act, but would require an increase of more than \$360 million. Equity can be accomplished through a “hold harmless” provision, but would require a minimum of 40% reduction to accomplish it in one year, or a minimum of 17% in each of five years. Los Angeles County has identified multiple strategies to achieve per case equity, while at the same time addressing concerns raised by other stakeholders in this epidemic.

*The use of living AIDS cases reported by the Centers for Disease Control and Prevention in place of a ten-year weighted band.*

Absent a nation-wide standard on HIV surveillance and reporting, Los Angeles County urges you to support the use of living AIDS cases, with a transition to living HIV cases upon the availability of reliable, consistent data from all eligible jurisdictions. The current ten-year weighted band approach substantially under-estimates the total number of individuals living with AIDS in Title I jurisdictions. It is also significant that the ten-year weighted band disregards individuals with an AIDS diagnosis older than ten years, a cohort of people with AIDS that is increasing due to the success of new treatments. The use of living AIDS cases to replace the existing ten-year weighted band is sensible and straightforward.

*Increased appropriations, including a minimum increase proportionate to the increase in living AIDS cases among eligible jurisdictions.*

We must also consider appropriations that keep pace with the epidemic. Over the last five years the average annual AIDS growth rate among the fifty-one Title I eligible metropolitan areas (EMA) has been approximately 10.5%, while the increase in CARE Act Title I appropriations, controlling for newly funded jurisdictions, has been approximately 8%. Cases in Title I eligible metropolitan areas (ENM) comprise approximately 75% of all AIDS cases nation-wide; in California, more than 90% of those living with AIDS live in a Title I EMA.

An increase in appropriations proportional to the increase in living AIDS cases is critical to the ability of health jurisdictions to meet the expanding need for services to people living with AIDS and to ensure appropriate care for those with HIV who do not have an AIDS diagnosis.

*Institutionalization of the Minority AIDS Initiative to ensure sustained financial investment to jurisdictions experiencing significant case loads among people of color.*

As the national AIDS epidemic continues to expand in communities of color, a steady stream of resources is required to meet the tremendous care, treatment and support needs of communities of color. The Minority AIDS Initiative (MAI) has distributed resources among Title I EMAs based on the number of living AIDS cases among people of color.

The effect of the MAI, if not the intent, is to correct to some extent the effect of the "hold harmless" provision. A considerable number of underfunded Title I EMA's are the same jurisdictions that have the highest proportion of people of color with AIDS. Institutionalizing the Minority AIDS Initiative would further the effort to improve capacity in communities of color to respond more effectively to the epidemic. Furthermore, we need to ensure that capacity is sustained over the course of the epidemic. Year-to-year appropriations to support the Minority AIDS Initiative does not allow jurisdictions to plan, support and implement long-term grassroots strategies.

*More progressive guidance for CARE Act Title I supplemental funds.*

The supplemental portion of Title I is intended to address severe need. The competitive application process does not consider measures of severe need that are standardized across eligible jurisdictions, rendering it difficult to assess the success of the supplemental program in identifying and addressing severe need.

The striking, historical reality is that supplemental funds have been awarded in proportions roughly equivalent to the formula awards, thereby doubling the effect of the allocation methodology used for the formula award and exacerbating the disparity of funds among jurisdictions.

Los Angeles County supports the use of standardized measures of severe need, including the rapid growth in the number of people with HIV/AIDS, the increasing diversity of clients to be served, the relative costs of providing services, the increased complexity of care and the lack of infrastructure and capacity to provide services.

Furthermore, Los Angeles County endorses AIDS Action Council's recommendation that severe need criteria play a larger role in final Title I supplemental award decisions. The supplemental program could be used to redress the long-standing funding disparities evident in the formula award.

Los Angeles County is the second most impacted jurisdiction in the country. As we are challenged to maintain and improve the delivery of services for people with HIV/AIDS, we also face stark realities. The hope for an effective vaccine appears to be far away. Social factors that fuel disease, especially homophobia, racism, poverty, gender inequality and drug abuse, continue to rage in our country. HIV complacency challenges HIV prevention efforts on a daily basis. We have limited resources.

For thousands of Americans, the Ryan White CARE Act has improved the quality of life and has allowed some—too many—to die with dignity. The multi-titled structure of the CARE Act has provided an important framework for communities to develop responsive service delivery systems. Coordination among Titles, however, must be improved. The planning of services by local Title I planning councils must be coordinated with Title II planning efforts at the state level and with providers directly funded by Title III, Title IV and Part F. To achieve this, the same mandate for coordinated planning placed on Title I planning councils should be placed on those entities responsible for local services funded by Title II, Title III, Title IV and Part F.

In the spirit of cross-title coordination and expansion of local control, Los Angeles County endorses AIDS Action Council's recommendation to allow non-university based dental programs to participate in the CARE Act Part F reimbursement program. Increasing the number and geographic diversity of dental service providers will improve access and ensure more effective coordination with other services.

Every year, jurisdictions funded with CARE Act resources must establish and approve AIDS care and treatment funding priorities. It is always a difficult task. It is even more difficult when the ability to establish a service delivery system of sufficient capacity is crippled because of limited investment by local jurisdictions and states or by allocation methodologies unresponsive to documented need and long-standing funding inequities.

Los Angeles County joins the request of the AIDS Action Council that the CARE Act remove disincentives for local jurisdictions to contribute to HIV care and treatment. The existing maintenance of effort requirements discourage contribution of resources because it may trigger a long-term obligation. It is incumbent that we con-

sider alternatives to increasing local contribution for HIV/AIDS care and treatment services without threatening the infrastructure of health delivery systems.

Efforts to set in place responsible funding mechanisms will ensure that over the course of this epidemic jurisdictions which continue to be heavily impacted can rely on fair, equitable and need-based federal allocations in the future. I applaud the leadership and vision of Mr. Coburn and Mr. Waxman for including in House Resolution 4807 mechanisms to address the inequities in funding that have resulted unintentionally.

Absent an increase in appropriations, a two percent "hold harmless" provision would require more than twenty years to achieve per capita funding equity. In fact, the effect of this proposal appears to be substantially different from its intent. The relative position of the only jurisdiction currently benefiting from the "hold harmless" provision would improve, increasing from 188.7% of overall per capita allocation now to a projected 227.1 % of overall per capita allocation in the fifth year of the next authorization period. This effect is caused by the discrepant rates of growth in AIDS cases, based on the data reported by the CDC.

The Los Angeles community appreciates your efforts to safeguard the systems of health and support services for thousands of Americans living with HIV/AIDS, and respects your advocacy and leadership to ensure that we accomplish fair and equitable federal health care funding across the country. I urge you to appropriate resources fairly so that all severely impacted jurisdictions have an opportunity to respond effectively to this ongoing public health crisis.

Thank you for your time and for your consideration of these important matters.

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PREPARED STATEMENT OF W. SHEPHERD SMITH, PRESIDENT, AMERICANS FOR A  
SOUND AIDS/HIV POLICY

Thank you, Mr. Chairman and other distinguished members of this committee, for the opportunity to appear before you once again. I would like to begin by congratulating Congressman Bliley for his efforts to have these hearings before rushing into a re-authorization of this act last year. The pressures on him to move forward quickly in the fall were ill advised, and he showed considerable courage in standing up to often times unreasonable, if not-unethical, lobbying tactics. The Republicans in the Senate should be congratulated, as well, for their effort to not re-authorize Ryan White in 1994.

The reason that it is critical that this important AIDS care act be reviewed carefully is that it is fundamentally flawed in its present form. The basic error in the Act is in its formula for distribution of care dollars. It was based on AIDS prevalence, which is an accumulation of all AIDS cases from the beginning of the epidemic. As we know, unfortunately, about 60 percent of those individuals have died. Consequently, a disproportionate share of proceeds went to cities that had the earlier epidemics of HIV and AIDS, and did little for areas with rapidly growing new case loads.

You will hear significant amounts of data from the Government Accounting Office which has done an excellent job in evaluating where monies went under the old formula and what a redistribution of those dollars means to cities and states most impacted today. To illustrate the disparity in distribution of Ryan White dollars under the old formula, a city such as San Francisco received approximately \$4,300 per case while an individual from Chicago received approximately \$1,600, and in some rural areas of the country as little as \$640 apiece. It is fundamentally unfair to have such significant disparities for people who are suffering from this disease since they all face substantial needs.

As the only AIDS organization which openly opposed Ryan White re-authorization in the form that was put forward last year, we would encourage this committee to look carefully at suggested formulas since nearly anything can be done with numbers. The ideal way to distribute dollars would be to give aid to those people who are either HIV positive or have symptomatic AIDS who need care; i.e., those living with the disease today in need of care. However, that is quite difficult to do since as a nation we have focused very little on HIV disease, rather we've put the bulk of our attention on end-stage symptomatic AIDS. Even there our record keeping is something less than perfect in that many people, perhaps as many as 10 to 20 percent of AIDS cases, go unreported for a number of reasons; and often where contact is lost with an individual they may have died but are still listed as people living with AIDS. Consequently, you're dealing with an inexact science that requires some healthy repair.

It is our suggestion that dollars be distributed to state public health departments for distribution based on HIV infections and AIDS cases that accurately reflect those

people living with this disease today who have medical needs in their jurisdictions. This can be done by greater reporting of HIV and more medical/public health involvement of those suffering. This suggestion, of course, brings with it the combining of Titles I and II. I'd like to articulate now the benefits of combining these Titles and giving State Public Health Directors and their State AIDS Directors more flexibility in responding to this changing epidemic in their respective states.

The AIDS epidemic as we know it is changing dramatically. What was thought to be a disease of predominantly white gay men is rapidly and unfortunately becoming a disease of color. This last year over 55 percent of AIDS cases reported by the CDC were people of color. What is alarming about these numbers is the rapid increase in percentages within various racial and ethnic groups. For example, AIDS cases in 1994 within the African American Community grew by 3 percent of the total AIDS cases reported, and now show that community over-represented in the epidemic by three times.

I would like to illustrate the dramatic disparity between the rates of AIDS cases in these two primary communities, the African American and the White community, as reported by the CDC last fall. The attached charts came out of the report that AIDS is now the leading cause of death among all men age 25 to 44. However it is by far the leading cause of death among Black men and the second leading cause of death among White men in that age group. The graph illustrates a similar dramatic rise among Black women versus White women. I would like to also interject that this issue of dramatic disparity should come as news to no one since military data in the mid 180s, which was focused on HIV infections, showed that these trends would ultimately occur (even though at the time the ratio of whites to Blacks was significantly greater in AIDS cases).

1985 to 1988 data showed that black women in the armed forces had higher rates of HIV infection than white men; a time when most people believed this was nearly exclusively a white man's disease. The military data illustrates our need to look more closely at trends in HIV infections, which ultimately result in AIDS cases. By doing this we can plan much more effectively for future resource needs and changes.

The purpose in illustrating the differences in rates and the changing face of this epidemic is to say that within each state needs also change year to year. We are seeing right now, for example, the greatest increases in HIV infected infants occurring in the rural South rather than the Northeastern metropolitan areas. By combining Titles I and II it will allow states to better direct resources in response to the changing dynamics of the epidemics in their respective areas. It could be argued, in fact, that all Ryan White Titles be combined and dollars distributed on cases by state with little federal involvement. However, I think there are reasons why some small portion of dollars should have federal control; so that efforts can be better coordinated at a national level for what is a series of regional epidemics that affect the entire nation as the epidemic spreads to new areas.

As you move forward in your consideration of Ryan White reauthorization we would encourage you to evaluate this special health issue funding in respect to all other health issues. We have set a precedent with this particular program that may or may not be applicable to long-range health care financing objectives. When the first Commission on HIV issued its report in June of 1988, it raised the question of the challenge posed by HIV in respect to financing. I'd like to include a quote from that valuable document:

"The Commission believes that the financing issue is one of the most difficult problems of the HIV epidemic. It is not easy to answer the questions about treating AIDS and HIV infection apart from other devastating sicknesses and diseases. If we can make changes in our financing system, do we do it only for those with HIV or do we do it for everyone? Allocating limited healthcare resources when the needs are so great presents a significant challenge."

So we would, therefore, encourage the Committee to look at Ryan White reauthorization in respect to Medicare, Medicaid, Social Security Disability Income and other benefit plans that individual states have set up in respect to caring for those suffering from this disease. While we fully support reauthorization funding levels for this Care Act, we nevertheless feel it is important to evaluate this program in respect to other programs presently in place and those that may be anticipated in the future since this is a five year re-authorization measure. The reality is that there may be ways to enhance benefits for those who suffer from HIV and AIDS through other mechanisms and we would want the Congress to retain flexibility in being able to do that in the future; and to evaluate if this is a good model for other medical conditions, which it may well be.

In respect to funding levels I don't believe anyone in the AIDS community believes we will ever see the unprecedented growth in funding we saw under the Reagan and Bush administrations. We do expect, however, to see the continued com-

mitment from this Congress and Administration that this issue has received in the past. But funding should be based on realistic needs and should be in perspective to needs of all people with serious illnesses. We, therefore, encourage the Committee to fully fund Ryan White at its present suggested level, but in a way that creates greater equity to all in need and fundamentally embraces our fairness doctrine.

Fairness to Americans for a Sound AIDS/HIV Policy means that those individuals with needs receive benefits equally. This Congress has the opportunity to structure Ryan White reauthorization so that those with the greatest needs today are the primary beneficiaries. And it is a fact that those with the greatest needs today are individuals from communities of color. In respect to how this can best be done, we suggest the following:

(1) Base distribution of dollars by state on numbers of people living with HIV and AIDS who have care needs. This expanded definition to include HIV positive individuals who don't necessarily fit the AIDS case criteria will benefit women and children who often receive substandard care because they don't meet present case definitions for AIDS. If states are unable to define, because of a lack of HIV reporting, those individuals who presently are living with HIV and AIDS who need care, then we would suggest the formula be based on the last two and one-half years of cumulative AIDS cases. We believe this would be a reflective number of total numbers of people presently living with HIV and AIDS.

(2) We are troubled by the double counting in respect to formulas and feel that by combining Titles I and II we can largely eliminate this measure in present Ryan White formula configurations.

(3) We would hope that dollars are distributed to locations where people are presently living with HIV and AIDS rather than to where they were originally diagnosed, as is part of the present Ryan White formula. As the epidemic changes in focus we may find that more people from city areas move back to their rural homes, particularly in the South, and that the needs would grow significantly there. Such a formula change would then incorporate our concept of fairness.

(4) We hope that added measures of means testing be applied to those receiving benefits. While the present formula does restrict benefits to a large degree, we believe it important that tighter measures be required so that dollars be given to those who truly need them and can't afford such benefits otherwise.

(5) Lastly, the program needs to be evaluated critically in respect to bureaucratic waste. Are there ways to reduce red tape and any excessive program costs so that more dollars can go to those in need and not to a bureaucratic infrastructure?

In conclusion, I would like to share a little from our experience in this epidemic. This past year we helped over 8,400 children and families affected by this disease in some way, making us one of the largest AIDS service organizations in the country, if not the largest. Most of our clients come from underserved communities and the most often heard complaint is that while funds are available to others, they often aren't to them. There is inequity today created by the Ryan White Care Act that must be changed. And we must remember that this epidemic itself is changing rapidly in composition. Any measure this Congress enacts must take into consideration the needs of those truly needy, the needs of those in communities of color, and the needs of women and children.

The benefit of our suggested expanded definition of including HIV positive individuals who have care needs combined with the formula change we hope will result ultimately in a decreasing epidemic. By giving greater focus to HIV rather than just end-stage disease AIDS we will ultimately be able to provide optimal medical care to those who need it and allow those infected to have the opportunity not to infect others. Because of our over focus on AIDS rather than HIV most people in the United States today who carry the virus are totally unaware that they are infected and most often have no idea they have even been exposed to anyone infected. Consequently, we have an epidemic largely out of control, one which has the potential unfortunately to lead us soon to believe that this is a disease of color. The truth is that this is a sexually transmitted disease that will end up where all STDs end up and that's among sexually active young people of all races, particularly heterosexuals.

As the Committee formulates final language on this Act, I would like you to remember the first point of the executive summary of the Presidential Commission on HIV issued in June of 1988:

"The term 'AIDS' is obsolete. 'HIV infection' more correctly defines the problem. The medical, public health, political, and community leadership must focus on the full course of HIV infection rather than concentrating on later stages of the disease. Continual focus on AIDS rather than the entire spectrum of HIV disease has left our nation unable to deal adequately with the epidemic. Federal

and state data collection efforts must now be focused on early HIV reports, while still collecting data on symptomatic disease."

So while you are essentially focusing on care for those in end-stage disease, a careful restructuring of formulas and distribution of dollars will hopefully affect the course of this epidemic so that such funding can ultimately be eliminated entirely when this epidemic is eliminated from our country. Thank you.



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Amy Herman, Executive Director

July 10, 2000

Re: Reauthorization of the Ryan White  
Comprehensive Care Act

Dear Members of the Commerce Committee:

The *Ryan White Comprehensive AIDS Resource Emergency (C.A.R.E.) Act* is due to expire in September, 2000. This piece of legislation provides funding for crucial programs to combat the AIDS epidemic. The Senate has already passed its CARE Act reauthorization bill. NYAC urges the House to pass its reauthorization bill before the C.A.R.E. Act expires this fall.

To inform you in your decision-making, I am enclosing a copy of the New York AIDS Coalition's (NYAC) paper on the Ryan White Comprehensive AIDS Resource Emergency Act. The paper provides consumer and provider perspectives on the importance of CARE Act funds to New Yorkers living with HIV/AIDS. It also provides a range of recommendations that we hope you and your colleagues will consider during reauthorization discussions.

The New York AIDS Coalition is an alliance of 200 community-based HIV/AIDS organizations located in every corner of New York State. NYAC promotes cooperation among the many communities affected by the epidemic and facilitates diverse communities in advocating with one voice for increased funds and fair and responsive AIDS-related policies.

**NYAC urges Congress to reauthorize the Ryan White Care Act to ensure the continuity and enhancement of care that New Yorkers living with and at risk of HIV/AIDS still require. For further recommendations, please review NYAC's paper.**

Thank you for your consideration. We appreciate your attention to the important issue of funding for HIV/AIDS programs. If you have any questions about the enclosed report feel free to contact Jacqueline Vimo at 212/629-3075x102.

Sincerely,

Amy Herman

# **NYAC** *The New York AIDS Coalition*

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**Position Paper on:**  
**Ryan White**  
**Comprehensive AIDS Resource**  
**Emergency**  
**(C.A.R.E.) Act**  
**Reauthorization 2000**

**NYAC Policy Department**

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The New York AIDS Coalition unites more than 200 community-based HIV/AIDS and social welfare organizations throughout New York State. Established in 1988 to promote cooperation among the many communities affected by HIV and AIDS, NYAC assists communities to advocate with one voice on all levels of government. NYAC advocates for fair policies and sufficient funding to respond to the AIDS epidemic.

*This paper was developed in consultation with **Christina Kazanas***



## Introduction

In order to inform the CARE Act Reauthorization process, the New York AIDS Coalition (NYAC) has prepared this paper to educate legislators and the public about key issues facing consumers and providers of Ryan White services. NYAC worked with its member organizations and their clients in developing this paper to highlight their unique concerns and perspectives regarding CARE Act Services in New York State.

The New York AIDS Coalition unites more than 200 community-based HIV/AIDS and social welfare organizations. Established in 1988 to promote cooperation among the many communities affected by HIV and AIDS, NYAC assists communities to advocate with one voice on all levels of government. NYAC advocates for fair policies and sufficient HIV/AIDS related funding.

NYAC urges Congress to reauthorize the Ryan White CARE Act in order to ensure the continued and enhanced provision of still greatly needed services and programs to address the AIDS crisis.

## What is the Ryan White CARE Act?

The Ryan White Comprehensive AIDS Relief Emergency (CARE) Act was enacted by Congress on August 6<sup>th</sup>, 1990 to provide care and treatment for the thousands of Americans living with HIV/AIDS. At that time, the AIDS epidemic had been growing at an alarming rate and posed a threat to health care systems that were poorly equipped to manage the demand in HIV/AIDS-related services. Six years later, in 1996, the number of people infected and affected by the epidemic continued to grow, and in response, the CARE Act was reauthorized. Since 1990, the Ryan White CARE Act has been the cornerstone of the nation's public health response to AIDS and has played a central role in securing access to appropriate care and services for Americans living with HIV/AIDS.

CARE Act funds are used to provide the continuum of services in New York State and across the country that are necessary to support the health care needs of people with HIV/AIDS. Each of the CARE Act's program five titles addresses specific needs; however, together they create a seamless web of services designed to meet the needs of a wide range of populations. The five components of the CARE Act play a vital role in improving the quality of life of people living with HIV and their families. By focusing on preventative medicine and supportive services designed to increase access to and availability of health care services, Ryan White has contributed to a reduction in the use of costly inpatient care and has increased access to care for underserved populations. The success of Ryan White-funded programs has most clearly been reflected in the decline in the AIDS death rate over the last decade.

**Medications Alone Cannot Effectively Fight the Epidemic.** The 10-year success of the CARE Act relies on the belief that medications alone cannot effectively fight the AIDS epidemic. While new medications have been extremely effective in reducing AIDS death rates, complimentary supportive services funded by the CARE Act have been a major factor contributing to the fact that the numbers of deaths are as low as they are. Without Ryan White programs and services, the effectiveness of medications is significantly weakened. Supportive services such as case management, counseling, nutrition and transportation assistance, and treatment adherence programs, among others are essential to extending and improving the lives of people living with HIV/AIDS. This comprehensive approach makes the CARE Act cost-effective and necessary to the continued decline in AIDS deaths. Additionally, recent statistics indicate that the decline in AIDS deaths may in fact be slowing down, pointing to the need for sustained efforts to combat the epidemic. The continued support for programs funded through Ryan White are especially crucial in light of claims that "AIDS is over," a myth which has been fueled by the AIDS death rate decline.

The decline in the AIDS death rate, while a positive trend, has also had ramifications for CARE Act funded programs, including those in New York State.

Increased life expectancy among people with HIV/AIDS has resulted in an increased demand on the HIV/AIDS care infrastructure. According to AIDS Action, a federal AIDS advocacy organization, Ryan White providers across the country have experienced 30-40% increases in the number of new patients enrolling in their programs. NYAC member organizations administering Ryan White programs report that since the inception of their services, client loads have dramatically increased. The ability of many of these organizations to meet the demand relies on continued and increased funding from the Ryan White CARE Act. Programs are working well beyond their capacity in their struggle to meet the demand for services that can enable people with HIV/AIDS to live longer and healthier.

If the nation's public health systems are to continue to meet the challenges presented by the HIV/AIDS epidemic to New York and all U.S. States, it is essential that government and community unite to support innovative solutions to fight the AIDS epidemic. The CARE Act legislation is scheduled to expire on September 30, 2000. It is a necessary component of the fight against HIV/AIDS, and NYAC strongly supports its reauthorization; however, rapid reauthorization should not come at the cost of amending Ryan White to include provisions for surveillance activities such as partner notification, names reporting and mandatory infant testing. In order to ensure a sustained response to the AIDS epidemic, we must reauthorize the CARE Act without the inclusion of provisions for surveillance. We must reauthorize the CARE Act *now*.

## The HIV/AIDS Epidemic in New York State and New York City: An Epidemiological Case in Support of Ryan White CARE Act Reauthorization

The current state of the HIV/AIDS epidemic in New York illustrates the continued need for well-coordinated, comprehensive care and support systems like those the CARE Act is responsible for sustaining. Initial statistics illustrate that the AIDS death rate decline had stabilized in 1999, indicating that the AIDS epidemic in New York City is far from over. Among the most significant statistics include the following:

- More than 122,500 AIDS cases were confirmed in New York State through the end of 1997. New York State leads the country in both annual and cumulative AIDS incidences – over 19% of the nation's AIDS cases confirmed through December 1997.
- New York State has the highest incidence rate in the United States, with more than 72 AIDS cases diagnosed per 100,000 people (1997).
- New York AIDS cases represent a much higher proportion of intravenous drug users (IDUs), women and people of color than any other state.

Exposure Category	New York State (%)	United States (%)
Injecting Drug Users	44.1	25.2
People of Color	71.4	54.9
Women	21.8	16.0

- The AIDS epidemic in New York continues to be dominated by cases diagnosed among people of color, IDUs and men.

Exposure Category	Percent of Confirmed 1997 AIDS Cases in NYS
Men Who Have Sex With Men	35.1
IDU	24.2
MSM/IDU	3.9
Heterosexual Contact	13.4
Other	23.4

Race/Ethnicity	Percent of Confirmed 1997 AIDS Cases in NYS
White	33.3
Black	44.7
Hispanic	20.6
Asian/Pacific Islander/Native American	1.0

Gender	Percent of Confirmed 1997 AIDS Cases in NYS
Male	78.0
Female	22.0

- AIDS case incidence rates vary widely by geographic area in the state. Eighty percent (80%) of New York State's total AIDS cases are located in New York City, yet the cumulative case rate per 100,000 people varies between the five boroughs: from 570.4 in Staten Island, to 2,852.1 in Manhattan.

While AIDS case rates in upstate New York seem relatively lower, the impact per capita is extremely high. In upstate New York, the case rate ranges from 18.9/100,000 in Hamilton County to 243.3 in Rockland County. These rates are much higher in those counties which house correctional facilities. In many upstate counties, however, high AIDS case rates in larger cities were hidden by low rates in the rest of the county. When we look at the upstate Ryan White Regions, we see that these metropolitan areas boast high case rates:

Ryan White Region	Cumulative Case Rate 100,000 through* December 1997
Albany	214.1
Binghamton	75.6
Buffalo	144.5
Lower and Mid-Hudson	390.3
Nassau/Suffolk	224.3
Rochester	173.9
Syracuse	177.6

- As indicated above, New York City represents 80% of AIDS cases confirmed statewide, and 17% of reported cases nationwide. Nearly one in four pediatric cases in the United States have been reported in New York City.

As of June 1999, there have been 113,535 adult cases of AIDS diagnosed among New York City residents, with a cumulative case rate of 1,745 per 100,000 people over age 13. Men make up 77.6% of diagnosed cases (case rate of 2,759/100,000), while 22.3% of cases occurred among women (case rate of 712/100,000). A total of 1,857 New York City children below the age of 13 have been diagnosed with AIDS, yielding a pediatric AIDS case rate of 150 per 100,000.

Throughout the City, men who have sex with men and intravenous drug use are the major transmission categories for diagnosed AIDS cases among men, accounting for 85% of all cases. Among women, IDU and heterosexual contact account for 84% of cumulative diagnosed AIDS cases.

Broken down by race and ethnicity, African Americans account for 42% of cases in the City, while Hispanics make up 31%.

These statistics point to the continued urgency of addressing the AIDS epidemic in New York State. The Ryan White CARE Act must continue to support and enhance existing programs while facilitating an effective response to the exponential growth of AIDS case rates in underserved populations. The CARE Act must be reauthorized *now* in order to meet the demands of fighting the AIDS epidemic.

## A Case for Reauthorization: Ryan White Titles At a Glance

The CARE Act consists of five titles, each addressing a specific set of needs, yet complementing each other to provide a seamless web of comprehensive services for people living with AIDS.

**Title I** provides emergency formula and competitive grants to those metropolitan areas most heavily affected by the HIV/AIDS epidemic. Metropolitan areas qualify for Title I funding if they have a population of at least 500,000 and report a cumulative AIDS caseload of at least 2,000 over the most recent 5 years. There are currently 49 eligible metropolitan areas (EMAs).

Title I funds may be used to provide outpatient primary medical care, sub-specialty medical care, dental care, medications, treatment education, laboratory tests, home health care, mental health treatment, substance abuse treatment and counseling, medical case management and benefits counseling, assessment for work entry and re-entry, legal and client advocacy services, transitional housing, food and nutritional services, and transportation to care services. Local planning councils assess and prioritize local needs and develop plans for the delivery of comprehensive HIV/AIDS health care services.

Title II provides formula grants to the state health departments in all 50 states, the District of Columbia, and the territories. Each state must have a comprehensive plan for the delivery of HIV services, including how Title II funds will be used to complement present services. Title II funds may be used to operate HIV care consortia, fund state health insurance continuation, home-based care services, and to purchase AIDS-related drugs for low-income individuals through the AIDS Drug Assistance Program (ADAP). Additionally, since fewer jurisdictions can qualify for Title I funds, Title II funds are also used by states to provide the same range of HIV/AIDS services throughout the state that could be provided under Title I.

In 1996, Congress created a separate funding line in order to appropriate funds directly to the AIDS Drug Assistance Program (ADAP). These funds are used specifically for the purchase of HIV/AIDS-related drugs, and allow core Title II funds that are allocated for care services to be preserved while providing access to HIV/AIDS medications to a larger number of people.

Title III provides competitive grants to community-based clinics and public health providers serving traditionally underserved populations. The goal of Title III programs is to deliver early intervention and ongoing comprehensive HIV/AIDS health care services to these populations, including HIV counseling and testing, primary care, and prescription drugs. In some areas of the country, especially in rural areas, Title III is the only source of medical care and other critical HIV services.

Title IV provides competitive grants to pediatric, adolescent and family HIV care programs to provide coordinated care services and access to clinical research by linking care services to clinical research programs.

Title V provides competitive grants for projects of national significance. Title V also provides funds to educate and train health care providers in HIV/AIDS care through the AIDS Dental Reimbursement Program and the AIDS Education & Training Centers (AETCs). As the training arm of the Ryan White CARE Act, the AETCs ensure that health care providers have access to the most up to date information and training on competent and compassionate HIV/AIDS care and the HIV/AIDS Dental program helps to provide training in and access to much needed HIV dental care.

## The Importance of Ryan White Programs from Consumer and Provider Perspectives

In developing this paper, NYAC consulted with its member agencies and clients of member agencies who provide or receive Ryan White services. Two 2-hour client focus groups were held for New York City and upstate New York clients to share their thoughts on the Ryan White services they receive and to explain the impact these services have had on their lives. Focus group participants represented consumers of programs offered across all 5 titles. Additionally, over 15 phone interviews were held with city and upstate Ryan White providers across all titles. Providers shared their opinions and observations on the importance of CARE Act programs and what they observed as unmet needs that existed for their clients. Through these focus groups and phone interviews, NYAC has learned from those on the frontlines about the importance and the sheer necessity of the Ryan White CARE Act. Included among our findings are the following points:

**Importance of Supportive Services:** Consumers and providers alike continuously stressed the importance of supportive services, such as case management, support groups, treatment adherence, legal advocacy and transportation. Many consumers stated that if it were not for supportive services that they may not have continued seeking primary health care in the consistent manner they currently do. Supportive services like mental health support groups and respite care allowed people living with HIV/AIDS feel like they were a part of a community, and assured them that they were not alone in their struggle. Supportive services like transportation allowed many consumers to make their appointments and receive timely, regular health and support services that they normally would not be able to get to, especially in upstate New York, where public transportation is inadequate or non-existent. Providers often stated that primary care is simply not enough to fight the disease – that the supportive services that Ryan White allows them to offer play just as large a part in keeping people healthy and alive as basic medical care and treatment.

**Ryan White Programs as Only Source of Services:** In upstate New York, Ryan White-funded programs often represent the only source of HIV-specific care in a community or county. Often, the nearest services are hundreds of miles away, and without the presence of adequate public transportation, they are often impossible to get to. People living with HIV/AIDS in many communities in upstate New York have only one place to go where they can receive comprehensive services. Without the CARE Act, they would be left behind, become sicker, and die.

**Ryan White Programs Offer Services in Atmospheres That Encourage Consumers to Use Them Regularly:** Consumers repeatedly stated that one major reason they continued to use Ryan White services is because of the safe and respectful atmosphere that exists in many of these programs. Consumers stressed the importance of staff that understand HIV/AIDS and the specialized nature of the programs as factors that led them to first seek services at agencies. Working with staff that was sensitive to HIV/AIDS issues contributed to their continued use of agency services. Ryan White allows agencies to offer services to community members that meet the clients “where they are” and that take careful consideration of how HIV and AIDS affects individuals.

**Ryan White CARE Act Funds Cover a Range of Services Medicaid is Unable to Cover:** Providers unanimously agreed that Medicaid alone is simply incapable of providing the range of comprehensive services that Ryan White enables agencies to provide. If Ryan White were not reauthorized, and the Federal government allowed

Medicaid to take over payment of services, this "mainstreaming" of HIV/AIDS medical services would result in lost supportive services that are necessary for successful treatment of HIV/AIDS. There was also concern expressed about the ability of Medicaid to adequately reimburse for medical and primary care services. If Medicaid reimburses at a lower rate, providers may be faced with having to scale down their services, refuse to take on additional clients, or go out of business all together. In addition, changes resulting from recent welfare reform have decreased the number of people eligible for Medicaid benefits. Accordingly, Ryan White is often the *only* source of support for people living with HIV and AIDS.

**Ryan White CARE Act Funds Enabled Programs to Expand Their Services:** Providers of Ryan White services stated that prior to receiving Ryan White funding, their programs existed, but on a much smaller scale and with unstable, uncertain, and severely limited funding streams. Ryan White funding enabled providers to expand the scope of their services to meet the needs of their communities, as well as reach a much larger number of people. In some cases, Ryan White funding created brand new programs and networks in areas where there were no agencies providing certain needed services. Likewise, providers emphasized their extremely limited ability to conduct fundraising to replace a theoretical loss of Ryan White funding in the event of reduced awards or elimination of the CARE Act in its entirety. In the absence of adequate funding, many of their programs would cease to exist at all, leaving entire communities without AIDS-specific care and support programs.

**Case Reporting Systems:** A major concern with many providers was the lack of a standardized, user-friendly reporting system for Ryan White programs. Currently, not all agencies administering Ryan White programs have a standardized reporting system in place at their agency. Without proper and complete case reporting, it is impossible to develop a clear picture of the quality of the services provided and received. Development of a standardizing reporting system can assist EMAs, states, and community-based organizations in coordinating services and allocating resources where they are needed most. Finally, funding for the creation of a reporting system should not come at the expense of services. Rather, new resources should be created to fund reporting systems.

### NYAC Policy Recommendations Regarding the 2000 Reauthorization of the Ryan White CARE Act

Through our work with our member organizations and their clients, NYAC has developed the following recommendations concerning the reauthorization of the CARE Act. These recommendations were based on input from members and on the findings of our focus groups. It is our hope that these recommendations adequately reflect the concerns of our member organizations that provide Ryan White Services and those of their clients as well.

**The Ryan White Comprehensive AIDS Relief Emergency Act Should Be Reauthorized in 2000.** NYAC asserts that the services provided by Ryan White programs in New York State are vital to low-income, uninsured and underinsured people living with HIV/AIDS and their affected families. Ryan White programs represent the cornerstone of AIDS service systems in every locality and EMA in New York State that receives CARE Act funding. CARE funded programs often represent the only source of medical care and support for people with HIV/AIDS in many areas in upstate New York. To not reauthorize the CARE Act would mean the elimination of services necessary to the lives of thousands of people in New York State.

**NYAC Supports Maintaining the Current Structure of the CARE Act.** The current structure of the Ryan White CARE Act is effective in creating a comprehensive approach to the planning and delivery of services. Each of the titles provides for a specific set of needs that together create an effective, seamless web of services that reach a wide range of populations infected and affected by HIV/AIDS. The current structure also allows for significant community involvement in service delivery and resource allocation. This

community involvement and influence can help ensure that resources are reaching those most in need and are addressing the most pressing service needs in the community.

**NYAC Supports a Funding Formula for Both Title I and II (non-ADAP) based on Living AIDS Cases Until Sufficient Data Becomes Available from HIV Surveillance.** Eventually, HIV case reporting data will most likely be used in calculating the formula. NYAC supports the use of this data, but only after all states implement an HIV surveillance system and only after enough time has been granted to states to work out problems in their reporting systems to create the most accurate picture of HIV infection in each state, city and community. While it is necessary to improve HIV surveillance systems, it is crucial to ensure that surveillance activities are not funded by CARE Act funds that were intended to pay for the care of people living with HIV and AIDS.

**NYAC also Supports a "Hold Harmless" Provision that Limits the Formula Reductions to Any Title I EMA Because of a Decrease in the Number of AIDS Cases.** Drastic reductions in funding would prove disastrous to existing Ryan White infrastructures that have been established over the past 10 years. In order to prevent this, EMAs should be "held harmless" and not punished for decreases in the number of living AIDS cases in their area.

**NYAC Urges a Stronger Commitment to Reaching and Serving Underserved Populations.** The CARE Act should continue to utilize Titles III, IV and Part F together with the local planning bodies for Titles I and II to ensure that underserved populations have improved access to care and treatment. NYAC supports a greater commitment on the part of the federal government to supporting Title III and IV programs which are designed to meet the needs of hard to reach and underserved persons such as women, adolescents, substance user, people of color, homeless populations, and others.

**NYAC Asserts that Ryan White CARE Act Funds Should NOT Be Authorized to Pay for Mandatory Partner Notification, HIV Names Reporting, or Newborn Testing Activities.** NYAC strongly opposes any attempt to include mandatory partner notification, HIV names reporting, or mandatory newborn testing for HIV in authorization language. NYAC believes that policies such as mandatory partner notification may have the effect of deterring people from seeking care if they feel their confidentiality or personal safety will be compromised or violated. CARE Act resources should not be allowed or mandated to fund such activities as they detract from the medical and supportive services that the CARE Act was intended to provide.

**NYAC Supports an Expansion of the Authorized Funding Levels.** NYAC supports expanding the authorized funding levels for all titles in the CARE Act to enable EMAs, states, community based organizations and public health providers to meet the needs of low income, uninsured and underinsured people living with HIV/AIDS.

**NYAC also Supports Reauthorization Language that Strengthens the Participation of Ryan White Service Consumers on Local Planning Councils.** The Ryan White CARE Act should mandate greater participation of consumers on local Ryan White Planning Councils. Greater consumer participation will allow for a more accurate allocation of funding to service categories that are of high priority to consumers.

Ryan White must be reauthorized *now* to ensure the continuity of care and prevention programs for all New Yorkers; however, we must not sacrifice essential services for the sake of expediency by amending Ryan White to include surveillance activities that will jeopardize the funding for programs designed to care for people living with HIV/AIDS. At its inception, the Ryan White CARE Act was perceived as an emergency relief fund, the "payer of last resort." Over the course of the time, changes in the epidemic and in the public health care system have turned the CARE Act into the payer of *only* resort in many ~~cases~~ cases. The Ryan White CARE Act is a necessary component of efforts to sustain an effective response to the ongoing AIDS epidemic. Failure to reauthorize the Ryan White CARE Act now could cost New York millions of dollars and thousands of lives.